Standards and benchmarks and associated user guide for assessing the performance of TB surveillance

Emily Bloss, PhD

Division of Tuberculosis Elimination
Centers for Disease Control and Prevention

WHO Global Task Force on TB Impact Measurement
9 May 2012
Acknowledgments

- **Contributors to the development of the standards and benchmarks checklist and/or user guide:** Ibrahim Abubakar, Laura Anderson, Lori Armstrong, Amal Bassili, Ana Bierrenbach, Jaap Broekmans, Ted Cohen, Andrei Dadu, Connie Erkens, Katherine Floyd, Philippe Glaziou, Vahur Hollo, Joseph Imoko, Nico Kalisvaart, Hillary Kipruto, Eugene McCray, Sai Pothapregada, Babis Sismanidis, Hazim Timimi, Chen Wei, Norio Yamada, Matteo Zignol

- **Countries contributing to the work around standards and benchmarks:** Brazil, China, Egypt, Estonia, Japan, Kenya, Netherlands, Thailand, Uganda, UK, USA
Questions for the Task Force

- What are your general comments on progress to date in the development of standards and benchmarks for TB surveillance and vital registration systems?

- What are your suggestions regarding the remaining questions *(highlighted in red text in background document 2.b)* that have arisen during the development of the standards and benchmarks but have not yet been resolved?

- What are your ideas/recommendations for an appropriate strategy for rolling out the use of the surveillance checklist of standards and benchmarks?
Background
Task Force strategic areas of work

- Surveys of the prevalence of TB disease
- Methods to estimate disease burden
- Strengthening routine surveillance
  - The goal is the direct measurement of TB cases and deaths from notification and vital registration data
    - TB notifications in surveillance system ~ TB incidence
    - TB deaths in vital registration system ~ TB mortality
Why strengthen surveillance?

- Estimates of disease burden are currently highly reliant on expert opinion
  - Two main reasons why this is the case
    - TB cases are diagnosed but not reported
    - TB cases are not diagnosed

- Vital registration data are not frequently utilized by National TB Programs

- Currently no systematic method for assessing data quality and coverage
Framework for assessment of TB surveillance data

DATA QUALITY
- Completeness
- No duplications, no misclassifications
- Internal and external consistency

TRENDS
Do surveillance data reflect trends in TB incidence and mortality?
- Analyse time-changes in notifications and recorded deaths alongside changes in case-finding, case definitions, HIV prevalence and other determinants of changes in TB incidence and TB mortality

ARE ALL TB CASES AND DEATHS CAPTURED IN SURVEILLANCE DATA?
- "Onion" model
- Inventory studies
- Capture re-capture studies
- Prevalence surveys
- Innovative operational research

TB notifications = TB incidence
TB deaths in VR system = TB mortality

IMPROVE surveillance system

EVALUATE trends and impact of TB control

UPDATE estimates of TB incidence and mortality
If appropriate, CERTIFY TB surveillance data as direct measure of TB incidence and mortality
Framework for assessment of TB surveillance data

- Framework and associated tools applied in regional workshops conducted for 96 countries
  - Revision of estimates
  - Develop plans for strengthening surveillance system

- Lacked definition of essential characteristics and quantitative measures against which to assess the surveillance system

April 2009 – June 2010
December 2010 – July 2011
Standards and benchmarks (S&Bs): Definitions

- **Standards** are general statements about the characteristics that define a high-performance TB surveillance system.

- **Benchmarks** define in quantitative terms wherever possible the level of performance that is considered good enough to meet the standard.
Standards and benchmarks for TB surveillance: Purpose

- Assess a surveillance system’s ability to accurately measure TB cases and deaths in all settings in a standardized way
  - Use surveillance data for direct measurement
  - Identify and better quantify shortcomings in surveillance systems that need to be addressed

- Inform tuberculosis program staff, policy-makers and partners about aspects of surveillance systems that need to be strengthened to improve TB control
Development of the standards and benchmarks for TB surveillance
Principles underpinning the development of standards and benchmarks for TB surveillance

- Framework for assessment of TB surveillance
- Feedback and experience from regional workshops
- TB epidemiology
- Evidence-based, whenever possible (WHO data and literature)
- High performing systems used as models
- Aimed for a minimum set of standards
- Applicable across different geographic areas (high and low burden settings) and systems (electronic and paper-based)
- Involved partners from national programs and technical agencies
Timeline for development of standards and benchmarks
Timeline for development of standards and benchmarks

- September 2008: Third Task Force meeting, adopted framework
Timeline for development of standards and benchmarks

2008                   2009                 2010                     2011                      2012

March 2010
Task Force meeting, S&Bs first introduced in background document
Timeline for development of standards and benchmarks

April 2009 - December 2010
Regional workshops
Timeline for development of standards and benchmarks

- July 2011: First draft of S&Bs developed
Timeline for development of standards and benchmarks

July – September 2011
First draft of S&Bs field tested

Brazil, China, Egypt, Estonia, Japan, Kenya, Netherlands, Thailand, UK, USA

2008 2009 2010 2011 2012
Timeline for development of standards and benchmarks

September 2011
Meeting of sub-group
Timeline for development of standards and benchmarks

- November 2011: Small group refined checklist
Timeline for development of standards and benchmarks

- **January 2012**: First draft of user guide
Timeline for development of standards and benchmarks

- **March-May 2012**: Re-test of checklist and user guide
- Countries: Kenya, Uganda, UK, USA
Lessons learned during development of standards and benchmarks for TB surveillance

- Standards and benchmarks checklist and assessment process generally perceived to be useful and feasible
  - Changes made to address parts of the checklist that didn’t work

- Timeframe needed to conduct assessment is ~ 1 week
  - Some components of the assessment require considerable more time and effort

- Requirement for some technical background to conduct assessment
Lessons learned during development of standards and benchmarks for TB surveillance

- Some challenges to identifying standards and benchmarks that are appropriate for all systems and settings
  - In some cases, different standards for electronic and paper-based systems

- Trade-off between feasibility/uptake and most stringent methods
  - Evidence from recent studies may be used in some instances

- Need for instructions to explain and standardize methods for implementing checklist
  - User guide drafted
Standards and benchmarks for TB surveillance: User Guide

- Rationale and methods are explained for each standard and benchmark
- Examples help illustrate the recommended methods
- Corrective actions are provided, if the benchmarks are not met
- A glossary of terms is included
Overview of the standards and benchmarks for TB surveillance: A checklist
Standards and benchmarks for TB surveillance: Overview

- Checklist consists of a set of 15 standards and their associated benchmarks
  - 14 standards are related to measurement of TB cases and one is related to measurement of TB deaths

- Checklist includes standards and benchmarks related to data quality, system coverage, TB mortality data, and surveillance of drug resistant TB (DRTB), TB/HIV and TB cases in children
Standards and benchmarks for TB surveillance: Intended use

- Designed to allow a national assessment for the most recent complete calendar year
  - Lag time may range from no delay to one year

- An assessment of a TB surveillance system using this checklist would take place every 3-5 years
Standards and benchmarks for TB surveillance: Intended use

- Checklist can be used by in-country staff for self-assessment or by external reviewers, e.g.
  - Global Fund
  - National Program Reviews

- External peer review and endorsement of the findings by the WHO Global Task Force on TB Impact Measurement will be necessary for a national system to be ‘certified’
For a country's TB surveillance system to be certified as providing a direct measurement of TB cases:

- 11 standards need to be met
  - 2 are specific to paper-based systems
  - 3 are specific to electronic case-based systems
  - 2 assess system coverage

For a country's TB surveillance system to be certified as providing a direct measure of the number of cases of DR-TB, TB/HIV, and TB in children specifically, 3 additional standards must be met

For a surveillance system to provide a direct measure of TB deaths, there is one standard that must be met
# Standards and benchmarks for TB surveillance: Data Quality

<table>
<thead>
<tr>
<th>STANDARDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>B1.1</strong> Case definitions are consistent with WHO guidelines</td>
</tr>
<tr>
<td><strong>B1.2</strong> TB surveillance system is designed to capture a minimum set of variables for reported TB cases</td>
</tr>
<tr>
<td><strong>B1.3</strong> Scheduled periodic reports (e.g. quarterly reports) are accounted for at national level <em>(For paper-based systems only)</em></td>
</tr>
<tr>
<td><strong>B1.4</strong> Data in scheduled periodic reports (e.g. quarterly reports) are complete and internally consistent <em>(For paper-based systems only)</em></td>
</tr>
</tbody>
</table>
### Standards and benchmarks for TB surveillance: Data Quality

<table>
<thead>
<tr>
<th>STANDARDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>B1.5</strong>  Data for each variable in the minimum set are complete for all reported cases <em>(For electronic systems only)</em></td>
</tr>
<tr>
<td><strong>B1.6</strong>  Electronic system has the features required for data consistency and completeness <em>(For electronic systems only)</em></td>
</tr>
<tr>
<td><strong>B1.7</strong>  Duplicated reports of the same TB episode are identified and removed <em>(For electronic systems only)</em></td>
</tr>
<tr>
<td><strong>B1.8</strong>  Number of reported TB cases is internally consistent (within country)</td>
</tr>
<tr>
<td><strong>B1.9</strong>  TB surveillance data are externally consistent</td>
</tr>
</tbody>
</table>
## Standards and benchmarks for TB surveillance: Coverage

<table>
<thead>
<tr>
<th>STANDARDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>B2.1  All diagnosed cases of TB are reported</td>
</tr>
<tr>
<td>B2.2  Population has good access to health care</td>
</tr>
</tbody>
</table>
Standards and benchmarks for TB surveillance: Vital Registration

<table>
<thead>
<tr>
<th>STANDARDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>B3.1 Vital registration system has high national coverage and quality</td>
</tr>
<tr>
<td>STANDARDS</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>B4.1</td>
</tr>
<tr>
<td>B4.2</td>
</tr>
<tr>
<td>B4.3</td>
</tr>
</tbody>
</table>
Next steps

- Review of standards and benchmarks by Task Force
- Final re-test of standards and benchmarks in 2-3 countries
- Finalization of standards and benchmarks and user guide by end of 2012
  - Set of readily prepared datasets to be accessible to countries
- Roll-out of checklist in a variety of low and high burden countries
  - Institutionalization within Global Fund?
Questions for the Task Force

- What are your general comments on progress to date in the development of standards and benchmarks for TB surveillance and vital registration systems?

- What are your suggestions regarding the remaining questions (highlighted in red text in background document 2.b) that have arisen during the development of the standards and benchmarks but have not yet been resolved?

- What are your ideas/recommendations for an appropriate strategy for rolling out the use of the surveillance checklist of standards and benchmarks?
Remaining questions after testing of standards and benchmarks checklist

- **B1.2** - Is it appropriate for the benchmarks to require data (age and sex dis-aggregations for all case types) that will not be captured by paper-based R&R systems that follow the 2006 WHO guidelines?

- **B1.7** - Is there a need for a standard related to duplicate records for paper-based systems?

- **B1.8** - Can better/additional benchmarks be suggested to examine internal consistency?
Remaining questions after testing of standards and benchmarks checklist

- B2.1 - Given the challenges to measuring in a standardized and quantifiable way the second benchmark ("TB reporting is a legal requirement that is strongly and systematically enforced, with penalties (financial and other) for non-reporting or incentives for reporting"), are there other recommendations to assess under-reporting?

- B2.1 - Is the cut-off of the past 2-3 years appropriate or too recent for when a previously conducted inventory study was to have taken place?

- B2.2 - Are the current benchmarks sufficient for B2.2? If not, can better/additional benchmarks be suggested to examine access to care (or another way to get at the level of undiagnosed cases)?
Remaining questions after testing of standards and benchmarks checklist

- Will ‘passing’ a standard be possible, if a valid explanation is provided, even if a benchmark is not met?
  - B1.9 - EP-TB in a few EU and other high-income countries?

- Should some form of grading scheme be adopted to allow broad categorization of the current status of progress (e.g. A*, A, B, C)?