Encyclopedia of Data and Evidence Resources

To Support TB Planning and Programming

CONCEPT FOR DISCUSSION
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1. INTRODUCTION

1.1 Purpose

The third pillar of the End TB strategy outlines the importance of using research to inform and improve implementation of TB control programs,

“Most innovations cannot be translated into effective local action without careful planning and adaptation, and partnership with stakeholders. In addition to routine surveillance, well-planned and well conducted research is required to assess national and local epidemiological and health system situations, socio-behavioural aspects of health care seeking, adherence to treatment, stigmatization and discrimination, and to evaluate different implementation models.”

The tuberculosis community has developed and continues to develop innovative research and analysis resources to support TB programmes and their partners to plan, budget, implement and evaluate their TB control efforts. Many of these resources answer questions about the epidemiology, systems and patient experiences that are crucial to understand as TB programmes work to halt the epidemic.

From a TB programme’s perspective, sorting this proliferation of research and analysis resources can at times become daunting task. It may be only after a research or analysis resource is implemented that the programme realizes that they hoped it would answer a different programmatic question than expected. Or it may be that the output of the resource was not in the form that was of most use to the programme in their day-to-day work. Additionally, with the continued proliferation of new resources there may be opportunities for collaboration or integration between organizations who maintain or implement the research resources.

The encyclopedia is intended to address some of these challenges and opportunities. It contains profiles of several common research and analysis resources used by TB control programmes today. The profiles of each resource are brief. They provide information about each resource with three goals in mind – 1) that TB control programmes and their partners can better identify which resources are most appropriate for the questions they would like to answer and 2) provide a platform for the global TB community to better understand the universe of resources available and 3) where there may be opportunities for increased collaboration amongst research and analysis partners.

In addition to the individual profiles, there is also a section that outlines how these resources might fit together. Given the importance of having a cross-cutting picture of the TB situation, this concept attempts to highlight some of the synergies between different tools and a potential sequence for how tools can be utilized.

This is the proof-of-concept version of this encyclopedia, drafted amongst a consortium of national and global TB partners. As such, there are a limited number or resources included in this version of the encyclopedia. Discussions about the next phase of the work have included expanding the number of resources and building an online platform for countries to share their experiences using tools and recommendations to improve the use of those tools in implementation settings. The inclusion of any of the resources in this encyclopedia does not suggest any official recommendation of the following resources.
1.2 Audience

The encyclopedia is intended for national TB programmes, local TB programmes and other partners using data and evidence for TB control planning. The encyclopedia will be most useful helping these stakeholders understand how and when different evidence resources could be used. It may help guide stakeholders as they select new evidence tools to implement or think about how to further utilize their existing resources. As the encyclopedia continues to evolve, we anticipate that users of these tools will be able to add comments, questions and suggestions for improvement to any of the resources included in the encyclopedia. Ultimately, the resources highlighted here are most useful if they respond to a need of those stakeholders who are planning, programming and implementing for TB control.

1.3 Types of Data Resources

The resources included in the encyclopedia serve a variety of functions. To help differentiate the tools and the purpose they provide, each of the resources has been mapped to one of the functions included in Figure 1. In some cases, resources work across several functions and, in other cases, resources work within a single function.
1.4 Contents of Data Resource Profiles

Each resource profile contains the same type of information, intended to give potential users a clear, concise understanding of the tool. Most of the tools included in the encyclopedia also have longer, more detailed guidance documents. Links to existing guidance documents are included in the respective profiles. The profiles include:

- Implementation Cost – Approximately how much does it cost to implement this resource (on average)?
- Implementation Time - What is the maximum number of months it would take an NTP to implement this resource?
- Periodicity - How often should the resource be implemented, or new data collected? How often should the outputs be reviewed?
- Description - How would you describe the resource in 2-3 sentences?
- Programmatic Metrics - How does this resource help inform policy and programming for priority gaps along a patient's pathway to care? What are the key metrics that are the output of this resource and how do they map to a patient's pathway to care?
- Scenarios for Using the Resource – What are the top three reasons (scenarios) for why and when a country should implement this resource? And three reasons (scenarios) for why and when a country may not need to implement this resource?
- Pre-Requisites - Are there data (or non-data) resources that the resource is dependent on? For example, the Patient Pathway Analysis requires some type of care seeking data (e.g. DHS, Prevalence survey or HEUS) and some type of service availability data (e.g. SPA or SARA) to be implemented.
- Implementation Partners – Which partners are available to provide technical assistance for the implementation of this tool?
- Available Resources – What resources are available to inform the implementation and use of this resource?
- Case Study of Country Use - The case study provides an example of how the resource has been used successfully in a country setting. What were the key inputs to the resource? What were the key outputs? How did this resource inform programming and priority setting in the country?
2. COMPARISON OF RESOURCES

2.1 Using Evidence in the TB Planning Process

This encyclopedia is being drafted in parallel with a whitepaper that outlines a new conceptual framework for using data and evidence in TB programming. The aim of this framework is 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... At a high level, the framework differentiates between three primary planning steps: (1) High-Level Priority Setting, (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.”

Each of the evidence resources in this encyclopedia can support TB programmes in one or several of the steps outlined in this framework. The individual profiles of evidence resources included in section three of the encyclopedia show the specific data points that TB programmes can pull from each evidence resource. Figure 2 below also shows a collation of these metrics into a single table, outlining how different resources can be brought together to help build a comprehensive picture of TB control in a given setting.
<table>
<thead>
<tr>
<th>Problem Prioritization</th>
<th>Not seeking care</th>
<th>Seeking care, not diagnosed/notified</th>
<th>Treated, not cured</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&gt; Percent of symptomatic or asymptomatic prevalent TB patients who are not seeking care</td>
<td>&gt; Percent of patients who are diagnosed by public and private providers, but not notified to the NTP</td>
<td>&gt; Percent of patients with access to treatment services on their first visit to health facility</td>
</tr>
<tr>
<td></td>
<td>&gt; Estimate of initial care seeking patterns among sectors and levels of the health care system</td>
<td>&gt; Percent of patients with access to diagnostic services on their first visit to health facility</td>
<td>&gt; Percent of prevalent TB patients with previous TB treatment history</td>
</tr>
<tr>
<td></td>
<td>&gt; Percent of prevalent TB patients who had sought care, but not yet received a diagnosis</td>
<td>&gt; Percent of prevalent TB patients who had sought care, but not yet received a diagnosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt; Ratio of prevalent TB patients to notified TB patients</td>
<td>&gt; Ratio of prevalent TB patients to notified TB patients</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Root Cause Analysis</th>
<th>Not seeking care</th>
<th>Seeking care, not diagnosed/notified</th>
<th>Treated, not cured</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; Reasons for not seeking care when symptoms of TB are present</td>
<td>&gt; Reasons for not seeking care when symptoms of TB are present</td>
<td>&gt; Factors associated with underreporting</td>
<td>&gt; Analysis of factors associated with catastrophic patient costs</td>
</tr>
<tr>
<td>&gt; Hours lost by patient</td>
<td>&gt; Time from symptoms to treatment initiation</td>
<td>&gt; Diagnostic availability at different health facilities</td>
<td>&gt; Total costs borne by patient and patient’s household (direct medical costs, direct non-medical costs and indirect costs)</td>
</tr>
<tr>
<td>&gt; Diagnostic availability at different health facilities</td>
<td>&gt; Percent of prevalent TB patients who were not positively identified by symptom screening, x-ray and smear microscopy</td>
<td>&gt; Treatment availability at different health facilities</td>
<td>&gt; Treatment availability at different health facilities</td>
</tr>
</tbody>
</table>

**Tool Name**
- Inventory Study
- Patient Cost Survey
- Patient Pathway Analysis
- Prevalence Survey
2.2 Interdependencies Among Resources

There are important interdependencies among the resources included in the encyclopedia. These interdependencies can be helpful to consider when thinking about which analytical tools may be most useful to support planning and programming. Reviewing potential interdependencies can also help identify areas where partners can collaborate on implementing several new tools at once.

The visual below highlights relationships between different tools. It is not a comprehensive visual, but is illustrative of some of the important relationships between several of the tools included in this encyclopedia.
An inventory study is a study of the level of under-reporting of TB cases. TB inventory studies compare the number of cases meeting standard case definitions recorded in all or a sample of public and private health facilities with the records of cases notified to local and national authorities.

**YOU MIGHT WANT TO IMPLEMENT IF:**
- The TB surveillance system is missing a considerable proportion of the TB cases that occur each year, and estimates of TB incidence that rely on expert opinion to estimate the proportion of cases being missed are very uncertain
- A large proportion of cases are thought to be diagnosed and treated by health-care providers that are not collaborating with the national TB programme (NTP)
- The country has an excellent surveillance system and clear evidence is needed that it captures all (or virtually all) cases, such that reported (notified) cases can be used as a direct proxy for TB incidence

**YOU MIGHT NOT NEED TO IMPLEMENT IF:**
- The TB surveillance system is missing a considerable proportion of the TB cases that occur each year, but uncertain estimates of TB incidence based on expert opinion are considered satisfactory
- There is a large non-NTP sector where TB cases are being diagnosed and treated, but a precise estimate of the number of these cases is not considered necessary
- The country has an excellent surveillance system, but it is not considered necessary to demonstrate that no cases or only a negligible number of cases are going unreported through a scientific study

**PRE-REQUISITES**
- Case-based data & personal ID
- Standard case definitions across all providers
- Expertise in sampling design
- Adequate staffing and funding
- Care providers outside NTP to participate

**MORE INFORMATION/RESOURCES**
More information about inventory studies is available here: http://www.who.int/tb/publications/inventory_studies/en/

Guide - How to design, implement and analyze an inventory study
The Mapping and Analysis for Tailored disease Control and Health systems strengthening (MATCH) approach strengthens health systems to inform decision making and target interventions using existing data, mapping and spatial analysis techniques. Core to this approach is an analytical framework which utilizes multiple sources of spatial, temporal and demographic disaggregated data with the aim to identify most pertinent groups of missed people with TB throughout the pathway of care at subnational level. Mapping and analyzing geographic patterns of TB notification data and triangulating these with patterns of laboratory service supply and performance as well as other social determinants of TB provides insight into where and why people with TB are “missed” either because they are not diagnosed, or diagnosed but not reported to national surveillance systems.

**PROGRAMMATIC INPUT**

What are key metrics from the MATCH approach that can inform programming for priority gaps along a patient’s pathway to care?

**YOU MIGHT WANT TO IMPLEMENT IF:**
- The TB epidemic is expected to affect different risk groups with inequitable access to TB services across the different regions covered by the TB program
- The TB program activities are not equally effective to detect, diagnose and treat people with TB across different regions covered by the TB program
- The effectiveness of interventions requires differentiation of intervention planning and prioritization of resource allocation

**YOU MIGHT NOT NEED TO IMPLEMENT IF:**
- The TB program data are not digitally available at subnational level
- Laboratory results are not digitally available at subnational level
- Spatial data corresponding to subnational reporting units are not available

**PRE-REQUISITES**

What other resources are required to implement a MATCH analysis

- Routinely collected TB Programme and laboratory data digitally available at subnational level
- Spatial data of the point locations of TB service providers OR spatial data of the outlines of reporting administrative areas
- Commitment and resources to routinely analyze subnational data to plan, monitor and evaluate subnationally differentiated interventions

**IMPLEMENTATION PARTNERS**

NTP, KIT

**MORE INFORMATION/RESOURCES**

More information about MATCH is available here: https://www.kit.nl/health/service/kit-match-approach-enhancing-tb-care-coverage/

Manual
National Tuberculosis Programme User’s Manual

Data Management Plan for MATCH Analysis

SPARK
Rationale, innovation and outputs of MATCH in countries
TB case notification gaps – indications of under detection - MATCH in Bangladesh

In Bangladesh the MATCH approach was implemented using district level TB case notifications data which were integrated with socio-economic data from the 2013 census as well and routine laboratory data. During a participatory data analysis workshop the NTP, together with their implementing partners (BRAC, ICDDR,B, MSH), collaboratively mapped and analysed these data using the MATCH framework.

Results
In the central-southern region (yellow highlighted districts), TB case notification rates were considerably lower than the country average and also compared to the CNR in directly adjacent districts. Analysis and triangulation with other program components showed that:
• Test rate is low but the proportion of bac+ patients among all notified is comparatively high
• Positivity rate of tests performed is low
• The poverty rate in these areas is relatively high as compared to the country average

Programmatic Hypotheses
These findings led to the following hypotheses:
• The information on socioeconomic status and risk factors suggest no reason to believe the actual burden in this area is significantly lower than in the neighboring districts
• Low test rates and low positivity rates suggests many patients are not reaching quality diagnosis
• Low coverage of microscopic facilities indicate poor coverage of diagnostic services
• Above average percentage of bacteriologically confirmed patients among the low number of notified patients suggests that also many smear negative and extra-pulmonary patients might be missed

Potential Interventions
Interventions to be considered in these areas after verification of hypotheses:
• Need to increase presumptive case finding through improved screening in facilities and community.
• Improve coverage of Xpert testing for all microscopy negative and x-ray for B- presumptive cases.
• Conduct more supervisory visits to find out the root cause of lower notification rate over the years
**3.3 PATIENT COST SURVEY**

TB patient cost surveys have two primary objectives: 1. To document the magnitude and main drivers of different types of costs incurred by TB patients (and their households) in order to guide policies to reduce financial access barriers and minimize the adverse socioeconomic impact of TB. 2. To determine the baseline and periodically measure the percentage of TB patients (and their households) treated in the NTP network and incurring catastrophic total costs due to TB.

### PROGRAMMATIC INPUT

What are key metrics from an inventory study that can inform programming for priority gaps along a patient’s pathway to care?

<table>
<thead>
<tr>
<th>NOT SEEKING CARE</th>
<th>SEEKING CARE, NOT DIAGNOSED/NOTIFIED</th>
<th>TREATED, NOT CURED</th>
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<tbody>
<tr>
<td></td>
<td>Total costs borne by patient and patient's household (direct medical costs, direct non-medical costs and indirect costs)</td>
<td>Analysis of factors associated with catastrophic patient costs</td>
</tr>
<tr>
<td></td>
<td>Time from symptoms to treatment initiation</td>
<td>Hours lost by patient</td>
</tr>
</tbody>
</table>

### YOU MIGHT WANT TO IMPLEMENT IF:

- Existing evidence suggests that patients may be dropping out of TB care due to high costs of care seeking, diagnosis and treatment and the national program wants to better quantify the magnitude of these costs

### YOU MIGHT NOT NEED TO IMPLEMENT IF:

- TBD

### PRE-REQUISITES

What other resources are required to implement a patient cost survey?

- TB epidemiology
- Health financing
- Health insurance programmes
- Health care fee structures
- Health care delivery models
- Social protection schemes

### IMPLEMENTATION PARTNERS

WHO

### MORE INFORMATION/RESOURCES


**Handbook**

How to conduct and disseminate results of patient cost surveys

<table>
<thead>
<tr>
<th>COST</th>
<th>TIME</th>
<th>IMPLEMENT</th>
<th>REVIEW</th>
<th>DATA GENERATION + DATA ANALYSIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>$27-166k</td>
<td>6-12M</td>
<td>5YR</td>
<td>1YR</td>
<td>---------------------------------</td>
</tr>
</tbody>
</table>
The PPA aims to describe the steps TB patients take from the initial point of seeking care to the point of being cured. At the same time, the analysis reviews the availability of TB screening, diagnosis, and treatment at various levels of the health system. By examining the alignment of care seeking with service availability, the PPA may reveal where TB patients experience delay during care seeking or treatment initiation, access inappropriate care, or are lost to follow-up during their journey toward cure.

**Programmatic Input**

What are key metrics from a PPA that can inform programming for priority gaps along the pathway to care?

**Problem Prioritization**

- Estimate of initial care seeking patterns among sectors and levels of the health care system
- Percent of patients with access to diagnostic services on their first visit to health facility
- Percent of patients with access to treatment services on their first visit to health facility

**Root Cause Analysis**

- Diagnostic availability at different health facilities
- Treatment availability at different health facilities

**You Might Want to Implement If:**
- The TB surveillance system is missing a significant share of the estimated burden and the NTP is uncertain where these patients may be within the health system
- NTPs do not have a good understanding of how well their TB control system is aligned with patient care seeking patterns
- NTPs want to understand how better align TB services with patient care seeking and differentiate the implementation of those services across subnational areas

**You Might Not Need to Implement If:**
- The NTP does not have access to data on patient care seeking patterns
- The NTP does not have access to data on the number of facilities in the country and their capacity to deliver TB services
- The country has a strong surveillance system that captures most of the estimated burden of TB

**Pre-Requisites**

What other resources are required to implement the PPA?

- Care-seeking data (e.g. HEUS, DHS, LSMS, prevalence survey)
- Service availability data (e.g. diagnosis and treatment locale)

**Implementation Partners**

LINKSBRIDGE, WHO

**More Information/Resources**

More information about the PPA is available at www.linksbridge.com/our-work/tb-ppa. Resources include:

JID Supplement - case studies demonstrating use in country programming

How-To Guide - step-by-step instructions on how to conduct a PPA

Example Workbooks - Tableau and Excel example workbooks
CASE STUDY

KENYA PPA - OVERVIEW

In Kenya, the PPA was conducted at three geographic levels:
1. National Level Urban
2. Rural Comparison
3. 47 Counties

The PPA helped the NTP to target interventions to improve alignment of TB service delivery with patient care seeking, with an aim to efficiently identifying patients that are lost within the health system.

DATA SOURCES

Patient pathway analyses use commonly available national surveys and data sources, in Kenya these sources included:
- National Health Facility Master List (HFML)
- Kenya Household Health Expenditure and Utilization Survey (KHHEUS)
- Kenya Service Availability and Readiness Assessment Mapping (SARAM) Kenya NTLD databases on microscopy and Xpert capacity and patient treatment records
- Kenya Demographic and Health Survey (DHS)

PPA OUTPUT

INTERPRETING THE RESULTS OF A PPA

A Private sector facilities are important places of initial care seeking, with over 40% of patients preferring to start their care seeking journey in either informal or formal private sector care (column 1).

B Despite significant care seeking in private sector facilities, only 12% of the estimated burden is notified from private sector facilities (column 6), suggesting that there may be patients who seek care in the private sector who are not diagnosed, not put on treatment or not notified to the NTP.

C In places where care seeking is highest (Level 2 facilities), smear microscopy coverage remains low, requiring sample transport or patient referral systems in order for patients to receive a diagnosis.

D Treatment availability appears limited as well at L2, with only 37% of facilities having treatment services available (column 4). However, in Kenya drugs are distributed where patients will be treated (column 6), so treatment is well aligned with patient preferences for care.
Surveys of the prevalence of TB disease are important for four major reasons: 1) to obtain a direct measurement of the absolute burden of disease caused by TB; 2) to measure trends in the burden of disease caused by TB; 3) invaluable information can be gained from a survey, beyond both a single point-estimate of the burden of TB and measurement of trends; 4) results can be used alongside an in-depth analysis of surveillance data and programmatic data, as the basis for a comprehensive update of estimates of disease burden (incidence and mortality as well as prevalence).

**YOU MIGHT WANT TO IMPLEMENT IF:**
- **Group 1 Criteria** - 1. Estimated prevalence of smear-positive TB ≥100 per 100,000 population and 2. Accounts for ≥1% of the estimated total number of smear-positive TB cases globally and 3. Case detection rate (CDR) for smear-positive TB ≤50% or >100%
- **Group 2 Criteria** - 1. Estimated prevalence of smear-positive TB ≥70 per 100,000 population and 2. Accounts for ≥1% of the estimated total number of smear-positive TB cases globally and 3. Estimated HIV prevalence rate in the adult population (15 to 49 years) ≥1%
- **Group 3 Criteria** - 1. Estimated prevalence of smear-positive TB ≥200 per 100,000 population and 2. Accounts for ≥0.5% of the estimated total number of smear-positive TB cases globally
- **Group 4 Criteria** - 1. Nationwide survey implemented between 2000 and 2007 or 2. Nationwide survey planned before 2010

**PRE-REQUISITES**
- Strong commitment from NTP
- Reliable procurement
- Organization to manage survey
- Community participation
- Lab capacity, especially culture
- Funding

**IMPLEMENTATION PARTNERS**
WHO

**MORE INFORMATION/RESOURCES**

Handbook on tuberculosis prevalence surveys
ScreenTB is a web-based tool to assist TB program managers in the design of TB screening programs. It enables easy comparison of different TB screening methods that could be applied in a given country, or to different risk groups at the national or subnational level. It allows program managers to assess the expected risks and benefits of potential diagnostic tools.

### PROGRAMMATIC INPUT

What are key metrics from SCREEN-TB that can inform programming for priority gaps along a patient’s pathway to care?

**NOT SEEKING CARE**

- Number of people expected to be screened
- Number of cases missed by screening
- Total cost of screening

**SEEKING CARE, NOT DIAGNOSED/NOTIFIED**

- Number of true culture positive TB cases that may be detected

**TREATED, NOT CURED**

- Number needed to screen (NNS)
- Cost per case detected by screening

### YOU MIGHT WANT TO IMPLEMENT IF:

- Your country has a large number or a large proportion of TB patients that present to health facilities and are not diagnosed
- Your country experiences low rates of treatment success and/or durable cure, and you wish to explore the extent to which false positives may contribute to the problem
- You wish to optimize the total cost of TB screening and/or the cost per case detected

### YOU MIGHT NOT NEED TO IMPLEMENT IF:

- Your country already has data on the metrics provided by the tool (see description)
- Most TB patients in your country are detected and successfully treated with current screening methods, and the cost is acceptable
- There is a large number of patients in your country that are undetected because they present to facilities without TB diagnostic tools, and you have a successful TB screening model from other facilities/geographic areas that you are ready to scale up

### PRE-REQUISITES

What other resources are required to implement SCREEN-TB?

- TB prevalence estimates
- Size of selected risk groups
- TB prevalence in risk groups
- Acceptability of screening tool
- Diagnostic test accuracy
- Cost of screening and Dx tests

### IMPLEMENTATION PARTNERS

WHO, NTP

### MORE INFORMATION/RESOURCES

The SCREEN-TB Tool is available here: https://wpro.shinyapps.io/screen_tb/. Additional resources related to TB screening include:

- Guidance: Systematic screening for active tuberculosis: principles and recommendations