



**Accountability
Consortium**

TBAC

STAKEHOLDER REPORT 2025

**Reflecting on a year of community insight, advocacy,
and progress in South Africa's TB response**

An annual report by the TB Accountability Consortium.



**AS WE LOOK AHEAD,
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CONFIDENCE THAT
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**TOGETHER,
WE CAN
-- AND WILL --
END TB.**

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01

FOREWORD

The foundations of possibility have been laid. Opportunities are now on the horizon.

What started out as a year of volatility, uncertainty and seeming chaos in the health sector in South Africa is culminating in year of possibility.

When US President Donald Trump issued notices announcing widespread freezing of its foreign assistance in January this year, many in the healthcare sector were left stranded.

In South Africa alone, according to our calculations, the funding accounted for more than USD488million – or R7 billion, covering 24 000 employees, stationed within public healthcare facilities providing both patient and support services.

The dismal narrative that accompanied these cuts would, however, not survive.

Despite these constraints, we have continued to make meaningful progress in strengthening South Africa's TB response.

In March the National Department of Health launched the End TB Campaign to accelerate testing and awareness, reaffirming our collective ambition by calling on us to help reach the target of testing 5million people for TB. The idea was that we would initiate another 240 000 people onto treatment.

These gains are as a result of collective efforts over the last four years. The last year, in particular, saw civil society march to the department of health demanding action and the department responding with a series of actions that could integrate civil society into the response.

In addition the National Department of Health in conjunction with the National Health Laboratory Services have since unveiled the public-facing TB dashboard, as prompted as civil society. This is a milestone that has begun to transform how we think about transparency, accountability, and the power of data in driving real change from both the department side and civil society.

And in October, the South African National Aids Council relaunched the South African chapter of the Global TB Caucus – a move that reaffirms political commitment to making TB a national priority, spotlighting the need for increased focus on an age-old disease that is preventable and curable – but still remains the number one infectious disease killer in South Africa claiming the lives of 56000 people every year.

Back home at the TB Accountability Consortium, heeded the call to find ways to accelerate testing. Doing what we do best, we focussed our efforts on advocacy by developing a civil society advocacy toolkit to galvanise the enthusiasm of TB advocates across the country and help them see the value of the work that they do.

This has been met with an advocacy support programme to boost their abilities to host events that would destigmatise TB in their communities and encourage testing, particularly among those 60 000 people who are missed by the National Department of Health each year.

Through these achievements collectively, we have laid the foundations for a more people-centred TB response — one where advocates in communities can direct the agenda based on the realities, they face every day. Under normal circumstances, politics dictates the pace and priorities of health systems. But through our work with local partners, civil society, and researchers, we are helping shift that balance -- allowing people to influence their environments by participating in all forms of local accountability.

We are ending this year with a renewed sense of direction and a stronger collective will to narrow the missed patient gap. Across provinces, communities are beginning to see the value of using data not just for reporting, but for action. The reality is that good data gives people the opportunity to activate their voices and shape the response around what matters most -- access, dignity, and justice.

As we look ahead, we do so with confidence that the partnerships we have built and the advocates we continue to support will carry this work forward. Together, we can -- and will-- end TB.

Thank you for contribution. Thank you for your trust. And thank you for your co-operation. The success that has been recorded by TBAC could not have been possible without you, our partners.

We look forward to another year -- one where we concretize the possibility that has formed this year and where we move one step closer to our end goal of ending TB in our lifetime.

Yours in advocacy,

Russell Rensburg,
TB Accountability Consortium

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02

THE YEAR THAT WAS

2025: A year of listening, learning and levelling up the TB Response

From launching reports to petitioning politicians, submitting comments on the budget to developing advocacy plans and training community members, it's been a busy year for the TB Accountability Consortium.

For the consortium the activities that have captured the last 11 months have all fallen within the central themes of advocacy, accountability and community engagement.

And these have been underpinned by key partnerships, an ongoing agenda to be guided by data and the overarching mandate of improving the implementation of South Africa's National Strategic Plan.

The goal at the end of the day? To improve the way in which TB is implemented in South Africa so that we reduce deaths and increase testing.

For TBAC, 2025 has been a year of possibility and progress as we petitioned political leadership to understand the importance of making TB a national priority.

ADVOCACY IN ACTION: LISTENING TO COMMUNITIES

The central concept around advocacy is the idea that people are able to partner up to raise their voices and influence decision-makers to bring about change.

One central partnership has been the work the consortium has undertaken with the SA National Aids Council Civil Society Forum's TB Technical Task Team.

Aside from allowing the consortium to input into key national discussions around TB, it has resulted in the relaunch of the South African TB Caucus where parliamentarians were able to reaffirm their political commitment to TB through the Barcelona Declaration.



The declaration symbolises a renewed era of leadership, partnership, and cross-sector collaboration in the fight against TB.

On a provincial level the partnership has also allowed TBAC to provide key technical assistances that has resulted in the formation of civils society forums in both the western and Eastern Cape provinces.

But the partnership with SANAC was not the only key partnership that came about this year. TBAC also welcomed the AIDS Healthcare Foundation (AHF) and the National institute for Occupational Health as new partners into the consortium, strengthening our collective response to TB and HIV. This partnership highlighted the importance of tackling stigma, improving integrated care, and addressing the social determinants of health that drive TB — from poverty to overcrowding.

And while we engaged with politicians and national stakeholders, we kept an ongoing presence online through media advocacy.

We launched a new campaign Lalela and re-energised our ongoing Sitshele campaign to advocate to policymakers and decision makers.

Lalela: Is'khathi Soku Lalela is directly translated

as "it's time to listen," and it's directed at politicians. The campaign captured TBAC's central message: policymakers must listen to those on the ground and act on the voices of communities living with and affected by TB.

Through storytelling, short videos and targeted online advocacy, Lalela brought policymakers face to face with the human realities behind South Africa's TB crisis. The campaign called for TB to be recognised as a national emergency, for testing and resources to be scaled up, and for government to fully implement the National Strategic Plan (NSP).

Sitshele meaning "tell us" is our campaign to make TB a national health emergency by encouraging people to share how TB has affected them and their families. As part of the campaign, we collect stories from people affected by TB across the country to show government and policymakers the real impact of the disease and why it must be treated as a national priority. This year, Sitshele continued with a focus on testing, expanding the campaign from one language to isiXhosa (Thetha), and Afrikaans (Spieg). Positive stories have been aimed at reducing stigma and motivating others to get tested, while stories about challenges were meant to help identify gaps and keep government accountable.

DRIVING POLITICAL ACCOUNTABILITY

Political accountability has become somewhat of a buzzword in SA.

At TBAC, however it's at the core of what we do: **holding politicians to account.**

Our efforts at political accountability this have included launching our 4th State of TB in South Africa Report, From Crisis to Opportunity: Accelerating Testing to End TB. The report underscored the urgency of data-driven decision-making and called for stronger oversight through a public-facing TB dashboard.

We've once again gone to Parliament to present before the Standing Committee on Appropriations, calling for improved oversight of TB funding and stronger provincial implementation mechanisms.

BUILDING CIVIL SOCIETY POWER

As critical as all these initiatives are, we have continued to keep communities at the centre of our narrative.

This is because it's impossible to fight TB without the support of the communities it affects most.

So to help our communities TBAC also launched its Civil Society Advocacy Toolkit, Tackling TB in

Our Communities, to empower local advocates. The toolkit equips TB champions with practical knowledge to advance advocacy in their communities.

However, we did not stop there.

In the Eastern Cape we took the toolkit to all five districts training local advocates on the importance of their roles in the fight against TB.

And in the Western Cape, we joined forces with partners such as TB Proof and the SANAC Civil Society Forum and other local TB organisations to host the TB Summit in Khayelitsha. The summit amplified survivor voices, bridged research and lived experience, and strengthened collaborative action between communities and policymakers.

LOOKING AHEAD: TURNING POSSIBILITY INTO PROGRESS

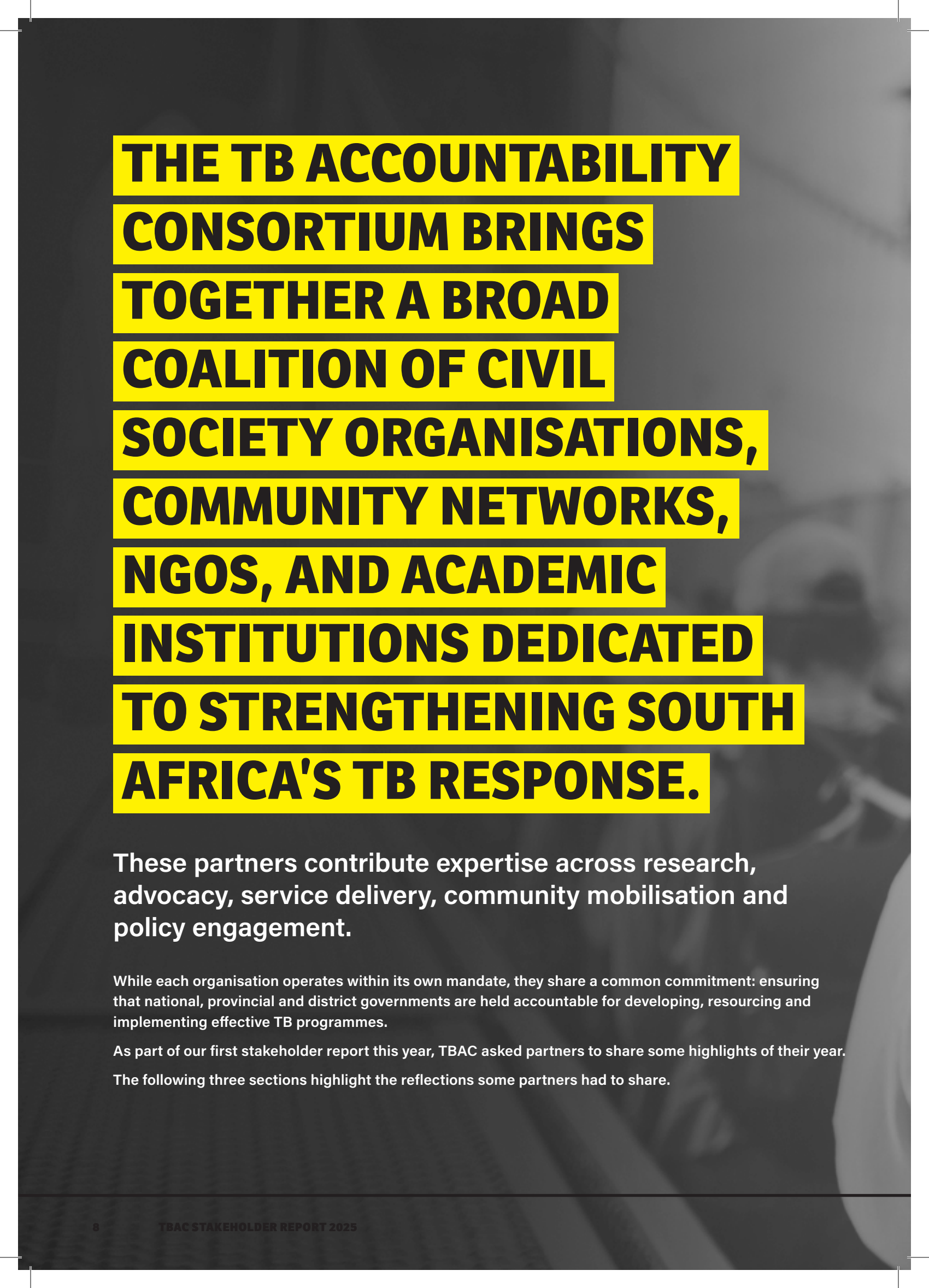
As 2025 draws to a close, the TB Accountability Consortium stands at the threshold of a new phase. TBAC's work this year demonstrated that when communities are empowered, data is made visible, and leaders are held accountable, South Africa can close the gap on missed patients and move closer to ending TB.

The year reminded us that advocacy works, accountability matters and communities are --and always will be -- at the heart of the TB response.





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THE TB ACCOUNTABILITY CONSORTIUM BRINGS TOGETHER A BROAD COALITION OF CIVIL SOCIETY ORGANISATIONS, COMMUNITY NETWORKS, NGOS, AND ACADEMIC INSTITUTIONS DEDICATED TO STRENGTHENING SOUTH AFRICA'S TB RESPONSE.

These partners contribute expertise across research, advocacy, service delivery, community mobilisation and policy engagement.

While each organisation operates within its own mandate, they share a common commitment: ensuring that national, provincial and district governments are held accountable for developing, resourcing and implementing effective TB programmes.

As part of our first stakeholder report this year, TBAC asked partners to share some highlights of their year. The following three sections highlight the reflections some partners had to share.



03

PARTNER FOCUS

TB PROOF: turning advocacy into impact in the Western Cape and beyond

Over the past three years, TB Proof focused on strengthening accountability of national, provincial and district Departments of Health for delivery of TB testing as outlined in the TB Recovery Plan.

As a foundation for this work, we conducted stakeholder interviews and published findings in a peer-reviewed journal, which informed recommendations to close policy implementation gaps. TB Proof leveraged existing accountability platforms to highlight gaps in TB policy implementation and influence decision-makers.

At national level, TB Proof participated in the SANAC Civil Society Forum TB Task Team and the newly established TB Technical Task Team to co-develop advocacy letters. These letters were submitted to the Minister of Health in 2023, 2024 and 2025. A key advocacy ask — establishing a public facing TB dashboard — was realised when the NDoH launched the district-level dashboard on 24 October 2025. At a provincial level, we developed an advocacy letter to the Western Cape HoD to scale up TB testing.

To strengthen provincial implementation of the Targeted Universal TB Testing (TUTT) policy, TB Proof drafted a Standard Operating Procedure

for operationalisation within Cape Town Metro TB services and is part of the technical working group for finalisation. The SOP was presented and adopted at the provincial management in August 2025. This process positions TB Proof as a supportive collaborator to the Western Cape DoH while also maintaining pressure for implementation progress.

TB Proof's engagements with primary health care facilities in the Khayelitsha Eastern Substructure identified testing challenges and the need for a coordinated district-level approach. TB Proof co-hosted the Khayelitsha TB Imbizo in March 2024 and secured commitment to monthly TB meetings, which have continued and become more structured. TB Proof also led the pilot of TB Contact Cards at Michael Mapongwana Clinic, resulting in 485 cards distributed, 83 returned (17%) and 126 contacts initiated on TPT to date. Contact Cards are now being piloted at a second site and will be rolled out metro-wide as part of the

“Close The Gap” campaign. TB Proof led the development of the SOP to support this scale-up.

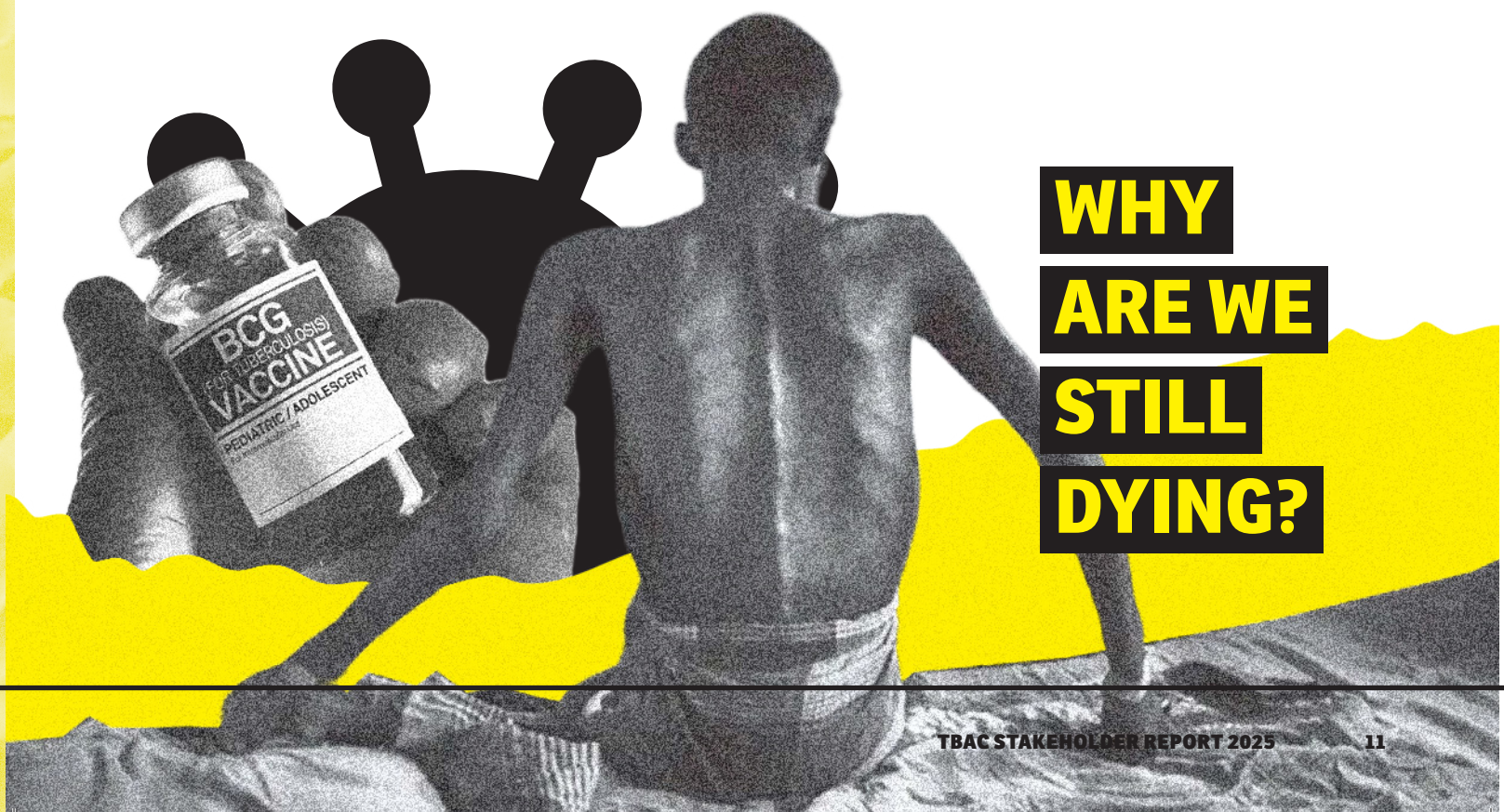
TB Proof strengthened civil society and community advocacy by training and mentoring TB Champions. From July 2023, 11 local Delft champions were trained on TB policy, stigma, and TUTT, and implemented ThinkTB campaigns through community events, social media, traditional media and local testing initiatives. Champions presented advocacy priorities to Delft CHC, resulting in invitations to facility meetings to prioritise TB testing and data review. In April 2025, 18 Khayelitsha champions were trained to pilot Community-Led Monitoring (CLM) tools in facilities, linking community feedback to facility action. TB Proof co-developed TB pamphlets and posters which were endorsed, printed and distributed by the Western Cape Department of Health & Wellness on TB care, including testing, reaching over 10 000 people. Early CLM data highlighted gaps in TUTT/TPT training and the need for offsite testing, informing co-planned Quality Improvement initiatives.

The Delft TB Champions project contributed to a reduction in TB test positivity at intervention sites, with Delft CHC decreasing from 15.2% in 2022 to 10.3% in June 2025, and Elsies River Clinic from 15.4% to 13.0%. A video was commissioned to showcase the impact of the Delft TB champions’ work.

Across national, provincial, facility, and community levels, TB Proof’s work strengthened accountability, supported community-led advocacy, enhanced collaboration, and supported sustainable mechanisms for policy implementation.

LESSONS LEARNED

Early engagement with health authorities and community leaders proved essential for co-creating tools like the TB Contact Card and IEC materials, fostering ownership and sustainability. TB Champions played a pivotal role in increasing TB testing and reducing stigma through trusted community relationships and active engagement with health workers. Their feedback highlighted the need for after-hours and community-based testing, locally produced IEC materials, and partnerships to address food insecurity during testing drives. Finally, we learned that well-organised events—with administrative support and interactive, age-appropriate activities—significantly improved participation and testing uptake, reinforcing the importance of combining structure with community-driven energy.



**WHY
ARE WE
STILL
DYING?**

04

PARTNER FOCUS

AIDS Health Foundation: expanding reach and deepening impact in 2025

In 2025, the AIDS Health Foundation (AHF) intensified its efforts to strengthen South Africa's fight against TB through a series of high-impact initiatives spanning multiple provinces.

CHAMPIONING CHILDHOOD TB AWARENESS IN KWAZULU-NATAL

In KwaZulu-Natal, AHF anchored the province's World TB Day commemorations through the "Stop TB in Children" campaign, held at the KwaMashu Community Residential Units (CRU) in Durban. The initiative targeted children and families from the units and surrounding schools — two secondary and four primary schools — with educational activities and resources designed to improve understanding of TB symptoms and prevention.

Working in partnership with the Department of Health, eThekweni Municipality, Aurum Institute, Health Systems Trust, Zoe Life, Khula Youth, and the Gugu Dlamini Foundation, the event combined awareness-raising with service delivery.

Children received educational packs, and adults were offered a suite of health services including TB screening, laboratory specimen (GeneXpert) collection, chest X-rays, mental-

health assessments, and nutritional screening. The event underscored AHF's holistic approach to TB care: blending education, prevention, and early diagnosis with community empowerment.

EXPANDING SCREENING AND TESTING IN THE EASTERN CAPE

The Dutywa TB Drive in the Eastern Cape was a standout example of community-based screening at scale.

Over several days in April 2025, AHF and its partners — TB/HIV Care, NHLS, Mbashe Sub-District Health, Acuity Innovations, and traditional leaders — conducted coordinated TB drives across multiple localities, including Govan Mbeki Hall, Dutywa Grounds, Sofute Hall, and Mangati Komkhulu.

The campaign achieved remarkable reach: over 230 chest X-rays were conducted across four events, resulting in dozens of abnormal findings that led to follow-up sputum testing.



WITH ACTIVITIES IN KWAZULU-NATAL, THE EASTERN CAPE, AND GAUTENG, AHF DEMONSTRATED ITS COMMITMENT TO BRINGING TB AWARENESS, SCREENING, AND TREATMENT CLOSER TO COMMUNITIES MOST AFFECTED BY THE DISEASE -- AND TO THE HEALTH WORKERS WHO SERVE THEM.

Across the drives, over 140 sputum samples were collected, with multiple TB cases diagnosed and initiated on treatment the same day. In addition, more than 90 individuals underwent HIV testing, with all who tested positive started on treatment immediately.

These outcomes reflect a robust model of integrated TB and HIV service delivery — made possible through collaboration between government, civil society, and innovative private sector partners. The Dutywa initiative not only identified new TB cases but also strengthened trust between communities and the health system, while building the capacity of outreach teams through shared learning.

BUILDING SKILLS AND CAPACITY ACROSS GAUTENG

In Gauteng, AHF continued its focus on health-care worker capacitation and community-based testing. Across the Johannesburg and Sedibeng health districts, 52 community health workers received training on Targeted Universal TB Testing (TUTT) and Point-of-Care diagnostics such as urine-LAM (U-LAM). An additional 200 nurses, doctors, and data capturers were trained on TB screening and testing protocols, including modules on drug-resistant TB. AHF's role as a training facilitator in the province's Basic TB and DR-TB courses further cemented its leadership in knowledge transfer and health-system strengthening.

Complementing in-person efforts, AHF hosted a virtual TB webinar that engaged 79 University of Johannesburg students, using animated learning tools to explain TB transmission, prevention, and the importance of early detection.

AHF's on-the-job refresher trainings in three Johannesburg Health District facilities — ORT CHC, Cosmo City Clinic, and Braamfischer Clinic

— reached 33 clinicians, while quarterly district-wide training sessions at Sizwe, Helen Joseph, and Sandton facilities equipped over 200 clinicians to improve TB/HIV integration and case management.

AHF also played a prominent role in World Stop TB Day build-up activities across the West Rand District. The foundation led campaigns at Cosmo City Clinic and supported events at Braamfischer and Extension 7 Clinics. At the Gauteng regional main event, AHF's presence was felt through large-scale awareness drives targeting mining-sector workers and their families. Over 11,500 condoms and information materials were distributed, reinforcing the connection between TB, HIV prevention, and overall community well-being.

Through its 2025 initiatives, AHF reached a variety of South Africans — from children in KwaMashu to miners in Gauteng and rural families in Dutywa. Its integrated model of education, testing, treatment, and training continues to bridge the gap between policy and practice, empowering communities and health workers alike.

As South Africa advances toward its goal of ending TB, AHF's provincial footprint and collaborative partnerships stand as vital pillars in the national response.



05

PARTNER FOCUS

How TBHIV Care is contributing to strengthening TB Accountability

Over the past year, TB HIV Care advanced a community-centred TB advocacy and accountability agenda, strengthening partnerships, promoting data use, and preparing for the 5 Million End TB Campaign launched in April 2025.

TB HIV Care supports public health service delivery and health systems strengthening in priority Eastern Cape districts: Amathole, Chris Hani, and OR Tambo, due to their high HIV burden.

Despite national gains reflected in SABSSM VI (overall national prevalence declining from 14.0% in 2017 to 12.7% in 2022), the Eastern Cape continues to carry a high and uneven HIV burden that threatens progress toward epidemic control. SABSSM VI data show particularly high prevalence in the sexually active 25–49 year age group (27.7%), with a striking sex disparity: women aged 25–49 have a prevalence of 35.4%, compared with 17.1% among men of the same age. At sub-provincial level, several districts (Chris Hani, Amathole, Alfred Nzo) report double-digit prevalence (13.9–14.4%), while other districts (for example, Nelson Mandela Bay at 9.7%) show lower,

but still substantial, levels. These patterns point to concentrated transmission among adult women and to geographical “hotspots” where prevalence remains high; they also expose gaps in prevention and treatment coverage, gender-sensitive programming, and targeted district-level responses. Without intensified, age- and sex-tailored prevention, improved linkage to care, and district-focused resource allocation informed by the SABSSM VI findings, the Eastern Cape risks persistent transmission, continued inequities in HIV burden, and setbacks to provincial and national HIV control goals.

In collaboration with the Western Cape Department of Health, THC provides community-based, targeted universal testing for TB (TUTT) for close household contacts of people with TB. TUTT is an important strategy for TB control.

In the Western Cape undiagnosed and untreated TB significantly contributes to ongoing transmission, with one infectious person potentially infecting 20 or more people annually. In South Africa, TB is fueled by poverty, inequality, migration, and limited access to timely screening. Between 1 August 2023 and 16 August 2024, the Western Cape recorded 349,149 GeneXpert/NAAT tests, confirming 50,392 TB cases (14.8% positivity) and 4,453 TB-related deaths. While

tackling TB and HIV remains top priority, the Western Cape government also emphasizes broader health goals, including promoting healthy lifestyles, reducing violence, and strengthening mental, maternal, and women's health.

These strategies are aligned with UNAIDS 95-95-95 targets, it focuses on finding missing cases, expanding HIV treatment and retention in care, achieving viral suppression, and addressing TB/HIV co-infection.

OUR KEY FOCUS AREAS AND ACHIEVEMENTS INCLUDE:

1

Community TB Dialogues: Facilitated dialogues to raise awareness, reduce stigma, and promote community participation in TB response.

2

School TB Dialogues: Partnered with the Department of Health to conduct TB education in schools, empowering learners as TB ambassadors.

3

Multi-Stakeholder Engagements: Collaborated with municipalities, traditional and faith leaders, and civil society to align community TB interventions with local priorities.

4

Community Systems Strengthening: Built the capacity of community-based organisations, TB ambassadors, and civil society to engage in TB programme monitoring and advocacy.

5

Data for Accountability: Supported the roll-out of Tier.Net, DHIS, Helium dashboards, and E-Labs devices to improve real-time data use for decision-making at facility and district levels.

These efforts **strengthened community trust, improved accountability, and reinforced TB HIV Care's leadership** in community-driven TB advocacy.



But we noted the following challenges, lessons and innovations:

Some challenges included limited funding for scaling up community-led TB advocacy, persistent TB-related stigma in rural and peri-urban areas and data inconsistencies across reporting systems affecting timely decisions.

Our lessons and innovations included:

-  Integrated Advocacy: Aligning TB advocacy with HIV, community health, and social support programmes to ensure efficiency and sustainability.
-  Digital Accountability: Using DoH systems and dashboards to strengthen evidence-based reporting and data transparency.
-  Community Storytelling: Engaging TB survivors and advocates to share experiences, reduce stigma, and promote health-seeking behaviour.
-  Collaborative Partnerships: Leveraging municipalities, schools, and community structures to enhance ownership and inclusivity.

These adaptive strategies have enabled TB HIV Care to remain responsive, resilient, and community-led in its advocacy work.

MAKING A CONTRIBUTION TO STRENGTHENING TB ACCOUNTABILITY

TB HIV Care's advocacy work has strengthened TB accountability at community, district, and national levels through:

- Evidence-Based Advocacy: Leveraging analytics and dashboards to identify gaps, track progress, and guide resource allocation.
- Community Voice and Participation: Ensuring communities shape TB priorities and hold decision-makers accountable.
- District-Level Accountability Dialogues: Facilitating regular review meetings for sub-district TB managers to support coordination and joint problem-solving.
- Civil Society Capacity Strengthening: Equipping local organisations to sustain advocacy and engage in governance processes.
- Alignment with National Priorities: Supporting the 1.1 Million ART Close the Gap and 5 Million End TB campaigns as part of South Africa's national TB response.

These efforts contribute to a more transparent, equitable, and community-driven TB response.

THE WAY FORWARD

The year reaffirmed that collaboration, innovation, and community leadership are central to ending TB.

TB HIV Care will continue to deepen partnerships with government, civil society, and communities, expand data-driven advocacy for transparency and measurable progress, scale up community and youth engagement through schools and ensure alignment between local implementation and national priorities.

As the 1.1 Million ART Close the Gap and 5 Million End TB campaigns progress, TB HIV Care remains committed to a united, people-centred approach to ending TB in South Africa.



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06

OUR CHAMPIONS

Championing the cause of TB: a look at the ambassadors working in South Africa's communities

South Africa has a collection of TB ambassadors that are hard at work in communities across the country making a difference around TB. Let's have a closer look at the people behind the champions, learn more about their work, the challenges they face, their successes and how their lives have changed since being diagnosed and recovering from TB.

LEHLOHONOLO THOBAKGALE

Lehlohonolo Thobakgale was the just 13-years-old and still at school when she was first diagnosed with TB. While other students spent their days hanging out with friends, Lehlohonolo's spent many days suicidal thinking about how she would live with TB for the rest of her life.

Her TB diagnosis meant that she was isolated from her peers who often avoided sitting near her fearing that they may become infected. Aside from severe coughing, she lost a lot of weight and had difficulty attending school. This misunderstanding and lack of awareness around TB deeply affected her emotional wellbeing.



"AT SCHOOL, IT WAS DIFFICULT FOR ME TO EXPLAIN MY CLINIC VISITS," SHE EXPLAINS.

AND AT THE CLINIC, NURSES WOULD SEPARATE PEOPLE WITH TB FROM OTHER PATIENTS.

"THIS MADE ME FEEL EMBARRASSED AND SHAMEFUL ABOUT HAVING TB," SHE ADDS.

At home, Lehlohonolo lived with a large extended family of about 10 to 12 members. It was her grandmother who initially spread the TB to her uncles. Eventually it reached her.

But witnessing this motivated her to learn more about the disease and help others avoid the same experience. After completing school, Lehlohonolo committed herself to raising awareness about TB and breaking the stigma surrounding it.

She now works as an orphan coordinator -- a role that allows her to engage with vulnerable children and families, many of whom are affected by TB and HIV. Through her work, she educates them about TB prevention, treatment adherence and the importance of compassion towards those living with the disease.





THEMBI NKOMO

Before Thembi Nkomo was diagnosed with TB for the first time she had a normal life. The Mpumalanga born mother of one worked as an orange picker and she had dreams of becoming a social worker. But everything changed when she got TB for the first time.

"When I first got TB, I was living a normal life even though I had been living with HIV for quite some time," she recalls. "In 1998, my immune system started weakening which led to my first diagnosis of pulmonary TB. I was working then, but today I am no longer working because of TB."

And since then she has been diagnosed with TB four more times.

"In 2002, I contracted TB again, this time it was extrapulmonary TB that affected my bones. And in 2021, I got TB once more which was particularly severe as I was bedridden for few days. It was also difficult for doctors to tell me since I was already on dialysis due to kidney failure. They found the TB in my heart."

For Thembi being diagnosed with TB so many times has resulted in severe physical and emotional challenges. There were times that as a result of her disease she suffered from mental health struggles and lost hope of ever getting better.

"At some point I felt like I was losing my mind because of TB. The treatment affected my mental health so much because I had to take many pills and

I experienced severe side effects," she says. "There was a time I did not want to live anymore but I had to tell myself that I will not lose my life from TB. And with the support I received at home, I continued adhering to my treatment and I am now better."

And as a result of repeated treatment, including the use of the streptomycin injections, Thembi now suffers from partial hearing loss and her kidneys have failed so she needs dialysis.

"Because I contracted the disease many times, the treatment has also affected me in many ways. I have also had to receive streptomycin injections and I am currently on dialysis. All of this has resulted in partial hearing loss."

It was this personal experience with the disease that encouraged Thembi to become actively involved in raising awareness about TB.

"I NOW VISIT CLINICS TO EDUCATE AND RAISE AWARENESS ABOUT TB. ALTHOUGH I DON'T GET PAID FOR THIS BUT EDUCATING PEOPLE ABOUT TB ALLOWS ME TO SUPPORT PEOPLE IN MY COMMUNITY."

Despite her difficulties and health challenges, she has decided to overcome her circumstances and use her experiences to educate others about TB in her community.

Thembi's TB awareness activities include clinic visits, public talks, one-on-one counselling sessions and community outreach. She is particularly active in Hlazenani in Mpumalanga where she regularly educates people about TB prevention, treatment and stigma reduction. She also participates in events on World TB Day, conducting engagements and community talks to further raise awareness.

"In my area, I always make sure to spend at least five minutes talking about TB during my clinic visits or any community gatherings. I also do one-on-one counseling sessions with people who need support especially with treatment adherence and have had many awareness talks where I tell people that TB is not the end of the world, it is both curable and preventable," she states.



MELIKHAYA LUTISI

Conducting TB advocacy in one of South Africa's biggest provinces is not easy feat due to the vast distances between communities and clinics. This is why Melikhaya Lusiti largely focuses on social media advocacy to spread messages and information about TB prevention, testing and treatment. Through these platforms, he also refers patients back to healthcare facilities for continued treatment and support. In addition to his online advocacy, Melikhaya also hosts radio segments dedicated to TB education on a local community radio station, reaching wider audiences and encouraging listeners to get tested and adhere to their treatment regimens.

One of his key contributions has been his membership in the Provincial TB Working Group, to which he was appointed by the Department of Health to represent civil society. In this role, he has successfully advocated for the inclusion of ex-mine worker representatives in the group to ensure that their health needs are addressed.

Melikhaya is also an active member of the Eastern Cape TB Caucus, where he represented the Civil Society Forum (CSF) as chairperson during the caucus induction. According to Melikhaya, one of the main challenges he faces in his advocacy work relates to limited resources, particularly the lack of data and transport funding needed to conduct community outreach.

BUT, DESPITE THESE CONSTRAINTS, HE CONTINUES TO USE SOCIAL MEDIA AS A COST-EFFECTIVE AND FAR-REACHING PLATFORM TO ENGAGE COMMUNITIES ON TB. HE IS, HOWEVER, HOPEFUL THAT ONGOING DISCUSSIONS WITH THE DEPARTMENT OF HEALTH AND OTHER PARTNERS WILL HELP IMPROVE SUPPORT AND RESOURCES FOR CIVIL SOCIETY INVOLVEMENT IN THE TB RESPONSE.



VICTOR MAMESHI

With red and white beads around his arms, his ibhayi tied around his waist and a distinctive kofia on his head, when Victor Mameshi walks into a room, most people can identify him as a traditional healer.

They will not be wrong about his calling. But what many may not know about this Uppington based traditional healer is that he has another different agenda. While he spends his days consulting for patients who ask for his help, Victor is also actively involved in community awareness and education around TB. And as a multiple drug resistant TB survivor, who is also living with HIV, he knows the importance thereof.

"TO EVERYONE WHO FEARS TAKING THEIR MEDICATION, YOU ARE RIGHT, IT IS NOT EASY BUT IT IS WORTH IT. WHEN YOU START FEELING BETTER AFTER THE FIRST MONTH, DON'T STOP YOUR TREATMENT. FINISH IT, BECAUSE THERE IS HEALING IN TB."

He believes that his community engagements contribute to strengthening the community's understanding of TB prevention, treatment adherence and stigma reduction. This year, Victor began his TB awareness activities in June. He used the first half of the year to complete his initiation process as a healer. As both a TB survivor and traditional healer, Victor plays an important role in facilitating collaboration between traditional healing practices and the health system.



"I hold programmes in parks, churches and schools, and even attend funerals and family events to talk about TB. I use these opportunities to encourage people to complete their treatment, educate them that TB is curable and reduce stigma in the community."

According to Victor, traditional healers in the area have also developed a stronger understanding of TB management, particularly regarding the need for early referral of suspected cases. He notes that "patients presenting with TB symptoms are now referred directly to clinics for testing and initiation of treatment.

Once patients have completed at least two weeks of treatment and are clinically stable, they may return to traditional healers for complementary care related to other health concerns."He says this has helped promote coordinated care, has improved treatment adherence and sort of strengthened trust between health facilities and traditional health practitioners.



MABUSI KGWETE

Before Mabusi Kgwete was diagnosed with TB, like many others she thought that TB was a disease that only affected the lungs in one's body. But her experience has taught her otherwise. That's because Mabusi was diagnosed with extrapulmonary TB in 2023, which affected her knee.

"It took a long time for me to be diagnosed because this started as just a normal pain in my knee, even though I had not fallen or been injured," she says.

"The pain progressed and my knee became swollen and hot when you touch it. I kept going to the clinic and it was only after being referred to the hospital that I properly got diagnosed."

In the year that she was diagnosed about 271,000 more people were diagnosed with TB in South Africa. Of those, 144,000 successfully completed treatment. Mabusi

was one of them. Today she is fully cured from TB. But TB has left Mabusi with lasting physical challenges. She is forced to use crutches because the TB bacteria damaged the cartilage and alignment of her knee, leaving it unstable and unable to support her weight. She is also scheduled for surgery to insert a metal implant to support her kneecap, which will enable her to walk independently. Despite these challenges, she actively raises awareness about TB.

Mabusi conducts community dialogues across KwaZulu-Natal and engages with patients during clinic visits, educating people on TB prevention, treatment adherence and the importance of early detection.

"WHEN I VISIT CLINICS, PEOPLE OFTEN TALK ABOUT THEIR JOURNEY TO RECOVERY, HOW THE TREATMENT AFFECTS THEM AND HOW LITTLE AWARENESS THERE STILL IS AROUND TB. THROUGH THESE CONVERSATIONS, I LEARN HOW PATIENTS ARE BEING TESTED, HOW TB AFFECTS THEIR DAILY LIVES, WHETHER THEY HAVE ACCESS TO NUTRITIOUS FOOD AND IF THEY ARE ADHERING TO THEIR TREATMENT AND WHAT SUPPORT THEY NEED," SHE NOTED.

DAVID MACANA

For 14 years David Macana worked in the country's platinum and gold mines digging for minerals from below the earth. And it was in this time that the 43-year-old from the North West province developed TB.

First he was diagnosed with pulmonary TB. After being treated his TB recurred for a second time. His third diagnosis was extra-pulmonary TB (TB meningitis), a more severe form of the disease that required him to take 24 pills every morning for 18 months.

"I'M A THREE-TIME TB SURVIVOR," HE NOTES. "THE THIRD TIME I WAS DIAGNOSED WITH EXTRA-PULMONARY TB WHICH WAS TB MENINGITIS AND I HAD TO TAKE 24 PILLS EVERY MORNING FOR 18 MONTHS. I WAS HOSPITALISED FOR NINE MONTHS AND FELT ISOLATED DURING THAT PERIOD," HE EXPLAINS.

Following his recovery, Macana founded an organisation that advocates for improved TB services, particularly for communities residing in and around mining areas. His initiatives particularly target men. Macana says that the anecdotal research conducted by his organisation on why men do not test for TB or access healthcare facilities, have identified several issues. There is a strong element of masculinity influencing men's health-seeking behaviour. Many men perceive accessing health services, including TB and HIV screening, as a sign of weakness.

Through one-on-one engagements, the research found that one of the major barriers relates to the design and structure of health facilities. Many men expressed that clinics in their areas appear to be



designed mainly for women, particularly pregnant women, which makes them feel out of place or uncomfortable seeking services there.

Another important finding is the presence of myths and socio-economic fears. Some men believe that TB is "not a man's disease," while others fear losing income if diagnosed, as treatment could prevent them from working. Being diagnosed with TB is also often associated with stigma, where men are labelled as weak.

Furthermore, many men tend to avoid direct testing, assuming that if their partners or family members test negative, they are also fine. According to David, this unfortunately often leads to late diagnosis, sometimes only after the disease has progressed to multidrug-resistant TB (MDR-TB).

To respond to these challenges, the organisation is working to raise awareness through simplified TB education materials and community dialogues. David continues to engage with stakeholders to strengthen access to screening, treatment and support for ex-mine workers and their families. The aim is to help men better understand TB and encourage them to access screening and treatment early.

REUBEN MALATJI

For Reuben Malatji, the motivation to becoming TB free was regaining his sex drive. When Reuben was diagnosed with TB in 2003, it affected his sex drive. His marriage was on the rocks and he was not happy. But the Limpopo based ambassador went to the clinic and started his TB treatment. Before long his energy levels were restored and he was then able to rekindle his marriage. Reuben now encourages more people, especially men, to get tested for TB and take treatment to help improve their health.

SPEAKING ABOUT BOTH SUCCESSES AND CHALLENGES IN HIS WORK WITH TB PATIENTS, HE EXPLAINS THAT SOME PATIENTS ARE EASY TO APPROACH AT THE CLINIC AND AGREE TO DO TB SCREENING WHEN THEY COME IN. THE CHALLENGES HE FACES INCLUDE SOME TB PATIENTS NOT COMING TO THE CLINIC REGULARLY, OFTEN DUE TO LACK OF MONEY.



He also struggles with transport to reach patients who need care and some patients have no caregivers at home, which affects their adherence to medication. Others lack motivation because they see slow progress. He also notes that his resources are limited.

However, despite these challenges, he continues to reach out to patients and support them to access TB care.



KGOSHIGADI SHAPO

It's been nearly 45 years since Kgoshigadi Shapo was diagnosed with TB. At the time of her diagnosis - in 1981- she was a Grade 12 student. This was an experience that shaped her professional career and inspired her work with TB clients.

Today she is a retired professional nurse and serves as a senior traditional leader in Limpopo province after losing her husband.

Drawing from her personal experience, Kgoshigadi now encourages patients by emphasising that TB can be cured and is not a fatal disease, as long as patients adhere to treatment for six months, monitor their symptoms and take precautions to prevent spreading the disease.

SHE ALSO HIGHLIGHTS THE IMPORTANCE OF HEALTH EDUCATION IN SCHOOLS, SUGGESTING THAT TEACHERS PROVIDE BRIEF MORNING HEALTH TALKS TO RAISE AWARENESS ABOUT TB AMONG STUDENTS.



Currently, she works with five local clinics in her area, collaborating closely with them to support TB clients in the community. One of her main challenges is the lack of transport, which makes it difficult to visit all clinics regularly. But she is still dedicated to her role and continues to provide guidance and support to TB patients.

LUDICK MABYANE

For Ludick Mabyane, the most important way to tackle TB in his community in the North West province is by focusing on community-led monitoring.

This is why he conducts facility visits to assess TB support groups and engages patients who are willing to form such groups within their communities. These support groups enable outreach to community members interested in participating in the TB agenda.

Through this coordination, Ludick also engages with TB survivors, conducting door-to-door visits to households to discuss the services they are receiving from nearby facilities and to gather suggestions for improvements. In addition, he mobilises communities and stakeholders for discussions on enhancing TB services within facilities.



His work also involves liaising with healthcare facilities to identify and implement improvements. If issues cannot be addressed at the facility level, Ludick escalates them to district authorities to ensure better service delivery.

NTSWAKI MOSIA

South Africa's statistics show that more than 54% of people who have tb are co-infected with HIV. For Free State based Ntswaki Mosia this statistic is her daily reality.

Ntswaki contracted HIV at a very young age. And in this time, she has been diagnosed with TB twice. During her first episode, she experienced night time coughing and had difficulty sleeping on her left side. After completing a 6-month treatment course, she was cured. But later she contracted TB again. This time she had to take her medication for nine months.

While she is now fully cured, TB left her with shingles and visible marks on her body. Ntswaki has started an organisation which has the goal of raising awareness about HIV and encouraging people to protect themselves so that children are not born with the disease. Speaking about the links between TB and HIV, Ntswaki says that the two diseases are closely connected.

"WHEN A PERSON HAS HIV, THEIR IMMUNE SYSTEM IS SEVERELY WEAKENED, MAKING THEM MORE VULNERABLE TO OTHER INFECTIONS SUCH AS TB, FLU, STIS AND CERTAIN CANCERS."



She says that it is particularly dangerous because a weakened immune system cannot effectively fight the bacteria.

In her organisation, work focuses on both adults and children born with HIV. While TB is mostly observed among adults, children may also contract TB through parents or other family members.

Ntswaki emphasises that TB, HIV and STIs are interconnected, and having HIV does not prevent a person from contracting TB. Both diseases must be addressed together.



THANDO ROLASI

When Thando Rolasi is not working in the hospitality industry, she dedicates her time in the Western Cape's Winelands offering TB care and health-related talks and community dialogues. This, she says, provides a space for individuals who were recently diagnosed with TB to share their experience, engage with her on their TB journeys or have a one-on-one session.

Thando was diagnosed with TB in April 2020 at the Kayamandi Clinic in Stellenbosch. At that time, Thando was only 24-years-old. During her visits to the Winelands Thando has found that many community members face financial challenges and often cannot afford basic necessities.

"YOU KNOW HOW MANY BLACK UNDERPRIVILEGED COMMUNITIES SOMETIMES CAN'T EVEN AFFORD FOOD, SO I WOULD SOMETIMES FIND SITUATIONS LIKE THAT WHERE PEOPLE DON'T HAVE ANYTHING TO EAT. I WOULD THEN HAVE TO DO SOMETHING ABOUT IT, LIKE MAYBE GIVE THEM SOMETHING TO EAT," SHE SAYS.



Here she tries her best to assist where possible. When she started out as an ambassador Thando's early challenges included not having an existing network to expand community outreach.

But to reach more people, she used social media, posting videos to raise awareness about TB. Over time, as she became officially recognised as part of SANAC, community members became more receptive to her engagement.

**IN EVERY
COMMUNITY,
WITH EVERY
VOICE, WE END
TB TOGETHER.**





**Accountability
Consortium**

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