TACKLING TB IN OUR COMMUNITIES

An advocacy toolkit for civil society:
Supporting South Africa's TB Response

2025 Edition

TB Accountability Consortium

About this advocacy toolkit

Being an advocate on an issue is not an easy job. You have to combine your passion with your purpose to work towards a goal. It takes courage and determination to fight for change.

Changing a policy, a process or the way a person thinks takes time and it needs patience as the change that is needed is considered.

This toolkit is a guide to help you as a community TB advocate on this journey. We want to help you see the importance of your role as an advocate and how you can make a difference in the communities that you work.

In this toolkit you will find:

- What advocacy is all about
- How to be an effective advocate
- What national TB policies exist in South Africa
- The messages that you can use for your advoacy
- What data driven advocacy is and why it matters
- Ways that you can advocate in your community

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01 Welcome

1. Why do we need advocacy in TB

In South Africa TB kills about 56,000 people each year — despite being preventable and curable. It remains the leading cause of death from an infectious disease in the country, especially among people living with HIV.

The country has made significant progress in the fight against TB over the last 10 years. TB incidence has dropped by 57% since 2015. And treatment coverage improved to 79% in 2023. There are also a variety of new tools and medication regimens that show better treatment outcomes, with additional medications currently being evaluated in clinical trials in South Africa and globally.

But there are still many challenges. As a start, TB deaths have only declined by 16% since 2015.

This is not enough – as it means that there are still 56 000 people who die from a curable and preventable disease each year.

One of the biggest challenges for the country is that there are groups of people that are not being tested, started on treatment and finishing their full treatment course of medication.

To help the country reduce its TB rates, South Africa has a National Strategic Plan for HIV, TB and Sexually Transmitted Diseases which sets out a way forward over the next five years to tackle TB. A central part of this plan is civil society involvement.

South Africa's civil society sector is uniquely positioned to bridge the gap between government, TB policy and community realities.

Civil society has a vital role in:
- Mobilising communities by encouraging them to get tested for TB and take their treatment.
- Demanding accountability and resources.
- Driving stigma-free, patient-centred care.

Civil society can support the TB response by increasing its advocacy efforts, improving accountability mechanisms and by mobilising communities.

ADVOCACY =

ISSUE + POWER + ACTION

02
What is advocacy?

2. Understanding advocacy

Advocacy is when people come together to raise their voices, stand up for their rights, and influence decision-makers to bring about positive change.

It helps communities to identify a problem and works on a plan to fix it. It's not just complaining—it's taking action, organising, and pushing for solutions and results from those in power.

Advocacy is about speaking out for change. It helps us to do the following things:

Raise awareness	**because**	People can't fix problems they don't know about
Influence leaders	**because**	Government listens when people are organised
Protect our rights	**because**	Rights are only maintained when we defend them
Create lasting change	**because**	It's not just about short-term help – it's about long-term change
Empower our communities	**because**	People feel stronger when they know they have power

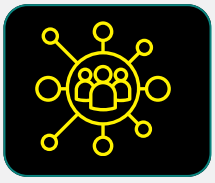
There are different types of advocacy:

Policy advocacy

Focuses on influencing laws, policies, or regulations. Usually targets government institutions, legislators, or policymakers. Example: Lobbying for TB diagnostic guidelines to include tongue swab testing.

Community-level advocacy

Grassroots-level mobilization to raise awareness and push for change locally. Builds capacity within communities to speak for themselves. Example: Local health committees advocating for improved TB clinic hours.



Individual advocacy

One-on-one support for individuals navigating systems or defending their rights. Common in social work, legal aid, and patient advocacy. Example: Helping a TB patient secure access to disability grants

Media and Public Advocacy

Uses traditional and social media to shape public opinion and put pressure on decision-makers. Often involves campaigns, storytelling, or strategic communications. Example: Running a stigma-reduction campaign on radio and WhatsApp.

Legal Advocacy

Litigation/ Rights-Based Advocacy): Involves using the courts or legal systems to challenge injustice or enforce rights. Example: Filing a case to ensure access to free TB treatment under a constitutional right to health.

Research and Evidence-Based Advocacy

Uses data, studies, and expert knowledge to inform and influence decision-making. Example: Publishing cost-effectiveness evidence to influence donors to fund community TB testing.

Targeted Advocacy

This is usually stakeholder-specific. It focused on persuading a particular influential group (e.g., donors, private sector, health workers). Often highly tailored messaging. Example: Convincing faith leaders to speak out against TB stigma.

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Five things you need to understand as an advocate

1. Advocacy starts with YOU

You are the expert of your own community. You see the problems. You have the power to do something about them.

2. Its about knowing your rights

If you know what you are entitled to—like access to health care, social grants, safety—you can demand that government and other leaders deliver on them.

3. It's about joining forces

One voice may be ignored, but when a group comes together and speaks with one message, decision-makers are more likely to listen. AS a community advocate it's important for you to build a TB network.

4. It's about action

Advocacy is not only protesting. It includes writing letters, attending meetings, collecting stories, using media, and showing government what change is needed.

5. It's a roadmap

Advocacy is like holding up a flashlight in the dark It shows where things are going wrong so others can see it too—and together we find the way forward.

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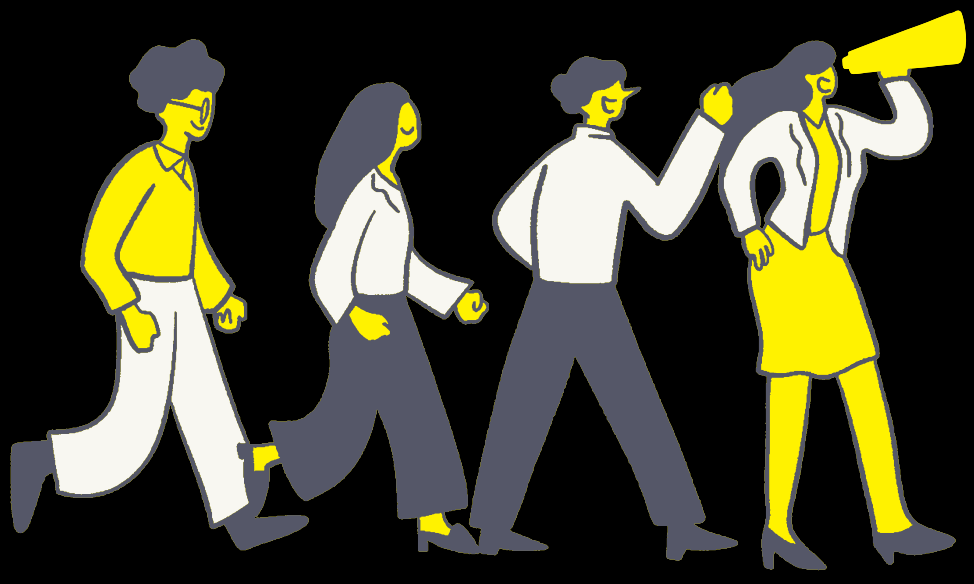
Effective advocacy



Being an effective advocate

This toolkit will help you to become an effective advocate by helping you think about the skills and knowledge you need to do the work of advocacy.

Across South Africa there are everyday examples that show us what effective advocacy is. If a clinic for example, runs out of TB medication and you as the TB champion has a meeting with the ward councillor to fix it, that's an everyday example of advocacy.

There are some basic skills that you can acquire to be an effective advocate:

A Understanding the issue

B Knowing the data

C Having a clear, simple message you can share

D Understanding your local context

E Having an action plan

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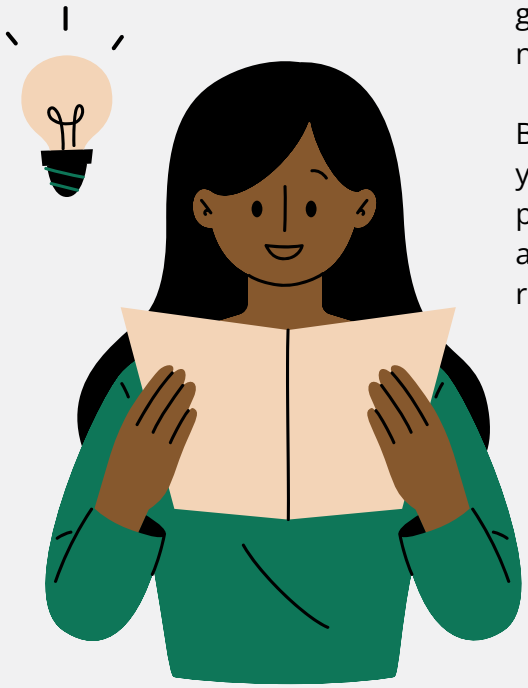
Understanding the issue



As a TB champion who has lived with TB, your experience and your journey is an important part of helping others on their journey and getting the government to understand why TB needs to be prioritised.

But to truly make an impact it would be helpful if you understood the issues around TB and the policies that influence the government's approach to TB and effectively how treatment is rolled out.

Familiarising yourself with TB policies

Whether you're working as a policy advocate or as a community advocate, it is helpful for you to be familiar with the policies that guide your work.

In South Africa, efforts to address TB are guided by three sets of documents:

1. The National Strategic Plan for HIV, TB and STIs (2023 -2028)
2. The National TB Programme's Strategic Plan (2023 - 2028)
3. The National TB Recovery Plan 4.0

To be an effective advocate you need to understand the importance of all these documents and when you need to be able to use them.

Here is a quick access guide to help you:

National Strategic Plan (NSP) for HIV, TB, and STIs (2023–2028)	National TB Programme (NTP) Strategic Plan (2023–2028)	National TB Recovery Plan 4.0 (2025–2026)
This document sets South Africa's goals to end TB by 2030. It aims to reduce TB incidence by 80% and TB deaths by 90% from 2015 levels. It has four goals to improve prevention, diagnosis, treatment, and a better health system. It calls for integrated services, stronger community systems, and bold innovations.	This is the operational roadmap to implement the TB component of the NSP. It focuses on five strategic pillars: 1. Communicate & Advocate 2. Find & Link 3. Treat & Retain 4. Prevent & Prepare 5. Monitor & Assess It emphasises person-centred care, use of data, and innovations like shorter treatment regimens and new diagnostic tools to help end TB.	This is a annual plan to intensify the country's efforts to meet the 2025 targets that will help South Africa end TB. It talks about the importance of strong collaboration between national and provincial departments, healthcare workers and communities. The key target is testing 5 million people for TB in 2025 to find "missing" TB cases and reduce deaths. It has both national and provincial targets around these.

A summary of the National Strategic Plan

The National Strategic Plan for HIV, TB, and STIs (2023–2028) outlines South Africa's renewed commitment to end HIV, TB and Sexually Transmitted Infections as public health threats by the year 2030.

It is a collaborative document developed by SANAC, in concert with NDoH, civil society and partner organisations.

The NSP has four goals:
1. Breaking down structural and social barriers to accessing services;
2. Ensuring equitable access to prevention, diagnosis and treatment;
3. Building resilient and integrated health systems;
4. Fully resourcing and sustaining the response through accountable institutions.

TB disproportionately affects key and vulnerable populations. These are people who previously had TB, people who have been in close contact with someone who has TB, people living with HIV, mineworkers, health care workers and prisoners.

It calls for the strengthening of TB prevention, especially among key populations, and the implementation of robust airborne infection control in healthcare settings and high-risk indoor environments.

The plan emphasises the urgent need to scale up the use of innovative diagnostic tools, treatments, and regimens to close the gap in case detection and new treatment regiments to improve outcomes for people with TB.

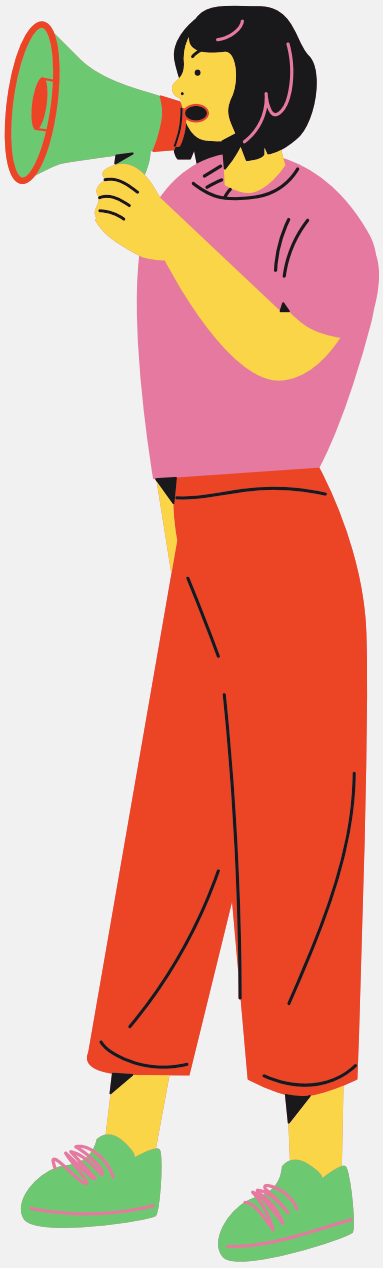
Community-led responses are considered fundamental to TB control. The NSP highlights the need to build the capacity of community-based organisations to deliver TB services, improve health literacy, reduce stigma and discrimination, and address mental health conditions and social support needs, which are often closely linked to TB vulnerability.

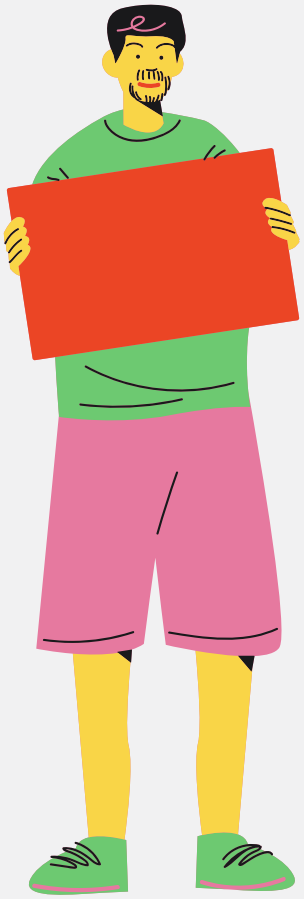
The inclusion of community-led monitoring, policy advocacy, and legal reform to create an enabling environment are also emphasised as key components of a successful TB response.

Integrating mental health into TB care is seen as essential, particularly because between 40% and 70% of people with TB are estimated to experience mental health disorders such as depression and anxiety, which in turn affect treatment adherence and outcomes.

The NSP also calls for expanded laboratory and diagnostic capacity, better supply chain systems, and increased use of data and technology to guide TB service delivery.

It urges the South African government and its partners to invest smarter in TB interventions, ensure adequate domestic and external financing, and strengthen multi-sectoral accountability mechanisms.





A summary of the National TB Recovery Plan

The National TB Recovery Plan 4.0 sets out South Africa's strategy for the period April 2025 to March 2026 to accelerate progress towards the End TB targets by building on previous achievements and addressing persistent gaps.

The plan aims to further reduce both TB incidence and mortality by an additional 5% during the implementation period by testing 5million people over the year.

It hopes to initiate about 60 000 "missing patients" into care. Missing patients are classified as people who know they have TB but are not yet on treatment plans.

Comprehensive monthly targets at both national and provincial level have been set.

The Recovery Plan outlines strategic objectives and measurable targets to help South Africa to test 5 million people for TB in 2025.

The plan prioritises the following objectives:

- Creating demand for TB services through advocacy and communication.
- Identifying and diagnosing more individuals with TB with the target of 5 million tests conducted each year for the next 5 years
- Ensuring linkage to care and improving retention in treatment
- Strengthening TB programmes in high-burden provinces and districts
- Enhancing the use of data for monitoring and decision-making

It highlights the country's high-burden provinces and districts, ensuring resources go where most needed.

It also flags the importance of integrating HIV and TB services because of the high co-infection rates.

And it highlights the importance of testing children, teenagers, men and miners who often fall through the cracks.

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The TB dictionary

Missing patients

In 2023, an estimated 270 000 people in South Africa had TB. However, of those, only 211 800 were actually identified and started on TB treatment.

The estimated 58 290 people who the health system did not diagnose or start on treatment are called “the missed patients.” This is a major gap in health services because many of these people may have actually went to a clinic for services, but never tested, or because TB testing services continue to be clinic-based. Either way, these people continue to have TB, but not provided the treatment needed to cure them.

If we can reach these people with the right health services, we will be able to increase the number of people on treatment, reduce the number of deaths and slow down or stop TB from being transmitted in our communities.

The people missed by the health system are different in different provinces.

It centres the community’s role by recognising the importance of community-based case finding and screening, campaigns to reduce stigma, and how collaboration with traditional leaders, healers, civil society, and faith-based groups can help in increasing TB testing efforts.

Targeted Universal Testing for TB (TUTT)

Targeted Universal Testing for TB is a policy that recommends that people at higher risk of TB be tested irrespective of whether or not they have symptoms. People at high risk for TB include those living with HIV, people who are contacts of a TB patient within the past year, or people diagnosed with TB in past 2 years. If the person tests negative, they are eligible for TB Preventative Therapy, which is known as TPT.

Each person with significant exposure to, or risk of having TB, should be tested and offered either preventative therapy or TB treatment. This is known as the TB test and treat approach.

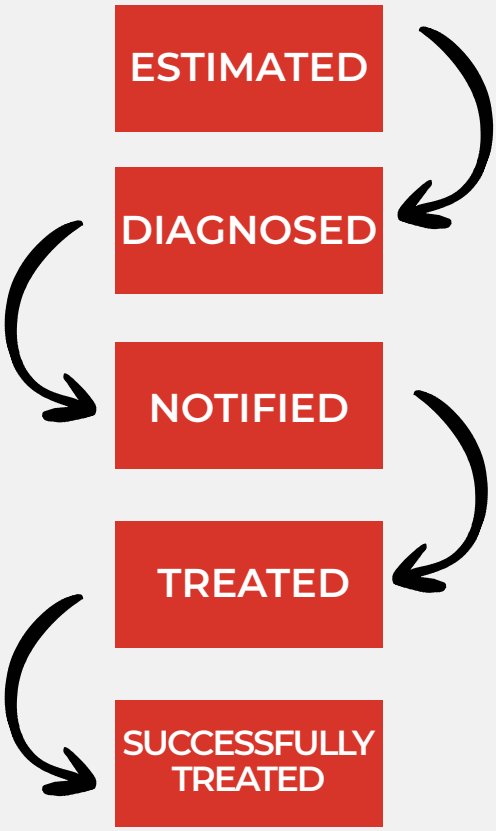
This testing policy is important because previously, only people that had signs and symptoms of TB (i.e., cough, fever, night sweats or weight loss) were tested. We now know that people can have TB but not always show typical signs and symptoms. Offering TB testing to everyone at risk, not just those with signs and symptoms, helps to expand health services to those that need it.

The TB care cascade

The TB care cascade is a way of monitoring how the health system gains and loses patients through the journey of TB. This is monitored from the time that they are thought to have TB, through to them taking a TB test, then being notified of the results, being initiated onto treatment, staying on their treatment and then finishing the course of treatment and leaving the health system.

The data in South Africa shows that we lose patients throughout this cascade. We now know that in 2023, there were 270,000 people who were estimated to contract TB.

Of these, 193,326 were diagnosed with TB. But only 135,036 were notified that they had TB. This shows that there are 58,290 people who were diagnosed with TB but did not start treatment. They are considered missing patients.



TB prevalence vs TB incidence

TB prevalence and incidence are distinct measures of the TB burden in a population. Prevalence refers to the total number of TB cases (both new and existing) at a specific point in time, while incidence refers to the number of new TB cases reported over a specific period, typically a year.

TB Preventative Therapy

Targeted Universal Testing for TB is a policy that recommends that people at higher risk of TB be tested irrespective of whether or not they have symptoms. If the person tests negative, they are eligible for TB Preventative Therapy, which is known as TPT.

This testing policy is important because the biggest gaps in South Africa's TB epidemic is with people who in the care cascade of TB – or the journey that people go through from the time that they believe they have TB until the time that they finish their treatment.

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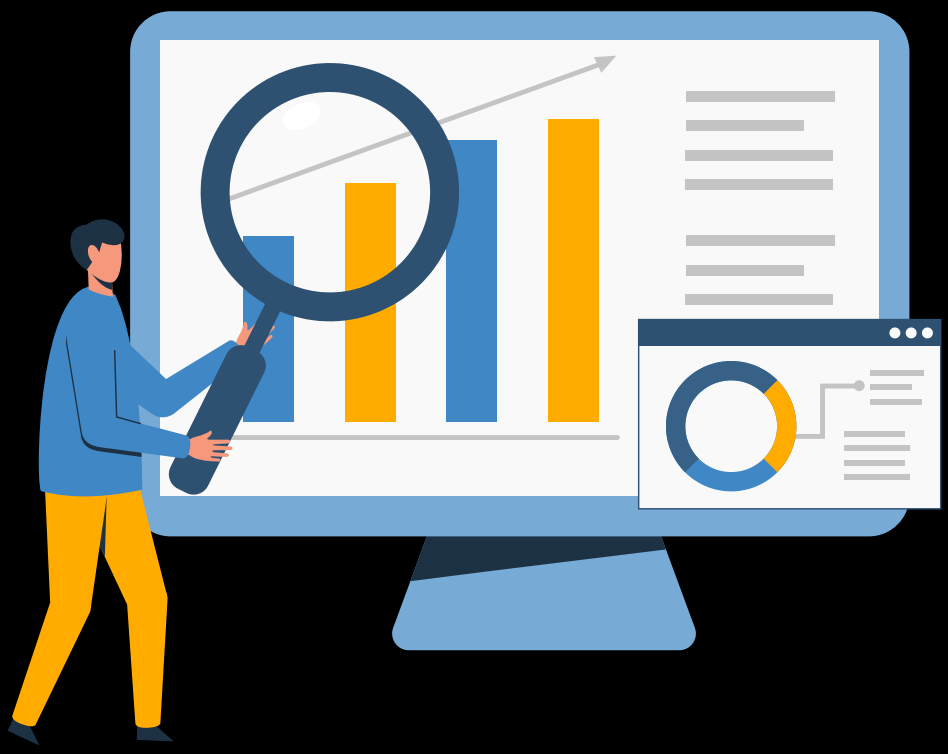
Using data to drive advocacy



Making a difference with data

The best way to convince people that something needs to change is to use the evidence that shows them what the problems are.

In TB we can use data-driven advocacy to highlight the scale of the epidemic, the gaps in service delivery, and the urgency of investing in prevention, diagnosis, and treatment.

This approach involves gathering and analysing data—such as TB incidence rates, treatment success rates, the people missed by the health systems, which groups of people are in need of targeted services, and the socio-economic impacts of TB—to build compelling, fact-based arguments for policy change and resource allocation.

Data can expose differences across provinces and districts. It can show how TB affects vulnerable populations and track the effectiveness of current interventions.

For example, evidence might reveal that certain communities have higher rates of drug-resistant TB due to limited access to diagnostic tools or treatment adherence support.

Presenting this information to decision-makers, funders, and the public strengthens the case for targeted investment and reform.

Data-driven advocacy also makes it easier to hold governments and health systems accountable.

When activists and communities have access to the numbers, they can ask better questions, demand better outcomes, and participate meaningfully in shaping TB responses that reflect their lived realities.

Understanding the targets: what are they and why they matter

In short, data turns advocacy into action. As a community advocate, if you understand what the data trends say, you can use it to inform the advocacy activities that you engage with your communities to create change.

For 2025, the big goal for the National Department of Health is testing 5 million people for TB so that we can diagnose 241 000 people.

Testing 5 million people will help the National Department of Health rapidly identify undiagnosed TB and improve the number of people start treatment.

But this will only work if testing is targeted at the right people, in the right places, and at the right times.

This large increase in testing can also get people diagnosed before they become really sick. By doing this, the government estimates it can reduce the number of people who die from TB by 5%. This number may seem small, but it amounts to 2800 less deaths for 2025 alone.

By increasing testing, getting more people on TB treatment, and helping people complete their treatment, we would help break the chain of TB transmission in our communities.

Numbers you need to know as an advocate

This is the number of people estimated to develop TB. In 2023, an estimated 270,000 people developed TB, including 13,000 (5%) with Drug Resistant TB.

270K
TB cases

This is the number of people who died from TB in 2023.

56000
Deaths

The campaign target

We need to test 5 million people for TB in 2025/26.
This means we must reach 416 667 people each month. Each province and each district has a number of tests to reach.

5 million
Tests

The problem

Currently there are about 58 000 people living with TB that the health system still has not diagnosed and started on treatment. Data has helped us estimate how many of these people are men or women, and their ages. Specifically, men make up 55% of those that still have not been diagnosed by the health system, and 42% of people with TB aged 15-35 years remain undiagnosed and not treated.

58000
missed patients

1

3.64 million

people tested for TB in 2024

2

190 474

people with lab-confirmed pulmonary TB in 2024

3

61%

of people with TB who are adult men (2023)

4

46%

of people with TB living with HIV (2023)

5

83%

of people completing their treatment for Drug Sensitive TB in 2023

08
Your advocacy message

Spreading the message

This year's goal is to increase testing to improve case finding around TB.

To help do this, the National Department of Health has a message that it is spreading. The message is "We need to test to End TB: Every Test Counts, Every Life Matters."

The idea behind the message is simple: **Find TB early, treat it quickly, stop the spread.**

As a TB champion going into the community, you can use this message to amplify the calls of the department to get people to test for TB.

But as a person who has had TB you can also use your experience and your journey to encourage people to test.

We have put together some potential messages that you can use to help convince people why they need to get tested for TB.

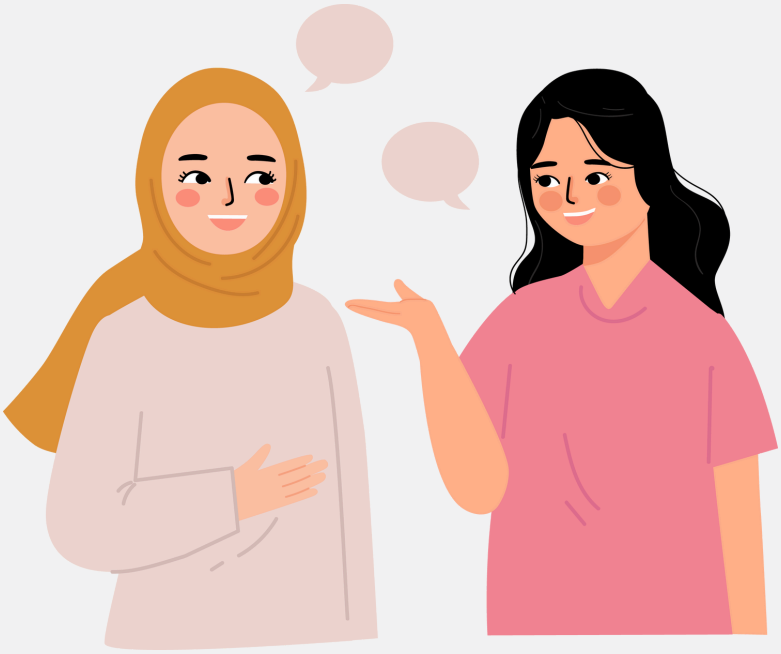
Using your story

- **Anyone can get TB – and anyone can be cured**
  TB does not discriminate. It can affect anyone, regardless of age, gender, or background. The good news is that it can be treated and cured with the right support.

- **Getting tested for TB is a sign of strength, not weakness**
  It takes courage to take care of your health. Getting tested helps protect your family, friends, and community.

- **The sooner you know, the sooner you can get treated – and the sooner you can get better**
  Early testing means early treatment. It saves lives and prevents the spread of TB to others.

- **TB is not a curse or a punishment – it's a disease like any other.**
  Just like diabetes or high blood pressure, TB is a medical condition that needs proper care. There is no shame in having it, no shame in getting help and lots of pride for defeating it.



- **There is free treatment for TB – and you don’t have to face it alone.**
  Testing and treatment are available at no cost at public clinics.

- **If you are coughing for more than 2 weeks? Don’t wait – get tested for TB.**
  If you or someone you know has a persistent cough, weight loss, night sweats or fatigue, it's important to get checked. It might not be TB, but it’s better to know.

- **Breaking the silence around TB starts with us.**
  Let’s talk about TB openly. The more we talk, the more people we can reach – and the more lives we can save.

- **You are not alone. Hundreds of thousands of South Africans have beaten TB – and you can too.**
  People recover from TB every day. With support and the right treatment, you can too.

09

Understand the local context

How does TB affect your community

So far we have spoken about the key information you need to know about TB, how you can use the data to inform your advocacy and some of the key messages that you can use when you are convincing people to get tested.

Now we want to focus on the work that you do in your communities.

To help you tackle TB in your community as a TB champion you need to know what data in your specific community you can use to convince people what the biggest challenges are around TB and why they need to take action.

Below we have listed some of the key pieces of information that you need to know when you are working on TB in your community

How does TB affect your community

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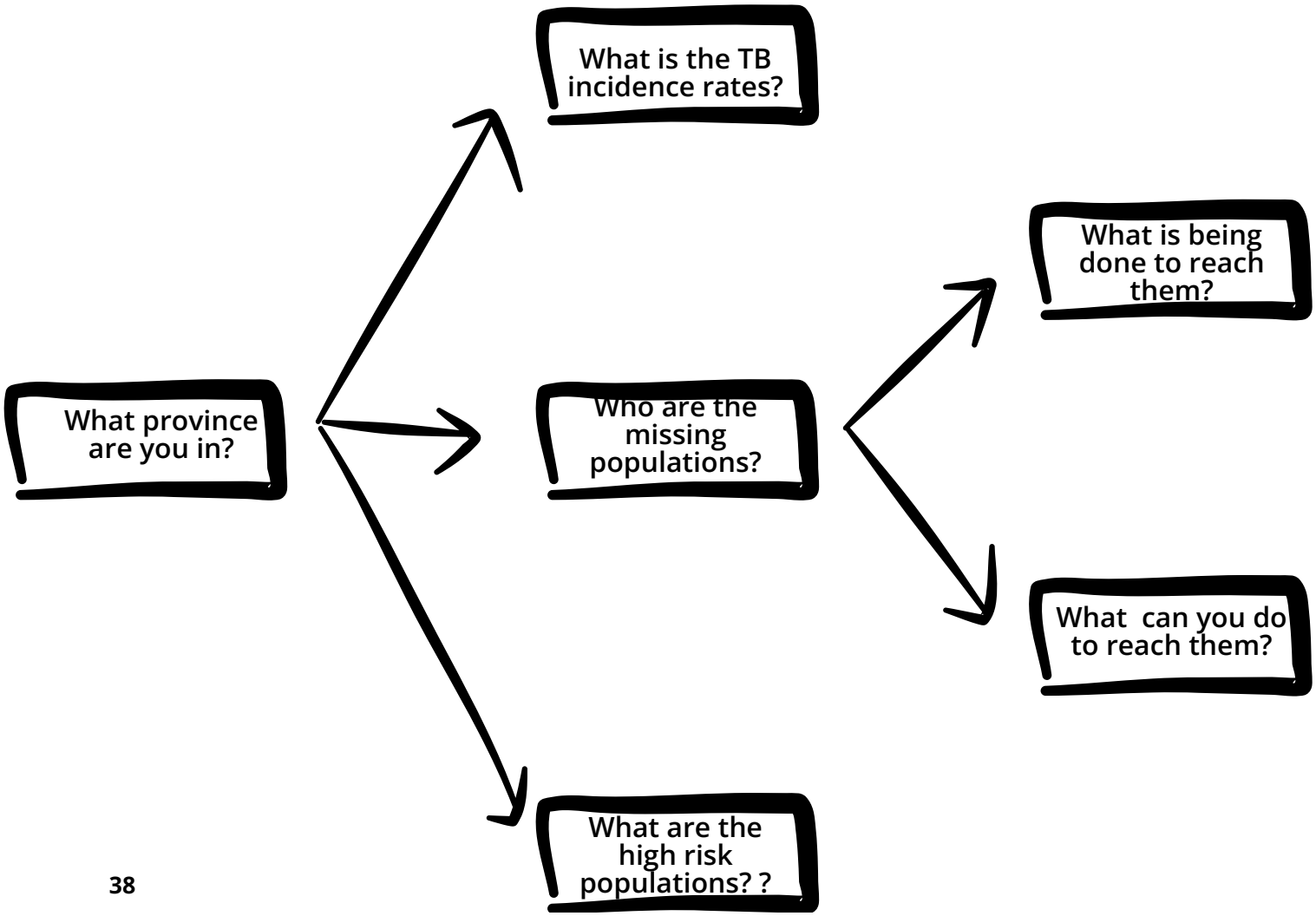

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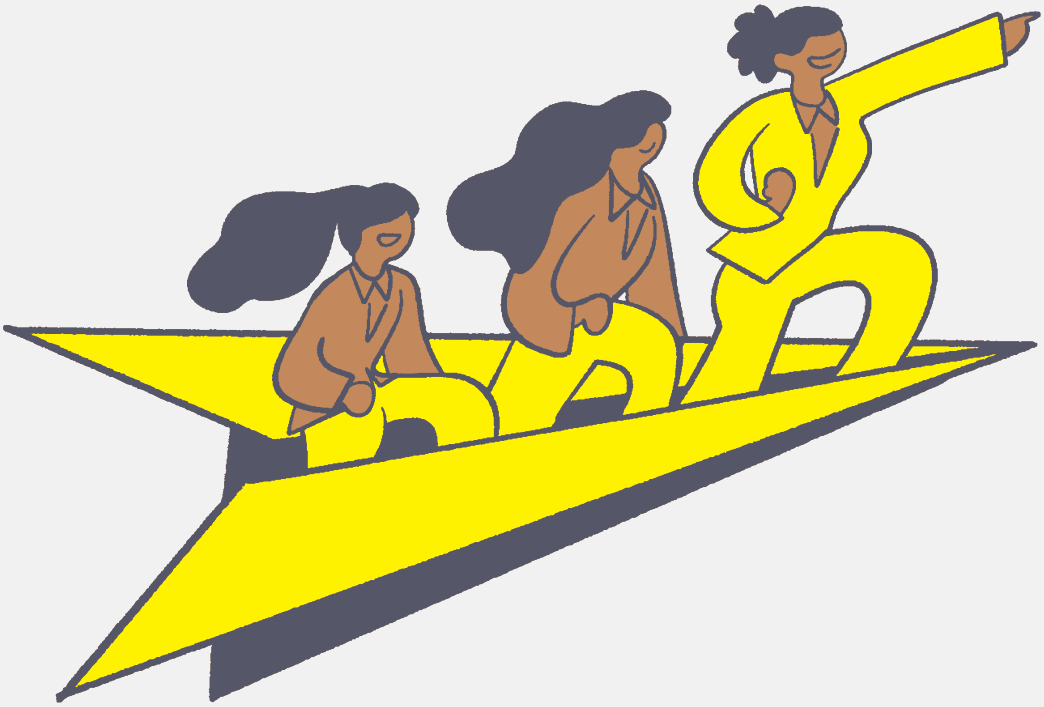
Putting together an action plan



Every effective advocate has an action plan. Now that you have the knowledge, the message and the data, you need to think about the advocacy initiatives that you can do in your community to beat TB.

These could include monitoring TB testing that takes place at your local clinic to make sure the clinic is testing people or helping people in your communities better understand who is at risk for TB and driving demand creation for people to get tested.

There are some simple advocacy techniques that you can incorporate into your work to help improve the TB response.

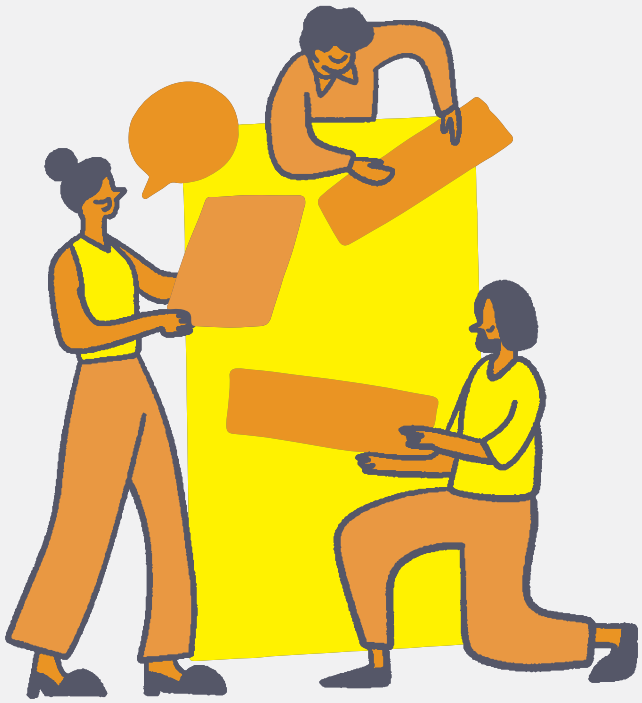
Here are a few ideas:

1. Monitor and report the gaps in service delivery at clinics

By using the data that you have gathered on how many TB tests need to be done in your province, district and local clinics, you can monitor the testing outputs at all levels of the health system.

This would be particularly helpful in provinces where the high burden TB districts are located. Here you can see how many tests were completed if there has been an improvement month to month and if the district is getting closer to its target.

As part of the monitoring, you can create a TB scorecard that shows how the local district compares, and you could share these with local advocacy groups and SANAC.



2. Educate communities on testing

You could also partner with local churches, mosques, Faith-Based orgsanisations, neighbourhood grouping and youth networks tohave information sessions that helps people understand why they should get tested for TB.

You could host small groups at a local hall where you share your TB story and encourage them to be part of the solution.

If you have neighbourhood groups you could also organise door-to-door symptom screening campaigns that refer people for testing.

3. Host a testing day

Once you have mobilised the community, you could host a testing day. Here you could partner up with the district Department of Health to do the testing.

Your job would be to encourage community members to get tested and to offer them support at the site so that they know they are not alone in this TB journey.

4. Set up an advisory desk at the local clinic

As someone who has lived with TB, you know the challenges that people could face when they have TB or even when they suspect they have TB. Stigma can result in people not starting treatment and not completing their treatment.

To help solve this problem, why not speak to your local clinic and set up an advisory table at the clinic where you can provide support for people with TB.

You could become an accountability partner for a person who needs encouraging words and reminders to take their medication. And you could build a community network that walks with people on their illness to health journey, from the point when they are diagnosed with TB, to when they start treatment, their treatment journey, and when they finish their treatment and are cured.

5. Create a TB network

As a TB champion you know best how difficult it is to stay on your treatment and to feel motivated to finish your house. It's so easy to lose hope.

When you have a friend, teacher, family member or even a healthcare worker who sends you motivation, you feel encouraged to continue.

In your community you could be that motivational voice. Why not start an accountability network making sure people at your clinic who have been diagnosed with TB take their medication. You could use face-to-face sessions to be an accountability partner or you could start a WhatsApp or Facebook group.

Your WhatsApp or Facebook group could also encourage others in the community to get tested, to share their TB stories and to report problems that they have.

You could also use this group to share factsheets about TB that can help to educate the community about TB and their role in the fight.

You could develop an entire network of TB champions that make sure the community becomes TB free.

Thank You

These are just a few ideas to get you thinking about how you can be an effective advocate.

As someone who has been working in your community you may have better ideas on how you can engage people to understand the importance of getting tested for TB.

It's important to remember that you don't always only have to engage people when they are in a healthcare setting – you could engage them at the shopping mall on a Saturday, as a special presentation during community hobby club meetings and senior citizen gatherings.

There are a wide variety of times that you can find people. But as someone who is working in the community, you will know what would work best.

We hope you feel inspired as a TB champion and community TB advocate!

Reach out to TBAC

Website	www.tbac.org.za
Email	info@tbac.org.za
Facebook	@TBAccountabilityConsortium
X	@TBAC_sa

The Civil Society Advocacy Toolkit is an initiative of the TB Accountability Consortium. The consortium is a platform created to co-ordinate and consolidate advocacy for improved TB services at all levels of government. It works to hold government and non-governmental organisations to account to ensure adequate budgets, comprehensive plans and the effective implementation of such plans.