Advances, Challenges, and Lessons Learned from CRVS Scale-Up Initiatives in 19 countries

IUSSP/UNFPA Expert Group Meeting, Population Data for the 21st century: Advances in data collection methodologies, New York, December, 2019

Philip Setel, PhD
Vital Strategies
psetel@vitalstrategies.org
Presentation Outline

1. Bloomberg Philanthropies Data for Health Initiative
   • Purpose, Logic Model and Measurement
2. Examples of cross-country progress
   • Legal and Regulatory Review and Reform
   • Verbal Autopsy integrated into routine CRVS system
3. Country Examples
   • Peru, Bangladesh, Rwanda
4. Future directions
The Bloomberg Philanthropies Data for Health Initiative
Introduction

• Presentation concerns the production of routine civil registration and vital statistics data

• ‘Advances in data collection methods’ mostly operational:
  • Supporting countries to fix broken or poorly functioning CRVS systems, leading to universal registration, hence complete and reliable vital statistics

• Holistic approach based on principles of:
  • Government ownership and leadership
  • Capacity building
  • Sustainability and scalability
Data for Health Initiative

- **Purpose**: Improve population health by partnering with countries to collect and use accurate public health information
  - Strengthen civil registration systems, including cause of death
  - Help policy makers better use data to make decisions
  - Sub-set of countries:
    - Complement traditional health surveys with innovative mobile phone surveys
    - Strengthen cancer registries
- Eight-year commitment of Bloomberg Philanthropies in partnership with Australian Department of Foreign Affairs and Trade
- First institutionalize system changes and demonstration of scalable, sustainable impact on systems and processes
# Theory of Change & Areas of Technical Assistance

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>OUTPUTS</th>
<th>OUTCOMES</th>
<th>IMPACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve CRVS Governance and Coordination</td>
<td>e.g. New regulations, legislation, inter-ministerial MOUs, system-wide M&amp;E</td>
<td>All necessary inter-ministerial collaboration and coordination</td>
<td>Enabling environment exists for best-practice CRVS system</td>
</tr>
<tr>
<td>Including, e.g.: Legal and regulatory framework; National CRVS Committee</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve Registration of Births and Deaths</td>
<td>e.g. Systems changes (SOPs, etc) and Increased number of notified and registered births and deaths</td>
<td>Best practice birth and death registration system</td>
<td>Increased Birth and Death Registration Completeness</td>
</tr>
<tr>
<td>Including, e.g.: Redesigned business processes and SOPs for births and deaths occurring both in and outside of facilities; active notification and registration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve Facility Cause of Death Data</td>
<td>e.g. System changes (SOPs, etc) and high quality ICD coded mortality data from the health sector and medico-legal death investigation system</td>
<td>Best practice ICD-coded mortality data production system</td>
<td>Improved Quality and Representativeness of Cause of Death Data</td>
</tr>
<tr>
<td>Including, e.g.: Introduction of standard MCCOD and ICD; MCCOD and ICD training; support for cause of death data quality assurance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve Community Cause of Death Data</td>
<td>e.g. System changes (SOPs, etc) and Verbal Autopsy data on representative sample of community deaths</td>
<td>Best practice community mortality system (VA)</td>
<td>Improved Availability of Timely, Usable, High Quality Vital Statistics</td>
</tr>
<tr>
<td>Including, e.g.: Support and limited funding to establish nationally representative verbal autopsy surveillance as part of the CRVS system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve production, dissemination and use of vital statistics</td>
<td>e.g. System changes (SOPs, etc) and Vital Statistics or Mortality Reports</td>
<td>Best practice vital statistics production</td>
<td></td>
</tr>
<tr>
<td>Including, e.g.: Support for preparation and use of national vital statistics or mortality report</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Vital Strategies
**Measurement**

**Key Metrics:**
- Number of VAs conducted
- Number of CRVS Tools and Manuals Produced
- Number of countries producing vital statistics
- Number of articles published on CRVS
- Number of people trained in any CRVS area by face-to-face training
- Number of people trained in any CRVS area by e-learning
- Number of countries with people trained in any CRVS area

**Output Indicators**
- OP1 Number system level changes births
- OP2 Number of system level changes deaths
- OP3 Number of system level changes COD facility deaths
- OP4 Number of system level changes COD home deaths
- OP5 Number of D4H-produced training packages adopted for country use
- OP6 Training resource production

**Outcome Indicators**
- OC1 CRVS Governance and Coordination Score
- OC2 Composite score birth registration
- OC3 Composite score death registration (TRACER)
- OC4 Composite score COD facility and MLDI causes of death
- OC5 Composite score COD home deaths
- OC6 Composite score Vital Statistics Production
- OC7 Training completeness
- OC8 Proportion of medical schools teaching proper cause of death certification as part of pre-service curriculum

**Impact Indicators**
- I1. Birth notification completeness
- I2. Birth Registration Completeness
- I3. Percent health sector births notified to CR
- I4. Death notification completeness
- I5. Death registration completeness (TRACER, VSPI)
- I6. Percent health sector deaths notified to CR
- I7. Vital Statistics Performance Index Quality (VSPIq)
- I8. Percent of deaths with medically certified COD in the last calendar year
- I9. Percent of deaths with unusable COD in the last calendar year
- I10. Length of mortality cause list
- I11. Number of medically impossible diagnoses in the last calendar year
- I12. Percent of deaths with age or sex unspecified in the last calendar year
- I13. Percent VA completeness in target/sample populations in the last calendar year
- I14. Vital Statistics or Mortality Report published annually for at least past three consecutive years
- I15. In the last calendar year, sex ratio of registered births within a year of occurrence
- I16. Sex ratio of death registration completeness in the last calendar year
- I17. Geographic gap in death registration completeness in the last calendar year
Partners

• CDC Foundation
• Global Health Advocacy Incubator
• Johns Hopkins University, Bloomberg School of Public Health
• UN Economic Commission for Africa
• UN Economic and Social Commission for Asia and the Pacific
• US Centers for Disease Control and Prevention
• University of Melbourne
• World Health Organization
Examples of Cross-Country Progress
Legal and Regulatory Review and Reform

- 14 Countries undertook review of CRVS legal and regulatory environment (through 2018)
  - Enabled critical inter-governmental exchange of data for the first time
  - Identified fundamental gaps in governing legislation and proposed births and deaths acts *de novo*
  - Established duty of health sector to use international standards for cause of death of assignment and reporting
  - Sanctioned health sector cadres to serve as notifiers of vital events
Innovative Applications of Verbal Autopsy

- Tanzania, Rwanda, Bangladesh, Myanmar
  - **Purpose**: to derive nationally representative picture of causes of deaths occurring outside of hospitals

- Brazil, Shanghai
  - **Purpose**: to reduce the proportion of deaths coded to unusable or uninformative causes (e.g. ‘heart failure;’ ‘cancer’)

- Philippines
  - **Purpose**: to function as a decision aid to medical officers charged with certifying home deaths with access to medical records

- Colombia
  - **Purpose**: to derive accurate picture of mortality in remote, rural locations where most deaths occur at home
Country Examples
Bangladesh: Introduced Active Registration

- CRVS Secretariat at the Cabinet Division, ORG and the Ministry of Health and Family Welfare collaboration
- Enforcement of existing mandate for frontline medical workers to assist with the civil registration of births and deaths.
- Birth and death registration up from 50% to 83% and from less than 10% to 90%, respectively
- ‘Kaliganj model’ adopted for national scale and replicated in at least one sub-district in each division of Bangladesh so far
Bangladesh: Better Cause of Death Data

• Better Facility Cause of Death Data:
  • New certificate meets WHO standards since 2017
  • Government rollout to 56 major hospitals so far; 100% district level hospitals by 2021
  • 44,000 properly coded medical certificates of cause of death that can be analyzed for policy and planning

• Understanding Community Mortality:
  • Approximately 75% of deaths in Bangladesh occur outside of hospitals with no doctor in attendance
  • Verbal autopsy to be implemented in nationally representative sample, including USD 1.2m investment by government
  • Over 25,000 verbal autopsies have been collected, giving the government access for the first time to cause-of-death data for communities collected as part of routine CRVS activities.
Peru: Automating Facility Mortality Data

- Government had concept of online death certification for physicians at hospital (SINADEF)
- Implemented at major Lima hospitals and expanded to additional public facilities with connectivity
  - Workarounds for offline entry
- From 2017-18 online certification of deaths increased from 19% of annual deaths (35,215) to 39.9% (73,792) of annual deaths
- Reduced lag time in data availability from years to weeks
- Based on success, government allocated USD$6.75m to expand and sustain SINADEF
- SINADEF now operating in 370 institutions nationwide
Peru: Mortality Report

- First trend analysis of leading causes of mortality at national and subnational levels
- Resulted in policy directives related to
  - Pneumococcal vaccine expansion
  - Increased screening for cervical and breast cancer
  - Increased access to medications for mental illnesses
- More complete data now possible via SINADEF
Rwanda: Improving Death Registration and Cause of Death Data

• 2016-17 review of the CRVS legal framework resulted in new proposed births and deaths act and two ministerial orders:
  • Established all hospitals as registration points for births and deaths
  • Mandated the use of international standard medical certificate of cause of death
  • Ensure timely reporting of high quality mortality data from hospitals
• Also recognized frontline service providers as legitimate registration agents
  • Home-Based Care Providers
Challenges and Lessons Learned
Operational Challenges and Lessons Learned

- Legal and regulatory reform is necessary, feasible, and has impact in relatively short period of time
- CRVS Committees favor impact
- Facility-based sources of mortality ripe for improvement
- Sustainable data quality assurance systems rare
- NSOs can be wary of completeness and quality issues but often just need new protocols, SOPs, or skills
- Demand for representative samples for cause of death surveillance can be difficult to create
- Being intentional about fostering institutionalization and commitment to scale – always
Technical Challenges and Lessons Learned

• What we need
  • Denominators for death registration completeness in small areas

• What we do
  • \( \text{CDR}_{\text{national}} \times \text{Estimated Midyear Pop} = \text{Total Expected Deaths} \)
  • Or consultant-led exercise in complex indirect methods

• What we’re doing about it
  • Working with NSOs and international statisticians to develop and apply new, easy, and sustainable methods

• What we’re going to do in future
  • Ensure institutionalized capacity and suitability of methods for routine updating (e.g. reliance on routine and administrative data sources)
Technical Challenges and Lessons Learned

• What we need
  • A single, agreed, validated, best-performing automated verbal autopsy cause of death assignment method (e.g. algorithm; panel of algorithms; NLP and AI…)

• What we do
  • Make a reasoned decision about which to use based on competing claims of performance from among three to four single algorithm solutions

• What we’re doing about it
  • Promoting a consortium approach
  • Calling for multi-country evaluation study
  • Calling for proper study to validate alternative automated approaches and for development of new methods

• What we're going to do in future … for now
  • Rely on incremental improvements, being transparent about limitations, decisions on which algorithms to use, etc.