Task Force framework for assessment of surveillance data using examples from Tanzania, Brazil and Russia

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Task Force framework

**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

**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

TB notifications ≈ TB incidence
TB deaths in VR system ≈ TB mortality
Standards or benchmarks for direct measure of TB incidence and mortality

- To be attained by TB surveillance system
- To be attained by TB surveillance data
- To be attained for direct measurement of trends
- To be attained for surveillance systems to be considered as missing negligible number of cases and deaths
Progress in applying framework (2009)

4 regional workshops (red) with > 50 countries, 3 country missions (blue)
What do we do in the workshops and country visits?

- Analyze notification and programmatic data
- Document expert opinion
- Review and revise TB burden estimates
- Assess notification system and data quality
- Develop targeted plan of studies and activities to improve surveillance and M&E
1. Data quality
Data quality

1. **Completeness** of notification data and other quality checks
   - Are all reports complete and compiled?
   - Are there duplications and misclassifications?

2. **Internal consistency**
   - Is there more sub-national variability in notification rates than expected?
   - Is there more variability over time than expected?
   - Is laboratory diagnosis of documented quality?

3. **External consistency**
   - Are proportions and rates consistent with current knowledge on TB epidemiology?
Removing duplicates in Brazil (2006)

<table>
<thead>
<tr>
<th>New cases</th>
<th>Notification rate</th>
<th>Change (%)</th>
<th>Cured (%)</th>
<th>Change (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>before</td>
<td>after</td>
<td>before</td>
<td>after</td>
<td>before</td>
</tr>
<tr>
<td>74,492</td>
<td>69,802</td>
<td>39.9</td>
<td>37.4</td>
<td>-6.3</td>
</tr>
</tbody>
</table>

Source: Bierrenbach A et al. IJTLD 2010 (in press)

Duplicates/misclassifications inflate TB notification rates
Trends in TB notification rates by case type in Tanzania

- Smooth curve in line with HIV epidemic
- Consistency in the distribution of case types over time
- Reporting of retreatment case initiated 2001
Overdispersion of TB notification rates, only partially explained by HIV prevalence.
Indicators for internal and external consistency by region in Tanzania - 2007

% new / all: consistent, but above expected value

% pulm / new: consistent, variations in line HIV prev.

World Health Organization
Standards/benchmarks for TB surveillance system

- NTPs routinely assess completeness of reporting of TB notification data
- Clear documentation of changes to case definitions and reporting of cases for at least the last 10 years
- Data on case finding efforts and main determinants of TB are available for several years
- NTPs have a case-based electronic TB database
- NTPs check and correct for duplications and misclassifications in notifications: linkage within the last 3 years covering a period of at least 5 years
- NTPs perform inventory studies using routinely collected data and through special studies where appropriate (large number of providers TB care not linked to NTP).
- NTPs analyse TB mortality data from vital registration systems
Standards/benchmarks for TB surveillance data

- **Limited missing data** for main variables, for at least 10 years.

- **Limited variability** over time and space, for at least 10 years, or notification data show considerable variability, which can be explained.

- **Data consistent with expected values** based on TB epidemiology knowledge.

- **Limited duplications and misclassifications** in full audits and spot checks, for at least 5 years.
2. Trends
Do surveillance data reflect trends in incidence and mortality?

1. Have notifications been increasing, decreasing or stable over time?

2. Were there any changes in case-finding efforts and/or recording and reporting that might have affected notifications over time?

3. How have factors that may influence TB incidence changed over time, and have they had any impact on underlying TB incidence?
Factors affecting TB notifications in Tanzania

↑ notification mirrors ↑ case finding and HIV, but difficult to disentangle given lack of data disaggregated by HIV and case type, for ≠ years
Source of referral of TB notifications in Russia

Impact of changes in notification policy
Standards/benchmarks for direct measurement of TB trends (examples)

- Trends in TB notifications assessed to mirror trends in incidence:
  - Trends in TB notifications mirror trends in incidence after corrections for changes in case definitions, policies in reporting and case finding
    - Need notifications disaggregated on HIV status by case type, at least in high HIV burden countries
  - Trends in TB notifications mirror trends in TB mortality, and no evidence in changes in case fatality rates

- Trends in TB deaths assessed to mirror trends in mortality:
  - No evidence of changes in consistency in coding, policies in reporting and coverage of the VR system over 10 years
3. Are we capturing all cases and deaths?
Are we capturing all TB cases and deaths?

1. What proportion of incident cases are missing from routine notifications and why?

2. What proportion of TB deaths are missing from the vital registration systems and why?
The Onion Model

All TB cases

1. Recorded in notification data
2. Notified cases
3. Diagnosed but not notified cases
4. Presenting to health facilities, but undiagnosed
5. Access to health facilities, but don't go
6. No access to health care

Un-diagnosed cases
### Estimates in Tanzania before and after discussions

<table>
<thead>
<tr>
<th>Onion layers (% total new cases missed in each layer)</th>
<th>Before discussions</th>
<th>After discussions</th>
<th>Source of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. No access to health care</td>
<td>6.3</td>
<td>6.3</td>
<td>-93% pop within 10 km basic health care unit</td>
</tr>
<tr>
<td>5. Access but do not go</td>
<td>2.7</td>
<td>5</td>
<td>↑ diagnosis TB following introduction recent interventions</td>
</tr>
<tr>
<td>4. Presenting but not diagnosed</td>
<td>2.4</td>
<td>9</td>
<td>↑ diagnostic delay</td>
</tr>
<tr>
<td>3. Diagnosed by public non-NTP</td>
<td>0.9</td>
<td>0.9</td>
<td>- Exclusive distribution of TB drugs by NTP</td>
</tr>
<tr>
<td>2. Diagnosed by NTP but not notified</td>
<td>1.5</td>
<td>1.5</td>
<td>-</td>
</tr>
<tr>
<td>Sum of % of missing cases: layers 2 to 6</td>
<td>13.8</td>
<td>24</td>
<td>-</td>
</tr>
<tr>
<td>Country's CDR (2007)</td>
<td>86.2</td>
<td>75</td>
<td>-</td>
</tr>
</tbody>
</table>
Can we avoid having to depend on expert opinion?

- Inventory studies
- Vital registration data
- Capture-recapture studies
- Prevalence of TB disease surveys (health care seeking behaviour)
- Innovative operational research
Substantiating expert opinion

- **Access to health** from demographic and health surveys data (Layer 6)
- **Overall performance of health systems** as measured by: (Layer 5, 6)
  - Infant mortality ratio
  - Number of primary health care units or doctors per population
  - % of assisted births
- **Performance of TB diagnostic systems** (Layer 4, 5)
  - % people who died from TB (Vital registration data) and never accessed TB diagnosis and treatment
  - EQA of labs
  - KAP studies (health seeking behaviour), delay studies
- **Contribution of different TB care providers** (Layer 3)
  - Health expenditure in the private or nongovernmental organization sectors, out-of-pocket expenditure
- **TB drug distribution** (Layer 2)
Standards/benchmarks to be attained for surveillance systems to be considered as missing negligible number of cases and deaths

- VR systems meet minimum standards of quality and coverage
- Excellent geographical and financial access to health care facilities where TB diagnosis is available
- Staff have proven competency to diagnose TB
- Bacteriology laboratories are quality assured
- Limited or negligible undernotification from the private sector as evidenced by:
  - Limited health care expenditures in the private sector (e.g. \( \leq 5\% \))
- Limited or negligible undernotification from the public sector as evidenced by:
  - All public providers only have access to anti-TB drugs following notification of a TB case
Framework for Tanzania

DATA QUALITY
- Completeness – appears to be verified, BUT analysis not available at national level
- Cannot assess duplications/ misclassifications since data are aggregated (not case-based);
- Data mostly consistent, within ranges expected, but extreme values in a few regions

TRENDS
- Do surveillance data reflect trends in TB incidence and mortality?
- HIV and case-finding have affected trends in notification BUT difficult to disentangle effects - notifications disaggregated by HIV status not available and data on case-finding only available at national level

ARE ALL TB CASES AND TB DEATHS CAPTURED IN SURVEILLANCE DATA?
- Relied on "Onion" model based on (mostly) expert opinion combined with some evidence about health system coverage/access and some TB-specific KAP study data
- notifications ≈ TB incidence
  VR TB mortality ≈ TB deaths

DATA QUALITY
- Improving surveillance
- Update estimates of TB incidence and mortality
- Evaluate trends and impact of TB control
- Implement updated R&R recommendations

1. Roll-out case-based ERR
2. Routinely assess data quality esp. in "outliers"
3. Strengthen M&E supervision
4. Implement updated R&R recommendations

HIV and case-finding have affected trends in notification BUT difficult to disentangle effects - notifications disaggregated by HIV status not available and data on case-finding only available at national level

Data do not yet provide direct measurement. Incidence estimates revised downwards (CDR up). Prevalence survey will provide important new data
Major lessons learned

- Vital importance of case-based electronic R&R systems
- Data on notifications by case type disaggregated by HIV status need to be routinely collected, especially in high HIV-prevalence setting
- Need to strengthen analytical capacity
- Need for improvement for supervision of M&E
- Need to progressively increase reliance on data to assess cases missed by surveillance and progressively reduce use of expert opinion
- Need for standards and benchmarks
- Need for better availability and use of vital registration data, as well as more inventory studies and operational research
Major next steps

- Further workshops and country missions with Global Fund
- Train group of consultants to participate in country missions
- Develop and reach agreement on standards / benchmarks
  - Working group to further develop standards/benchmarks
- Help countries transition to TB electronic R&R
  - Minimum standards for a TB electronic R&R system + software specifications needed to achieve them
- Develop training material (SOPs, guidelines):
  - Operational research to assess data quality and M&E systems
  - NTP supervision of M&E activities
  - Programme review missions
- Jointly review M&E GF grant applications
Questions to the Task Force

1. What are your general comments on progress to date in applying the Task Force framework?

2. Do you agree with the proposed next steps? Is there anything important that is missing or should be deleted?

3. Which of the standards listed in the annex do you agree or disagree with, and do you have any suggestions for additional standards that could be used?

4. Would you be willing to be part of a small working group responsible for further development of standards and benchmarks that would need to be met for surveillance data to be considered a direct measurement of disease burden?