

Sample Vital Registration With Verbal Autopsy: A New Approach for Collecting Mortality Data

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Accurate statistics on basic demographic events are the foundation of rational health and public policy. Yet these are lacking for the vast majority of the world's poorest countries. In Sub-Saharan Africa, for example, fewer than ten countries have vital registration systems that produce usable data. Mortality statistics from facility-based routine health information systems are likewise inadequate in countries where the vast majority of deaths occur at home and are never medically certified.

In particular, data on both the number and causes of death in developing countries are virtually nonexistent. Reliable data on levels – let alone causes – of adult death simply do not exist for the majority of developing countries (Timaues and Jasseh, 2004). Mortality estimates must be patched together and modeled from limited sources of data such as surveys, censuses, and demographic surveillance sites (in the few countries where they

exist). This method does not provide an adequate foundation for setting health sector priorities or for assessing program progress and impact.

Additionally, the strong relationship between health and poverty is becoming clearer and more central to global initiatives for development. Similar to mortality data, poverty estimates for most developing countries are rarely collected from more than a small sample of households and are typically derived from data that are only infrequently updated and can be of questionable reliability. This lack of appropriate social and demographic data hinders effective policy development.

The dearth of information to guide policy development and program formulation is due to factors such as limited data collection techniques, lack of local capacity, lack of political awareness and support, and financial constraints. Censuses and periodic household surveys are heavily relied upon for the production of indicators for use in policy planning and evaluation. However, they are insufficient to meet the current demands for timely data. Censuses occur too infrequently, and household surveys rarely collect data from samples large enough to provide reliable national or subnational estimates for adult mortality. In addition, censuses and household surveys usually rely on substantial external technical assistance and are not always effective mechanisms for long-term capacity building. There remains a critical lack of human and financial capacity for the routine collection of essential health, demographic, and social statistics in developing countries. The strengthening of in-country capacity for collection, dissemination, and use

is a way to obtain the information required while reducing dependence on external technical expertise and ensuring local adoption.

Given the paucity of high-quality country-level data on both mortality and poverty, countries cannot make, monitor, or evaluate policies and initiatives based on information derived from their own populations. Nor can the global community reliably measure trends and the progress of major initiatives in poverty reduction or the fight against AIDS, tuberculosis, malaria, and other diseases disproportionately affecting the poor. Measuring advances made – much less ensuring their equity – is virtually impossible due to the lack of reliable data.

Against this backdrop, the need for social and demographic indicators is increasing. For example, 189 countries have accepted the Millennium Development Goals (MDGs) as a framework for poverty reduction and sustainable development (United Nations, 2003). Most countries lack data that are required to measure progress toward the MDGs. The President's Emergency Plan for AIDS Relief also has a set of indicators for assessing the impact of the program (U.S. Department of State, 2004). In addition, data are needed to evaluate progress in sectoral reform and the impact of poverty reduction strategies under the Heavily Indebted Poor Countries (HIPC) initiative.

What is the best way to collect data on social and demographic indicators that can then be used for planning, implementing, and evaluating policies and programs that are effective, equitable, and beneficial? One viable option is a sample vital registration system. If

verbal autopsy is added to this type of system, causes of death can also be ascertained. A sample vital registration system with verbal autopsy (SAVVY) is a sustainable community-based data collection system that can generate data needed to estimate social and demographic indicators. SAVVY builds on decades of experience from both sentinel demographic surveillance and sample vital registration systems and uses a validated verbal autopsy tool to ascertain 57 causes of death at all ages (Setel et al., 2005).

The foundation of SAVVY is demographic surveillance. A fully implemented SAVVY system consists of a number of demographic surveillance sites throughout a country selected using multi-stage probability sampling. Following an initial census of SAVVY sites to determine resident populations, a network of supervised lay reporters continues to enumerate all births, deaths, and migration through annual or semiannual 'census'-update rounds. An active system of mortality surveillance runs in parallel to the census system in which all deaths will be followed up at the household level with a verbal autopsy interview implemented by trained staff.

Census-update rounds offer the chance for rider or nested surveys on health service coverage, family planning and reproductive health, poverty, or environmental and behavioral risk. As part of a well-coordinated national information strategy, SAVVY data can complement the results of national household surveys such as the Demographic and Health Surveys (DHS), Multiple Indicator Cluster Survey (MICS), and labor force participation or household budget surveys.

SAVVY consolidates and adapts best practices in sample and sentinel demographic surveillance techniques, sampling methodologies, and verbal autopsy practices from systems around the world. China, India, and Tanzania all have experience with sample vital registrations systems that have functioned to provide data on cause-specific mortality (Setel et al., 2004). In addition, research demographic surveillance sites, such as those in the INDEPTH Network, provide valuable experience in the collection of detailed demographic data (INDEPTH Network, 2002).

Measure Evaluation and the U.S. Census Bureau are working with several countries to begin implementation of SAVVY-like systems to improve the collection of information on vital events and mortality in particular. This paper describes the most important components of a SAVVY system.

Components of a SAVVY System:

Sampling

One important feature of a SAVVY system is the use of probability sampling to select surveillance sites throughout the country. The surveillance sites will be chosen to produce nationally representative sample estimates of mortality rates by cause, as well as potentially other vital statistics, health indicators, and related socioeconomic characteristics. Country sample designs will be based on the overall project objectives established by the in-country stakeholders and donors, and will take into account resources and operational constraints, as well as considerations for statistical efficiency.

One likely sampling approach is to use multi-stage probability sampling to select the sites. Under this approach, a subnational unit such as a district is the primary sampling unit. Enumeration areas within the selected districts serve as the secondary sampling units. In this approach, all households in selected enumeration areas are included in the SAVVY sample.

Baseline Census and Updates

A key component of a SAVVY system is demographic surveillance, which consists of a baseline census and continuous monitoring of demographic events (e.g., births, deaths, and migration). The baseline census provides information for obtaining the population denominators for the surveillance sites as well as recording demographic events. Annual or semiannual updates of the census provide information to update the population denominators and identify events. The census and census updates also provide the sampling frame for rider or nested surveys.

Each country implementing a SAVVY system will determine the level of detail of information to be collected in the census. However, it is possible to have questions on a variety of topics (e.g., marital status, educational attainment, household relationships, or orphan status) and still maintain a fairly simple census form.

Mortality Surveillance

Another key feature of a SAVVY system is continuous mortality surveillance. Mortality surveillance entails active reporting of deaths and stillbirths in the surveillance sites. All deaths thus identified that occur in the site are followed up at the household level, after an appropriate mourning period, by trained verbal autopsy interviewers who conduct a verbal autopsy with the family members or caregivers of the deceased.

The verbal autopsy tool to be used in a SAVVY system begins with an open narrative section in which the respondent describes the events leading up to the death. The next section of the verbal autopsy consists of a structured questionnaire with a symptom durational checklist. Other information such as previously diagnosed conditions, medications used, health service use, place of death, and some behavioral and environmental risk factors is also collected. The information collected during the verbal autopsy is coded to a standard International Classification of Disease (ICD) mortality tabulation by a panel of physicians independently classifying each death.

The verbal autopsy instrument proposed for SAVVY systems was developed based on work done in the Adult Morbidity and Mortality Project (AMMP) in Tanzania and in China's Disease Surveillance Point System. The instrument can classify 57 causes of death to ICD-10 codes (WHO, 1993). A validation study on these two systems found that the verbal autopsy tool could ascertain several causes of death at all ages and that the verbal autopsy tool performed well in two countries with different mortality patterns (Setel et al., 2005).

Enumerators, Key Informants, and Verbal Autopsy Interviewers

One of the important features of a SAVVY system is that people from the surveillance site do much of the work. Community members within the surveillance site select an enumerator and a key informant from their community. These enumerators and key informants are essentially volunteers who are paid a nominal fee for their work. The community typically knows the verbal autopsy interviewer as well. For instance, he/she may work at the local medical clinic. As with the enumerators and key informants, the verbal autopsy interviewer may receive a small payment for each interview.

The enumerators conduct the baseline census and the annual updates of the census. They are trained before the baseline census and receive a refresher course before the update census rounds. The key informants are responsible for continuously recording the vital events (births and deaths) that occur throughout the year in the surveillance site. When a death occurs, the key informant notifies the verbal autopsy interviewer of the death. The verbal autopsy interviewer then conducts a verbal autopsy.

Using community members to implement the system has several advantages. The enumerators, key informants, and verbal autopsy interviewers are essentially volunteers who are paid only a minimal fee, which keeps the overall cost of the system low. The use of community members also helps to build trust within the surveillance site. The use of community members to implement the system both builds capacity within the sites and also helps to ensure the sustainability of the system.

SAVVY Outputs

A SAVVY system, once fully functioning, will be able to provide data on vital events at the national level. In particular, it will be able to provide adult mortality and cause of death data that are not currently available from any other source.

In addition to the vital statistics data, a SAVVY system can potentially provide data on many other topics. Information can be collected either in the census update rounds or in nested/rider surveys on topics such as educational attainment, poverty, gender equity, household/family structures and dynamics, and health care usage. Because the system is designed so that the enumerator visits each household in the surveillance site every year to update the census, the opportunity exists to ask questions on a range of issues that are of interest to either policymakers or people involved in monitoring and evaluation.

Are There Alternatives Sources of Data?

One obvious question, when considering a SAVVY system, is whether there are other sources that can be used to obtain the data? The most logical alternative source for data on vital statistics is a fully functioning universal vital statistics registration system, and this may be a long-term goal. However, in the countries in which SAVVY systems are being considered, the vital statistics registration system is either nonexistent or nonfunctioning. Neither setting up a universal vital statistics system where there is none nor fixing an existing non-functioning vital statistics system is necessarily a practical solution in the short term. There needs to be considerable national commitment,

sufficient infrastructure and local capacity, and, more importantly, sufficient funds to establish and maintain a universal vital statistics system. These elements are lacking in many developing countries.

Information on deaths from facility-based information systems are not a reliable alternative for mortality estimates because in many developing countries the majority of deaths occur at home and the deceased may never have had contact with the health care system. These “home” deaths would never be counted in a facility-based system, thus any mortality estimate based on this type of system would be biased.

Household surveys can provide high-quality nationally-representative data for many indicators, and they can provide estimates of infant and child mortality. However, household surveys do not have large enough samples to provide reliable estimates of adult mortality, particularly by cause. More significantly, household surveys typically do not occur annually, whereas SAVVY has the potential to provide annual estimates of certain indicators.

Research-oriented demographic surveillance sites (such as those in the INDEPTH Network) also provide high-quality data that can be used to estimate mortality for that site. They also provide an excellent platform for clinical trials and effectiveness studies. However, these research sites are not representative of the entire country. These sites are often selected because there is a high incidence of a certain disease (e.g., malaria or HIV/AIDS). Additionally, few countries have more than one or two research-oriented

demographic surveillance sites, which makes producing nationally representative estimates of mortality problematic.

Conclusion

SAVVY is a practical option for collecting information on mortality, particularly cause-specific adult mortality, which is not available from any other source. This approach also has the ability to provide timely data on other indicators. SAVVY is building on techniques, experience, and expertise from around the world. The success of the Indian Sample Registration System (SRS) and the China Disease Points System, demonstrate that a sample system can work to provide much needed information (Setel et al., 2004). SAVVY also presents an opportunity to design a sustainable integrated information system in countries currently lacking data needed for policy development, program formulation, and continuous monitoring and evaluation of development projects.

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