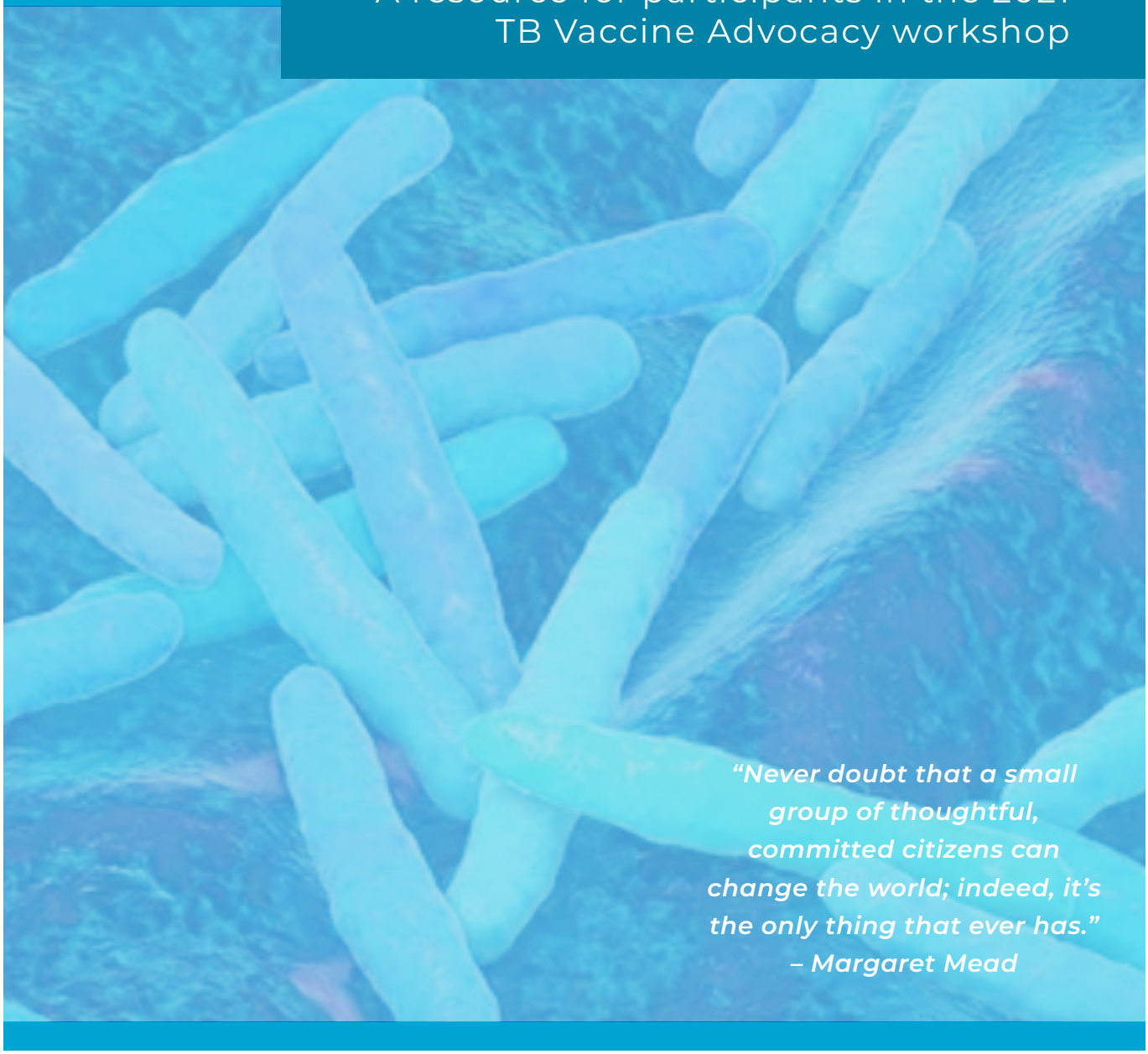
TB VACCINE ADVOCACY TOOLKIT

A resource for participants in the 2021 TB Vaccine Advocacy workshop



"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."
– Margaret Mead

University of Cape Town LUNG INSTITUTE

20 YEARS OF TB RESEARCH

satvi TOWARDS A WORLD WITHOUT TB

Stop TB Partnership

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ABOUT THIS TOOLKIT

This toolkit was developed as supporting resource to the TB Vaccine Advocacy workshop which was funded by the STOP TB Working Group on New Vaccines during January 2021. The goal of the toolkit is to help solidify your knowledge on TB, vaccines and advocacy so that you are better equipped to engage in your own advocacy activities.

Challenged with facing three pandemics, South Africa's health and well-being is under threat. While COVID-19 and HIV are two diseases that most South Africans are clued up on, largely due to the media attention they receive, TB disease is not treated with the same sense of urgency. However, South Africa has one of the highest TB incidence rates and is regarded as being at the forefront of the global TB pandemic. TB is one of the leading causes of death in South Africa even though treatment to cure the disease is widely available through the national TB program.

As in the rest of Africa, the TB pandemic is fuelled by the HIV pandemic. In South Africa, approximately 60% of patients with TB are living with HIV or are co-infected. TB is an infectious disease and is described as an opportunistic infection. This means that it is more likely to occur in people with weakened immune systems. Since HIV is a disease attacking and weakening the immune system of its host, positive individuals are at a much greater risk of becoming infected with and developing TB disease. The prevalence of HIV, TB and co-morbidity between HIV and TB are serious health concerns for South Africa, affecting marginalized groups, like women and those from poorer communities, to a much greater extent than the general population.

While it is important to develop better TB drugs, quicker TB diagnosis tests and an effective TB vaccine which prevents TB, if we are to curb TB in South Africa, this will not be enough to bring about change. It is important to secure the support of the decision-makers, policymakers and anyone else who can commit the necessary resources and enact supportive policies that will see solutions implemented. For innovations and solutions to result in sustainable change and improvement, we need resources and political will that is informed by the experts and, very importantly, the communities who understand what is needed.

Advocacy is a powerful tool for change; a mechanism to become a champion for better health.

MAY 2022

TUBERCULOSIS

WHAT IS TB

Tuberculosis (TB) is caused by the *Mycobacterium tuberculosis*, a bacterium. TB is contagious disease and usually attacks your lungs. This is known as pulmonary TB. However, TB can also spread through the body to other organs such as the brain, kidney or spine, This form of TB is called extra-pulmonary or disseminated TB.

HOW DO YOU GET INFECTED WITH TB?

- The TB bug is spread through the air from one person to another when a person who has TB, coughs sneezes, spits sings or even laughs.
- The TB bug (the germ) can stay in the air for up to 6 hours, during which time another person can inhale it and become infected.
- People with low or compromised immune systems are more likely to develop TB disease when exposed to the TB bug. These include people who:
  - people living with HIV or other chronic illnesses which weaken their immunity.
  - Children whose immune system is under-developed
  - Elderly people who have a weakened immune system.
  - People who have Diabetes mellitus.
  - People who are dependent on substances like drugs, cigarettes and alcohol.
  - People who work in mines or workplaces where they are exposed to pollutants or substances which effect their immune systems.

STAGES OF TB

1 ***Exposure***

This happens when a person has been in contact with, or exposed to, another person who has TB. This person will have a negative skin test, a normal chest X-ray, and will not display any of the signs and symptoms of the disease.

2 ***Latent TB infection***

In this stage a person has the TB bacteria in his or her body but does not show symptoms of the disease (asymptomatic). The infected person's immune system is able to ward off the TB organisms, and the TB then remains inactive throughout life in most people who are infected. This person would have a positive skin test, but a normal chest X-ray.

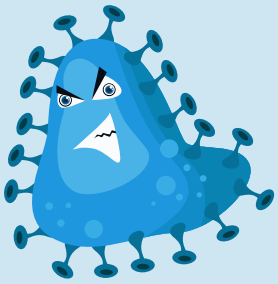
3 ***TB disease***

In this stage the person has signs and symptoms of TB, also described as symptomatic, and infectious, which means they can transmit the bug to other people. This person would have a positive skin test and a positive x-ray.

SIGNS AND SYMPTOMS

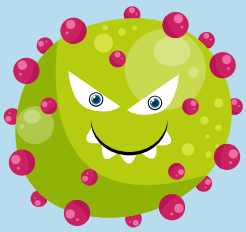
- Coughing for more than 3 weeks.
- Coughing up blood.
- Chest Pain, or pain when breathing / coughing.
- Unintentional weight loss.
- Fatigue.
- Fever / Chills.
- Night sweats.
- Loss of appetite.

THE DIFFERENT WAYS TB PRESENTS IN HUMANS



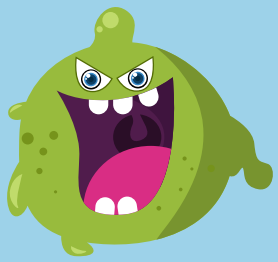
Drug sensitive TB: DS – TB

- **Type:** Most common kind of TB.
- **How is it treated:** All TB drugs effective if taken properly.
- **Treatment duration:** Shorter treatment time – 6 months.
- **Effectivenes of treatment:** Most people recover fully after completing their treatment.



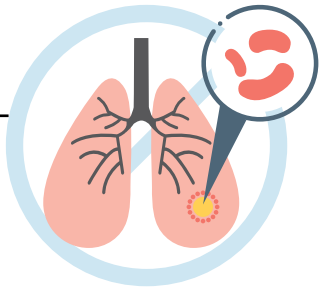
Multi-drug Resistant TB: MDR-TB

- **Type of TB:** Resistant to TWO common TB drugs , Isoniazid (INH) and Rifampacin (RMP).
- **How is it treated:** Longer treatment time – 9 months to 2 years.
- **Treatment duration:** Can develop if medication not taken correctly – acquired TB.
- **Effectivenes of treatment:** Infected by bacteria from a person with active drug resistant TB – primary TB.



Extensive Drug Resistant TB: X - DR

- **Type of TB:** Resistant to FOUR or more common TB drugs, of which 2 is INH and RMP.
- **How is it treated:** Strain developed due to mismanagement of anti-TB drugs.
- Can be acquired or primary.
- **Treatment duration:** Complicated treatment regime – less effective treatment.
- **Effectivenes of treatment:** Hospitalization required.



TREATMENT

TB is a complex bacterium and doctors have to use several drugs in combination to fight TB. This is not an easy fight because each of these medicine are not strong enough on their own to treat people. Doctors treating TB patients use a combination of at least 4 medicines to be effective. If the TB strains are resistant to medicine, more medicines are added to their treatment plan.

While TB can be cured with antibiotics, it is a complex treatment journey with many serious potential side effects. These include:

- Itchy skin.
- Skin rashes, bruising or yellow skin.
- Upset stomach, nausea, vomiting, diarrhoea or loss of appetite.
- Lack of feeling or tingling in the hands or feet.
- Yellow eyes.
- Dark coloured urine.
- Changes in your eyesight, particularly changes in red or green colour vision.

PREVENTION

Because we live in a high burden TB country where many people are exposed to the TB germ every day, it is almost impossible to prevent exposure. However, there are a few practical steps you can take to minimize your risk of getting TB or prevent it from spreading if you are infected.

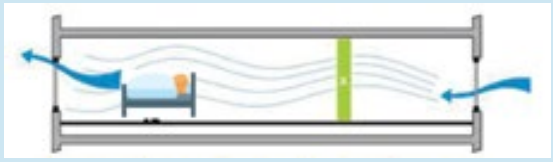
1. If you have **symptoms** of TB, go to your clinic for a **TB screening (free** at local community health centres).

2. Always **open the windows** when **traveling** by taxi or bus.

please provide link to new taxi graphic

3. Open the windows and door at **school**, in **church** and in your **home**.

4. Sleep in a **well-ventilated** place.



5. If you have a **cough** you should always **cover your mouth** while you cough. You should try to use with a cloth, a tissue or the inside of your elbow when wearing long sleeves.

6. **Avoid crowded places** when you are still infectious, e.g. church and meetings/gatherings inside enclosed spaces.

WORLD TB DAY

Globally, World TB Day is observed on the 24th of March, and usually organisations use the whole month of March to raise awareness about this public health threat and efforts to eliminate.

The 24th of March commemorates the day that a scientist by the name of Dr Robert Koch astounded the scientific community by announcing that he had discovered the cause of the devastating and deadly illness that, at the time, was killing one in seven infected people. His discovery paved the way for the diagnosis and cure for TB.

UCT Lung Institute Community Open Days

World TB Day 2019: UCT Lung Institute Information table at Health Open Day, Lentegeur Cape Town

World TB Day 2019, UCT Lung Institute staff and CAB at the Cape Town Health World TB Day Open day, Maynardville, Cape Town

World TB Day, Maynardville, Cape Town.

World TB Day Health Open Day, Pumlani, Cape Town

Carina Choice, drama and comic book to raise awareness about TB and clinical research

The "Carina's Choice" comic book was created by SATVI, with the support of the Stop TB Partnership to raise awareness of TB and clinical research. The drama was translated into English, Afrikaans and Xhosa to share information on tuberculosis, the need for TB vaccines, clinical research and the community's rights in clinical research.

Youtube: https://www.youtube.com/watch?v=pAosgZO-O0k&t=68s

UCT Lung Institute Community Open Days

On World TB Day (24 March 2015), SATVI partnered with the Department of Education and AERAS, a global not-for-profit TB vaccine research group, to raise awareness about TB amongst primary and secondary school children in the Worcester area. The program, which was rolled out in four schools in Worcester area, teaches children about the signs and symptoms in a fun and interactive way, and reached about 5 000 children with its message.

Kick TB School Program, Robertson.

World TB Day Three Peaks TB Awareness Challenge

For World TB Day 2019 (24 March 2019) the South African Tuberculosis Vaccine Initiative (SATVI) team tackled the World TB Day Three Peaks Challenge which entailed ascending up Devil's Peak, Platteklip Gorge and Lions Head in one day, in a bid to raise awareness

Walkers on Lions Head, Cape Town.

Walkers on Table mountain, Cape Town.

Professor Tom Scriba handing over donation to Mrs Linda Sibeko and a member from Ikamva Lethu community soup kitchen.

Three Peaks World TB Day Race, Foot of mountain.

Walkers on Signal Hill, Cape Town.

TB under the Spotlight Science Engagement, 2018

For World TB Day 2018, SATVI collaborated with the University Stellenbosch, the South African Medical Research Council (SAMRC), as well as the Departments of Education and Health in launching the TB under the Spotlight Science Engagement. The 60-minute program lets learners explore a science exhibit where they learn how TB is diagnosed, the signs and symptoms of TB, TB treatment and the inner workings of a TB laboratory. They also get to do a practical experiment in extracting DNA from wheat germ.

Launch of Tb under the Spotlight Science Engagement

World TB Day 2019, UCT Lung Institute staff and CAB at the Cape Town Health World TB Day Open day, Maynardville, Cape Town

Launch of Tb under the Spotlight Science Engagement

World TB Day 2018, Learners UCT Lung Institute staff and CAB at the Cape Town Health World TB Day Open day, Maynardville, Cape Town

Beat TB Program- Lienkie's Lungs drama, 2017

Lienkie's Lungs was a local developed drama, developed by a unique partnership between the South African Tuberculosis Vaccine Initiative (SATVI), the UCT Drama School and the Mothertongue project, was recently aired on the Hectic Nine 9 youth program. The play was developed in 2015 and was performed at various primary health clinics and community centres in the Cape Winelands and highlighted at the 2016 Worcester Easter Basaar. The drama was performed by actors drawn from the Mothertongue Project and the Zwelethemba community in Worcester. The drama is highly visual, with costumes and props, catchy songs and lots of movement.

During May 2017 the cast of Lienkie's Lungs and Dr Michèle Tameris featured on the SABC Hectic Nine 9 youth magazine program. The drama was developed in a collaboration between Mothertongue a community-based theatre program and SATVI with a Wellcome Trust Public Engagement grant.

Youtube: https://youtu.be/GMcdl7edX_8

Empileswini Community Health Clinic, Worcester

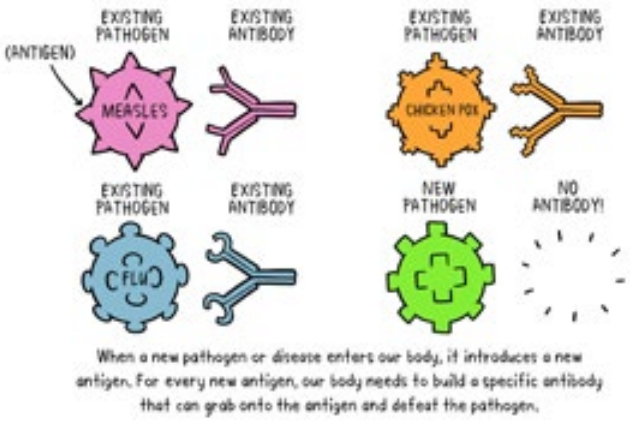
VACCINES

Vaccines have revolutionised health care and the quality of life of many people saving millions of lives across the world over time.

Not that long ago, people were living in fear of falling ill from infectious diseases like chickenpox, measles, hepatitis and even polio. Today these disease conditions are no longer serious threats thanks to scientific advancements of vaccines which are use to prevent many diseases.

HOW DO VACCINES WORK?

Vaccines work by training the human's immune system to recognise and combat pathogens, when they are exposed to germs such as viruses or bacteria at a later stage in their life.. To develop immunity, certain molecules from the pathogen are introduced into the human body to trigger an immune response.



These molecules, which are called antigens, are present in all viruses and bacteria. By injecting these antigens into the body, the human immune system can safely learn to recognize them as hostile invaders, produce antibodies, and remember them for the future when the human is exposed to the germ. If the bacteria or virus reappears, the immune system will recognize the antigens immediately and attack aggressively well before the pathogen can spread and cause sickness.

A FEW IMPORTANT VACCINES AND THE DISEASES THEY PREVENT

A FEW IMPORTANT VACCINES USED IN SOUTH AFRICA TO PREVENT DISEASE

VACCINE	DISEASE PREVENTED
Bacillus Calmette-Guerin (BCG) Tb vaccine	Serious forms of TB such as TB of brain, miliary TB.
Polio	Polio
Pneumococcal	Pneumonia
Measles	Measles
Mumps	Mumps
Rubella	Rubella
Yellow fever	Yellowfever
HPV vaccine	Cervical cancer

THE HERD IMMUNITY IMPERATIVE

Vaccines don't just work on an individual level. They protect entire populations because once enough people are immunized, vaccinated it becomes difficult for disease to break out in large number of people. Essentially, a bacteria or virus simply won't have enough eligible hosts to establish a foothold and will eventually die out entirely. This phenomenon is called "herd immunity" or "community immunity," and it has made it possible to prevent pandemics by diseases which once were devastating to humans such as the flu, polio, measles and many more.

This Herd immunity is critical because there will always be a percentage of the population that cannot be vaccinated, such as infants, young children, the elderly, people with severe allergies, pregnant women, or people with compromised immune systems. Thanks to herd immunity, these people are kept safe because diseases are not able to spread rampantly through a population.

Public health officials and scientists continue to study herd immunity and identify key thresholds, but one telling example is the country of Gambia, where a vaccination rate of just 70% of the population was enough to eliminate Haemophilus influenza type b (HIB) disease entirely. (The HIB microbe is the cause of bacterial meningitis and pneumonia in children.)

IS THERE A VACCINE FOR TB?

The Bacille Calmette-Guerín (BCG) vaccine is the only vaccine we currently have to protect humans against TB.

It was first used in 1921 – a hundred years ago, and is still in use! BCG has been an integral part of the South African childhood immunisation program due to the high TB burden and consequent risk of infection in babies and children. This vaccine has been proven effective in protecting children against more serious forms of Tb like milliary (blood-borne TB) and TB meningitis (TB of the brain). However, it has been found to only have limited efficacy in protecting adults from TB disease.

Albert Calmette
(1863-1933)

Camille Guerín
(1872-1961)

Unfortunately, some countries like South Africa, have experienced problems with the procurement and availability of the BCG vaccine in recent years. This has led to many infants not receiving the compulsory BCG vaccine injection as part of their routine vaccinations. Concerns have been raised about the effects that the shortages have on the health and livelihoods of children and their families.

Aside from the BCG vaccine which is only effective in protecting babies and younger children, we do not have any other vaccines available to prevent TB. This is also of great concern because research shows that you have had TB before, you are much more likely to develop TB disease again

WHY DO WE NEED A NEW VACCINE AGAINST TB?

We need a new TB vaccine which:

- is effective in protecting people of all ages from TB.
- provides protection against all strains of TB, which including the drug resistant TB strains.
- is safe to use as a preventative measure.
- protects people from recurrent TB (where people recover from TB, but develop TB again later in their life.)
- lowers the rates mortality and morbidity associated with TB.
- stops the spread of TB disease.
- brings economic benefit to government not having to pay for expensive anti-TB drugs and to patients would then not have pay out of pocket expenses associated with treatment.

ADVOCACY

WHAT IS ADVOCACY?

Defining advocacy is not always that straight forward since many people have different understandings of what it means, and debates have arisen as to which definition is the most appropriate.

A few definitions of advocacy:

1. It is understood as acting in favour of or pleading for a specific cause, group, policy or idea.
2. Advocacy is about influencing people, policies, structures and systems in such a way that change occurs.
3. It is a means of effectively communicating your cause or concern in a way that is passionate and accepted by the audience.
4. It is a strategic action supported by a plan with the goal of making your cause known publicly

TYPES OF ADVOCACY

Self-Advocacy

Individual speaks for her or himself

Individual Advocacy

An individual act with, or on behalf of, another person who has a concern or an issue.

Group Advocacy

Several People advocate together for a common cause

Systems Advocacy

Broader systems, policy change targeted at impacting on TB control strategies through policies and health programs at country level, provincial and even district level.

POLICY ADVOCACY

Policy advocacy is the **deliberate process** of **influencing decision- makers** in support of **evidence-based policy change**.

Policy advocacy is a deliberate process that requires planning and strategy. It is not effective if done haphazardly.

It aims to influence decision-makers. Policy advocacy tries to influence those who have the formal power to make the change.

Policy advocacy seeks changes that are evidence-based. You should have program experience or data to prove the issue is important and the suggested solution will help.

The goal of policy advocacy is to achieve a desired policy change. It is not enough to just educate policy makers. We want to them to take a preferred action. Policy change can happen at a global, national, or sub-national level.

10 PARTS OF AN ADVOCACY STRATEGY

PART 1: Your advocacy issue.

PART 2: Your advocacy goal.

PART 3: Your target decision-makers and influencers.

PART 4: Your decision-maker's core concerns.

PART 5: Your advocacy obstacles.

PART 6: Your advocacy assets and gaps.

PART 7: Your advocacy partners.

PART 8: Your advocacy tactics.

PART 9: Your advocacy messages.

PART 10: Your plan to measure success.

TB ADVOCACY RESOURCES

Here we provide a list of resources which you can use in conducting advocacy events.

Global TB Report

The World Health Organisation publishes the Global Tb report a comprehensive and up-to-date assessment of the TB epidemic, and of progress in prevention, diagnosis and treatment of the disease at global, regional and country levels.

Available at:

Country level TB Reports

The World Health Organisation generates country level TB reports based on data reported by countries in the WHO's global TB database. These show TB data and progress towards attaining TB targets as well as TB budgets.

Available at:

District Health Barometer

The Health System Trust produces a District Health Barometer, a comprehensive statistical and analytical resource providing an overall view of the district health performance covering 52 health districts in nine provinces.

There is a section dedicated to TB.

Provincial TB Dashboard

The Western Cape Government has developed a public TB dashboard to help monitor the province's TB response. The TB dashboard provides data on the number of TB tests, test positivity, TB cases and deaths by municipality/subdistrict.

Available at:

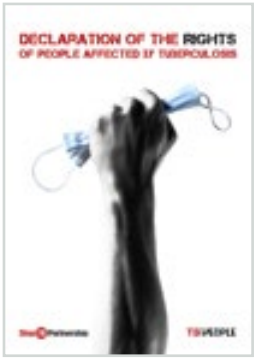
STOP TB PARTNERSHIP ADVOCACY RESOURCES

TB Partnership Publications

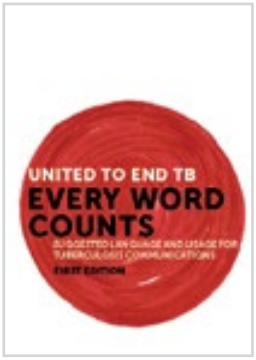
The Stop TB partnership is a global network organisation which is made up of international and tecnial organisations, governments, resaerch and funding agencies, NGO's, civil society, community groups who fight against TB through its working groups. They produced the following resources which are invaluable for advocacy for TB vaccines. There are a number of other publications which should form part of your reading.

Tuberculosis Research funding trends

This report, produced by Treatment Action Group shows the levels of funding committed at international and country level.



On 14 May 2019 the Declaration of the Rights of people affected by Tuberculosis was launched to inform and empower people and communities affected by TB to be able to claim and protect their right to a life free from TB and when necessary to ensure equitable access to quality TB prevention, diagnosis and treatment, free from stigma and discrimination.



Every word counts

The language guide was developed to change the 'changing the mindset, language, and dialogue on TB' as one of the key paradigm shifts required to reach the End TB Goals.

Impact of COVID on TB epidemic from a community perspective.

Report which presents community inputs on the impact of COVID on the fight against TB.

World TB day Campaign materials

The Stop TB partnership maintains a webpage dedicated to information and campaign materials you can use in TB advocacy events. The partnership makes available the theme for Worl TB Day and campaign materials. There are print materials and materials you can use in online campaigns.

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CREDITS AND ACKNOWLEDGEMENTS

Co-authors: Zani de Witt UCT Lung Institute
Kelvin Vollenhoven South African Tuberculosis Vaccine Initiative
Michèle Tameris South African Tuberculosis Vaccine Initiative, University of Cape Town
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