Progress in strengthening CRVS for the monitoring of causes of death

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Civil Registration (CR) is the compulsory, continuous, universal and permanent recording of vital events such as births and deaths. From these records, vital statistics (VS) on births, deaths, causes of death, fertility and mortality (and where migration data is also available – population estimates) can be produced for policy and planning. This document reviews the status of the global cause of death (COD) data generated by civil registration and vital statistics (CRVS), initiatives to strengthen the monitoring of COD, and the use of COD data for monitoring TB mortality.

1. Monitoring causes of death

There are a number of potential COD data sources for generating mortality statistics, including:

1. Civil registration and vital statistics systems (CRVS), associated with numerous administrative and statistical benefits for public and private entities and considered the foundation of modern administrative systems - functional CRVS systems are a key responsibility of the state and are essential for good governance and improved accountability;¹

2. Vital events enumeration in representative sample areas coupled with verbal autopsy (VA) to determine probable cause of death. These methods are commonly known as sample registration systems (SRS) and SRS with VA, they do not register vital events but only enumerate them. In other words, they provide no legal documentation on the occurrence of a vital event (birth or death) to individuals. An SRS collects information on vital events from a representative sample of the population, usually through a selection of a sample of communities within districts or other administrative units. Some countries have established nationally representative sample registration systems that generate regular data on fertility, mortality and causes of death. The method requires active case finding of vital events in the sample sites, and usually involves a dual system of case finding. VA is often used to collect information from families on the causes of death;

3. Household surveys (episodic or continuous) using direct or indirect methods of mortality estimation; possible follow-on survey to apply VA to reported deaths in order to ascertain

cause of death. Household surveys, supported by censuses, are the main source of data of mortality statistics, and to a lesser extent causes of death, in countries that do not generate vital statistics from a CRVS system. A major advantage is that data can be disaggregated using multiple stratifiers, in particular socio-economic status. The disadvantages include long intervals between surveys, large sample size requirements to generate subnational estimates, reliance on retrospective information and recall errors;

4. Longitudinal health and demographic surveillance in selected sentinel sites. Health and Demographic Surveillance Studies (HDSS) have the potential to play an important role in CRVS system development, including in terms of assessment of completeness of the birth and death registration. However, single HDSS are of limited usefulness for national mortality and cause of death statistics, as they are usually established in a limited number of locations and cannot be considered nationally representative;

5. Censuses; possible follow-on survey to apply VA to reported deaths in order to ascertain cause of death. The census has obvious limitations in terms of frequency. Most surveys focus on children, but the need to track maternal mortality, and to some extent the HIV/AIDS epidemic, resulted in increased investments in adult mortality-specific data collection. In several countries, VA modules in health surveys or special mortality surveys are used to obtain an idea of the relative importance of causes of death. Cause of death information on selected causes, notably maternal mortality, has been collected in several censuses.

6. Health care facilities - Hospital data on causes of death by age and sex are needed for multiple purposes. Cause specific mortality statistics, including case fatality rates, provide an indication of the quality of care. Ministries of Health often pay considerable attention to hospital cause of death patterns;

7. Community-based reporting. For deaths occurring outside of health facilities, where there is a crucial lack of doctors to certify the cause of death, the village chiefs or any designated informants are given the responsibility of recording the deaths and also to guess-estimate the most probable cause of death. With no medical training, such lay reporting is certainly of very limited value.
A global CRVS investment plan\(^2\) proposes explicit targets for mortality statistics, including that by 2030, 80% of deaths in children under 5 are reported, disaggregated by age and sex; 100% of causes of death in hospitals are reliably determined and official certified; 80% of countries have community assessments of probable cause of death determined by VA using international standards.

With 15 of the 17 Sustainable Development Goals (SDGs) requiring CRVS data to measure their indicators, investing in CRVS systems is a key step in SDG monitoring\(^3\). Death registration data, including with medical certification of the cause of death and cause of death coded using International Classification of Diseases (ICD), are the preferred source of information for monitoring mortality by cause, age and sex. However, there are major gaps in the coverage of death registration and persisting quality issues in death registration data. In 2015, 27 million deaths were registered with a cause of death out of 56.4 million (48%) globally. Of them, 21.4 million were reported to WHO (79%), but only 12.9 million (48%) with a meaningful ICD code.

The two main dimensions of quality which impede the use of death registration data for public health monitoring are: (a) failure to register some deaths; and (b) missing, incomplete or incorrect information on cause of death. If too few deaths are registered, or the quality of cause-of-death information is too poor, death registration data cannot be used to reliably monitor mortality by cause.

In order to assess the overall quality of death registration data, WHO has developed the concept of COD data “usability”, denoted \(U\) and defined as the percentage of all deaths which are registered with meaningful cause-of-death information:

\[
U = ε (1 - g)
\]

where \(ε\) denotes the proportion of registered deaths (completeness) and \(g\) the proportion of ill-defined causes coded using so-called garbage codes, that is, codes that are not appropriate for classifying an underlying cause of death. A selected set of ICD-10 garbage codes include: A40–A41 (streptococcal and other septicaemia); C76, C80, C97 (ill-defined cancer sites); D65 (disseminated intravascular


coagulation [defibrination syndrome]); E86 (volume depletion – for example, dehydration); I10, I26.9, I46, I47.2, I49.0, I50, I51.4–I51.6, I51.9, I70.9, I99 (ill-defined cardiovascular); J81, J96 (ill-defined respiratory); K72 (ill-defined hepatic failure); N17–N19 (ill-defined renal failure); P28.5 (respiratory failure of newborn); Y10–Y34, Y87.2 (injuries of undetermined intent); R00–R94, R96–R99 (signs and symptoms not elsewhere classified).

Usability is a key indicator of the utility of the data generated by national death registration systems in monitoring mortality rates. Together with information on reporting status, WHO has used data on usability to categorize national death registration data reported to WHO as very low, low, medium or high quality (Table 1 and Figures 1-2).

### Table 1. Quality of death registration data reported to WHO by Member States, assessed for the period 2005–2015, by WHO region

<table>
<thead>
<tr>
<th>WHO region</th>
<th>High quality</th>
<th>Medium quality</th>
<th>Low quality</th>
<th>Very low quality or no data</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>43</td>
<td>47</td>
</tr>
<tr>
<td>Americas</td>
<td>10</td>
<td>18</td>
<td>4</td>
<td>3</td>
<td>35</td>
</tr>
<tr>
<td>SE Asia</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Europe</td>
<td>33</td>
<td>12</td>
<td>8</td>
<td>0</td>
<td>53</td>
</tr>
<tr>
<td>East Med</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>13</td>
<td>21</td>
</tr>
<tr>
<td>West Pacific</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>14</td>
<td>27</td>
</tr>
<tr>
<td><strong>World</strong></td>
<td><strong>49 (25%)</strong></td>
<td><strong>38 (20%)</strong></td>
<td><strong>26 (13%)</strong></td>
<td><strong>81 (42%)</strong></td>
<td><strong>194</strong></td>
</tr>
</tbody>
</table>

“High quality” refers to countries reporting at least 5 years of data to WHO, reporting latest year of data by ICD code, and with average usability during this period ≥ 80%. “Medium quality” refers to countries reporting at least 5 years of data to WHO, reporting latest year of data by ICD code, and with average usability ≥ 60% and < 80%; or to countries reporting at least 5 years of data to WHO,
reporting with a condensed cause list, and with average usability ≥ 80%. “Low quality” refers to countries reporting any data by ICD code with average usability ≥ 40% and < 60%; or to countries reporting any data with a condensed cause list with average usability ≥ 60% and < 80%. All other countries reporting death registration to WHO are considered to have very low quality data.

Figure 1. Percentage of deaths assigned to a garbage code against completeness, and resulting WHO usability category, selected countries
2. Strengthening CRVS

Strengthening CRVS has increasingly become a priority for many countries and the global development community. The formal registration of vital events underpins the realization of civil, social and political rights by providing evidence of individual identity and family relationships. CRVS is associated with numerous administrative and statistical benefits for public and private entities and is considered the foundation of modern administrative systems.

The establishment and maintenance of comprehensive civil registration requires political will and long-term efforts to build up the necessary administrative infrastructure and create community awareness and participation in the act of registration. However, many countries and development partners also have expectations that support to CRVS system strengthening will result in the rapid availability of reliable vital statistics – including mortality and cause of death statistics – and that it will generate accurate population denominators for the calculation of coverage indicators. 

Figure 2. Quality of death registration data reported to WHO by Member States, 2005-2015. See Table 1 for the definition of categories of data quality.
A number of countries have now made major improvements in both completeness and quality of cause-of-death assignment in death registration data, and two examples are highlighted later in this report. In the Islamic Republic of Iran, the recording of deaths with detailed cause-of-death information was scaled-up from 5% in 1999 to 90% in 2015. These and other success stories have very clearly demonstrated that a long term strategy of investment in CRVS systems, including regular assessment of the quality of cause-of-death data, can bring about substantial improvements in the data used for monitoring.

Major efforts and commitments are underway to strengthen CRVS systems, particularly in Africa, Asia, and the Pacific countries and regions. In 2014, the World Bank and partners launched the Global Financing Facility, a multi-stakeholder partnership that supports country-led efforts to improve the health of women, children, and adolescents through innovative approaches to resource mobilization and systems building, including the development of CRVS systems for measuring and monitoring progress.

The Global Strategy for Women’s, Children’s and Adolescents’ Health (2016-2030) and its associated monitoring and accountability process draw attention to the importance of strengthening country data, including CRVS systems. The Every Newborn: An action plan to end preventable deaths, adopted in 2014, includes a specific objective: to “count every birth and death for women and babies including stillbirths, invest in CRVS, ensuring that the poorest are counted”, and calls for governments and partners to invest in improving birth and death registration systems by 2020.

In 2015, the Summit on Health Measurement and Accountability for Results in Health issued a five-point call to action that included efforts to ensure that countries have well-functioning CRVS systems alongside other sources of health information such as household surveys and censuses. Furthermore, the Summit set 2030 targets for all births to be registered in the CR system; 80 percent

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of deaths to be notified, registered, medically certified, and disaggregated according to age and sex; and all hospitals to report causes of death using the International Statistical Classification of Diseases and Related Health Problems (ICD), with VA to ascertain causes of death in communities. Multiple partners are moving these action points forward working through the Health Data Collaborative.8

Also in 2015, the Bloomberg Data for Health initiative was launched to tackle the challenge of the 35 million deaths (65 percent of all deaths) that remain unregistered and unrecorded each year and increase the numbers of deaths that have a documented cause recorded. Working with partners including the U.S. Centers for Disease Control and Prevention Foundation, the Johns Hopkins University, WHO, Vital Strategies, the Swiss Tropical and Public Health Institute, and the University of Melbourne, Data for Health aims to help more than 1 billion people in 20 countries in Africa, Asia, and Latin America live healthier, longer lives.9

To meet the challenge of establishing a sound evidence base for public health decision-making, there is a need to develop a strategic approach to improve mortality and causes of death statistics that is integrated with and supportive of CRVS system strengthening in countries. What is required is not a research initiative, but an approach that is part and parcel of country CRVS system strengthening plans. Such a systemic approach will avoid the creation of separate, competing systems and enhance the likelihood that investments in mortality statistics systems will be seen as integral to CRVS development.

An increasing number of countries are conducting national assessments of their CRVS and developing national strategies and investment plans. However, these plans do not always adequately address the generation of improved vital statistics, especially on mortality and causes of death. CRVS is the best source of information on mortality by age, sex and cause, if completeness and quality are high. All systems will however need regular quality control, to evaluate completeness and assess the quality of for instance cause of death ascertainment. In the absence of a comprehensive CRVS system, statistics on births, deaths and causes of death can be generated from several sources, including by applying

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direct and indirect demographic techniques to data collected in censuses and household surveys, and through demographic and health surveillance in selected or nationally representative sites.

Efforts to strengthen CRVS systems, although crucial, are unlikely to improve statistics in the short term as it generally takes more than a decade to implement a fully functioning system. Developing SRS, with VA for community deaths, in conjunction with CRVS strengthening will therefore be essential in bridging the current gap. Examples of countries currently implementing or working towards SRS include Bangladesh, Indonesia and Mozambique, while both China and India have long-term positive experience of using of such systems. To facilitate the collection of causes of death data in low-resource settings according to international norms and within minimum costs, WHO has developed a Start-Up Mortality List (SMoL) in line with the ICD that informs setting public health priorities and tracking progress towards national and international targets and goals. This list is designed to be a first step towards standardized reporting of causes of death in low-resource settings where capacities to code causes of death to ICD 3- or 4-digits are lacking. Currently Ghana and Tanzania have implemented SMoL in all their health facilities, Bangladesh has rolled it out in 6 hospitals and Rwanda and Mozambique are implementing it soon.

3. Monitoring TB mortality

TB mortality is a core indicator to monitor the impact of the End TB Strategy. The best sources of data about deaths from TB (excluding TB deaths among HIV-positive people) are CRVS systems in which causes of death are coded according to ICD-10 (although the older ICD-9 classification is still in use in few countries), using ICD-10: A15-A19 and B90 codes, equivalent to ICD-9: 010-018, and

http://www.who.int/healthinfo/civil_registration/smol/en/

Reported deaths from the analysis of TB treatment outcomes suffer from several limitations: reports are incomplete (deaths may occur among patients classified as defaulters or among patients not included in the analyzed cohort) and lack information on whether TB was the underlying cause.
When people with AIDS die from TB, HIV is registered as the underlying cause of death and TB is recorded as a contributory cause. Since one third of countries with VR systems report to WHO only the underlying causes of death and not contributory causes, VR data usually cannot be used to estimate the number of TB deaths in HIV-positive people. Two methods were used to estimate TB mortality among HIV-negative people:

- direct measurements of mortality from VR systems or mortality surveys (129 countries);
- indirect estimates derived from multiplying estimates of TB incidence by estimates of the CFR.

### 3.1. Estimating TB mortality among HIV-negative people from vital registration data and mortality surveys

As of July 2017, mortality data from 129 countries were used, representing 57% of the estimated number of TB deaths (among HIV-negative TB) globally in 2016.

Estimates for 18 countries, including India and for South Africa (adjusted for HIV/TB miscoding) were obtained from the Institute of Health Metrics and Evaluation (GBD 2015) at http://embargo.vizhub.healthdata.org/collaborators/gbd-search/, readjusted to fit WHO mortality envelopes (the estimated number of deaths in total) by using a multiplication factor equal to the ratio of WHO to IHME envelopes. The median country-year envelope ratio (WHO/IHME) was 1.03 (interquartile range, 0.92-1.05).

Among the countries for which VR or mortality survey data could be used, there were 1526 country-year data points 2000–2015, after removing 63 country-year data points with insufficient data quality as estimated by WHO (see first paragraph).

Reports of TB mortality were adjusted upwards to account for incomplete coverage (estimated deaths with no cause documented) and ill-defined causes of death (ICD-9: B46, ICD-10: R00–R99)\(^\text{13}\). It was


assumed that the proportion of TB deaths among deaths not recorded by the VR system was the same as the proportion of TB deaths in VR-recorded deaths. For VR-recorded deaths with ill-defined causes, it was assumed that the proportion of deaths attributable to TB was the same as the observed proportion in recorded deaths.

Missing data between existing adjusted data points were interpolated. Trailing missing values were predicted using a Kalman smoother or using the last observation carried forward or in the case of leading missing values, the next observation carried backwards.

In 2016, 57% of global TB mortality (excluding HIV) was directly measured from VR or survey data (or imputed from survey or VR data from previous years). The remaining mortality was estimated using the indirect methods described in the next section.

3.2. Estimating TB mortality among HIV-negative people from estimates of case fatality rates and TB incidence

In countries lacking mortality data of the necessary coverage and quality, TB mortality was estimated as the product of TB incidence and the case fatality rate (CFR) after disaggregation by case type as shown in Table 2, following a literature review of CFRs14:

$$M^- = (I^- - T^-)f^-_u + T^- f^-_t$$  

(2)

where $M$ denotes mortality, $I$ incidence. $f^-_u$ and $f^-_t$ denote CFRs untreated and treated, respectively and the superscript denotes HIV status. $T$ denotes the number of treated TB cases. In countries where the number of treated patients that are not notified (under-reporting) is known from an inventory study, the number of notified cases is adjusted upwards to estimate $T$ accounting for under-reporting.

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Table 2: Distribution of CFRs by case category

<table>
<thead>
<tr>
<th>TB treatment</th>
<th>CFR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not on TB treatment f_u</td>
<td>0.43 (0.28-0.53)</td>
</tr>
<tr>
<td>On TB treatment f_t</td>
<td>0.03 (0-0.07)</td>
</tr>
</tbody>
</table>

Figure 4 shows a comparison of 126 direct mortality estimates for 2015 and indirect estimates obtained from the CFR approach for the same countries. Of note, countries with VR data tend to be of a higher socio-economic status compared with countries with no VR data where the indirect approach was used.

Figure 4. Comparison of VR mortality (HIV-negative), horizontal axis (log scale) and mortality predicted as the product of incidence and CFR, vertical axis (log scale). Horizontal and vertical segments indicate uncertainty intervals. The dashed red line shows equality. The blue line and associated grey banner show the least-squared best fit to the data, with a slope not constrained to one.
3.3. Estimating TB mortality among HIV-positive people

TB mortality among HIV-positive is calculated using equation 2, exchanging superscripts - with +. The case fatality ratios were obtained in collaboration with the TB Modeling and Analysis Consortium (TB-MAC), and are shown in Table 3. The disaggregation of incident TB into treated and not treated cases is based on the numbers of notified cases adjusted for under-reporting.

Table 3: Distribution of CFR in HIV-positive individuals

<table>
<thead>
<tr>
<th>ART</th>
<th>TB treatment</th>
<th>CFR</th>
</tr>
</thead>
<tbody>
<tr>
<td>off</td>
<td>off</td>
<td>0.78 (0.65-0.94)</td>
</tr>
<tr>
<td>off</td>
<td>on</td>
<td>0.09 (0.03-0.15)</td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>off</td>
<td>0.62 (0.39-0.86)</td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>on</td>
<td>0.06 (0.01-0.13)</td>
</tr>
<tr>
<td>≥ 1 year</td>
<td>off</td>
<td>0.49 (0.31-0.70)</td>
</tr>
<tr>
<td>≥ 1 year</td>
<td>on</td>
<td>0.04 (0.00-0.10)</td>
</tr>
</tbody>
</table>

Direct measurements of HIV-associated TB mortality are urgently needed. This is especially the case for countries such as South Africa and Zimbabwe, where national VR systems are already in place. In other countries, more efforts are required to initiate the implementation of sample VR systems as an interim measure.

3.4. Disaggregation of TB mortality by age and sex

TB mortality in children was estimated from TB incidence in children using a case-fatality based approach\[^{15}\]. This approach distinguished case fatality children by age, anti-TB treatment status, and HIV/ART status.

Adult TB mortality was disaggregated by age and sex using the age- and sex-specific adjusted (for coverage and ill-defined causes) number of deaths from VR data in countries with vital registration

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systems in place. For countries without VR data, adult mortality was disaggregated by age, sex and HIV-infection status by applying CFRs to disaggregated incidence estimates, distinguishing CFR by anti-TB treatment status and HIV/ART status (see Tables 4 and 5). HIV-positive TB deaths in adults were distributed by age and sex proportional to age- and sex-specific HIV prevalence from UNAIDS estimates in such a way as to maintain the estimated total number of HIV-positive TB deaths.

4. Conclusion

The vision is to strengthen CRVS systems to generate reliable and continuous vital statistics including mortality statistics and cause of death, in particular to monitor national and internationally-set goals. CRVS systems have the potential to produce data disaggregated to the lowest administrative unit on a routine basis for monitoring the impact of health interventions. Key considerations when selecting mortality data sources are the expected uses and users the information. This implies sharing available mortality data with analysts and users while respecting standards for individual privacy and data confidentiality. Building links across sectors and programmes will avoid fragmentation, maximize data utility, and develop capacities for the compilation, analysis, and use of mortality data. The wide range of available sources for generating mortality statistics is both an asset and a challenge. The variety of strategic options implies that countries at different stages of statistical development will be able to identify ways of producing the needed mortality data. On the other hand, there is a risk of diverting limited resources in multiple directions none of which will prove entirely satisfactory. CRVS investment plans should prioritize interventions that will yield improved mortality statistics in the short term while simultaneously contributing to CRVS enhancement. National CRVS plans should prioritize CRVS platform development and identify complementary data sources as a function of country needs and capacities. The National Bureau of Statistics in collaboration with the Ministry responsible for Civil Registration, the Ministry of Health and other relevant Ministries and institutions should be the responsible agencies.

National TB programmes need to engage with agencies in charge of CRVS and producing COD data
and use TB mortality data to monitor national TB epidemics and evaluate case fatality ratios in subpopulations including by age and sex, to prioritize programme interventions. Record-linkage studies of the completeness of CRVS records of TB deaths and records of case fatalities in national databases of TB cases should be considered to improve the quality of TB mortality data.