



Community-Led Monitoring Framework

EMPOWERING COMMUNITIES TO END TB

About Stop TB Partnership

The Stop TB Partnership (STP) brings together expertise from a broad spectrum of country, regional, and global partners in our shared mission to revolutionize the TB space and end TB by 2030. Founded in 2001, the STB Partnership is a UN-hosted organization that takes bold and smart risks to serve and amplify the voices of the people, communities, stakeholders, and partners from countries affected by TB. We are guided by three strategic goals:

- To advocate, catalyse, and facilitate sustained coordination and collaboration among partners
- To support the development, replication, and scale-up of innovative approaches and tools
- To facilitate global, equitable access to TB diagnostics and medicines

We believe that our strategic and technical expertise and our willingness to push boundaries are crucial factors in reaching the targets and commitments agreed on at the United Nations High-Level Meeting on TB by Heads of State and the TB community at large to end TB by 2030.

STP operates through a secretariat in Geneva, Switzerland.

To learn more about STP and our work, visit http://www.stoptb.org.

About International Treatment Preparedness Coalition

The International Treatment Preparedness Coalition (ITPC) is a global network of people living with HIV and community activists working to achieve universal access to optimal HIV treatment for those in need. Formed in 2003, ITPC actively advocates for treatment access across the globe through the focus on three strategic pillars:

- Treatment education and demand creation (#TreatPeopleRight)
- Intellectual property and access to medicines (#MakeMedicinesAffordable)
- Community monitoring and accountability (#WatchWhatMatters)

To learn more about ITPC and our work, visit www.itpcglobal.org.

About this Framework

The OneImpact Community-Led Monitoring (CLM) Framework is the result of five years of experience implementing OneImpact CLM with support from the U.S. Agency for International Development (USAID) and the Global Fund Strategic Initiative to Find the Missing People with TB. The Framework captures and builds on lessons learned from Cambodia, DR Congo, Indonesia, Mozambique, Tajikistan, Tanzania, and Ukraine, in addition to Azerbaijan, Belarus, Kyrgyzstan and Kazakhstan, supported by TB-REP¹. The Framework is provided to support small and large-scale OneImpact CLM interventions for an integrated and sustained TB response.

TB-REP is a regional TB Eastern Europe and Central Asia project implemented by the Center for Health Policies and Studies (PAS Center).

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Development of this Framework has been led, guided, and informed by country experiences over five years. Each partner contributed towards the development and advancement of the OneImpact digital platform and OneImpact CLM Framework in multiple and different ways. The following organizations implemented OneImpact CLM activities (included are some highlights of their key contributions):

- Tajikistan: The Stop TB Partnership
 Tajikistan supported the development of the original prototype in partnership with Dure Technologies, and the Stop TB Partnership. It was the first to roll out OneImpact, providing the foundational experience on which the OneImpact CLM digital platform and Framework were built.
- Tanzania: The Eastern Africa National Networks of AIDS and Health Service Organizations (EANNASO) highlighted the importance of national and local

- partnership engagement towards the success of OneImpact CLM. Lessons learned from Tanzania informed the conceptualization of OneGroup to oversee, guide, and monitor and evaluate OneImpact CLM.
- Cambodia: As a result, the OneImpact digital platform incorporated the OneImpact SMART Set-up, which allows countries to use local language and manage content independently, and the availability of the source code and installation guidelines.
- Indonesia: Lentera Kesehatan Nusantara, together with POP TB Indonesia, supported Lembaga Kesehatan Nahdlatul Ulama (LKNU) Indonesia, which led the OneImpact CLM project in the country. LKNU highlighted the importance of working with local community networks to successfully integrate OneImpact into local TB responses.
- Ukraine: TBpeopleUkraine highlighted the need for alternative OneImpact CLM models for sustainability and the centrality of human rights as the foundational principles of CLM.
- Mozambique: Associação Mocambicana para a Ajuda de Desenvolvimento de Povo para Povo (ADPP) demonstrated the effectiveness of engagement with the National TB Program and the use of CLM data to support health system priorities.
- DR Congo: Club des Amis Damien (CAD) advocated strongly for and ensured that human rights are at the core of OneImpact.
- Eastern Europe and Central Europe (EECA): EECA TB-REP regional team, PAS Center, Public Foundation, AIDS Foundation East-West in the Kyrgyz Republic, Saglamliga Khidmat Ictimai birliyi

(Public Union Support to Health) Azerbaijan, Defeat Tuberculosis Together Belarus, and ALE Kazakhs Union of People Living with HIV Kazakhstan highlighted the importance of leveraging a multi-stakeholder process for uptake and buy-in. They also highlighted the importance of partnership between each country's lead community-based organization and national TB programme to ensure that the needs, as articulated through CLM, are met and that the data and information generated can be integrated and used as part of the national TB monitoring and evaluation framework.

Global and regional TB community networks

- TBpeople developed and updated the OneImpact "Get Information" module. The "Get to Know Your Rights" module is based on the Declaration of the Rights of People affected by TB, developed by TBpeople. TBpeople also contributed to the "Get Connected" module.
- The Global Coalition of TB Activists (GCTA) reviewed and contributed to the OneImpact "Get Involved" and "Get Connected" modules.
- The Activists Coalition on TB Asia Pacific (ACT! AP), hosted by APCASO, contributed to the OneImpact "Get Connected" and "Get Information" modules.

- The African Coalition on TB (ACT) contributed to the OneImpact "Get Connected" module.
- Dynamique de la Réponse d'Afrique Francophone contre la Tuberculose (DRAF TB) contributed to the OneImpact "Get Connected" module.
- The TB Europe Coalition (TBEC) contributed to the OneImpact "Get Connected" module.

Additional contributions

- United States of America: Treatment Action Group (TAG) developed content for the OneImpact "Get Information" module.
- Zambia: Zambia Copperbelt Health Education Project (CHEP) developed and contributed to the OneImpact "Get Information" module.
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Contents

| 4 | | 77 | |
|----|--|-----------|--|
| ъ, | BACKGROUND | 43 | ONEIMPACT |
| | Acronyms and Abbreviations 2 | | IMPLEMENTATION |
| | Definitions 3 | | FRAMEWORK |
| | Rationale for OneImpact | | Key actors and roles 24 |
| | community-led monitoring 9 Introduction to community-led | | Implementation phases of OneImpact CLM 26 |
| | monitoring 11 | | Framework for OneImpact |
| | What are the community-led monitoring models? 12 | | CLM data privacy and network security 40 |
| | The principle of meaningful engagement in community- | | |
| | led monitoring 13 | 40 | |
| | | 44 | CONCLUSION |
| 1 | | | Communities closing the gap |
| 4 | ONEIMPACT | | to reach the TB targets 43 |
| | CONCEPTUAL | | |
| | FRAMEWORK | ΛC | |
| | OneImpact Clm definition 15 | 43 | RESOURCES |
| | OneImpact CLM model 15 | | |
| | OneImpact CLM approach 15 | | |
| | What does OneImpact CLM monitor? 15 | 47 | LIST OF |
| | About OneImpact CLM digital platform 16 | | ILLUSTRATIONS |
| | OneImpact CLM Conceptual Framework explained 20 | 40 | |
| | | 49 | ENDMOTEC |

BACKGROUND



Acronyms and Abbreviations

ACT African Coalition on TB

ACT! AP Activist Coalition on TB Asia Pacific

ADPP Associação Mocambicana para a Ajuda de Desenvolvimento de Povo para Povo

AAAQ Availability, accessibility, acceptability, and quality

(framework for elements of the right to health)

CAD Club des Amis Damien

CBO Community-based organization

CLM Community-led monitoring
CRG Communities, rights, gender

DRAFTB Dynamique de la Réponse d'Afrique Francophone contre la Tuberculose

EANNASO Eastern Africa National Networks of AIDS and Health Service Organizations

EECA Eastern Europe and Central Europe

GCTA Global Coalition of TB Activists

ITPC International Treatment Preparedness Coalition

KHANA Khmer HIV/AIDS NGO Alliance

LKNU Lembaga Kesehatan Nahdlatul Ulama

M&E Monitoring and evaluation

NGO Nongovernmental organization

NTP National TB programme

PII Personally identifiable information

SDGs Sustainable Development Goals

STP Stop TB Partnership

TB Tuberculosis

TBEC TB Europe Coalition

TPT TB preventive therapy

UHC Universal health coverage

UN United Nations

UNOPS United Nations Office for Project Services
USAID U.S. Agency for International Development

WHO World Health Organization

Definitions

Data privacy and security: Data privacy is the right to restrict use, access, disclosure, and dissemination of information. Data security comprises both technological and non-technological mechanisms that restrict the use, access, disclosure, and dissemination of information

Gender-transformative programmes and services: Gender-transformative programmes and services seek to transform gender relations to promote equality and achieve programme objectives by: 1) fostering critical examination of inequalities and gender roles, norms, and dynamics; 2) recognizing and strengthening positive norms that support equality and an enabling environment; 3) promoting the relative position of women, girls, and marginalized groups; and 4) transforming the underlying social structures, policies, and broadly held social norms that perpetuate gender inequalities.¹

Human rights-based TB response: Human rights are at the core of the World Health Organization (WHO) End TB Strategy, the Political Declaration of the UN High-Level Meeting on the Fight Against Tuberculosis, and the Stop TB Partnership Global Plan to End TB 2018-2022. A human rights-based TB response supports and enhances public health measures and good clinical practice. The approach is founded on the dignity and autonomy of people affected by TB and the critical role they must play in all aspects of the disease response. A rights-based approach places special focus on TB key and vulnerable populations; it demands a gender-sensitive response; and it leverages existing law at international, regional, and national levels to strengthen the response. This includes the rights to health, non-discrimination, privacy and confidentiality, information, and liberty. Respect for these human rights promotes the health and well-being of individuals and, in doing so, protects the public's health.2

Informed consent: This is a process for getting permission before conducting a health care intervention on a person, for conducting some form of research on a person, or for disclosing a person's information. A health care provider may ask a patient for consent to receive therapy before providing it. A clinical researcher may ask a research participant for consent before enrolling that person into a clinical trial. A researcher may ask a research participant for consent before starting some form of controlled experiment. Informed consent is collected according to guidelines from the fields of medical ethics and research ethics. It can be said that an informed consent has been given based on a clear appreciation and understanding of the facts, implications, and consequences of an action. Adequate informed consent is rooted in respecting a person's dignity.3

Meaningful community engagement in community-led monitoring (CLM): Meaningful community engagement refers to a deliberate process where affected TB communities have a prominent and active role along the CLM spectrum with an objective of ensuring access to quality, equitable, and rights-based care. This includes the planning, decision-making, data collection, advocating, and monitoring and evaluation processes. By implication, this means that: the needs of affected communities are prioritized; their varied and diverse expertise is recognized; and they are treated as equal partners, involved at all levels of the CLM process and supported, practically as needed, in the interest of a long-term and sustainable partnership.4

Network (computer network): A network is a group of computers and other devices, such as laptops, desktops, smartphones, tablets, and computer servers, that are linked together to, for example, communicate with one another, share resources, and exchange files through the use of a set of common communication protocols and digital interconnections.

Network security: Network security comprises the technological and operational policies and practices implemented to monitor and prevent unauthorized access, misuse, modification, or denial of a network of computers or devices, as well as the information and resources accessible through the network.

People affected by tuberculosis: People affected by TB refers to any person with TB disease or who previously had TB disease, as well as their caregivers and immediate family members, and members of TB key and vulnerable populations, such as children, health care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations, women, and the urban and rural poor.⁵

People-centred care: The World Health Organization defines people-centred health services as an approach to care that consciously adopts the perspectives of individuals, families, and communities to respond to their needs and preferences in humane and holistic ways and to ensure that they have the education and support they need to make decisions and participate in their own care.⁶

Personally identifiable information (PII):

Personally identifiable information includes any representation or presentation of information that permits the identity of an individual to whom the information applies to be reasonably inferred by either direct or indirect means.⁷ In essence, PII is any data or information that can be used to identify a specific person.

Right to health AAAQ framework: The right to health AAAQ framework comprises four essential elements of the right to health in Article 12 of the International Covenant on Economic, Social and Cultural Rights: availability, accessibility, acceptability, and quality of health facilities, goods, and services. The framework derives from General Comment No. 14 of the United Nations Committee on Economic, Social and Cultural Rights, the official interpretation and elaboration of the right to health at the international level. The first version of the AAAQ framework was introduced in a 1978 article in the Bulletin of the World Health Organization.

Social justice: Social justice refers to the principle that every individual and group is entitled to equal rights, opportunity, and treatment in social, political, and economic affairs, both in law and in fact, requiring the fair and compassionate distribution of social, political, and economic resources.

TB key and vulnerable populations: TB key and vulnerable populations comprise the most vulnerable, underserved, and at risk for TB. They include people who experience increased exposure to TB due to where they live or work, such as health care workers, miners, people living in urban slums, and prisoners. They include people who have limited access to TB services, such as the homeless, migrant workers, undocumented migrants, and women in settings with discriminatory gender roles or norms. They also include people at increased risk of TB because of biological or behavioural factors that compromise immune function, such as people living with HIV, people who are undernourished, people with diabetes or silicosis, and people who use tobacco.11

Statement on the Protection and Promotion of **Human Rights in OneImpact Community-Led** Monitoring: The Stop TB Partnership and implementing partners commit to protecting and promoting the human rights of people affected by TB through all aspects and operations of OneImpact community-led monitoring. The Stop TB Partnership and partners acknowledge the risks posed to rights, privacy and confidentiality, and non-discrimination in the collection and use of data in OneImpact CLM, and pledge to make every effort to protect these and all other human rights. The Stop TB Partnership and partners further commit to promoting the rights to health, information, non-discrimination, participation, and privacy and confidentiality as core objectives and foundational principles for OneImpact CLM.

Forewords

A FOREWORD FROM TB SURVIVORS

Built by us for us

uberculosis survivors, communities affected by TB, and civil society informed, guided, and developed OneImpact Community-led
Monitoring Framework: Empowering
Communities to End TB. Community-led monitoring is a key strategic response to combatting the challenges faced by TB survivors and communities affected by TB and overcoming the bottlenecks in ending the TB epidemic. OneImpact CLM alone, however, cannot meet the goal of ending TB by 2030 – it has to be driven and led by us as TB survivors and our communities.

OneImpact CLM responds to the commitments contained within the United Nations Political Declaration on the Fight Against TB to innovate health systems, meaningfully engage TB-affected communities, and transform the TB response to become rights based, people centred and gender transformative. It also

directly responds to the recent communities'
Calls to Action in <u>A Deadly Divide: TB</u>
<u>Commitments vs. TB Realities</u>, particularly in calling upon UN Member States and Heads of State to lead an effective TB response. More specifically, *OneImpact* responds to our call for inclusive CLM initiatives that identify and overcome challenges faced by people affected by TB that result in avoidable suffering and loss of lives. As COVID-19 ravages, there is also a strategic opportunity to fight the TB epidemic within the pandemic and to respond, using OneImpact, to the Calls to Action for CLM in <u>The impact of COVID-19 on the TB epidemic:</u> A community perspective.

In response to A Deadly Divide: TB
Commitments vs. TB Realities and The impact
of COVID-19 on the TB epidemic: A community
perspective, OneImpact provides an
opportunity for TB survivors, families, and
communities to connect with each other,



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engage with each other, help each other, and share experiences and challenges with TB. In this way, OneImpact ensures that we are not alone, that we have a voice, and that our challenges are understood and overcome. Through OneImpact, we can also meaningfully inform, shape, and enhance accountability in the TB response, so that quality TB care and support services are available, accessible, and acceptable to all. As this is a digital platform, information on barriers to services, human rights violations, and TB stigma are instantly available and reports on CLM indicators can be immediately generated. This significantly reduces resources required for data collection, analysis, and use.

This document provides clear guidance on why and how OneImpact CLM can be successfully implemented locally to empower, engage, and respond to the comprehensive needs of TB survivors, families, and communities while ensuring that CLM data informs and drives

change for a more robust evidence-based TB response.

To end TB by 2030, we need a creative, empowered movement of affected communities proactively driving rights-based responses to TB across the globe. We believe that OneImpact can support our goal and innovate our movement. If our community succeeds in reaching the goals of OneImpact, we will be a proud generation of people who kept our promise to end the devastation caused by TB.

We wish to commend and thank the Stop TB Partnership and International Treatment Preparedness Coalition for their vision and support. Now we call upon on the broader TB community to prioritize and invest in OneImpact CLM. Only together can we end TB.

A FOREWORD FROM DR. LUCICA DITIU, EXECUTIVE DIRECTOR, STOP TB PARTNERSHIP

People and communities must be at the heart of the TB response

nly people suffering from TB know that diagnostics and medicines alone will not end TB. People need so much more to beat it: a supportive environment, not social exclusion; information, not disinformation; love and empathy, not stigma and discrimination.

If we really want to have a lasting and sustainable response that will end TB, we need to shift the dynamic so that people, communities, and grassroots organizations are at the heart of the response. This shift will ensure that the needs of people affected by TB are understood, represented, prioritized, and responded to. There is nothing new here as this is stated and restated in the Global Plan to End TB, the Political Declaration of the UN High-Level Meeting on the Fight Against Tuberculosis, and A Deadly Divide: TB Commitments vs. TB Realities. Building on the Community, Rights and Gender (CRG) strategy of the Stop TB Partnership, the OneImpact Community-Led Monitoring Framework, digital platform, and implementation tools are additional instruments to further expand on our commitment to executing this shift to communities.

To ensure that OneImpact CLM is driven and owned by countries and communities, our colleagues from affected communities and organizations in Tajikistan informed and pilot tested the original OneImpact concept. Our colleagues from Cambodia, DR Congo, Indonesia, Mozambique, Tanzania, and Ukraine further tested and shared achievements and lessons learned. In this way, we were able to continuously learn from each other to produce a conceptual and implementation framework based on country and community experiences.

Today, after almost five years of trial, error, continuous learning, and successes, we and our colleagues are ready to share and hand over the results of our work to benefit all communities and countries committed to ending TB by 2030. This work belongs to our community colleagues and we hope that many other affected communities will benefit from it in order to identify and overcome barriers to TB services, find rapid and appropriate resolutions to human rights violations, and end TB stigma by 2030.

It is with great pride that the Stop TB
Partnership accompanied communities
affected by TB from across the world on this
OneImpact CLM journey. We will continue to do
so until we end TB.

With national commitments to advancing a CRG approach to TB, the motivation, solidarity, ambition, and drive from affected TB communities, guidance from technical partners, and investments from the donor community to scale up OneImpact CLM, I am sure that we can put communities first. Nothing can stop us.



DR LUCICA DITIUExecutive Director
Stop TB Partnership

A FOREWORD FROM **SOLANGE BAPTISTE**, EXECUTIVE DIRECTOR, ITPC

Using community data to transform the lives of people affected by TB

ommunity-led interventions are critical for safeguarding the health care gains of the past decades.

Community-led monitoring, in particular, plays a critical role in creating a structured, supported, meaningful, and accountable process so that people who receive and benefit from care can have a seat and a voice in the planning, implementation, monitoring, and evaluation of services that their lives and health depend on.

The International Treatment Preparedness Coalition (ITPC) has pioneered a community-led monitoring model that is not exclusive to a single disease, but instead can be broadly applied and implemented in other disease areas. I look forward to seeing our model applied to tuberculosis. We are excited to work with the Stop TB Partnership, to support the OneImpact initiative, and to stand in solidarity with the TB community.

TB remains the most common opportunistic infection in people living with HIV worldwide, and almost 60% of people estimated to be living with global HIV-related TB are undiagnosed and untreated. This is why TB remains the leading cause of death among people living with HIV; TB is responsible for one third of all AIDS-related deaths. We believe that our partnership represents a concrete step toward the integration of HIV and TB services and interventions, and we look forward to witnessing communities of TB survivors adopt this model and bring meaningful transformation to their lived experiences, especially at this time.

In 2020, COVID-19 reminded us that in addition to ensuring optimal prevention and treatment, we have to tackle nonbiomedical, root causes of disease outcomes. We cannot overlook inequalities, systemic racism, and other social factors that affect health outcomes. Community-led monitoring and advocacy have demonstrated real potential to help address urgent issues in the wider field of social justice in the decade ahead.

Therefore, it is our hope that this partnership leads to broader and innovative applications as communities take on the role of citizen scientists, fully empowered to gather the evidence that they need to inform targeted action at the local, national, regional, and global levels.



SOLANGE BABTISTE
Executive Director
International Treatment
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Rationale for OneImpact community-led monitoring

niversal health coverage (UHC) is not attainable without a strong tuberculosis response, and ending TB is impossible without UHC.¹² Ending the TB epidemic is a target of the Sustainable Development Goals (SDGs) that requires, in addition to research and innovation, the implementation of several public health, biomedical, human rights, and socioeconomic interventions.¹³ Strengthening community engagement and systems and innovating health systems lie at the heart of delivering UHC and are prerequisites to ending TB.

Today, TB is the top infectious disease killer in the world. Every year, some 10 million people fall sick with TB and an estimated 1.4 million die from TB.¹⁴ The added burden of <u>COVID-19</u> and its devastating impact on the TB response has made TB the major global health challenge of the 21st century.

The global distribution of TB shows that the disease disproportionally affects the poorest and most vulnerable, discriminated against, and marginalized people. This underscores the reality that fundamental social, economic, and structural inequalities are among the key factors sustaining the TB epidemic.¹⁵

The TB response should, therefore, not be limited to health centres, doctors, and medicine. Rather, it should also address the broader social determinants of health, foster an enabling environment, promote and protect the rights of people affected by TB, be gender transformative, and prioritize key and vulnerable populations.

The Stop TB Partnership (STP), through the Global Plan to End TB,16 reaffirmed that community engagement and systems strengthening (C), the promotion and protection of human rights (**R**), and gender equality (**G**) are key (CRG) components required to end TB. Likewise, the Political declaration of the highlevel meeting of the General Assembly on the fight against tuberculosis¹⁷ (2018) reaffirmed that to reach the global target to end TB by 2030, a CRG approach must be adopted. Today, the World Health Organization's (WHO's) Progress towards achieving global tuberculosis targets and implementation of the UN Political Declaration on Tuberculosis¹⁸ (2020) and the subsequent community perspective progress report, A Deadly Divide: TB Commitments vs. TB Realities (2020)19, are the most recent, explicit, and prominent articulations of this commitment to CRG in TB.

To support the operationalization of these commitments to CRG, STP and community and civil society partners developed a global CRG strategy, as well as CRG briefs, assessments, and tools. Some of this work includes the CRG Assessment, TB Stigma Assessment, 20 The Right to Breathe,²¹ Activating a Human Rightsbased Tuberculosis Response—A Technical Brief for Policymakers and Program Implementers,²² and the Declaration of the Rights of People Affected by Tuberculosis²³ As outlined in these documents, the TB response must adopt a rights-based approach that is grounded in international and regional treaties and national constitutions. This approach establishes the rights of people affected by TB, the obligations of governments, and the responsibilities of private actors in promoting accountability and access to solutions and remedies for all.24

Community-led monitoring of the TB response brings CRG principles to life. Driven by local needs and values, people affected by TB can exercise their right to participation, health, non-discrimination, confidentiality, and dignity. By monitoring, reporting, and generating information on their experiences and challenges with TB, people affected by TB also feed back to the TB care and support services and respective authorities who are responsible for protecting and promoting their rights.

Information and communications technologies present new opportunities for the achievement of global health goals²⁵ and can therefore boost the efficiency and effectiveness of CLM data collection, analysis, and reporting.²⁶ In response, STP, as part of its CRG strategy and commitment to innovation, developed the OneImpact CLM package (Framework, digital platform, and implementation tools) in partnership with community and civil society partners and Dure Technologies.

Introduction to community-led monitoring

ommunity-led monitoring is a system that increases accountability for health and social programmes. It involves people who have the most at stake recipients of services — in monitoring access to and quality of services and working to co-create solutions that improve them. CLM is based on routine and systematic oversight of local and national health and social systems and on consultations with community members to identify service gaps and areas for improvement and to inform advocacy campaigns and strategies. In health responses, CLM regards communities as key players within the health system infrastructure; it is communities that assess the quality of health services and advocate for corrective action. Here, "community" is a catch-all term that refers to groups of people who share interests, behavioural and cultural norms, and/or a geographic location. In the context of CLM, "community" refers to the beneficiaries of health and support services and the civil society entities that promote access to care.²⁷

TB global data often masks national realities and local disparities. CLM can therefore supplement national TB data by collecting information that would otherwise be excluded, producing shadow reports that hold governments accountable, and building evidence to inform civil society and community advocacy for improved care and services.²⁸

Community-**led** monitoring is managed, governed, and implemented by communities themselves. Community-**based** monitoring is done in settings or locations outside of formal health facilities.²⁹

In the context of this Framework, the word "communities" refers to any person or people with TB disease or who previously had TB disease, as well as their caregivers and immediate family members, and members of TB key and vulnerable populations, such as children, health care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations, women, and the urban and rural poor.³⁰

DIAGRAM 1: What community-led monitoring is and what it is not

COMMUNITY-LED MONITORING IS: Monitoring of the TB response by people affected by TB Monitoring indicators that are viewed as important by people affected by TB A platform for the TB response to hear from people affected by TB A platform for the TB response to hear from people affected by TB and respond to their needs

What are the community-led monitoring models?

There are many different models of communitybased and community-led monitoring. Four of the most common ones are (see **Table 1**):

- Downward accountability
- Citizens as service delivery watchdogs
- Local health governance mechanisms
- Social audits

Some CLM models collect routine data. Other models do cross-section sampling.

Terms to remember

What is the difference between communityled monitoring and community-based monitoring?

Community-led monitoring is managed, governed, and implemented by communities themselves.

Community-based monitoring is done in settings or locations outside of formal health facilities.

Table 1: Four common models of community-led monitoring³¹

| | MODEL | KEY APPROACHES | EXAMPLES |
|------|--|---|--|
| | MODEL 1 DOWNWARD ACCOUNTABILITY | Community hotlines Complaint handling systems Community feedback meetings | Save the Children's "Complaint and Feedback Mechanism" World Vision's "Citizen Voice and Action" OneImpact |
| (OO) | MODEL 2 CITIZENS AS SERVICE DELIVERY WATCHDOGS | Web-based online monitoring and reporting Community-driven operational research and quality improvements (e.g., needs assessments) Citizen charters Advocacy and campaigns | ITPC, Community Treatment Observatories Citizen Health Watch, Zimbabwe Stop Stockouts campaign Community user groups within Bamako Initiative (esp. in Benin, Guinea and Mali) Local health councils, Brazil |
| | MODEL 3 LOCAL HEALTH GOVERNANCE MECHANISMS | Participatory budgeting and procurement tracking via local health committees Community oversight committees | Crisis intervention teams, Avahan—the India AIDS Initiative |
| | MODEL 4 SOCIAL AUDITS | Community Score Cards Public hearings | CARE's Community Score Cards National Rural Health Mission, India STP / O'Neill Institute Enabling Environment Score Cards |

The principle of meaningful engagement in communityled monitoring

Community-led monitoring has a set of principles that frame and drive meaningful engagement with and by communities. The core principle is that CLM approaches are community-led: they "seek to improve the health and human rights of their constituencies, are specifically informed and implemented by — and for — communities and the organizations, groups, and networks that represent them". 32 Eliminating external influence from donors, policymakers, and others enables

greater ownership and decision–making power for communities, and, consequently, creates a more effective monitoring process.³³ While the watchdog aspect is intrinsic to the CLM process, its ultimate objective is to co-create solutions in collaboration with relevant stakeholders. Successful CLM mechanisms, from ITPC experience, have incorporated a collaborative platform for problem solving between communities, health care professionals, and health ministry and academic representatives.³⁴

Meaningful engagement and the consent of communities is essential for effective community-led monitoring. This often exists on a spectrum (**Figure 1**), too.

Figure 1: A spectrum of engagement for community-led monitoring of the TB response³⁵

INCREASING IMPACT ON DECISIONS

| THE SPECTRUM OF MEANINGFUL COMMUNITY ENGAGEMENT IN THE TB RESPONSE | | | | | | |
|---|---|---|---|--|--|--|
| INFORM | CONSULT | INVOLVE | COLLABORATE | EMPOWER | | |
| People affected by TB share experiences and design CLM indicators that are important from their perspective. | People affected by TB report TB challenges. | People affected by TB receive regular feedback on how their input has informed changes or influenced decisions. | National TB programmes and community organizations partner with people affected by TB in the analysis of CLM data, formulation of advocacy messages, and development of alternative solutions to identified challenges. | People affected by TB make final decisions and lead advocacy initiatives, use CLM data, and implement activities on the agreed-on changes and solutions. | | |

CONCEPTUAL FRAMEWORK



OneImpact CLM definition

OneImpact community-led monitoring empowers people affected by TB to access health and support services, claim their rights, and identify and reduce stigma. Through an innovative mobile app, OneImpact CLM encourages and facilitates the participation of people affected by TB in all aspects of TB programming to activate a human rights-based, people-centred response. In doing so, OneImpact CLM combats the central challenges in the TB response at the individual and community levels while generating essential information and data to better understand and combat them at the programmatic level to end TB.

OneImpact CLM model

While not discrete or distinct, OneImpact CLM falls primarily under Model 1, Downward accountability (**Table 1** in the previous section), as it *uses* a community mechanism to report and handle challenges faced by people affected by TB and leverages existing community systems to report back to affected communities.

OneImpact CLM approach

Putting people at the heart of the TB response is critical for ending TB. Every year, health systems miss millions of people affected by TB because of barriers to health services, human rights violations, stigma, and a lack of access to support services. OneImpact CLM is a direct response to these core challenges.

Using an innovative mobile app, OneImpact CLM provides people affected by TB with accurate and actionable information, links them with nearby clinics, peers, community health workers, and health workers and encourages them to report the challenges they face in a convenient, routine manner while maintaining their safety. In doing so, OneImpact CLM

supports people affected by TB to successfully complete their TB journey while strengthening responsiveness of TB programmes and making TB programmes more accountable, with special attention to gender-related and human rights-related barriers to services as experienced by key and vulnerable populations.

In this way, OneImpact CLM combats the central challenges in the TB response at the individual and community levels while generating essential information and data to better understand and combat them at the programmatic levels to end TB.



What does OneImpact CLM monitor?

Ending the TB epidemic is a target of the Sustainable Development Goals that requires, in addition to research and innovation, the implementation of several public health, biomedical, human rights, and socioeconomic interventions.³⁶

In pursuit of this goal, OneImpact CLM aims to monitor, address, and/or overcome:

HUMAN RIGHTS VIOLATIONS

TB STIGMA

BARRIERS TO TB **HEALTH SERVICES**

BARRIERS TO TB **SUPPORT SERVICES**

Human rights violations

OneImpact CLM embraces human rights as an overarching goal. As such, OneImpact CLM monitors human rights violations or infringements, as they relate to discrimination and privacy and confidentiality, to promote the realization of human rights for people affected by TB.

TB stigma

OneImpact CLM monitors stigma experienced by people affected by TB to better understand and eliminate TB-related stigma, a target of the UN Political Declaration on TB.

These (human rights violations and TB stigma) are free-standing goals, that is, they are important in and of themselves, regardless of whether they improve access to TB services or individual health outcomes.

Barriers to TB health services

OneImpact CLM monitors barriers to TB health services, as they relate to the availability, accessibility, acceptability, and quality (AAAQ) of TB health services, to understand and break down these barriers.

Barriers to TB services are monitored separate and distinct from human rights infringements and stigma. Keeping these issues as separate and distinct indicators will, among other things, facilitate OneImpact CLM to measure the relationship and interaction between access to care, human rights violations, and stigma.

Barriers to TB support services

OneImpact CLM monitors barriers to TB support services to understand the social and economic needs of people affected by TB and to address these needs.

TB is a disease of poverty, and its transmission is sustained by malnutrition, overcrowding, a lack of education and access to legal aid, and other conditions associated with socioeconomic and social determinants of health. A modelling analysis has shown that global TB incidence would be reduced by 84.3% if poverty was eliminated and all individuals were enrolled in social protection programmes.37 As such, OneImpact CLM monitors access to social and economic services to identify and facilitate access to social protection services.

To ensure that TB challenges, as experienced by different genders, age groups, and key **populations**, are captured, the CLM data can be disaggregated by gender, age, and key populations.

About OneImpact CLM digital platform

The development of OneImpact, in partnership with TB-affected communities and Dure Technologies, began in 2016. It has continuously evolved and been updated based on country experiences. In December 2020, OneImpact Next Generation SMART Set-up was released; it was based on the cumulative experiences of 10 countries.

OneImpact is a digital platform made up of three tools that work together to provide a comprehensive community-led monitoring solution:

1. Downloadable mobile app for people affected by TB: The OneImpact App provides people affected by TB with information on TB, their rights, and TB care and support services, with spaces to connect virtually and opportunities to report challenges they face throughout the TB journey. Refer to Phase 3: Training.

The OneImpact App has five components:

- Get to Know Your Rights
- Get Information
- Get Access
- Get Connected
- Get Involved

"Get Involved" facilitates CLM.
Through it, people affected by TB can report the following **TB challenges**:
Refer to Phase 3: Training.

Image 1: OneImpact CLM platform

- 2. First Responder Dashboard: This dashboard allows first responders to track, coordinate, and respond to the challenges reported by people affected by TB. Refer to Phase 3: Training.
- 3. Accountability Dashboard: This is a platform for community advocates and other stakeholders to monitor and analyse trends on TB challenges and generate CLM reports for advocacy, action, and change. Refer to Phase 3: Training.

To enhance country ownership of the platform, OneImpact content can be managed, changed, and added to using the OneImpact SMART Set-up.





EMPOWERING COMM

OVERARCHIN

- Human rights-based TB response
- People-centred TB care

PROTECTION

& PROMOTION

OF HUMAN

RIGHTS

- Meaningful community participation in the response
- Actionable data on barriers to TB health & support services, human rights violations & stigma



Individual

- Reduction in discrimination
- Enhanced privacy & confidentiality
- Respect for dignity & autonomy



Community

- Respect for communities' dignity & autonomy
- Support for livelihoods, education, housing & social protection



Programmatic

- Human rights-based response
- Enabling legal & policy environment

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HUMAN RIGHTS VIOLATIONS



Individual

- More people diagnosed & treated
- More people accessing quality TB services
- Increase in treatment adherence & completion rates



Community

- Greater community participation in the response
- Empowered community advocacy

GOOD-**QUALITY TB SERVICES** ARE AVAILABLE, **ACCESSIBLE & ACCEPTABLE**

FOR ALL

BARRIERS TO TB **HEALTH**

SERVICES

Programmatic

- People-centred care
- Programmatic responsiveness & accountability
- Actionable data for systems strengthening

CROSS-CUTT

• Gender-transformative TB response

Programmat

AUNITIES TO END TB

G IMPACTS

- Informed TB community advocacy & strengthened systems
- Enhanced TB programmatic responsiveness & information systems
- Programmatic & legal accountability
- · Social justice

ELIMINATION OF TB STIGMA

Individual

- More people adhering to & completing treatment
- Protection against catastrophic health costs
- Access to justice





≤ P

Community

- Social, economic & psychological support
- Access to justice



TB STIGMA

B ENGES

> BARRIERS TO TB SUPPORT SERVICES

> > GOOD-QUALITY TB SUPPORT SERVICES ARE ACCESSIBLE FOR ALL

Programmatic

- People-centred care
- Increase in treatment adherence & completion rates



Individua

- TB stigma elimination
- Promotion of health-seeking behavior



Community

• Enhanced acceptance & support of people affected by TB



Programmatic

- Human rights-based response
- People-centred care
- Good-quality health services



ING IMPACTS

ic recognition & responsiveness for key & vulnerable populations

OneImpact CLM Conceptual Framework explained

OneImpact's Vision is an empowered, TB-free community.

OVERARCHING IMPACTS

In working toward this Vision, OneImpact aims to realize a series of Overarching Impacts. These are:

- A human rights-based TB response*
- People-centred TB care*
- Meaningful participation of people affected by TB in all aspects of the TB response
- Generation of actionable data on barriers to TB health and support services, human rights violations, and stigma (which can be disaggregated by different genders, age groups, and key populations)
- Empowered and informed TB community advocacy and strengthened community systems
- Enhanced TB programmatic responsiveness and strengthened health information systems
- Programmatic and legal accountability in the TB response
- Social justice for people affected by TB

CROSS-CUTTING IMPACTS

OneImpact will further achieve two essential Cross-Cutting Impacts:

- Gender-transformative TB programmes and services*
- Enhanced programmatic recognition and responsiveness for TB key and vulnerable populations*

To understand the specific TB challenges experienced by different genders, age groups, and key populations, OneImpact data can be disaggregated by gender, age group, and key populations. OneImpact can also be adapted and designed for specific genders, age group, and key populations based on the outcomes of the needs and feasibility assessment. Furthermore, gender-specific challenges can be captured under "Barriers to TB services" in the Onelmpact App.



To further realize this Vision and in light of these overarching and crosscutting impacts, OneImpact aims to generate information about and empower people affected by TB, with support from their peers, community health workers, and health workers to overcome **TB Challenges** in four categories: Human Rights Violations, TB Stigma, Barriers to TB health Servies and Barriers to TB support services.

HUMAN RIGHTS VIOLATIONS

- Right to health
- Right to be free from discrimination
- Right to privacy and confidentiality

PRIMARY IMPACT

PROTECTION AND PROMOTION OF HUMAN RIGHTS

Human rights of people affected by TB are protected and promoted

INDIVIDUAL LEVEL

- Reduction in discrimination against people affected by TB
- Greater protection for individual privacy and confidentiality for people affected by TB
- Enhanced respect for dignity and autonomy of people affected by TB
- Livelihood, education, housing, and social protection for people affected by TB

COMMUNITY LEVEL

- Increased social and economic prosperity for communities affected by TB
- Enhanced respect for dignity and autonomy of communities affected by TB

SYSTEMS/PROGRAMMATIC LEVEL

- Promotion of a human rights-based TB response
- Creation of an enabling legal and policy environment

TB STIGMA

- Self-stigma elimination
- Anticipated or perceived stigma elimination
- Stigma in the family or community elimination
- Stigma in health care elimination
- Stigma in employment elimination
- Stigma in education elimination

PRIMARY IMPACT

ELIMINATION OF TB-RELATED STIGMA

TB-related stigma experienced by people affected by TB is eliminated

INDIVIDUAL LEVEL

- Elimination of stigma experienced by people affected by TB
- Promotion of health-seeking behaviour by people affected by TB

COMMUNITY LEVEL

 Enhanced community acceptance and support of people affected by TB

SYSTEMS/PROGRAMMATIC LEVEL

- Promotion of stigma elimination in health care settings
- Promotion of people-centred care
- Improved quality of health services
- Elimination of TB stigma

BARRIERS TO TB HEALTH SERVICES

- AAAQ framework (available, accessible, acceptable, good-quality health facilities, goods and services)
- Right to health
- Right to be free from discrimination
- Right to information
- Right to participation

PRIMARY IMPACT

GOOD-QUALITY TB HEALTH SERVICES

Good-quality TB health services are available, accessible, and acceptable for all people affected by TB

INDIVIDUAL LEVEL

- Increase in the number of people diagnosed and treated for TB
- Increase in the number of people affected by TB accessing acceptable, good-quality TB services
- Increase in treatment adherence and completion rates

COMMUNITY LEVEL

- Improved community access to acceptable, good-quality TB services
- Increased participation of people affected by TB in the TB response
- Empowered community advocacy

SYSTEMS/PROGRAMMATIC LEVEL

- Promotion of people-centred care
- Strengthened programmatic responsiveness and accountability
- Improved availability and quality of health services
- Generation of critical data for health systems strengthening
- Elimination of TB stigma

BARRIERS TO TB SUPPORT SERVICES

- Right to health
- Access to mental health services
- Access to nutritional support
- Access to financial or income support
- Access to justice and legal aid

PRIMARY IMPACT

GOOD-QUALITY TB SUPPORT SERVICES

Good-quality TB support services are accessible to all people affected by TB

INDIVIDUAL LEVEL

- Increase in the number of people affected by TB accessing treatment support services
- Increase in the number of people adhering to and completing TB treatment
- Protection against catastrophic health expenditures
- Expanded access to justice for people affected by TB
- Promotion of positive mental health

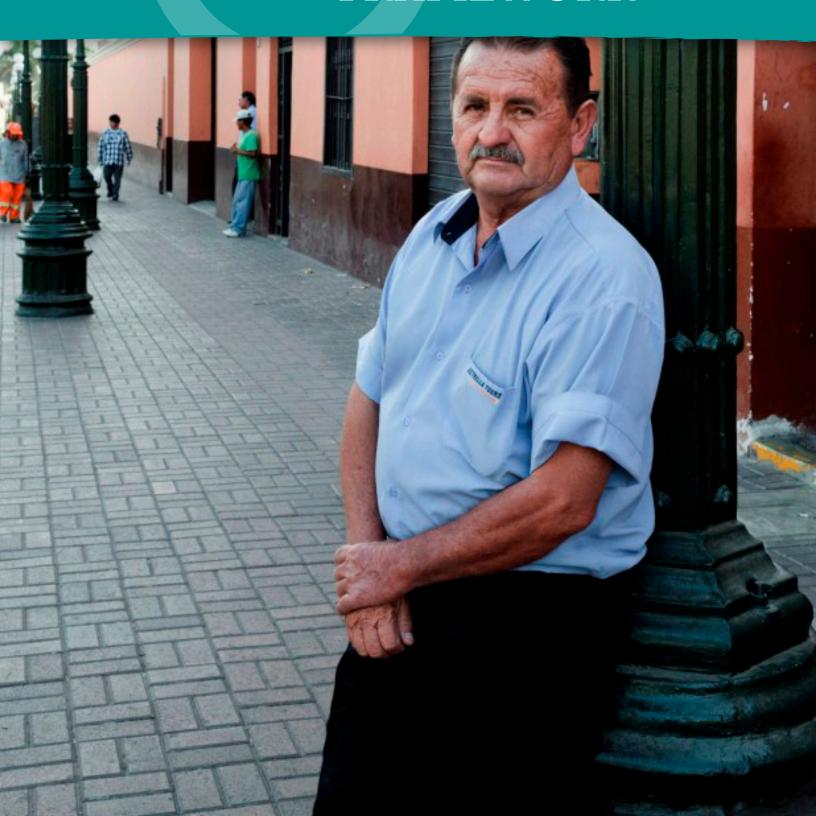
COMMUNITY LEVEL

- Increased social, economic, and psychological prosperity for communities affected by TB
- Expanded access to justice for communities affected by TB

SYSTEMS/PROGRAMMATIC LEVEL

- Promotion of people-centred care
- Increase in TB treatment adherence and completion rates

IMPLEMENTATION FRAMEWORK



nelmpact community-led monitoring can be implemented at different levels (test, subnational, and national). The needs and feasibility assessment can support decisions on whether to test OneImpact or implement OneImpact CLM at subnational or national levels. Host organizations should assess their budget, capacity, and number of potential app users, among other factors, to determine the right fit. The following provides some general guidance on scale:

Test: This is a small-scale project, usually in one or two urban districts. This level is suitable for covering areas with fewer than 10,000 people affected by TB, and should aim to collect a dataset that is 20-25% of the total (that is, if there are 5,000 people affected by TB in the area, then aim to collect 1,000-1,250 challenge reports).38 Starting small gives the host organization a chance to test the model and build capacity before scale-up.

Subnational: This covers more than one subnational area (such as districts). It is suitable for covering areas with 10,000-100,000 people affected by TB, and should aim to collect a dataset that is 10-15% of the total. Depending on the priorities of the organization, this category may be the most appropriate for very locallevel advocacy and may not require further scale-up.

National: This is implemented at national scale and should cover most areas of the country. This level is suitable for covering areas with more than 100,000 people affected by TB and should aim to collect a dataset that is 3-5% of the total.

Key actors and roles

Lead community or civil society implementer:

Every person affected by TB has the right to participate in the TB response, including in the design, governance, delivery, and monitoring and evaluation of the response. This is to ensure that TB care and support services are inclusive, accessible, and supportive of people affected by TB. People affected by TB, including vulnerable and underserved populations, should actively lead the planning, design, and delivery of the intervention, including data analysis and use at individual and community levels, through a lead community or civil society organization. This organization should therefore lead, implement, and be the focal point for the OneImpact CLM intervention.

OneGroup: In order to ensure that OneImpact remains responsive to community needs and that the data is validated and used for advocacy, the implementing organization should work collaboratively with a OneImpact Network of Experts Group ("OneGroup").39 OneGroup provides input into the adaptation and development of data collection tools (for example, OneImpact App, First Responder Dashboard, and Accountability Dashboard), supports the implementation of OneImpact, provides support on data analysis, and provides oversight on progress. OneGroup is comprised of key stakeholders (such as government, technical partners, and TB experts) and includes representatives from community and key and vulnerable population groups (for example: children; health care workers; ethnic minorities/ indigenous populations; the elderly; miners, ex-miners and their families; mobile populations; people living with HIV; prisoners; people who use drugs; rural populations living in extreme poverty; and urban slum dwellers), based on community needs and priorities (Figure 2).

Figure 2: Example of the structure of a OneGroup⁴⁰

| NATIONAL TB PROGRAMME (NTP) (CHAIR) | | | | | | |
|--|---|--|--|--|--|--|
| REPRESENTATIVE OF PEOPLE AF (Vice Chair) | FECTED BY TB NATIO | NAL TB SURVIVORS NETWORK (Secretariat) | | | | |
| Global Fund Country Coordinating Mechanism TB Representative (Member) | Member of National TB Technical Working Group (Member) | International NGO working on TB (Member) | | | | |
| The United Nations Children's Fund (UNICEF) (Member) | Academic institution (Member) | Local indigenous NGO working on TB (Member) | | | | |
| Key populations representative (e.g., mineworkers' association) (Member) | Women's representative (Member) | Representative of young people (Member) | | | | |
| Health facility representative from an area being monitored (Member) | International partner (e.g., USAID, WHO) (Member) | Member of National Multisectoral and Multi- stakeholder Accountability Review Mechanism (Member) | | | | |

Roles and responsibilities of OneGroup:

- Meets quarterly
- Reviews OneImpact data, interprets the findings, and harvests insights
- Validates Onelmpact data through discussion and triangulation
- Defines advocacy priorities based on OneImpact data
- Generates solutions to challenges identified in Onelmpact data
- Provides guidance on OneImpact implementation challenges



Evidence from ITPC's Community Treatment Observatory in **West Africa** suggests that the formation of advisory groups like OneGroup is a key way in which community-led monitoring becomes institutionalized and more sustainable.⁴¹ Lessons show that it is helpful for such advisory groups to be chaired by high-level decision-makers, such as representatives of the national TB programme (NTP).



LESSONS LEARNED

Lessons from OneImpact tests in the **Democratic Republic of Congo** and **Cambodia** suggest that it is critical to put in place mechanisms to evaluate, discuss, and analyse OneImpact data with the NTP. Setting up a OneGroup achieves this in a formalized and predictable manner. A data validation protocol for OneGroup is recommended. This should define the timeframe for OneGroup meetings, who can be in the room, and how meetings will be conducted.

Implementation phases of OneImpact CLM

When using and adapting OneImpact, please contact OneImpact@stoptb.org. STP will be able to provide more information on the availability of STP technical assistance or other partner assistance to support the roll out of OneImpact.

Led and facilitated by the lead communitybased organization (CBO) and supported by OneGroup, areas of intervention revolve around nine phases of implementation (described in Image 2), adapted from the World Health Organization, Handbook for the use of digital technologies to support tuberculosis medication adherence.42

BOX 1: OneImpact implementation phases

PHASE 1 **PHASE 3** PHASE 2 **FEASIBILITY** ADAPTATION. **TRAINING AND NEEDS** SOLUTION To orient all users on OneImpact **ASSESSMENT** DEVELOPMENT. **AND TESTING** For broad buy-in and uptake For a countryspecific solution MONTH MONTH MONTH 3-5 1-3 1-3 **PHASE 4** PHASE 5 PHASE 6 **LAUNCH** DATA **DATA USE** COLLECTION, To raise public For advocacy, awareness about action, and **ANALYSIS. AND** OneImpact CLM change REPORTING To produce reports and communication messages based MONTH MONTH MONTH on CLM data 5-12 3-5 5-12 PHASE 7 PHASE 8 PHASE 9 **CLOSING THE** MONITORING **SCALE-UP FEEDBACK** AND For sustainablility LOOP **EVALUATION** and the integration of To share with Using the Stop TB CRG into the TB affected M&E framework response communities how their input has informed the TB MONTH MONTH MONTH response 5-12 5-12 13

PHASE 1

Feasibility and needs assessment

The lead CBO, in collaboration with OneGroup, guides the needs and feasibility assessment. The purpose is to ascertain the needs and challenges faced by the affected community, as well as the availability, provision, and gaps in the existing local TB care and support services, to determine whether OneImpact CLM can be implemented as a supportive intervention and digital solution to improve the TB response.

Separately to the needs and feasibility assessment, a legal landscape assessment should be conducted. A legal landscape assessment is a process to identify, understand, and ensure compliance with all the relevant laws, policies, and regulations identified by OneImpact CLM. A legal landscape assessment is not about norms or principles, but rather ensuring that OneImpact implementers understand and abide by all applicable law in the legal jurisdictions in which they are operating. To conduct a comprehensive and accurate legal landscape assessment, OneImpact implementers should engage a lawyer familiar with the relevant legal jurisdictions. OneImpact implementers should also engage the relevant government authorities when conducting the assessment to alert them to the project and seek their guidance in understanding and complying with applicable law and regulations. In particular, OneImpact implementers should engage any data protection authorities with jurisdiction over the project.

The results of needs and feasibility and legal landscape assessments should be captured in the OneImpact CLM Action Plan, which summarizes major project components. It is also a tool that can be used to reach decisions on potential adaptations to the intervention and digital platform.

Relevant resources

- OneImpact CLM Implementation Process
- Needs and Feasibility Assessment
- Legal Landscape Assessment and User Manual
- OneImpact CLM Action Plan

PHASE 2

Adaptation, solution development, and testing

OneImpact can be used in its current format or it can be adapted to meet the specific needs of a country or community to align with national and local TB needs and priorities.

If a country chooses to adapt OneImpact CLM, it should be adapted in two ways:

- Programmatically
- Technically

Programmatically: Developing and reaching consensus on the Onelmpact CLM Action Plan supports the adaptation process of Onelmpact CLM programmatically. To reach consensus on whether, how, and to what extent Onelmpact CLM (intervention) should be adapted will require discussions among OneGroup. To make these critical decisions, the NTP should host a multisectoral inception meeting of OneGroup where the lead CBO presents the outcome of the needs and feasibility and legal assessments (draft Onelmpact CLM Action Plan) and, through discussions, reach consensus on it.

Technologically: A workshop with affected communities to identify priority TB challenges, provide feedback on the generic app prototype, and suggest improvements to the app to make it country or community specific will support the adaptation of the OneImpact App. A workshop on the First Responder Inbox will provide a forum for first responders to provide feedback on the First Responder Inbox, and a meeting with those who will respond to CLM data (for

example, health facility, legal aid teams, and NTP) will provide an opportunity for data teams to provide input on the Accountability Dashboard.

OneImpact SMART Set-up allows country administrators to make ongoing adaptations and configurations, as per the evolving needs of the countries in a self-use mode. Adaptions can include configuring the forms in "Get Involved", updating "Near Me" facilities in "Get Access", and configuring and adapting information content in "Get Knowledgeable".

Once adaptation needs are identified, countries and communities should email the Stop TB Partnership at ta@stoptb.org to discuss technical assistance requirements and options.

Once adapted, OneImpact must be tested and approved by relevant decision-makers to assess whether it is meeting desired goals and expectations. To support testing, a communication process between OneImpact users and technical developers should be established to capture and translate input and feedback into technical adjustments to OneImpact.

Relevant resources

- OneImpact CLM Inception Meeting Template
- OneImpact CLM Action Plan
- OneImpact CLM Indicators
- OneImpact CLM Response Protocol
- OneImpact CLM Budget Template

Minimum technology requirements

The OneImpact App can be accessed using the following mediums:

- Online on an Android or iOS device (3G/4G/5G)
- Offline mode on Android or iOS device
- Web version for your PC

Version compatibility for smartphone devices

- Android: Version 6 and above
- iOS: Version 9 and above

Limited internet penetration

In places where there is limited internet penetration or limited access to phones, an assisted model can facilitate reporting issues. Examples are:

- A peer-support assisted model, where people give permission to someone to report on their behalf
- A facility-based assisted model, where people report using a facility device (phone, tablet and/or personal computer)

PHASE 3 **Training**

Based on the tested and approved OneImpact platform, training materials should be developed and used by people affected by TB, first responders, lead community and/or civil society organizations and advocates, health district officers, and national TB programme staff. Based on these user manuals, training modules should be developed and tested before use. Feedback during and after the trainings should be solicited to support country scale-up plans.

OneImpact CLM embraces human rights as an overarching goal. People affected by TB must know their rights to be empowered to claim them. There are different training materials and tools to support these trainings.

Furthermore, data privacy and network security are critical for the success of OneImpact CLM. They are necessary to ensure compliance with applicable law and regulations and to protect and promote the human rights of people affected by TB involved in the project. Training to highlight key principles and operational and technical protocols and mechanisms to ensure data privacy and network security for OneImpact CLM is therefore critical.

Relevant resources

- The Right to Breathe: human rights training for people with and affected by TB
- Activating a Human Rights-Based TB Response: A technical brief for policymakers and program implementer
- Declaration of the Rights of People Affected by TB
- OneImpact App Manual
- OneImpact First Responder Dashboard User Manual
- OneImpact Accountability Dashboard User Manual
- OneImpact SMART Set-up User Manual
- OneImpact Data Privacy and Network Security User Manual

PHASE 4 **LAUNCH**

To raise awareness about OneImpact CLM and to encourage uptake of OneImpact among people affected by TB, a launch event should be held. The resources listed below can also be used in health care settings, training settings, and other appropriate settings.

Relevant resources

- OneImpact App poster
- Onelmpact video

PHASE 5

Data collection, analysis, and reporting

DATA COLLECTION PROCESS

OneImpact data is collected from TB-affected communities that report TB challenges through the OneImpact App. If people affected by TB are not able to use the app (if, for example, they are not comfortable using smartphones or they are too sick), OneImpact can be operated by their family members, social workers, treatment supporters, or other peers or persons who the TB-affected person has entrusted to respond on their behalf.

Data collection may be passive or active, or both. The option chosen will depend on resource availability and the kind of work that the implementing organization does. If the implementing organization has regular contact with people affected by TB, it is recommended that a combination of active and passive data collection is done.

Passive data collection: The organization implementing OneImpact relies on word of mouth to encourage people affected by TB to download the app and use it to report TB challenges.

Active data collection: The organization implementing OneImpact creates structured times and spaces for people affected by TB to download the OneImpact App and use it to report TB challenges. This might include dedicated time on the agenda during treatment literacy sessions, during active case finding outreach, or in other community gatherings.

QUALITY ASSURANCE (DATA ACCURACY)

Each reported TB challenge is captured and electronically stored in the First Responder Inbox, which is managed by the CLM data manager or managers (who have signed confidentiality agreements). For data accuracy and quality purposes, data managers must validate or decline each reported challenge, based on a country-specific protocol. This might include checking if the person reporting the challenge is registered and linked to a health facility (to screen for people who are not registered at a health facility using the app) or if they reported the challenge more than once within a defined timeframe (that is, to screen for duplication errors). Data validation is critical for the data analysis and reporting components of OneImpact CLM. It gives implementers and those expected to use and respond to the CLM data confidence that the data is accurate, clean, and appropriate.

DATA ANALYSIS

The OneImpact Accountability Dashboard makes data analysis simple, but effective data analysis requires comparison. When analysing OneImpact data, key considerations include:

Disaggregation of data by age, gender, **location, and population.** Look for inequities in the data to focus advocacy and responses on those most left behind.

Trend analysis over time. Using data from at least three different points in time, analyse trends to determine if things are getting better, getting worse, or staying the same.

Benchmarking against another data source. It can be useful to compare OneImpact data with national data, data from another country, or data from another region within a country. This provides a benchmark for progress.

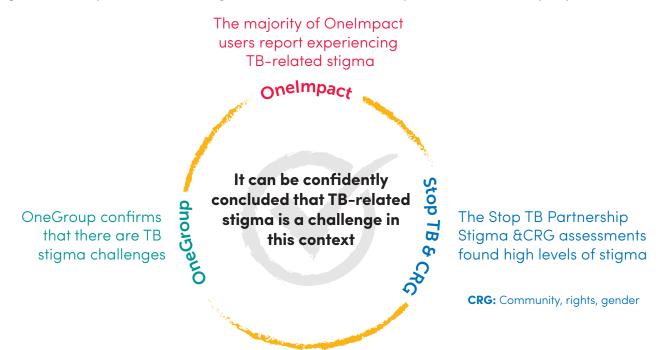
Comparison with national targets or commitments. CLM data can be very powerful if it is placed side by side with targets or commitments, pointing to the gaps between the two. It can also identify whether CLM has had any positive effects on health outcomes through its implementation.

Combining qualitative and quantitative data.

Numbers are powerful, but they do not tell the whole story. Often, it is more effective to combine statistical data with a narrative explanation to capture the "what", as well as the "why". For example: 70% of OneImpact users report experiencing stigma and discrimination (quantitative data); inbox messages confirm that the most common reason for TB stigma is a lack of information among family members (qualitative explanation).

Triangulation with other data sources. To have increased confidence that OneImpact data is an accurate reflection of true reality, it can be useful to "triangulate" data with other sources.

Figure 3: Example of a data triangulation exercise for OneImpact CLM data analysis phases



DATA REPORTING

Depending on the audience or the forum, different formats of OneImpact data reporting may be most suitable. **Table 2** provides a list of ways that OneImpact data can be reported and some suggested audiences for each method.

Table 2: Ways of reporting OneImpact data and possible audiences for each method

| REPORTING METHOD | POSSIBLE AUDIENCE(S) |
|-----------------------|--|
| Factsheets | Civil society and community groups |
| Dashboard screenshots | Health www staff, Country Coordinating Mechanisms |
| Press releases | Media, journalists |
| Long-form reports | Funding partners, researchers |
| Infographics | Civil society and community groups |
| Policy briefs | Government decision-makers |
| Slide decks | Participants at conferences, webinars, and learning events |
| Shadow reports | National TB programme, Stop TB Partnership |
| Case studies | World Health Organization, technical working groups |
| Journal articles | Academics, scientists |

PHASE 6

Data use

OneImpact data can be used in different ways. Generally speaking, there are four main change pathways along which OneImpact data can be used.

Change pathway #1

Use OneImpact data to respond to individual challenges reported by people with TB

This would be done by the lead CBO that is implementing OneImpact, by consulting the OneImpact First Responder Dashboard, and coordinating or responding to TB challenges reported.



In the OneImpact project in Indonesia, LKNU had one data operator servicing two areas, responding to reported challenges. In the **Democratic Republic** of Congo, Club des Amis Damien had a TB specialist doctor seconded from the NTP and a psychologist, who were able to respond to the medical and psychological challenges reported. This was a key success factor. In Tajikistan, Stop TB Partnership Tajikistan had a specialist doctor and psychologist from the NTP as part of the response team.



It is important to remember that the TB community organization that is implementing OneImpact cannot possibly solve all the challenges reported through the app. There will likely be larger systemic challenges – such as drug stock-outs or stigma and discrimination — which require collaboration with partners and advocacy at the policy level.

Change pathway #2

Use OneImpact data to advocate with key decision-makers

This pathway would include local-level advocacy with health centre staff to convince them to change the way TB care and support services are provided. It could also include national-level policy advocacy with the NTP, TB Technical Working Group, Global Fund Country Coordinating Mechanism, or other decisionmaking body.



In Tanzania, EANNASO convened Annual Dialogue Forums where it would interpret the data and come up with the advocacy messages. In Indonesia, meetings with the media to share and disseminate results were effective. In Cambodia, KHANA identified the need to show the OneImpact Accountability Dashboard to the Community Council, which oversees the running of health centres. In Tajikistan, Stop TB Partnership Tajikistan Celebrity Champions delivered key advocacy messages through their social media channels, based on OneImpact CLM data. In Ukraine, TBpeopleUkraine founded a multisectoral initiative group to provide support to overcoming the major challenges reported via OneImpact. The group members, including TB community representatives and national and local health and legal experts, address the array of challenges reported, including status disclosure, stigma and discrimination, and other rights violations. In DRC, Club des Amis shares CLM data regularly with the Country Coordinating Mechanism.

Change pathway #3

Use OneImpact data to motivate strategic investments

In 2020, just half of the global TB funding need was met (US\$6.5 billion was made available against a total need of \$13 billion). OneImpact data can be used to justify or rationalize

investments in TB programmes, especially those which are community led or target key and vulnerable populations that face disproportionate levels of risk and barriers to accessing TB services.

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In funding requests submitted to the Global Fund to Fight AIDS, Tuberculosis and Malaria for the 2020–2022 cycle, the following countries included OneImpact: Cambodia, DR Congo, Haiti, Indonesia, Kyrgyzstan, Mali, Mozambique, Tajikistan, Uganda, and Ukraine.

Change pathway #4

Use OneImpact data to inform the national TB response

This might include using OneImpact data in high-level monitoring and evaluation (M&E) forums, such as national multisectoral and multi-stakeholder accountability review mechanisms. Or it could include monitoring one's own performance if the organization that is implementing OneImpact is a TB service provider.



In Mozambique, the ADPP discovered that the majority of household contacts of OneImpact App users were not screened for TB. The organization implements active case-finding projects in the area, so the data revealed challenges with their own performance. Based on the data, the organization implemented a quality improvement plan with their outreach workers. This resulted in 27 children under the age of five years initiating TB preventive therapy (TPT).

Data use for primary impact

OneImpact data can be used to overcome challenges, support advocacy, strengthen health and community responses, inform programmatic decision–making, evaluate interventions, support community engagement, and build the evidence base for people–centred TB care and a rights–based TB response. Based on experiences during OneImpact projects, options for data use include:

Good-quality TB services are available, accessible, and acceptable for all people affected by TB

Increase accountability of service providers to recipients of care. OneImpact data can be used to improve the availability, accessibility, acceptability, and quality of TB services. This can be done by sharing OneImpact data with health care workers, health facility staff, and health facility structures (for example, local health councils and community user groups).



Experience from OneImpact projects suggests that it is important to collaborate and cooperate with health care workers and health facilities to find solutions to challenges. Collective problem solving usually works better than finger pointing. This

message should be made clear from the very beginning of implementation: data will be used to co-solve identified challenges, not to get any individual person into trouble. Protection and promotion of the human rights of people affected by TB

Strengthen access to legal support services. The OneImpact App provides an opportunity to share information with people affected by TB on the availability of legal support services.



In Ukraine, TBpeopleUkraine built a collaboration with free legal services and employed a psychologist to provide free consultations for people affected by TB. In turn, OneImpact data can be used to monitor and evaluate the impact of interventions to strengthen access to legal support.

Improve community participation in the TB response. OneImpact is an available tool to improve and scale up support for community participation interventions that are people centred, human rights based, and gender responsive.



In Ukraine, TBpeopleUkraine established an expert group of people affected by TB (within the multisectoral initiative group), who support the resolution of challenges reported. This group also works in partnership with the national TB programme and in cooperation with the Public Health Center of the Ministry of Health of Ukraine and TBpeopleUkraine.



Tanzania prioritizes the use of OneImpact in its National Strategic Plan for Tuberculosis and Leprosy 2020-2025.44

Reduction and elimination of TB-related stigma experienced by people affected by TB

Training health care workers: In the health care setting, OneImpact data may be used for training and supporting health care workers to overcome personal and institutional discriminatory attitudes and actions and strengthening accountability for discriminationfree health care.45



In Ukraine, TBpeopleUkraine trained a network of family doctors on OneImpact who now orient people newly diagnosed with TB on OneImpact.



Lessons from the OneImpact project led by ADPP in Mozambique suggest that health care workers are not always aware of the challenges that people with TB face, and when confronted with OneImpact data, they can be urged to improve the quality of care they provide.

Monitoring progress on stigma reduction. OneImpact data can be used to monitor national commitments on reducing TB-related stigma and discrimination.



In Côte d'Ivoire's Five-Year Plan for Human Rights, HIV and Tuberculosis 2021–2025, OneImpact is prioritized to monitor stigma, discrimination, quality of care, and access to services for people with TB.

Good-quality TB support services are accessible to all people affected by TB, especially those undergoing treatment

TB ("patient") cost surveys: OneImpact data may be used as a supplemental data source for TB cost surveys, as the OneImpact App collects information on people with TB who are undergoing treatment and report having to pay for TB tests, TB medicines, and TPT, but don't have enough money to do so. It also collects data on transport costs as a barrier to accessing TB services at facility level.



In Ukraine, TBpeopleUkraine shares CLM data regularly with all stakeholders, including the Public Health Center of the Ministry of Health of Ukraine and the National Health Service of Ukraine. In one instance. CLM data revealed a trend in the inappropriate and unregulated supply of nutritional support for people with TB. This information was shared with the National Health Service of Ukraine during the National Dialogue on TB (October 2020). In December 2020, the working group of experts revised the National Health Service Package to include: "Support and treatment of adults and children with tuberculosis at the primary level of care"; and "Diagnosis and treatment of adults and children with tuberculosis in outpatient and inpatient settings".

PHASE 7

Closing the feedback loop

(engagement and advocacy)

The goal of OneImpact community-led monitoring is to stimulate positive and corrective action that ensures that:

- Good-quality TB health services are available, accessible, and acceptable for all people affected by TB
- Human rights of people affected by TB are protected and promoted
- TB-related stigma experienced by people affected by TB is reduced and eliminated
- Good-quality TB support services are accessible to all people affected by TB

Implementers should always strive to make feedback constructive.

OneImpact CLM collects real-time data on current experiences of TB-affected communities to respond to the challenges and to identify, analyse, and communicate identified gaps within a reasonably short time. As such, it transforms findings into advocacy action and engagement at various levels. Such information may also show whether a programme is achieving intended results.

Feedback loops for OneImpact projects (from identification of challenges and limitations to advocacy with decision–makers) should last three to six months or shorter. The feedback loop for OneImpact projects done at scale (which are therefore collecting a large amount of information) may last longer, but implementers should always strive to keep this as short as possible.

Feedback on OneImpact data, advocacy messages, and effected changes should be shared with health service providers, decision-makers, and, most importantly, the people who provided the data. The last group of people is very important.

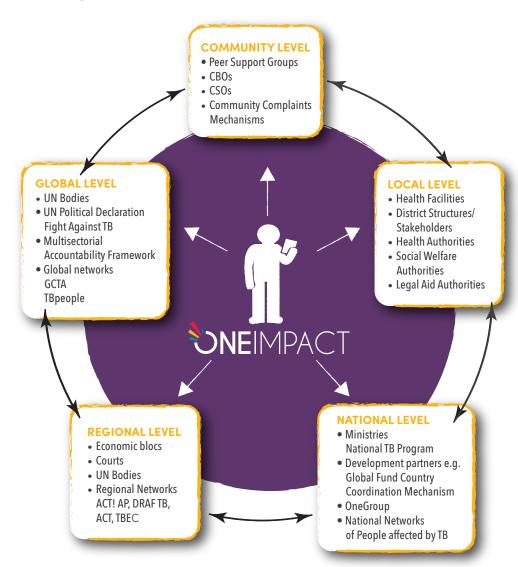


Feedback to OneImpact app users is a must

It is very important to provide feedback to OneImpact App users. If TB communities that report challenges through the OneImpact platform do not see what is being done with the information they provide or if they do not see any changes happening, they may be reluctant to continue participating in the project. OneImpact implementers should provide regular feedback to app users on findings, how data is being used, and the key advocacy wins that were achieved.

Creating a OneImpact CLM feedback engagement loop — for advocacy priorities and interventions — should be defined and addressed at different entry points (that is, individual, community, local, national, regional, and global levels) that are best fit to negate, address, and overcome the TB challenges. For example, if people affected by TB are reporting that they are paying for TB treatment in public facilities, community engagement and advocacy efforts should target the national TB programme to clarify its national policy, strengthen its training guidelines, or take corrective actions at implicated health facilities to ensure that people affected by TB never pay for treatment again.

Figure 4: Accountability structure



PHASE 8

Monitoring and evaluation

To track and identify OneImpact CLM project gaps and to improve implementation to achieve the OneImpact goals and objectives, ongoing monitoring should take place. In addition, the project should be evaluated (baseline and end of project) to inform scale-up plans. The results of M&E should be continuously shared and discussed with OneGroup.

Relevant resources

 OneImpact CLM Monitoring and Evaluation Plan

PHASE 9 Scale-up

Lessons learned from the test project should be shared and discussed within OneGroup and programmatic and technological lessons learned should be applied to inform scale-up plans. A validation meeting to share the outcome of the test project and OneGroup discussions should be held; these should be multisectoral, like the inception multisectoral meeting at the beginning of the project. To support these discussions, the following should be noted and discussed:

Scale-up

- Sustainability
- Integration
- Value for money
- Scale-up

OneImpact is designed to support large-scale projects. To scale up or expand OneImpact community-led monitoring in the community or country context, OneImpact Next Generation is designed in a way that it can onboard a significant volume of users into the system and allow them to report TB challenges across different locations at the same time. The

OneImpact App is secured, encrypted, easily accessible to a wider audience, and compatible across multiple and lower versions of devices.

The plug-and-play mechanism of the system using OneImpact SMART Set-up and the availability of the source code and technical documentation allows the programme implementers to scale up or expand OneImpact CLM with minimal technical knowledge. The resolution mechanism helps filter challenges across different regions, districts, and facilities; this is a key lesson and request from countries and, therefore, an added feature of the First Responder Dashboard and Accountability Dashboard. The Accountability Dashboard is smart enough to auto-detect challenges from different geo-locations without the user going through the hassle of entering their region or district.

Moreover, OneImpact Next Generation platform scale-up is possible due to the following key system parameters:

- Minimal app size for download and installation
- User-friendly interface
- Less waiting time (approximately 50 milliseconds)
- Structured information dissemination
- Organized reporting of challenges
- Access to more categories of facilities and point of interests
- Community engagement through forum and group chats
- Engagement options—like/comment
- OneImpact SMART Set-up for making changes on the fly and disseminating information
- Guided steps and automated responses
- 360-degree user satisfaction
- Modular nature of the platform—it can be adapted based on a country's capacity and

readiness. For example, those few countries that do not have peer support network groups to respond to community needs can still scale OneImpact by providing other services, like community forums, knowledge content, and nearby facilities.

The platform can also be scaled to other vulnerable communities, like people affected by HIV and COVID-19.

In addition, different models of OneImpact CLM can be used depending on the availability of smartphones among people affected by TB. For example, when smartphone penetration is not high, an assisted model can be used; this allows different people or actors to report on behalf of people with TB with their permission and consent. This data can be stored separately in the Accountability Dashboard to keep data sets clean (such as in Ukraine). In addition, OneImpact can be integrated into channels that are not based on the use of the internet and/or smartphones, for example, USSD, IVRS, SMS, and missed call services.

Sustainability

The OneImpact Next Generation platform is sustainable in the following ways:

- Availability of the source code
- Availability of technical and user documentation
- Availability of the dashboard (entire platform) in local languages
- Availability of CLM data and information in real time
- Downloadable charts of CLM
- End-to-end data encryption
- Restrictions to capture screenshots in the app to avoid personal data loss
- Security compliance
- Latest and reliable technology stack
- Device compatibility
- Categorized indicators

- Aggregated data based on various filters
- Transition/navigation time within different pages in milliseconds
- Plug and play in local country set-up
- OneImpact SMART Set-up, allowing countries to adapt the platform based on evolving needs in a self-use mode without any dependencies.

Once adaptation needs are identified, countries and communities should email the Stop TB Partnership at ta@stoptb.org to discuss technical assistance requirements and options.

Integration

The OneImpact Next Generation platform is capable of the following integration:

- Integration with local and national eco-systems
- Compatible with DHIS2 and cloud services
- Integration with social media channels, such as Facebook, WhatsApp, LINE, and Telegram
- Integration with country-specific VAS services, such as USSD, IVRS, SMS, and missed call services
- Adaption to spaces and templates for other health issues, such as HIV, malaria, and COVID-19
- Integration with conversational artificial intelligence with touch-free interactions
- Integration with assisted models and adding multiple profiles

Value for money

OneImpact is designed for scale and maximizing social return on investment made by countries. This is even more evident when countries scale the solution to reach more communities without proportionally increasing investments, a true illustration of economies of scale. The OneImpact Next Generation platform is a value-for-money model in the following

ways:

- Free access to the source code
- Free access to the technical and user documentation
- Free access to the generic app and the dashboard
- The community or country can request technical assistance to roll out and expand usage
- Capability to integrate with multiple channels

- Ongoing adaptation by countries in a self-use mode without any additional costs
- The same OneImpact model can be also leveraged by communities affected, for example, by HIV, malaria, and COVID-19.

Once adaptation needs are identified, countries and communities should email the Stop TB Partnership at ta@stoptb.org to discuss technical assistance requirements and options.

Success factors for OneImpact CLM

- Starting small with the intention to scale up
- Strong TB community organizations
- Working relationships with the national TB programme and other local authorities
- Inclusion of OneImpact in national strategies and plans
- Implementation in areas with high smartphone penetration
- Translation of the platform into local languages
- Ability of implementing organization to make backend adjustments to the OneImpact app

- Bi-directional communication and information exchange between app users and implementers
- Active and ongoing engagement with stakeholders to interpret and validate the data
- A focus on local-level data collection and use, as well as national-level policy advocacy
- A combination of rapid response and systematic community-led monitoring and advocacy
- Sustainable financing

Framework for OneImpact **CLM** data privacy and network security

ata privacy and network security are critical for the success of OneImpact community-led monitoring. They are also necessary to ensure compliance with relevant laws and regulations and to protect and promote the human rights of people affected by TB involved in the project. As explained in the terms and definitions section, data privacy is the right to restrict use, access, disclosure, and dissemination of information. Data security comprises technological and non-technological mechanisms that restrict the use, access, disclosure, and dissemination of information. Similar to data security, network security comprises the technological and operational policies and practices implemented to monitor and prevent unauthorized access, misuse, modification, or denial of a network of computers or devices, as well as the information and resources accessible through the network.

Key concerns for data privacy and network security

Ensuring data privacy and network security for OneImpact CLM is critically important to address three key concerns:

- Safeguarding OneImpact users' data is necessary to protect against violations of human rights. If sensitive personal information collected during OneImpact CLM is misused or accessed by unauthorized personnel, it may result in violations of the right to privacy and confidentiality, the right to be free from discrimination, or the right to health of people affected by TB involved in the project.
- Guaranteeing data privacy and security is necessary to ensure compliance with the law. Most countries have laws that regulate the collection, storage, use, and disposal of

- personal information, particularly in the form of digital data. Protecting data privacy and network security is, therefore, critical to avoid legal sanction and penalties, such as fines or injunctions, that may disrupt OneImpact CLM and harm implementing organizations.
- Data privacy and network security are key to achieving the OneImpact Vision and its overarching, cross-cutting, and primary impacts. In this respect, protecting the personal information of people affected by TB involved in OneImpact CLM is necessary to build and maintain community trust and to prevent political liability and "chilling" effects. In other words, failure to protect personal information collected by OneImpact will erode the community's trust in the app and "chill" their willingness to support and participate in OneImpact CLM.

If OneImpact users do not believe that their personal information will be kept private and secure or if they experience harm resulting from the use or misuse of their personal information, it will destroy the community's trust in the app and the OneImpact CLM project. This, in turn, will discourage other community members from participating in the first place. Negative community experiences stemming from the failure to keep OneImpact data private and secure may also cause political liability. Public authorities may refuse to support or engage or even try to shut down — OneImpact CLM if community members are harmed during the project.

Operational and technical guidance

To ensure data privacy and network security, OneImpact implementers should adopt the following set of operational and technical protocols, procedures and mechanisms (these are explained in detail in the OneImpact Data Privacy and Network Security User Manual):

- Require personnel to sign OneImpact confidentiality agreements.
- Prepare a OneImpact incident response plan.
- Conduct periodic Onelmpact data audits.
- Require use of passwords and multi-factor authentication (MFA) to access the OneImpact network.
- Implement data and network access controls:
 - Role-based access control
 - Public WiFi and virtual private networks (VPNs) policy
 - Antivirus software
 - Auto-lock.

- Ensure that OneImpact data provided to third parties is de-identified and anonymized.
- Segment the Onelmpact network.
- Implement a OneImpact data deletion and destruction policy.
- Conduct regular maintenance and upkeep of the Onelmpact network.

Relevant resources

 OneImpact Data Privacy and Network Security User Manual

CONCLUSION



Communities closing the gap to reach the TB targets

B is the major global health challenge of the 21st century and it affects key and vulnwerable populations the most. To end TB, it is essential that a holistic community, rights and gender (CRG) approach is taken to reach every person affected by TB.

In 2018, the United Nations (UN) held its firstever high-level meeting on TB (UN HLM on TB) titled "United to End TB: An Urgent Global Response to a Global Epidemic", elevating the discussion on the status of the global TB epidemic and how to galvanize efforts to end it by 2030, to the level of heads of state and heads of government.

In December 2020 Stop TB Partnership in collaboration with TB affected communities launched A Deadly Divide: TB Commitments versus TB Realities. The report, which complements the 2020 Progress Report of the UN Secretary-General, outlines the urgent need for a TB response that is equitable, community-led, right-based, and peoplecentered to reach the targets and commitments in the UN Political Declaration on TB. Developed by the Stop TB Delegations that represent Affected Communities, Developing Country NGOs, and Developed Country NGOs, with inputs from 150 community partners from over 60 countries, the report provides operational guidance on how countries and other stakeholders can enhance accountability and realize the necessary paradigm shift. The report includes a Call to Action that focuses on six key Areas of Action, based on the 5 key asks that TB communities presented at the United Nations High-Level Meeting on TB in 2018, with the addition of a sixth Area of Action on COVID-19.

These are:

1

Reaching all people through TB detection, diagnosis, treatment, care and prevention.

2

Making the TB response rights based, equitable and stigma-free, with communities at the center.

3

Accelerating the development of, and access to, new tools to end TB.

4

Investing the funds necessary to end TB.

5

Committing to multisectoral accountability and leadership on TB.

6

Leveraging COVID-19 as a strategic opportunity to end TB.

To meet these calls and to advance a TB response that is rights-based, equitable and stigma free with communities at the centre requires the meaningful engagement and consent of people affected in all aspects of the TB response, including monitoring and evaluation. OneImpact community-led monitoring (CLM) is one approach to monitoring and evaluating the TB response, using innovation to achieve its goal. Led by communities OneImpact CLM contributes to advancing commitments and targets in the Political Declaration of the High-Level Meeting of the General Assembly on the Fight Against Tuberculosis and the Calls to Action in the Deadly Divide: TB communities Vs TB Realities to end TB by 2030.

OneImpact partners wholeheartedly thank the affected communities who developed tested and led this work and make an impassioned plea to the donor community and the TB community at large to prioritize OneImpact CLM interventions, as complementary actions and support that can identify and overcome barriers to access, TB stigma and human rights violations to reach the missing millions with TB.

The clock is ticking, so now is the time to maintain and scale-up support and investments in OneImpact CLM so that affected communities are engaged, informed, and can lead us in this fight to end the TB epidemic by 2030.

RESOURCES



PHASE 1

Feasibility and needs assessment

- OneImpact CLM Implementation Process
- Needs and Feasibility Assessment Template
- Legal Landscape Assessment Template and User Manual
- OneImpact CLM Action Plan

PHASE 2

Adaptation, solution development, testing

- OneImpact CLM Inception Meeting Template
- OneImpact CLM Action Plan
- OneImpact CLM Indicators
- OneImpact CLM Response Protocol
- What is OneImpact CLM Monitoring?
- OneImpact CLM Budget Template

PHASE 3

Training

- Declaration of the Rights of People Affected by TB
- The Right to Breathe
- Activating a Human Rights-based Tuberculosis Response—A Technical Brief for Policymakers and Program Implementers, and the Declaration of the Rights of People affected by TB
- Onelmpact App User Manual
- OneImpact Response Dashboard User Manual
- OneImpact Accountability Dashboard User Manual
- OneImpact Smart Set-up User Manual
- OneImpact Data Privacy and Network Security User Manual

PHASE 4

Launch

- OneImpact CLM App poster
- OneImpact CLM video

PHASE 8

Monitoring and evaluation

 OneImpact CLM Monitoring and Evaluation Plan

Community-led monitoring case studies

- ITPC case study
- Onelmpact K+ Cambodia Case Study
- OneImpact TB Tolongi DRC Case Study
- OneImpact Sehat Indonesia Case Study
- OneImpact Mozambique Case Study
- OneImpact Ukraine Case Study

LIST OF ILLUSTRATIONS



Diagram 1: What community-led monitoring is and what it is not

Table 1: Four common models of community-led monitoring

Figure 1: A spectrum of engagement for community-led monitoring of the TB response

Image 1: OneImpact CLM platform

Diagram 2: OneImpact community-led monitoring conceptual framework

Figure 2: Example of the structure of a OneGroup

Image 2: OneImpact community-led monitoring implementation phases

Figure 3: Example of data triangulation exercise for OneImpact CLM data analysis

ENDNOTES



- Interagency Gender Working Group. The Gender Integration Continuum Training Session User's Guide, USAID (2017), https://www.igwg.org/ wp-content/uploads/2017/12/17-418-GenderCon tTraining-2017-12-12-1633_FINAL.pdf.)
- 2 Activating a Human Rights-Based Tuberculosis Response: A Technical Brief for Policymakers and Program Implementers, Global Coalition of TB Activists, Stop TB Partnership, Northwestern Pritzker School of Law Center for International Human Rights (2020).
- 3 Elsayyad, Ahmed (2014). "Informed Consent for Comparative Effectiveness Trials", New England Journal of Medicine. 370 (20): 1958–1960. doi:10.1056/NEIMc1403310.
- 4 Adapted from the ICAP CQUIN Community Engagement Framework (draft), 2019...
- 5 TBpeople & Stop TB Partnership. Declaration of the Rights of People Affected by Tuberculosis (2019), http://www.stoptb.org/assets/ documents/communities/FINAL%20 Declaration%20on%20the%20Right%20of%20 People%20Affected%20by%20TB%2013.05.2019. pdf.
- 6 WHO. Service Delivery and Safety: What Are Integrated People–Centred Health Services, https://www.who.int/servicedeliverysafety/areas/people-centred-care/ipchs-what/en.
- 7 U.S. National Institute of Standards and Technology. Information Technology Laboratory:Computer Security Resource Center, https://csrc.nist.gov/glossary/term/PII.
- 8 International Covenant on Economic, Social and Cultural Rights Art. 12, Dec. 16, 1966, 993 U.N.T.S.3.
- 9 UN Committee on Economic, Social and Cultural Rights. Gen. Comment No. 14 on the Right to the Highest Attainable Standard of Health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), UN Doc. E/C.12/2000/4 (11 Aug. 2000).
- 10 T Tanahashi (1978). "Health service coverage and its evaluation", 56 Bull. World Health Organ. 295–303, https://www.ncbi.nlm.nih.gov/pmc/

- articles/PMC2395571.
- 11 Global Plan to End TB, http://www.stoptb.org/ assets/documents/global/plan/GPR_2018-2022_Digital.pdf.
- 12 https://www.who.int/tb/features_archive/UHC_day_2017_side_event/en/.
- 13 Kingsley N Ukwaja (2018). "Social protection interventions could improve tuberculosis treatment outcomes", The Lancet Global Health, https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30523-0/fulltext.
- 14 Progress Towards The Achievement Of Global Tuberculosis Targets And Implementation Of The Political Declaration Of The High-Level Meeting Of The General Assembly On The Fight Against Tuberculosis: Report of the Secretary-General, United Nations General Assembly (16 September 2020), https://www.who.int/publications/m/item/overview-progress-towards-achieving-global-tuberculosis-targets-and-implementation-of-the-un-political-declaration-on-tuberculosis.
- 15 Barter, Devra (2012). Tuberculosis and poverty: the contribution of patient costs in sub-Saharan Africa—a systematic review https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3570447/.
- 16 Global Plan to End TB, http://www.stoptb.org/ assets/documents/global/plan/GPR_2018-2022_Digital.pdf.
- 17 UN Political Declaration on TB (2018). https://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/73/3,
- 18 UN Progress towards achieving global TB targets and implementation of the UN Political Declaration on TB, https://www.who.int/ publications/m/item/ overview-progress-towards-achieving-globaltuberculosis-targets-and-implementation-ofthe-un-political-declaration-on-tuberculosis.
- 19 Stop TB Partnership. A Deadly Divide: TB Commitments vs. TB Realities (2020), http:// www.stoptb.org/assets/documents/ communities/The%20Deadly%20Divide_TB%20

- Commitments%20vs%20TB%20Realities%20 FINAL%20HLM%20Report.pdf.
- 20 Stop TB Partnership. TB Stigma Assessment Implementation Handbook, http://www.stoptb. org/assets/documents/communities/STP%20 TB%20Stigma%20Assessment%20 Implementation%20Handbook.pdf.
- 21 The Right to Breathe, http://www.stoptb.org/ assets/documents/communities/The%20 Right%20To%20Breathe%20(REV)_22jan2020. pdf.
- 22 Activating a Human Rights-based Tuberculosis Response, https://drive.google.com/ file/d/1b9LafHkKMJ7Bam-Gfu0_no8ryCb3EYf7/ view.
- 23 Declaration of the Rights of People Affected by Tuberculosis, http://www.stoptb.org/assets/ documents/communities/FINAL%20 Declaration%20on%20the%20Right%20of%20 People%20Affected%20by%20TB%2013.05.2019. pdf.
- 24 Brian Citro et al (2016). "Developing a Human Rights-Based Approach to Tuberculosis", Health and Human Rights Journal, https://www.ncbi. nlm.nih.gov/pmc/articles/PMC5070676/.
- 25 World Health Organization Global Strategy on Digital Health 2020–2025, https://www.who.int/ docs/default-source/documents/ gs4dhdaa2a9f352b0445bafbc79ca799dce4d. pdf?sfvrsn=f112ede5_68.
- 26 The Global Fund to Fight AIDS, Tuberculosis and Malaria (2020). Towards a Common Understanding of Community-based Monitoring and Advocacy, https://www.theglobalfund.org/ media/9632/ crs_2020-02cbmmeeting_report_en. pdf?u=637319005551530000.
- 27 Adapted from ITPC (2021). How to Implement Community-led Monitoring and Advocacy: A Community Toolkit.
- 28 ITPC. Community-led Monitoring and Research, https://itpcglobal.org/our-work/ community-led-monitoring-research/.

- 29 Global Fund to Fight AIDS, Tuberculosis and Malaria (2019). Technical Brief: Community Systems Strengthening. https://www. theglobalfund. org/ media/4790/ core_communitysystems_technicalbrief_en.pdf
- 30 Declaration of the Rights of People Affected by TB, http://www.stoptb.org/assets/documents/ communities/FINAL%20Declaration%20on%20 the%20Right%20of%20People%20Affected%20 by%20TB%2013.05.2019.pdf.
- 31 LSE & Frontline AIDS (2016). Four models of community-based monitoring: a review. A report prepared for the Global Fund to Fight AIDS, Tuberculosis and Malaria.
- 32 World AIDS Day 2019 report. Power to the people [Internet]. UNAIDS org. 2019 [cited 09 November 2020]. Available from: https://www. unaids. org/ en/20191226_WAD2019_report_power_people.
- 33 ITPC (2021). How to Implement Community-led Monitoring and Advocacy: A Community Toolkit.
- 34 ITPC (2021). How to Implement Community-led Monitoring and Advocacy: A Community Toolkit.
- 35 Adapted from IAP2 Public Participation Spectrum. Online at https://cdn.ymaws.com/ www.iap2.org/resource/resmgr/pillars/ Spectrum_24x36_Poster.pdf.
- 36 Kingsley N Ukwaja (2018). "Social protection interventions could improve tuberculosis treatment outcomes", The Lancet Global Health, https://www.thelancet.com/journals/langlo/ article/PIIS2214-109X(18)30523-0/fulltext.
- 37 Kingsley N Ukwaja (2018). "Social protection interventions could improve tuberculosis treatment outcomes", The Lancet Global Health, https://www.thelancet.com/journals/langlo/ article/PIIS2214-109X(18)30523-0/fulltext.
- 38 This sampling methodology is adapted from ITPC and UNAIDS Community Treatment Observatory Toolkit (forthcoming). It aims to

- ensure representative sampling in community-led monitoring initiatives. For the purposes of OneImpact, the sampling uses challenge reports instead of individual app users, for reasons of practicality.
- 39 The OneImpact Advisory Group is modelled after the International Treatment Preparedness Coalition's "Community Consultative Group", which is used in their Community Treatment Observatory (CTO) model. See ITPC (2019). The Community Treatment Observatory (CTO) Model Explained: How Communities can Collect and Analyze Health Data to Ensure Accountability and Drive Change. Page 9. Online at https:// itpcglobal.org/wp-content/uploads/2019/02/ ITPC-CTO-Model-Full-Eng.pdf
- 40 Adapted from ITPC (2020). "They Keep Us On Our Toes"—How the Regional Community Treatment Observatory in West Africa improved HIV service delivery, strengthened systems for health, and institutionalized community-led monitoring. Page 13. Online at https://itpcglobal. org/wp-content/uploads/2020/10/ITPC-2020-They-Keep-Us-On-Our-Toes.pdf.
- 41 ITPC (2020). "They Keep Us On Our Toes"—How the Regional Community Treatment Observatory

- in West Africa improved HIV service delivery, strengthened systems for health, and institutionalized community-led monitoring. Page 12. Online at https://itpcglobal.org/ wp-content/uploads/2020/10/ITPC-2020-They-Keep-Us-On-Our-Toes.pdf.
- 42 Handbook for the use of digital technologies to support tuberculosis medication adherence, https://apps.who.int/iris/bitstream/ handle/10665/259832/9789241513456-eng.pdf;i sessionid=FDE78E3BCCE02E7CD34A65A4CD63C C04?sequence=1.
- 43 World Health Organization (2020). Global Tuberculosis Report 2020. Page 129. Online at https://www.who.int/publications/i/ item/9789240013131.
- 44 Ministry of Health, Community Development, Gender, Elderly and Children (2020). Tanzania National Strategic Plan for Tuberculosis and Leprosy 2020-2025. Page 63.
- 45 USAID (2018). TB Stigma Measurement Guidance. Page 258. Online at http://stoptbstrategicinitiative.org/wp-content/ uploads/2018/07/TB_Stigma_Measurement_ Guidance_low.pdf.

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