Improving the Use of Evidence for TB Programme Planning: a framework for people-centered data consolidation and policy translation

TB is at a defining moment in its history. Global political will is at a high, and there is a concerted drive towards ambitious Sustainable Development Goals (SDGs). The Lancet Commission has emphasized the need to “explore how countries can improve outcomes and optimize use of available resources by realigning them to ensure that all tuberculosis care is people-centered and by prioritizing interventions that increase efficiencies in the delivery of tuberculosis services.”¹

Globally, there has been a concerted push towards increasing the availability of quality data, and ensuring that these data are used for decision-making and planning. Since the launch of the Millennium Development Goals, there has been increased focus on tracking and measuring country-level progress against key TB outcomes. Substantial investments in data systems, surveys, and tools have led to the availability of national and subnational data that are comprehensive, current and usable. Given this progress, there is unprecedented opportunity to use data and evidence to drive programmatic impact towards TB elimination, and it is imperative that the TB community capitalize on this moment.

Problem Statement
There is a sense of urgency at global and national levels to “find the missing people with TB” and ensure the care of all people with TB. The increasingly available data on epidemiology, health system capacities and patient behavior could facilitate more impactful, prioritized planning and resource allocation. While there is wider availability of data, this has not consistently been translated into decision-making for programmatic impact. Several persistent issues are hindering progress toward routine use of a robust evidence base:

- **Data and evidence are insufficiently translated for uptake into planning and priority setting processes.** Data in and of itself does not lead to evidence-based programming. Without rigorous synthesis and analysis, data can be misinterpreted, irrelevant, or worse, used to rationalize politically-driven programming or spending decisions. Currently, myriad data collection requirements often leave programmes with numerous data points that are disjointed, overwhelming, and difficult to apply to decision-making.

- **Patient-centered programming is not adequately supported by patient-centered evidence.** Planning efforts have historically centered around epidemiological data, and activities have been informed by the national level’s consideration of where they can provide services, rather than where they should to meet patient preferences. Several recent data efforts are strengthening what is known about patient care seeking patterns, and health system capacities.² These data have not yet been routinely incorporated into planning processes to enable a review of progress nor identification of programmatic priorities along the care continuum to ensure availability and


² Note: examples include Service Availability Readiness Assessments; Health Facility Master Lists, Catastrophic Cost Surveys, TB Prevalence Surveys
accessibility of diagnosis, treatment and support services wherever the individual at risk for TB initially engages the health system.³

- **Evidence generation has been heavily driven by top-down planning rather than in response to key programmatic questions formulated by NTPs.** Various donor requests for evidence-based plans are not harmonized nor synchronized with country-level planning processes. Countries can be locked into perpetual planning cycles without time for implementation and learning, which makes a robust data consolidation process for each plan nearly impossible.

**Theory of Change**

This white paper describes a process in which data and evidence are used as the foundation for the classic programming model of identifying impact goals, and then defining the appropriate inputs, outputs and outcomes to create the desired impact.⁴ It aims to foster a culture of data generation and use that yields practical and programmatically relevant bodies of evidence in support of national and sub-national planning cycles. The vision is for a future in which:

- **Evidence generation is driven by programme needs.** Countries identify programmatic gaps and generate / compile evidence that will help them to make decisions about how to best allocate resources, and use data as part of their workflow to continuously and critically assess their efforts. Rather than being an additional burden, data use facilitates easier programmatic planning and decision-making.

- **Planning is data-driven, with evidence-based prioritization.** As countries undertake planning processes, they consolidate available data and evidence to create prioritized plans that optimize the impact of investments. Planning is an iterative process between national and sub-national stakeholders, and data and evidence can help countries to identify their programmatic priorities by looking at the system holistically, rather than through the lens of particular interests.

- **Evidence is reviewed and analyzed in a patient-centered manner across the care continuum.** Rather than being analyzed solely through epidemiological lenses, evidence is mapped according to community and patient perspectives. Planning is focused on identifying priority gaps and opportunities to ensure all people have access to quality services for TB prevention, diagnosis and care. At the local level, the appropriate services are aligned to what the local programmes understand about TB epidemiology and other priority health issues, peoples’ behaviors and preferences, and health system capabilities.

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³ Lancet, forthcoming
Methods
This white paper is the product of a collective effort among partners to promote country-led, data-driven, people-centered decision-making and planning. A key impetus for this effort is the recognized need for international partners to work collectively in support of country needs and interests, and address overlaps and inconsistencies in approaches which have been contributing to the issues described above.

Several in-person meetings and remote teleconferences have contributed to the conceptual framework presented in this document. This has included multi-stakeholder meetings in 2017 and 2018 in Guadalajara and Geneva focused on aligning approaches to using data and evidence to help find the missing TB patients. The Kenyan NTP applied the framework to a national data consolidation effort as part of a participatory process to develop a new national TB strategic plan (NSP) (this case study is described in the accompanying document).

The conceptual framework presented in this paper is a working draft, and is based on a limited number of country experiences. To refine and operationalize this framework on a wider scale requires the experience of and inputs from additional NTPs, and learning through implementation.

Framework for using data and evidence in planning
At a high level, the framework presented in this paper differentiates between three primary planning steps: (1) Problem Prioritization, (2) Root Cause Analysis and (3) Strategic Intervention Optimization. In other words, it aims to encourage a process for country-level planning that centers on asking the questions, (1) What are our biggest problems, (2) Why are they happening and (3) What can we do about it.
The proposed process uses the patient care continuum as a framework for analyzing programmatic gaps that are resulting in people with a high risk of TB infection or disease not being reached, people with active TB not accessing a health facility, people with TB not being diagnosed when they do reach a facility, or, if they are diagnosed, not being notified and/or effectively completing treatment.

(1) **Problem Prioritization:** The first step of the framework involves assessing the magnitude and scope of problems across a country’s epidemiology, patient behavior and health and social systems, so that countries can identify main priority focus areas. An assessment of the existing evidence against the care continuum can help to identify key gaps that limit progress in accessing, diagnosing and treating people with TB, as well as areas that are being successfully addressed and should be maintained. This priority-setting should occur at both national and sub-national levels. While national priority-setting is important, the distribution of TB disease, its risk populations, TB services, and related socioeconomic factors are highly heterogeneous, showing substantial subnational differences.\(^\text{5}\)

(2) **Root Cause Analysis:** Once the first step has prioritized the main programmatic priorities and described the landscape of missed opportunities to reach people with TB, it is necessary to analyze root causes contributing to these problems. By examining data sources such as published and official data, locally disaggregated data, and grey literature, as well as considering expert opinion, programmes can build a body of evidence to explore why certain patterns emerge, whether they are positive trends that should be sustained, or problem areas to be addressed. For each priority problem identified, sub-national variations can be assessed.

(3) **Strategic Intervention Optimization:** The identified root causes of the problem inform the focus for strategic interventions. These will likely include multi-sectoral and locally differentiated responses based on the contextualized root cause analysis. The priority-setting in step 1 does

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\(^5\) TB REACH, TB CARE, and Challenge TB case finding M&E, experiences and lessons learned account for a large proportion of this evidence base.
not preclude these differentiated responses; instead, it allows programmes to assess their level of effort and intervention budgets against their identified priorities. In the end, the priority problems and strategic interventions are aligned with available evidence.

**Figure 3: Alignment of Priorities and Interventions with Evidence**

1) **Problem prioritization**

The notion of prioritization can spark discomfort, as it denotes a hierarchy in which programmes are forced to categorize certain interventions as more important than others. However, prioritizing across resources, time and patient needs is a critical planning function, alongside continued efforts to mobilize sufficient resources to do everything necessary to end TB.

By attempting to do everything, programmes risk not prioritizing anything by default; as popularized by nudge theory, “there is no such thing as a neutral design”, meaning that if policies are not deliberate, they unintentionally bias certain priorities.\(^6\) Because current budgetary realities and human resource constraints make it impossible to conduct every activity addressed in many National Strategic Plans, the actual allocation of resources is either spread so thinly that few activities can be adequately conducted, or, when it comes to disbursements and budget, behind-the-scenes processes determine allocations that are not necessarily commensurate with need or even committed priorities. Budget shortfalls in NSPs are frequently upwards of 50%, and yet programming is commonly not prioritized within NSPs to ensure that funding is directed to the most impactful 50% of activities.

The process proposed in this document aims to foster prioritization according to an uncompromisingly patient-centered step-wise approach.

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**Box 1: Definitions:**

- **Data** are ‘observations about the social world, and can be quantitative or qualitative in nature.’ Data are chosen and collected by researchers, not simply ‘found’ (SAGE Dictionary of Social Research Methods, 2006). In this framework, data includes published and official data, locally disaggregated data, expert opinion and grey literature.

- **Evidence** is ‘information that bears on determining the validity (truth, falsity, accuracy, etc.) of a claim... Evidence is essential to justification’ (Dictionary of Qualitative Inquiry, 2014).

- **Priority**: A priority connotes something that is regarded as more important than others; in this framework, priorities define areas that are significant opportunities to reach people with TB.

- **Root cause**: The root cause of a priority problem is the initiating cause of an issue: in this framework, when asking ‘why’ a priority problem is occurring, programs review the chain of underlying issues which much be addressed to improve outcomes.
approach. All available data and evidence, typically derived from various national TB and/or health system surveys, assessments and TB surveillance systems, are consolidated along the care continuum by using the framework presented in Figure 4. Evidence can be organized in three key categories: epidemiology, people and systems.

All relevant stakeholders are encouraged to contribute additional knowledge and evidence that may not be captured by major TB and health systems data sources. For example, additional data sources can provide valuable insight on social issues (e.g. progress in UHC and social protection), the broader socio-economic environment (e.g. poverty reduction, economic development, demographic transitions, etc.), and people’s priorities, expectations and behavior. In addition, stakeholders at the sub-national levels, including local policy makers, health care providers and people with TB can provide critical information on TB epidemiology and the patient experience at the local level.

The approach aims to facilitate participatory discussion rather than prescribe the inputs for priority setting. Through the process of examining available evidence, stakeholders can jointly assess the magnitude of the issues and their significance when considering programmatic responses. Prioritization does not necessarily mean simply focusing where the greatest numbers of people are affected. For example, criteria could include severity (e.g. the morality and cost impacts of MDR or TB/HIV) and/or ethical considerations (e.g. a commitment to addressing pediatric TB regardless of burden). Stakeholders are expected make qualitative judgements on the levels of priorities along the care continuum, based on supportive evidence and data and values considerations.
The output of the priority-setting step provides a snapshot of the scale of patient, health system, epidemiological gaps mapped to the care continuum. An illustrative output helps identify the key systemic gaps limiting access: i.e., priority problems. Figure 5 demonstrates how a systematic analysis of TB programme performance mapped to the care continuum can help highlight major gaps as well as areas of success:

**Priority-Setting Example: The Diagnostic Gap**

An NTP has organized a participatory process with relevant stakeholders to review data and evidence from an epidemiology review, routine surveillance data, prevalence survey, patient pathway analysis, WHO TB Report, Health Expenditure and Utilization Survey, DHS and inventory study. Through reviewing the data and discussing programmatic priorities, the stakeholders completed the heat map above that highlighted the areas of programmatic priorities.

- **Priority gaps:**
  - **Major problem:** In the example in Figure 5, some of the most obvious gaps are DS and DR patients in the health system, who are not notified or diagnosed. The stakeholders recognized the need to better understand where and why this is occurring, and identify interventions to address these issues. In recent years, the NTP has invested heavily in procuring Gene Xpert machines, and is unsure whether the deployment of the new diagnostics already showed any positive changes in the situation.
  - **Minor problem:** On the other hand, evidence suggests that the NTP does well notifying all patients who are diagnosed by the public sector. The previous NSP had a primary focus on strengthening public sector reporting and data systems. The NTP decides to evaluate its activities in this area to identify what has contributed to this progress, such that they can prioritize sustaining these gains.

- **Multiple angles for prioritization:**
  - **Sub-national:** Upon revisiting the data sub-nationally, the NTP identifies three counties that are driving the priority gaps they identified, as well as two counties that house the majority of patients who are notified but not on treatment. The county
managers decided to look into what is contributing to these issues.

- **Human rights**: The NTP re-reviews the data with a focus on target populations, to identify the particular priorities to reach these people. They identify that they need to prioritize health care workers and school going children at high-risk for TB infection. They realize that they will have to make tradeoffs, and decide that they will define ‘second tier’ investments for areas that are not high-priority, so that they can focus on the pressing issues for these sub-populations.

For each identified problem, it is important to consider the magnitude of the problem (e.g. how many people are not presenting to health facilities or are not diagnosed). Then, the aim is to assess the progress already made in addressing this problem, and to score any remaining gaps between 1 (minor problem) and 5 (major problem). Figure 6 shows an NTP that has identified that the magnitude of people on treatment without success is very high, and that there has been minimal progress in this area. They decide to make this group of people a high priority.

As participants consider the relative priority of domains along the care continuum, evidence gaps may emerge that constrain informed decisions. By documenting these, the data consolidation process can yield an inventory of evidence needs that, if addressed, would enable even better decision-making and planning in future. Effectively, the process helps to build an evaluation and operational research agenda that directly responds to the evidence needs of the country.

**(2) Root Cause Analysis (RCA)**

Once the priority problems are identified, stakeholders can explore the root causes of these problems by reviewing bodies of evidence to identify factors contributing to the persistent gaps. There are various methodologies for conducting root cause analysis (RCA), including a fishbone, 5-Whys and causal tree. In all cases, an RCA can be understood as a sequential probing of why a problem exists. Specifically, the group asks why there is a certain priority problem, and then asks why of the response. Each response to a “why” prompt can be considered a determinant of the problem and a domain for action. Eventually, the sequential exploration of “why” will reach the root cause, which is frequently a form of economic or social constraint that is beyond the capability of a TB-specific response. It is likely the case that there are

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multiple valid determinants for each problem, or a major cause with multiple contributing factors, which differ by geographical region or care sector. Data may already be available to help with this analysis, or it may need to be collected to provide a comprehensive picture. Expert opinion, including focus group inputs from TB patients and health providers, can be an important input during this stage. Different tools can support this analysis, depending on the problem and context. A data-driven root cause analysis will help identify why certain problems persist, and begin to narrow the scope of possible interventions. It can also challenge longstanding biases and assumptions, as it requires persistently probing into potential causes of an issue.

In the example of the framework in action (Figure 6), the NTP prioritized patients who are not completing treatment. For these patients, one cause may be that they are unable to continue because of side effects. The cause of this is that patients feel nauseous when taking medicine, because they often take medicine on days where they have not eaten anything. This is because they cannot afford a regular food supply, because they lost their job due to illness. They did not have job security and could not get alternative work, as they were only trained for physical labor, and this stems from not having any formal education. These responses to the why’s are the determinants of an issue, and in the next step, we try to clarify the feasibility of and priority that should be given to addressing any / all of the determinants.

In an RCA, it will likely emerge that there are multiple factors contributing to a gap, differing from one geographical region or sector of care to the next. RCA at the subnational level is critical, and requires the interpretation of local TB programme staff working in both programme management and M&E. Performing an RCA is a critical step. Omitting it and assuming that interventions can be designed in direct response to the more visible problem might result in addressing the symptoms, rather than underlying causes, which may lead to sub-optimal or irrelevant interventions. Performing an RCA cannot be automated, as no single tool can provide the critical analysis necessary to identify all of the factors contributing to a problem. It requires that national and local planners walk through the prioritized problem in a rational way, while considering all relevant data.

National and local stakeholders should be empowered to analyze their specific problems in innovative and deliberate ways, when their existing strategies are not reducing the burden of TB in the country and locality. In the context of TB, this means that we need to broaden the analytical scope and consider potential causal factors which are not routinely analyzed, including socioeconomic status of an
individual or community, physical and environmental factors which affect peoples’ access to services, e.g. road networks and quality, and prevalence of other co-morbidities.

Ideally when the root cause analysis has been performed, priority action domains emerge which may not have been clear before. As with the example above, the major gap may have been identified as poor treatment adherence, while the root cause analysis revealed malnutrition as one of the prime contributors to this issue.

### Root Cause Analysis Example: Case Notification

During a participatory national planning process organized by an NTP, participating stakeholders have identified that a priority, persistent problem is that reported case notification rates remain lower than expected relative to the high estimated incidence rate, despite ongoing intensified community case-finding efforts undertaken by the NTP’s community health worker network. The notification system seems to be functioning well, indicating that there is no serious under-reporting of diagnosed TB cases; and yet, case notifications have not increased commensurately with the case finding efforts. As part of the process, the stakeholders completed an RCA to determine why notification rates are not increasing. They recognize that the data will require the interpretation of local TB programme staff working in both programme management and M&E.

Reviewing the inventory survey, the stakeholder identifies that in the urban north, there is insufficient and outdated diagnostic equipment available to handle the increased specimen examination workload and provide high quality diagnosis. They identify that that they were placing available diagnostics in level 4 facilities, where a minority of patients initiate care; additionally, the programme had not budgeted for specimen transport despite funding CHWs for active case finding.

In the rural south, the participants learned that anticipated stigma from CHWs resulted in TB patients not reporting their symptoms to CHWs or accepting screening in the first place. The stakeholders identified that there is low community awareness of available TB services, and people think that they will be taken away from their families. CHWs are tired and overworked, and become concerned if patients appear very sick and potentially contagious.

### (3) Strategic Intervention Optimization:

Based on findings from the root cause analysis, programmes can identify interventions that aim to effectively address the factors contributing to the problem, as well as interventions that are already working and should be sustained. Because resource limitations will likely necessitate making tradeoffs, it is important to assess which root causes have the biggest impact on the priority area.

It is then possible to identify interventions that could be feasible and have a high impact on the problem. Proposed interventions can be selected according to criteria that accounts for potential impact, cost-effectiveness and normative guidance. Interventions might be drawn from existing evidence bases, or could test innovative solutions that are grounded in theoretical evidence and past learning. In both cases, programmes learn and iterate based on continued data collection and analysis, and interventions should be accompanied by robust M&E systems to evaluate the intervention’s impact on the problems it aims to solve. Alongside intervention selection, it is also critical to identify who is best suited to take action, e.g. where the NTP needs to partner with different groups and sectors to effectively implement the identified interventions.
For example, where people are in the health care system but not diagnosed, inefficiencies in the health system must be addressed in a systematic manner. Depending on the cause of the issue, it may be best addressed with a referral network (people are in the system but do not access diagnostics until they cycle in and out several times); diagnostic network optimization (diagnostics are available but underutilized), and/or addressing financial barriers (people do not access care due to high direct and indirect costs), etc. Perhaps there is a pilot that has been working in one area that could be scaled and tested; perhaps there is a new programme that can be tested and iterated. This table demonstrates a way to identify potential interventions, and the importance of clarifying priority, potential impact, cost-effectiveness, and whether there is existing WHO guidance to support decisions.

<table>
<thead>
<tr>
<th>Action domain</th>
<th>Strategy</th>
<th>Priority</th>
<th>Impact</th>
<th>Cost-effectiveness</th>
<th>WHO guidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dx re-tooling and re-positioning</td>
<td>Xpert as initial dx</td>
<td>+++</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Integration of X-ray</td>
<td>+</td>
<td>+++</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Systematic screening in health care settings</td>
<td>Screening of PLHIV</td>
<td>+++</td>
<td>+++</td>
<td>+++</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Other clinical risk groups</td>
<td></td>
<td>Context specific ScreenTB can help</td>
<td>ScreenTB</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facility-based systematic screening</td>
<td></td>
<td>+++</td>
<td>++/+++</td>
<td>Screen guidelines</td>
</tr>
<tr>
<td>Childhood TB services</td>
<td>Strengthening diagnostic capacity at all levels</td>
<td>++</td>
<td>++</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Eliminating financial barriers</td>
<td>Review fee structure and benefit package in favour of early diagnosis of TB patients</td>
<td>++</td>
<td></td>
<td></td>
<td>Patient cost survey handbook</td>
</tr>
</tbody>
</table>
As the final step in the example of patients in care not seeking treatment, recall that one of the key underlying causes of unsuccessful treatment was malnutrition. Given this, the NTP assesses multiple options to improve treatment outcomes among patients with malnutrition (Figure 7). They identify systematic nutritional assessment and counseling, and nutritional support for patients as potential options. Mapping the impact and feasibility of these interventions, they recognize that while systematic assessment is highly feasible, it may only have moderate impact. They also find that providing nutritional support for all patients would not be very feasible and likely only have low-moderate impact, given that there is much less need among those without malnutrition. They identify that targeting nutritional support among patients with moderate acute malnutrition (MAM) or severe acute malnutrition (SAM) are the best combination of feasible and impactful.

**Strategic Intervention Optimization Example: Diagnostic Network Optimization**

An NTP has prioritized patients in the health system, not being diagnosed, as a major gap. They conduct sub-national analyses and identify that there are several counties driving this problem. One county knows their issue: they have two Gene Xpert machines, which are both in Level 4 facilities where the local population with TB rarely accesses care. They do not have a robust sputum transport system, and have relied on referring patients with presumptive TB from lower-level health clinics to the Level 4 facility. They have identified that this results in significant drop-off. The county realizes that a feasible intervention that would likely have an impact would be optimizing the diagnostic network, including improving the sputum transport options and moving one of the Gene Xperts to a lower-level health facility with high patient volume.

A different county simply does not have enough diagnostic options, and the National NTP decides to do a sub-national analysis to ensure that every county has access to at least some diagnostics for its patients.
Budgeting Interventions

At this point, it will be important to assess feasibility, potential impact and cost-effectiveness of interventions. At this stage, a programme may want to consider several resource scenarios; e.g. existing funding levels, increased funding, or an aspirational / fully financed budget. Under each scenario, the package of interventions that most effectively and efficiently target root causes and priority problems will need to be determined. This will require a new portfolio of evidence, including from modeling, cost-benefit analyses and impact evaluations.

This step will guide a programme through scenarios. For example, if a key priority is missed cases who are in the community, but resources are scarce and not all potential solutions can be implemented; is it more cost-effective to promote active case-finding in rural areas, or conduct contact tracing among family members of known TB patients?

At the end of the intervention optimization process, the resulting intervention foci and budgets should be commensurate with their identified priorities. The final budget will not be a 1:1 ratio to the priorities, particularly given that certain necessary commodities and activities are inherently more expensive than others. However, it should be considered in a proportional framework. For example, in the prioritization step, if the finding is that MDR-TB contributes to less than 3% of the epidemic, but has disproportionately high mortality and costs to the healthcare system, is it justified that the budget for MDR is 60% of overall budget allocation? Perhaps more importantly, what other areas have experienced shortfalls because of this tradeoff?

Conclusion/Call to Action

The framework described in this paper represents a paradigm shift for planning. It aims to leverage the momentum behind data and evidence generation, and move towards country-driven, evidence-based, efficient and integrated programme planning.

The end-point of this vision would suggest that countries develop a fully prioritized and budgeted NSP in 5-year cycles, or in sync with other national planning timelines. These NSPs would be the basis of a robust national response towards ending TB in line with the End TB Strategy and overall national moves towards UHC. In addition, such robust NSPs will be the basis for grant applications and reprogramming requests for major development and financing institutions such as the Global Fund. Countries would conduct data consolidation as an input to the mid-term review and the NSP development processes, and foster a culture of continual evidence review as new data emerge across the lifecycle of the NSP. Figure 8 demonstrates what this alignment of data consolidation and in-country planning cycles could look like in practice.
Next Steps

The Kenyan NTP piloted the process described in this white paper in April 2018 (see accompanying case study), and found the process to be highly productive. The majority of participants/stakeholders highly valued that the proposed process is participatory, evidence-driven and patient- and people-centered. The results of the initial stakeholder discussion will be taken forward to formulate the first draft of the new national strategic plan in the coming months.

A number of important suggestions were made from the stakeholders in Kenya. Among them, it has been requested to further fine-tune the process and materials, and develop a shortened/simplified version to be used in a sub-national process.

Given this positive experience in Kenya, it appears that the WHO should further develop the guidance documents and tools for countries to implement the approach. There have been expressed interest in implementing the approach with the national programmes of Philippines and Indonesia. With this further testing and refinement, WHO can work with stakeholders to identify how this can be scaled to transform the TB programming landscape into one that is increasingly evidence-based, country-owned and prioritized.