CRVS best-practice and advocacy
Summary: Maximising synergies between health observatories and CRVS systems

This *summary* has been adapted from 'Maximising synergies between Health Observatories and CRVS: Guidance for INDEPTH HDSS Sites and CRVS Stakeholders' available at **crvsgateway.info/file/6124/2104**

Background

The need

It is ironic that two major data intensive enterprises—national civil registration and vital statistics (CRVS) systems and population and health 'observatories' such as Health and Demographic Surveillance Systems (HDSS) or Sample Vital Registration with Verbal Autopsy (SAVVY) systems – monitor the same vital events (births, deaths, and causes of death) among the same populations in the same countries yet rarely collaborate, remain largely unknown to each other, and analyse and utilise their data in different ways and for different purposes.

As a consequence, birth and death surveillance expertise and data frequently remain locked in separate national silos. More worrisome, key analytical findings from the observatories are not seen as an integral part of either the national health information systems or the CRVS systems. This is not an either/or issue. Low and some middle-income countries need both an increasingly strong CRVS system and observatories that are collaborating and working synergistically.

The opportunity

Population and health observatory systems monitor pregnancies, births, deaths, and causes of death via verbal autopsy (VA). HDSS and SAVVY methods ensure both high enumeration coverage and high data quality for events occurring within their sentinel or sample populations.

There are at present forty-eight HDSS sites or SAVVY implementations located in low-income countries, mostly as part of a global network called INDEPTH.[1] Sixteen, or about one-third, are located in eight of the Data for Health (D4H) Initiative's participating countries. Therefore almost half of the countries currently participating in D4H have in place longitudinal health and demographic surveillance or SAVVY systems. However, with rare exceptions, health observatory sites have never been harnessed as routine technical partners for the national CRVS systems in any of these countries.

This is a major missed opportunity, not only for the national CRVS systems and the observatory sites themselves, but also for the volume of existing, accessible quality data that could and should be harnessed for national health planning.

Recommendations

There is a missed opportunity in using HDSS and SAVVY systems to strengthen CRVS systems to improve registration of vital events. For example, births, deaths, and causes of death captured by observatories but missed by the CRVS system could be identified and uploaded to the CRVS system to improve national registration completeness. The HDSS or SAVVY system could subsequently notify households that their registration certificates are ready for collection, thus facilitating formal birth and death registration functions in HDSS and SAVVY areas. In Tanzania and Zambia, community key informants report on newly occurred vital events within the SAVVY sites, and facilitate registration through the CRVS system for all identified births.[2]

One way to ensure all vital events in the HDSS or SAVVY system are registered is by installing a civil registration office in the sample area, or by giving another associated party stationed in the catchment area authority to register events and liaise with the central civil registry office. Alternatively, establishing an agreement with the civil registry office about periodic mobile registration to the area could provide the link between identified births and deaths in the area and formal registration of the events. If it is determined that predetermined documentation and witness accounts are sufficient information to substantiate the event, this information can be sent off so the event can be registered remotely.

Regardless of the method used to improve registration, it is critical that an identification and reconciliation process be established to identify events captured in the health observatories but not registered in the national CRVS system are identified and to ensure that double registration does not occur.

1 www.indepth-network.org

2 MEASURE Evaluation. *CRVS Strengthening with SAVVY Implementation.* Paper presented at the CRVS Strengthening with SAVVY Implementation: African Region Workshop, Lilongwe, Malawi; 2016.

Benefits and challenges of leveraging health observatories to improve CRVS systems

The following section outlines some practical guidance about how population and health observatories and CRVS systems can collaborate. Six different areas of potential collaboration between the health and demographic observatories and the CRVS systems were identified:

1. Use observatories to monitor CRVS completeness for birth and death registration.
2. Use observatories to understand the determinants of CRVS non-registration.
3. Compare cause specific mortality fractions between the two sources.
4. Link data between the two systems for assessing CoD diagnostic consistency.
5. Share expertise and skills.
6. Pilot CRVS interventions cost-effectively in observatory sites.

Use observatories to monitor CRVS completeness for birth and death registration

Populations within health observatories are potential "gold standard" populations through which the routine CRVS system can be validated and calibrated with regard to timeliness and completeness of reporting. For instance, the annual number of births and deaths recorded in each system could be compared to assess CRVS completeness. Discrepancies can be used to identify specific weaknesses in the CRVS system (or in the observatory).

Indeed, discrepancies are expected to be large since the underlying motivations of the two systems differ. Such discrepancies provide the basis for a much more informed discussion of issues and challenges, remedial actions, and other necessary interventions. This could leverage motivation and action for improving birth, death, and cause of death data collection and analysis in the CRVS.

Challenges

- To compare data from health observatory sites with the CRVS system, the observatory study site boundaries should be the same as the official boundaries used in civil registration data.[3]
- Non-residents might enter the observatory site to either die or give birth.[4]

Successes

- **Agincourt HDSS, South Africa.** The existence of a routine HDSS system made it possible to demonstrate that, between 1992 and 2014, the completeness of birth and death registration in the CRVS improved substantially.[3]
- **Asembo HDSS, Western Kenya.** Comparing CRVS data with those from the HDSS showed that recorded under-five mortality rates were two-fold lower in the CRVS system (32.7/1,000) than in the HDSS (64.5/1,000).[5]
- **HDSS, Thailand.** Matching the names of deceased people between the two systems showed that 11% of deaths had not been truly registered in the CRVS system, or were unable to be matched in the HDSS records.[6]

Use observatories to understand the determinants of CRVS non-registration

If observatory sites work collaboratively with CRVS systems to monitor the completeness of CRVS birth and death registration, it becomes a natural next step to assess the determinants of CRVS non-registration. The results of such assessments could then be used for needs-adjusted mobilisation campaigns.

In addition, collaboration with continuous household surveys could facilitate cost-effective qualitative studies to understand low compliance with CRVS reporting and CRVS client satisfaction. These assessments provide countries and sites with interesting joint research findings of high national value.

3 Joubert J, et al. Record-linkage comparison of verbal autopsy and routine civil registration death certification in rural north-east South Africa: 2006-09. *Int J Epidemiol* 2014; 43(6):1945-1958.

4 Garenne M, et al. Completeness of birth and death registration in a rural area of South Africa: the Agincourt health and demographic surveillance, 1992-2014. *Glob Health Action* 2016; 9:32795.

5 Arudo J, et al. Comparison of government statistics and demographic surveillance to monitor mortality in children less than five years old in rural western Kenya. *Am J Trop Med Hy* 2003; 68(4 Suppl):30-37.

6 Prasartkul P, Vapattanawong P. The completeness of death registration in Thailand: Evidence from demographic surveillance system of the Kanchanaburi Project. *World Health Popul* 2006; 8(3):43-51.

Challenges

- HDSS questionnaires need to include a routine CRVS-related question about whether the birth or the death was registered (eg "Has the birth/death been registered?"; "If not, why not?"; "Do you possess a birth/death certificate? If yes, could I see it?").

Successes

- **Asembo HDSS, Western Kenya.** Stratification by age showed that although an equal proportion of deaths in each age group were under-reported by civil registration, neonatal deaths were significantly more affected by under-reporting.[4] This quantifies the challenge of assisting families to register both the births and deaths of neonates dying in the first month of life.
- **Agincourt HDSS, South Africa.** Using demographic and socio-economic data collected through the HDSS, researchers were able to show that the main determinants for not registering a birth were the mother's age, education level, refugee status, and household wealth.[3] These gaps in the CRVS system are undetectable without the HDSS data.
- **HDSS, Tanzania.** A study compiled reasons for non-registration after a family had notified the village executive officer of the death, but had not reached out to the district civil registrar to fully register the event. The main explanations given included "household moved out of district" (33%), "transport issues" (31%), and "household was unwilling" (29%).[7]

Compare cause specific mortality fractions between the two systems

In settings where a reasonable proportion of deaths are registered by the CRVS system, it then becomes worthwhile to examine the cause-specific mortality fractions (CSMFs) between observatory sites and the CRVS system. Such a comparison would reveal misclassification patterns and discrepancies that could be used to identify further specific weaknesses in the CRVS system, or in the observatory sites.

Challenges

- If there is a small number of deaths registered in the CRVS system, comparisons will not be useful.

Successes

- **Asembo HDSS, Western Kenya.** The CRVS system markedly under-reported malaria and pneumonia deaths, but over-reported deaths due to measles compared to the HDSS.[4]
- **Agincourt HDSS, South Africa.** Comparisons showed that CSMFs were significantly different in the CRVS and HDSS systems for all but four of the fifteen causes being investigated.[3] Using the WHO target cause of death lists, HIV/AIDS was determined to be the main cause of death in the HDSS, but was only ranked twenty-first in the CRVS system.[2] The study showed systematic biases in the CRVS cause of death data. It also highlighted an opportunity to use HDSS data to facilitate adjustments in cause of death profiles with careful interpretation.

Link data between the two systems for assessing COD diagnostic consistency

In settings where a reasonable proportion of deaths are registered by CRVS, it becomes worthwhile to compare the case-by-case causes seen in the population. This provides another opportunity for population and health observatories to collaborate with CRVS: comparing the health observatory information with the official records, event by event.

With the increasing use of VA in CRVS systems, and the potential collaboration of health observatories with CRVS, the idea to develop national data repositories of events that have both a medically certified underlying cause of death from CRVS and a VA estimated underlying cause of death. Such repositories could be highly valuable in establishing the symptom-cause information needed to validate VA diagnostic algorithms.

Challenges

- Linking names between observatory sites and hospital records is challenging, often with low matching rates.
- When reported causes of death differ between matched records, determining how to reconcile and improve diagnosed COD may be challenging.

Successes

- **Agincourt HDSS, South Africa.** 61 per cent of deaths in the HDSS were individually matched to the CRVS system.[3] Using VA diagnoses as a reference, the study examined misclassification patterns for selected causes, sensitivity, and positive predictive value. Results were used to identify weaknesses within the systems.

7 Kabadi G, Mwanyika H, de Savigny D. *Innovation in monitoring vital events. Building health information systems: Vol. 31. Mobile phone SMS support to improve coverage of birth and death registration: A scalable solution.* Queensland, Australia: Health Information Systems Knowledge Hub, School of Population Health, University of Queensland, Australia; 2013.

Share expertise and skills

The effective and continuous collaboration of CRVS and health observatories would provide an excellent platform for technical exchange and data sharing between the two systems. Connecting demographic and analytic expertise between the communities will be mutually supportive, and should lead to greater confidence in CRVS data and its eventual use.

Importantly, the relationship should be supportive in improving CRVS completeness and quality without embarrassing the CRVS systems. The ultimate goal is to improve, not to replace, the CRVS.

Challenges

- There is a need to develop careful operating protocols to guarantee confidentiality of findings (eg develop joint protocols for data sharing) and to ensure good long-term working relationships between the sites, the CRVS authorities, and other stakeholders.

Successes

- **Many countries—such as Tanzania, Ghana and Kenya—**have found the skills and experiences built up in existing HDSS sites to be of great value when extending surveillance to cover a representative sample of the population or the whole country. Here, observatory staff members acted as master trainers of VA supervisors and interviewers as the VA intervention was extended nationally.[8]

Pilot CRVS interventions cost-effectively in observatories sites

As CRVS system improvement interventions are developed and applied, they could be first demonstrated and evaluated cost-effectively in the observatory sites. HDSS and SAVVY sites would also be ideal for cost-effective, head-to-head comparisons of VA methods so that sites have access to the latest experience of automated VA.

Summary and next steps

Population and health observatories (HDSS and SAVVY) should not be seen as stand-alone systems or substitutes for complete civil registration and vital statistics. Rather, they should complement CRVS systems. To maximize synergies of effort, it is important that population and health observatories do not function entirely separately from existing civil registration systems. Such health observatories should be operated in close collaboration with civil registration authorities to ensure that their efforts are effectively integrated into a full civil registration system.

Collaboration between the two systems will also help to create demand for improved vital statistics amongst national and local authorities, while ensuring political commitment and resource allocation. Lessons learned from population and health observatories should be used to support CRVS systems in low- and middle-income countries to better register and monitor vital events.

Countries wishing to form lasting collaboration between their CRVS systems and population and health observatories are encouraged to:

Have health observatory membership in National Mortality Committees. Step one in generating synergies between systems is always to connect the appropriate stakeholders. Most national CRVS systems have a national steering committee comprised of membership from a broad array of ministries and agencies who are concerned with CRVS. It would be important that experts from the HDSS and SAVVY systems are represented on the National Mortality Sub-Committee or Mortality Surveillance Committee.

Plan a starter project on completeness of CRVS births and deaths data. If there has been no prior working connection between the observatory and CRVS, the simplest is to start with a low cost (or zero cost) collaboration such as assessing completeness of CRVS registered births and deaths in the observatory area simply by comparing dated events captured in both systems over a recent one year period.

8 Lopez AD, et al. *Strengthening Civil Registration and Vital Statistics for Births, Deaths and Causes of Deaths: Resource Kit.* Queensland, Australia: Health Information Systems Knowledge Hub, School of Population Health, University of Queensland, Australia; 2013.

Add context to the completeness of CRVS births and deaths data. Once it is possible to know who is missed out by CRVS, the observatory site is in an excellent position to characterize the individual determinants of non-registration since this information is already available in the HDSS/SAVVY data set for each individual.

Compare and assess the quality of mortality data. If, following the above studies of completeness of mortality data in CRVS, the CRVS system documents a substantial portion of expected deaths; it then makes sense to do comparative studies of cause-specific mortality fractions seen in CRVS with those in the HDSS or SAVVY system.

Share and build skills. With any of the above steps underway it is likely much easier to imagine a variety of collaborations that will lead to mutual learning and reinforcement.

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