Maximizing Synergies between Health Observatories and CRVS:

Guidance for INDEPTH HDSS Sites and CRVS Stakeholders

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for the

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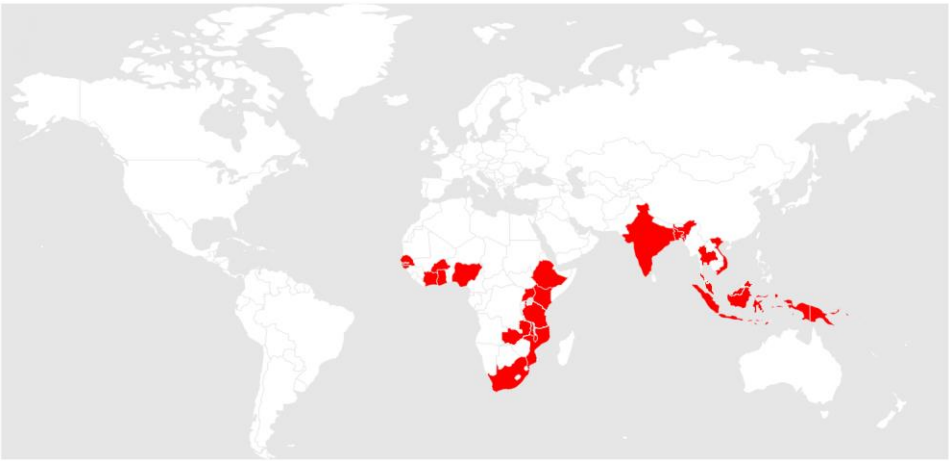
Contents

1. Introduction: The two solitudes

The need. It is ironic that two major data intensive enterprises—national Civil Registration & Vital Statistics (CRVS) systems and population & 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 population and health observatories are not seen as an integral part of the fabric 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 population and health observatories that are collaborating and working synergistically. This document makes the case for this and describes ways in which such collaboration can work to strengthen CRVS.

The opportunity. HDSS/SAVVY[1] population and health observatory systems monitor pregnancies, births, deaths, and causes of death via verbal autopsy (VA), and provide islands of relative excellence for such data. 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-seven HDSS sites or SAVVY implementations located in low-income countries, mostly part of a global network called INDEPTH (www.indepth-network.org) (Figure 1) (INDEPTH Network, 2017b); sixteen, or about one-third, are located in eight of the Bloomberg Philanthropy's' Data for Health Initiative (D4H) participating countries (Table 1). 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, INDEPTH HDSS sites have never been harnessed as routine technical partners for the national CRVS in any of these countries. This is a major missed opportunity, not only for the national CRVS systems and the HDSS sites themselves, but also for the volume of existing, accessible quality data that could and should be harnessed for national health planning. It is also an opportunity that nevertheless can be addressed relatively quickly, as this Guidance Document outlines.



[1] In this report we use HDSS and SAVVY interchangeably (HDSS/SAVVY) since the arguments we put forward apply to both systems.

Figure 1. Countries with HDSS or SAVVY sites (INDEPTH Network, 2017b; MEASURE Evaluation, 2016)

Table 1 List of countries with HDSS or SAVVY sites for potential CRVS linkage (INDEPTH Network, 2017b; MEASURE Evaluation, 2016)

Country	HDSS sites or SAVVY
Bangladesh*	Bandarban HDSS
	Chakaria HDSS
	Matlab HDSS
Burkina Faso	Kaya HDSS
	Nanoro HDSS
	Nouna HDSS
	Ouagadougou HDSS
	Sapone HDSS
Côte d'Ivoire	Taabo HDSS
Ethiopia	Arba Minch HDSS
	Butajira HDSS
	Dabat HDSS
	Gilgel Gibe HDSS
	Kersa HDSS
	Kilite Awlaelo HDSS
Gambia	Farafenni HDSS
	West Kiang HDSS (Associate Member)
Ghana*	Dodowa HDSS
	Kintampo HDSS
	Navrongo HDSS
Guinea-Bissau	Bandim HDSS
India*	Ballabgarh HDSS
	Birbhum HDSS
	Vadu HDSS
Indonesia*	Purworejo HDSS
	SRS
Kenya	Kilifi HDSS
	Kisumu HDSS
	Kombewa HDSS
	Mbita HDSS
	Nairobi HDSS
Malawi*	Karonga HDSS
	SAVVY
Malaysia	SEACO HDSS (Associate Member)
Mozambique	Chókwè HDSS
	Manhica HDSS
Nigeria	Cross River HDSS
	Nahuche HDSS
Papua New Guinea*	PiH HDSS
	Wosera HDSS (Associate Member)
South Africa	Agincourt HDSS

	AHRI HDSS Dikgale HDSS
Senegal	Bandafassi HDSS Mlomp HDSS Niakhar HDSS
Tanzania*	Magu HDSS (Associate Member) Ifakara HDSS (Associate Member) Rufiji HDSS (Associate Member) SAVVY
Thailand	Kanchanaburi HDSS (Associate Member)
Uganda	Iganga/Mayuge HDSS Kyamulibwa HDSS Rakai HDSS
Vietnam	Chililab HDSS DodaLab HDSS Filabavi HDSS
Zambia*	SAVVY

*Indicates D4H countries

Why now? Low and middle-income countries are currently facing a surge of interest in, and support for, strengthening their CRVS systems. This attention has been driven by an increased recognition of the value that such systems offer for social protection, Universal Health Coverage, and monitoring Sustainable Development Goals, among other benefits (AbouZahr et al., 2015; AbouZahr, Rampatige, Lopez, & de Savigny, 2012; Byass, de Savigny, & Lopez, 2014). There is, however, only one well-documented instance (South Africa) in which an HDSS site has stepped forward to work collaboratively with its national CRVS system to assess both the completeness and quality of routine data collected by the CRVS for the populations they both monitor (Garenne et al., 2016a, 2016b; Joubert et al., 2014; Kabudula et al., 2014). There is thus little global experience in forging functional linkages between population and health observatories like HDSS and CRVS systems, despite widespread recognition of the need to do so to overcome current fragmentation in data collection, analysis, and expertise (World Health Organization, 2014). WHO has recently called on established HDSS sites to help strengthen national capacity for CRVS. The leadership of the INDEPTH Network has likewise recently signalled its intention to redress this situation: it is currently seeking initiatives and methodologies to re-engineer such relationships (Sankoh & Byass, 2014). With Bloomberg Philanthropy's Data for Health Initiative support, the INDEPTH Network has added collaboration with CRVS as a key platform of its 2016-2021 strategic plans.

What is in this Guidance Document? The intent of this Guidance Document is to illuminate synergies that will ultimately help strengthen CRVS systems to improve registration and certification of births, deaths and causes of death, and increase the value of HDSS/SAVVY operations for national development. In this Guidance Document, we first set the stage for a better common understanding by describing the CRVS for HDSS/SAVVY managers, and the HDSS/SAVVY for CRVS managers. We then provide a Section on each of the six different thrusts (in increasing level of challenge) of potential collaboration that could be established between the health and demographic observatories and the

Maximizing Synergies between Health Observatories and National CRVS

CRVS:

1. Using HDSS/SAVVY to monitor CRVS completeness for births and deaths registration;
2. Using HDSS/SAVVY to understand the determinants that underlay CRVS non-registration;
3. Comparing cause specific mortality fractions between CRVS and HDSS/SAVVY;
4. Linking data between CRVS and HDSS/SAVVY for mortality cause concordance;
5. Piloting CRVS interventions cost-effectively in HDSS/SAVVY sites;
6. Sharing expertise and skills among and between the CRVS and HDSS/SAVVY systems.

This report is intended to provide practical guidance about how population and health observatories and CRVS can collaborate. It also adds recent advice from WHO, the Health Metrics Network, and the University of Queensland Health Information Systems Knowledge Hub, which show how HDSS and SAVVY sites can be used as stepping-stones to strengthen CRVS systems (AbouZahr et al., 2012; Health Metrics Network, 2008; Hill, Lopez, Shibuya, Jha, & Monitoring of Vital, 2007; Lopez et al., 2013). While HDDS and SAVVY sites cannot substitute for universal civil registration, their implementation can provide supplemental vital statistics until civil registration systems of sufficient quality and completeness are established and until representative cause of death statistics can be produced reliably from institutional sources (AbouZahr et al., 2012; Health Metrics Network, 2008; Lopez et al., 2013; MEASURE Evaluation & International Programs Center, 2009).

This report is a joint product of the Bloomberg Philanthropy's Data for Health Initiative at the University of Melbourne/Swiss Tropical and Public Health Institute's CRVS Innovation Hub and the INDEPTH Network. We acknowledge the contribution of participants at an INDEPTH/D4H joint international workshop who deliberated on this issue. The workshop was sponsored by the Data for Health Initiative and convened by INDEPTH in Accra, Ghana, May 24-26, 2016. Participants included: Osman Sankoh, Koku Awonoor, Martin Bangha, Titus Tei, Peter Asiedu, Randy Oduru, Evelyny Potakey, George Wak, Ernest Nettey, Emmanuel Dakwa, Dominic Atweam, Emmanuel Opoku, Kingsley Addo, Fidelia Dake, Grace Badiako, Ayaga Bawah, Isaac Lyatuu, Gregory Kabadi, Mark Collinson and Don de Savigny.

2. What is Civil Registration & Vital Statistics? [for population & health observatory managers]

Civil registration is defined by the United Nations as: "*the continuous, permanent, compulsory, and universal recording of the occurrence and characteristics of vital events (live births, deaths, foetal deaths, marriages, and divorces) and other civil status events pertaining to the population as provided by decree, law or regulation, in accordance with the legal requirements in each country*" (United Nations, 2017). A well-functioning civil registration is mandatory, permanent, continuous, and complete. It registers all vital events with high quality data in a timely manner (Ye, Wamukoya, Ezeh, Emina, & Sankoh, 2012). Complete, accurate, and timely civil registration is essential for quality vital statistics, which in turn provide critical input for the development of appropriate and responsive policies and programmes (United Nations, 2017; World Health Organization, 2017). Civil registration records are also a primary source of vital statistics, which are defined as: "the total process of: 1) collecting information by civil registration or enumeration on the frequency or occurrence of specified and defined vital events, as well as relevant characteristics of the events themselves and the person or persons concerned; and 2) compiling, processing, analysing, evaluating, presenting and disseminating these data in statistical form" (World Health Organization, 2017).

CRVS systems are complex, adaptive systems. They perform hundreds of actions on a daily basis to continuously register the occurrence of vital events and to produce vital statistics. Despite the fact that all CRVS systems have the same output objectives, each country's system has developed along separate paths. Each works within its country's unique approach to governance and policies, and is accountable to a different ministry, such as justice, security, local government, and health. National governments also differ in how they approach CRVS organization, implementation, processes, scale, partners, and capacities. All CRVS systems function within larger political, economic, social, health, and information systems, but nested within them are further sub-systems concerned, for example, with particular legal identities, civil registries, vital statistics, information technologies, etc.

In most countries, vital events (births or deaths) must be reported to an authority and then validated before being officially (legally) registered in a civil registration office (green boxes in figure 2). The affected family receives a legally valid document certifying the vital event, and some type of documentation is stored and archived by the system as a proof that the vital event occurred and has been registered. Information collected through the civil registration system is raw material that needs to be compiled, managed, and analysed to produce vital statistics that can then be shared with—and communicated to—different technical and non-technical audiences (blue boxes in Figure 2).

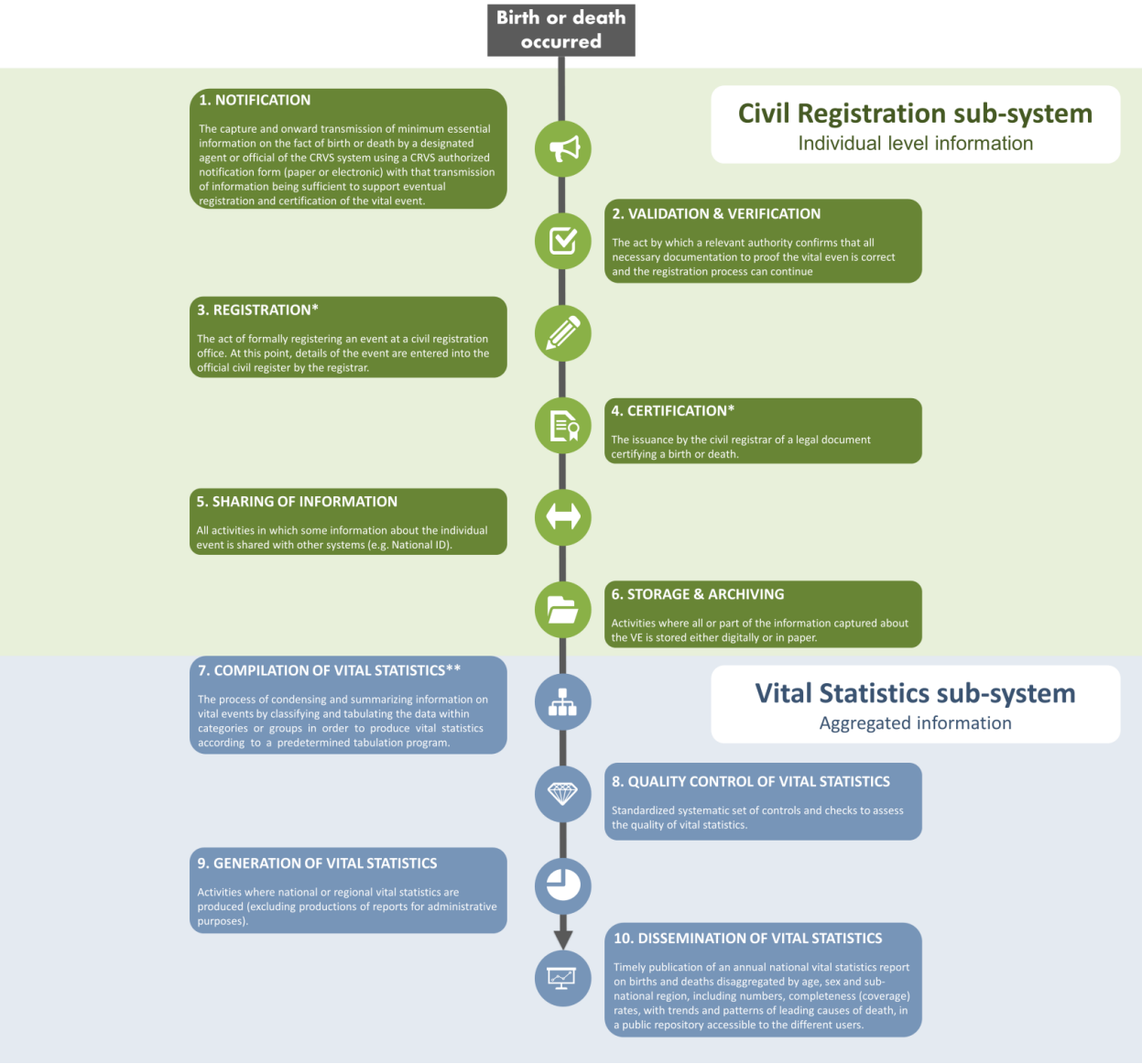


Figure 2. The Ten Milestones of CRVS

In the context of this Guidance Document, the advantages of CRVS systems are that they are: i) required by international law; and ii) continuously provide key data related to births, deaths, causes of death, fertility, and migration. They are also necessary for the implementation of successful social security systems and for tracking and ensuring civil rights. However, CRVS systems are extraordinarily complex (Figure 2). Slow progress in their performance suggests system failures rather than technical failure.

Implementing a fully-functional and complete CRVS system is beyond the capacity of most low-and some middle-income countries (Ye et al., 2012). The main problems that such countries face include: 1) incomplete registration of vital events, especially of deaths, in CRVS systems (low coverage and completeness); 2) poor medical certification of causes of death; 3) poor availability, inefficient compilation, and/or insufficient timeliness of compiled vital statistics; 4) inexperienced use of CRVS data

in the health sector; 5) poor understanding of the immense value of reliable birth, death, and cause of death data for local and national health planning and policy; 6) inadequate political will and commitment; 7) lack of adequate financial resources; and 8) culture of non-data use (Ye et al., 2012). Moreover, model-based and assumption-driven estimates cannot keep up with the burden of disease dynamics in countries that have an urgent, immediate need for real-time prospective data. To mitigate some of these immediate data and knowledge gaps—and to create both demand and skills while scaling up CRVS to acceptable completeness—it is reasonable to concentrate some resources on registering "smaller representative populations well", rather than "larger populations poorly" (AbouZahr et al., 2012; MEASURE Evaluation & International Programs Center, 2007). Hence there is growing interest of many countries to host population and health observatories such as HDSS or SAVVY operations.

3. What are Population and Health Observatories (HDSS and SAVVY)? [for CRVS managers]

HDSS. A Health and Demographic Surveillance System (HDSS) monitors key demographic events (pregnancies, births, deaths, causes of death, and migration), in addition to other health and socio-economic indicators of a total population that lives in a well-defined geographic area (Clark, 2004; INDEPTH Network, 2002; Sankoh & Binka, 2005; Ye et al., 2012) (Figure 3). Key outputs from HDSSs include all-cause mortality rates, cause-specific mortality fractions and rates, and life table probabilities, as well as fertility and migration rates. Other outputs include population and household characteristics (including social-economic status), disease burden, use of health services, and exposure to environmental risk factors. This type of data allows health threats to be monitored, population changes to be tracked through fertility and migration rates, and the effects of community-level interventions to be monitored, among other things; all of these factors then can be used to guide health policy making (Ye et al., 2012). The associated data on environment, education, immunization status, housing, access to water, sanitation, and energy provide deep explanatory contexts to the observed dynamics in health and demographic outcomes. In an HDSS, an initial baseline census is conducted of all households and residents in the defined geographic area; data is updated subsequently several times a year through enumeration update rounds.

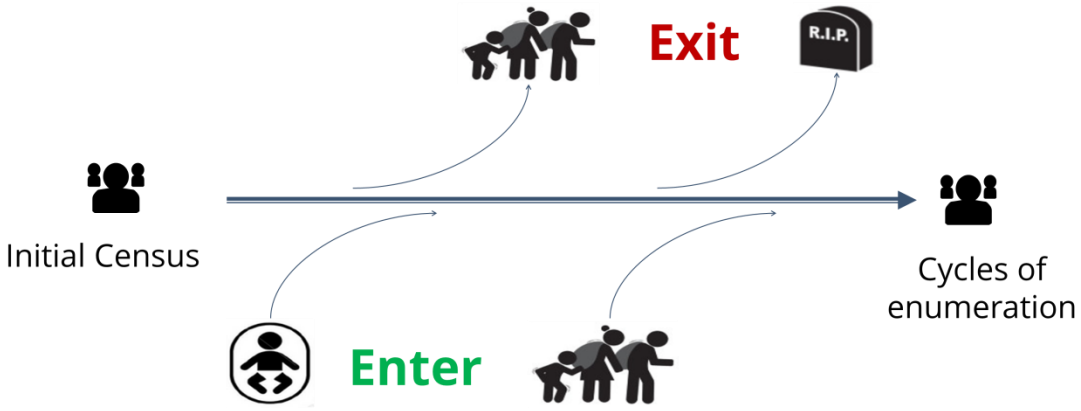


Figure 3. Illustration of Health and Demographic Surveillance System. Adapted from: (INDEPTH Network, 2017a)

SAVVY. Sample Vital Registration (SVR) is essentially an aggregation of many smaller HDSS clusters that focus exclusively on vital events (Ye et al., 2012). A SVR thus covers many areas that are sampled sequentially from an entire region or country. In these areas, the SVR system monitors vital events among a sample of individuals, households, and/or residential units (Ye et al., 2012). Thus, it is able to provide representative estimates for an entire region or country (Ye et al., 2012). A SVR system that includes active follow-up of deaths in the community to determine their likely cause of death is called "Sample Vital Registration with Verbal Autopsy (SAVVY)" (MEASURE Evaluation & International Programs Center, 2007) (Figure 4). It therefore allows for a determination of nationally-representative causes of death (MEASURE Evaluation, 2016).

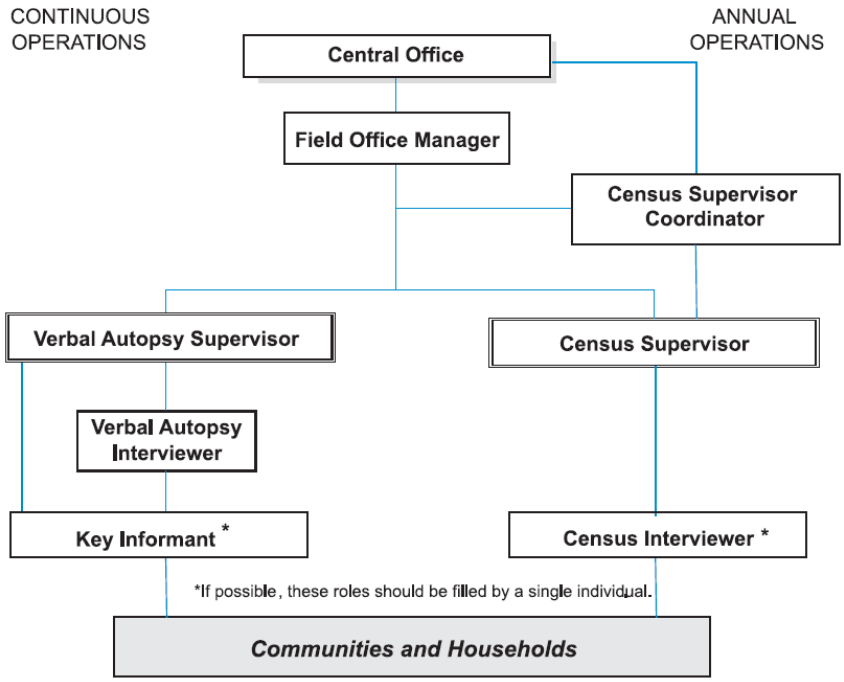


Figure 4. Chart of a Sample Vital Registration with Verbal Autopsy (SAVVY) System. From: (MEASURE Evaluation & International Programs Center, 2007)

The main advantage of HDSS/SAVVY systems is that their data is longitudinal in nature, contemporary (i.e., regular and up to date), and of high quality. In addition, they not only provide information about individuals, but also about households and their social and environmental contexts. Events by cause, age, and sex are linked to each individual in the resident population. In addition to their data benefits, these systems can also evaluate the effect of interventions, and thus provide good value for money. Furthermore, HDSS/SAVVY data can fully complement the Health Management Information System through population-based data that is independent of the use of healthcare services, and can therefore be used for health planning.

One of the challenges of HDDS/SAVVY sites is that they are perceived to be costly (Byass et al., 2002; Rommelmann et al., 2005; Ye et al., 2012). Their development and implementation are often funded by research funders, private institutions, international foundations, international public funds, and in-country universities and academic institutions (Lopez et al., 2013). Research conducted in HDDS/SAVVY sites, although of international value, is often insufficiently aligned with specific national policy interests and priorities to ensure support from governments and the use of the research findings by these authorities (Lopez et al., 2013; Ye et al., 2012). Their challenge to provide timely data that could be used in annual sector reviews is another challenge faced by HDSS/SAVVY systems (Lopez et al., 2013; Ye et al., 2012). It has also been suggested that the indicators used in and by HDSS/SAVYY should be generalized to other settings only with caution, since repeated measurement is itself seen to be a passive intervention; HDSS populations are more likely to be exposed to studies that provide interventions than populations in other regions (Byass, Worku, Emmelin, & Berhane, 2007; Garenne et al., 2016a; Ye et al.,

2012). Also, some believe that since HDSS/SAVVY systems continue run over a long period of time, a number of operational challenges and constraints may occur, such as respondent fatigue (Baiden, Hodgson, & Binka, 2006; Ye et al., 2012). There is, as yet, little evidence that this is the case. Another challenge faced by HDSS sites is the accumulation of unanalysed data (Baiden et al., 2006). Finally, compared to other well-known methods, such as census, demographic, and health surveys (DHSs), HDSSs collect data within a defined area and are therefore not nationally representative (this is not a problem with SAVVY, though) (Health Metrics Network, 2008; Lopez et al., 2013; Ye et al., 2012).

4. Using HDSS/SAVVY to monitor completeness for CRVS birth and death registration

HDSS/SAVVY populations are potential "gold standard" observatory 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 HDSS). 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. The progress of CRVS system performance over time could then be monitored using HDSS/SAVVY sites (see Section **Error! Reference source not found.**).

To compare data from HDSS/SAVVY sites with the CRVS system, the HDSS/SAVVY study site boundaries should be the same as the official boundaries used in CR data (Joubert et al., 2014). If this is not the case, methods need to be applied to identify whether a CRVS death/birth occurred within the HDSS/SAVVY boundaries (Joubert et al., 2014). One recognised problem of comparing the number of births and deaths between CRVS and HDSS systems is that some non-residents might enter the HDSS site to either die or give birth (that is, people coming back to die in their village of origin or very young women returning to their families for delivery) (Garenne et al., 2016a). Therefore, for high quality estimates of completeness, it would be preferable to include a routine question in the HDSS core questionnaire on whether and where the birth or the death was registered (Garenne et al., 2016a).

Several examples demonstrate the value of comparing data across the two systems to assess completeness and accuracy. A recent study in the Agincourt HDSS site in South Africa documented trends in completeness of vital events registration over a period of 25 years (Garenne et al., 2016a). The study used the precise number of total births and deaths as the denominator and the number of events effectively registered as the numerator, both of which have been known accurately since 1992 (Garenne et al., 2016a). 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 for all social strata (**Figure 5**) (Garenne et al., 2016b).

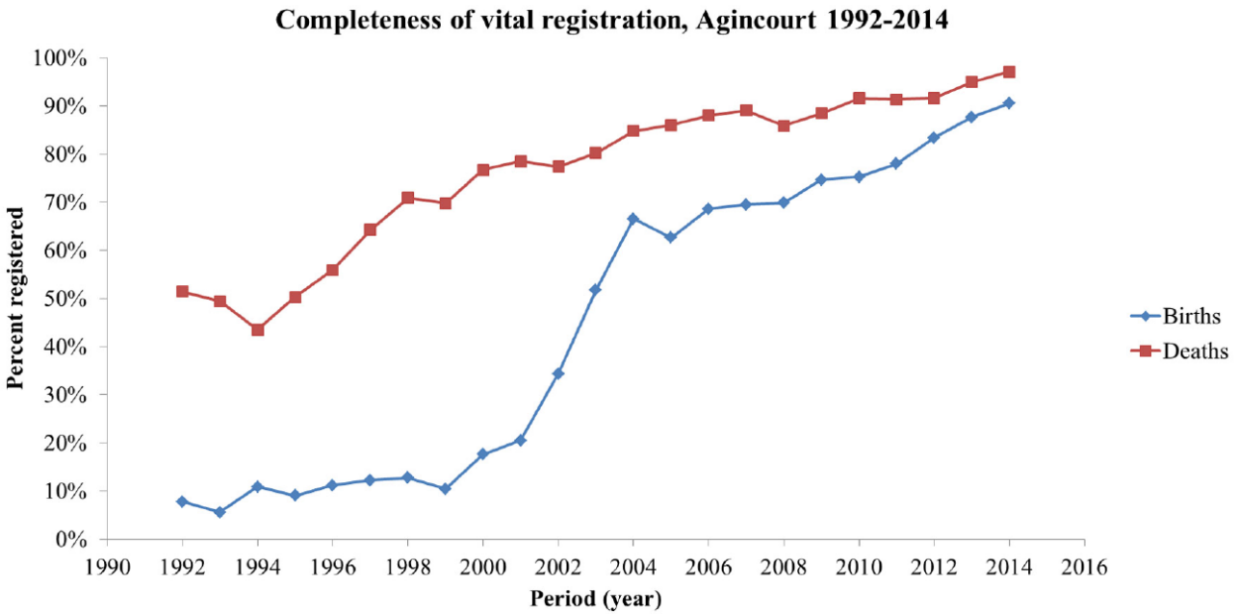


Figure 5. Completeness of birth and death registration, Agincourt HDSS South Africa 1992-2014 (Garenne et al., 2016a)

A study in Asembo, Western Kenya, compared data from government CRVS statistics with those from the HDSS for under-five deaths. It found that recorded mortality rates were two-fold lower in the CRVS system (32.7/1,000) than in the vital event monitoring (adaption of VA within a HDSS; 64.5/1,000) (Arudo et al., 2003). Another study from Tanzania conducted in the Rufiji HDSS to examine the completeness of routine CRVS (Kabadi, Mwanyika, & de Savigny, 2013) piloted a short message service (SMS) technology to increase completeness of birth and death registration (Kabadi et al., 2013). The village executive officer, who was notified by the affected family about the event, not only recorded the event in the appropriate register, but also sent a free SMS to the central database that was linked to the district civil registry (Kabadi et al., 2013). The family was required to travel to the district civil registrar to fully register the event; if it could or would not do so, the village executive officer received a SMS request to follow up with the household and record the reasons for non-registration (Kabadi et al., 2013). Figure 6 shows that during the reporting period September 2012 to February 2013, the HDSS reported more than seven times (379) the death events than were recorded by the enhanced CRVS system (CRVS+SMS: 54) (Kabadi et al., 2013). However, this was a significant improvement over the same period the previous year, when the HDSS had reported more than forty-seven times (379) the death events recorded by the routine CRVS system (CRVS: 8) (Kabadi et al., 2013).

Another example where completeness of death registration has been assessed comes from an HDSS in Thailand. HDSS data were matched with data from the CRVS system based on the names of the deceased person (Prasartkul & Vapattanawong, 2006). Matching by name was achieved for 87.5% of the deaths in the HDSS, although 98.4% of the respondents reported that they had registered the death in CRVS, resulting in a gap of 10.9% whose names could not be matched, or who had not truly registered

the death in CRVS (Prasartkul & Vapattanawong, 2006).

Lastly, according to a workshop report on "CRVS Strengthening with SAVVY Implementation: African Region Workshop," Malawi plans to use birth registration statistics to check completeness of birth reporting in the SAVVY sites and vice versa (MEASURE Evaluation, 2016).

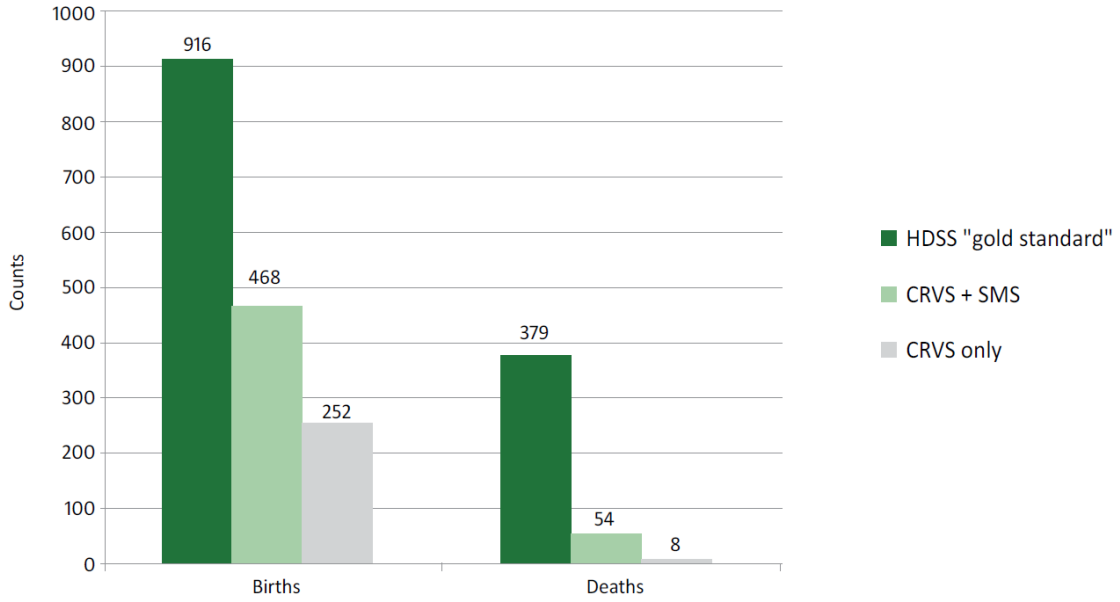


Figure 6. Comparison of HDSS, CRVS+SMS Notification, and CRVS only in recording (HDSS) and registering (CRVS) births and deaths in the same population.

In addition to assessing CRVS completeness, a further option could be that at the end of each comparison year, births, deaths, and causes of death captured by the HDSS/SAVVY but missed by the CRVS system could be uploaded to the CRVS system. The HDSS/SAVVY system could subsequently undertake actions to notify households that their registration certificates are ready for collection and therewith to facilitate formal birth and death registration functions in the HDSS sites. For example, community key informants in Tanzania and Zambia, who report on newly occurred vital events within the SAVVY sites, facilitated registration through the CRVS system for all identified births (MEASURE Evaluation, 2016).

Table 2. Summary of Actions and Benefits for Improving CRVS Completeness via Enhanced Collaboration with HDSS/SAVVY.

Action	**Benefit**
HDSS provides precise denominator of births & deaths	CRVS obtains **completeness** estimates of births & deaths
HDSS provides annual denominators for births & deaths	CRVS able to monitor **trends** in improving completeness of births & deaths
HDSS facilitates registration of missed events	CRVS able increase numbers of registered events
HDSS facilitates delivery of certificates to families	CRVS able to increase fulfilment of certification; HDSS able to provide an incentive for continued longitudinal household visits
HDSS illuminates determinants of non-registration	CRVS enabled to analyse neglected populations or groups. See next section.

5. Using HDSS/SAVVY to understand the determinants of CRVS non-registration of birth and death

If HDSS/SAVVY sites work collaboratively with CRVS to monitor the completeness of CRVS birth and death registration (Section 4), 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 mobilization campaigns. The main requirement for such investigations is that the HDSS questionnaire includes a routine CRVS-related question about whether the birth or the death was registered (e.g. "Has the birth/death been registered?"; "If not, why not?";"Do you possess a birth/death certificate? If yes, could I see it") (Garenne et al., 2016a).

Examples of such assessments include the above-mentioned study from Western Kenya. Here, stratification by age showed that although an equal proportion of deaths in each age group was under-reported by civil registration, neonatal deaths were significantly more affected by under-reporting (Figure 7) (Arudo et al., 2003). This quantifies the challenge of assisting families to register both the births and deaths of neonates dying in the first month of life.

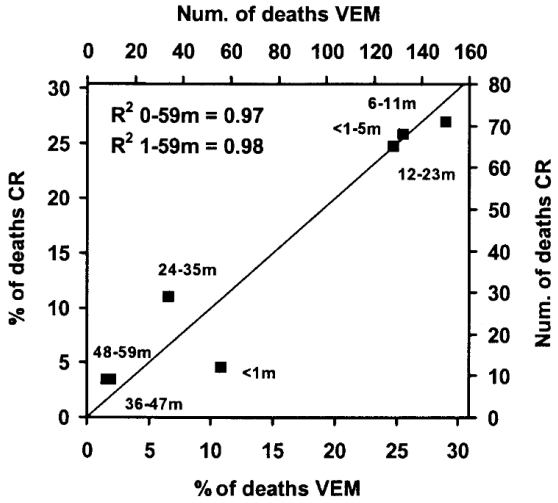


Figure 7. Correlation between civil registration (CR) and vital event monitoring for the age of deaths in children < 60 months of age in the Asembo study area.[2]

Another example of assessing determinants comes from Agincourt in South Africa (also mentioned above). Here, a study that used the HDSS's numerous demographic and socio-economic correlates at the household and individual levels to determine barriers to registering deaths and births showed that the main determinants for not registering a birth were the mother's age (low completeness for births to adolescent mothers), education level, refugee status, and household wealth (Garenne et al., 2016a). The

[2] Each right y-axis and upper x-axis represents the absolute number (Num.) of deaths, each left y-axis and lower x-axis represent the proportion of recorded deaths with that corresponding surveillance method. The cumulative proportion of deaths for each surveillance method is always 100%. The diagonal lines represent reference regression lines with a slope of 1 and no intercept of the proportions of deaths from two surveillance methods (Arudo et al., 2003)

last two determinants, in addition to age at death, were also major factors for not registering deaths (low completeness in under-five children) (**Figure 8**) (Garenne et al., 2016a). These gaps in the CRVS are undetectable without the HDSS data.

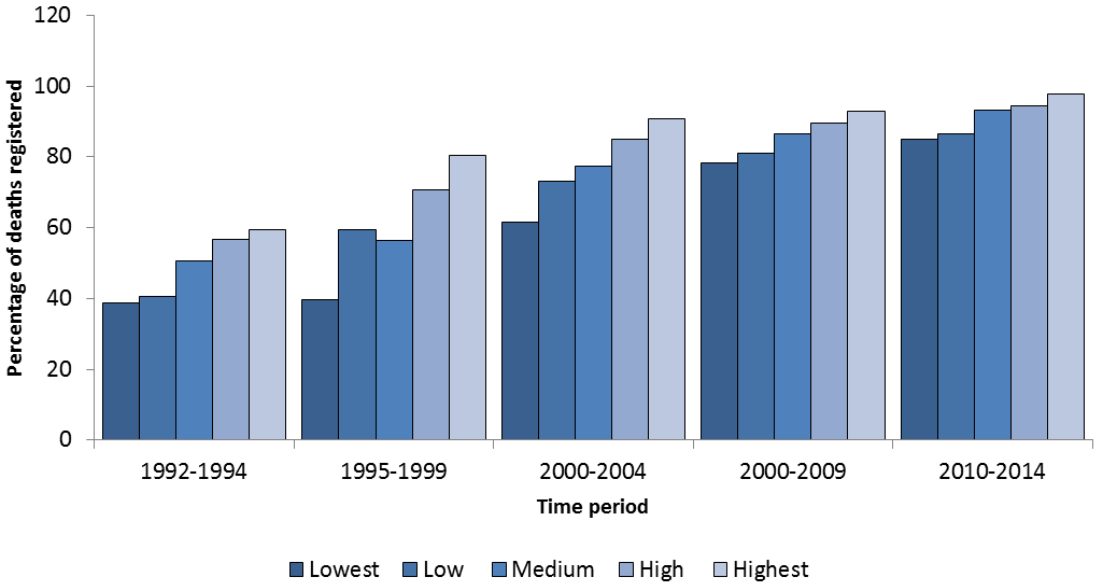


Figure 8. Percentage of deaths registered by household wealth across the time period of the Agincourt study, South Africa (Garenne et al., 2016a)

The above-mentioned study from Thailand also reported on some basic determinants of CRVS non-registration (Prasartkul & Vapattanawong, 2006). Similar to the Kenyan and South African studies, the Thailand study found that the percentage of non-registered deaths was highest among the youngest age group (under-five years), whereas there was no difference regarding the sex of the deceased person (**Figure 9**) (Prasartkul & Vapattanawong, 2006). The observed age pattern of death registration was seen to be useful for adjusting data from the CRVS system, calculating age-specific death rates, and constructing life tables (Prasartkul & Vapattanawong, 2006).

The Tanzanian 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%). “Cost issues” (6%), and “sickness” (2%) were stated less frequently (Kabadi et al., 2013).

In addition to the suggested analysis of determinants of non-registration, collaboration with continuous household survey operations could facilitate the cost-effective conduct of qualitative studies to understand low compliance with CRVS reporting and CRVS client satisfaction. These assessments provide countries and HDSS sites with interesting publishable joint research findings of high national value.

Figure 9. Percentage distribution of deaths registered by age in the HDSS Thailand (Prasartkul & Vapattanawong, 2006)

6. Comparing cause-specific mortality fractions between CRVS and HDSS/SAVVY

In settings where a reasonable proportion of deaths are registered by CRVS, it then becomes worthwhile to examine the cause fractions seen in the population. A comparative assessment of cause-specific mortality fractions (CSMFs) between HDSS/SAVVY sites and the CRVS system therefore provides another critical opportunity to demonstrate how these two systems could collaborate. 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 HDSS system). One of the main obstacles could be the small number of deaths registered in the CRVS system. In the Tanzanian study, for instance, only 2% of the deaths recorded in the HDSS were ever registered in the routine CRVS system (Kabadi et al., 2013), rendering the comparison of causes useless until completeness of death registration in CRVS reaches much higher levels.

In the above-mentioned study conducted in Western Kenya, agreement between the causes of death recorded in the CRVS and that noted in the HDSS system was weak. The CRVS system markedly under-reported malaria and pneumonia deaths, but over-reported deaths due to measles compared to the HDSS (which was based on VA estimates) (Arudo et al., 2003). The Agincourt study in South Africa likewise showed that CSMFs were significantly different in the CRVS and HDSS systems for all but four of the fifteen causes being investigated (Table) (Joubert et al., 2014).

Table 3. Agreement characteristics of civil registration and verbal autopsy diagnoses for the short list causes/cause groups: Agincourt HDSS, 2006–09 (Joubert et al., 2014)

Conditions	Total occurrences of the cause in CR system	On VA instrument				Cause-specific mortality fraction in CR data	Cause-specific mortality fraction in VA data	Per cent difference in cause-specific mortality fraction	95% CI
		Cause confirmed on VA instrument	Cause assigned to other causes in VA system	Received from other causes in VA system	Total occurrences of the cause in VA system				
1 Diarrhoea	365	20	345	49	69	17.1	3.2	−81	−85.2 to −75.9[a]
2 Tuberculosis	368	124	244	205	329	17.2	15.4	−11	−20.7 to 0.7
3 HIV disease	156	73	83	599	672	7.3	31.4	331	268.2 to 405.0[a]
4 Remaining infectious & parasitic disease	65	13	52	146	159	3.0	7.4	145	86.8 to 221.0[a]
5 Neoplasms	72	28	44	70	98	3.4	4.6	36	6.2 to 75.0[a]
6 Diabetes	45	15	30	21	36	2.1	1.7	−20	−43.8 to −13.3[a]
7 Meningitis	56	15	41	69	84	2.6	3.9	50	11.3 to 102.7[a]
8 Hypertensive disease	64	4	60	39	43	3.0	2.0	−33	−53.6 to −2.8[a]
9 Remaining heart disease	84	10	74	65	75	3.9	3.5	−11	−33.2 to 19.4
10 Cerebrovascular disease	111	34	77	65	99	5.2	4.6	−11	−28.7 to 14.2
11 Acute lower respiratory infections	293	21	272	93	114	13.7	5.3	−61	−68.3 to −52.3[a]
12 Other respiratory disease	72	4	68	11	15	3.4	0.7	−79	−87.7 to −65.0[a]
13 Symptoms & ill-defined conditions	79	4	75	64	68	3.7	3.2	−14	−37.1 to 17.8
14 External causes	123	96	27	47	143	5.8	6.7	16	2.4 to 32.6[a]
15 Remaining natural causes	184	35	149	98	133	8.6	6.2	−28	−40.7 to −12.0[a]
Total	2137	496	1641	1641	2137	100.0	100.0		

[a]The confidence interval indicates significant changes in the cause-specific mortality fractions ($P < 0.05$).

Additionally, using the WHO target causes 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 (Table) (Joubert et al., 2014). The study thus points to systematic biases in the CRVS cause of death data that need to be better explored and understood. However, it also highlights an opportunity to use HDSS data to facilitate adjustments in cause of death profiles with careful interpretation (Joubert et al., 2014).

Table 4. Ten leading causes of deaths from Verbal Autopsy (VA) and Civil Registration (CR), according to the WHO target cause list, Agincourt HDSS, 2006-09 (N=2,137) (Joubert et al., 2014)

Agincourt HDSS Verbal Autopsy (VA), according to WHO List			Civil Registration (CR), according to WHO List		
Rank	Ten leading causes	% of total	Rank	Ten leading causes	% of total
1	HIV disease	31.4	1	Respiratory tuberculosis	16.0
2	Respiratory tuberculosis	14.8	2	Diarrhoea/gastro, infectious	15.6
3	Pneumonia	5.2	3	Pneumonia	10.7
4	Cerebrovascular diseases	4.6	4	Cerebrovascular diseases	5.2
5	Septicaemia	4.5	5	Other blood & immune disorders	4.5
6	Meningitis	3.8	6	All other external causes	3.8
7	Diarrhoea/gastro, infectious	3.2	7	Other heart diseases	3.6
8	Other heart diseases	3.0	8	Hypertensive diseases	3.0
9	Symptoms & ill-defined	3.0	9	Other acute lower resp. infections	3.0
10	Transport accidents	2.4	10	Symptoms & ill-defined	2.7
Top 10 causes as % of total deaths		76.1	Top 10 causes as % of total deaths		68.0

7. Linking data between CRVS and HDSS/SAVVY for mortality cause concordance

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 (HDDSs, SAVVY) to collaborate with CRVS: comparing the HDSS information with the official records, event by event. We do recognise that this could be difficult, as the Agincourt HDSS study shows: of the 1,001 deaths recorded in the HDSS between 1992 and 1995, only 187 could be matched by name to hospital records (Kahn, Tollman, Garenne, & Gear, 2000). The Western Kenyan study could likewise only match fifty of 263 deaths recorded in the CRVS system with the 518 deaths recorded from active surveillance for all criteria (name, sex, residence, date of death) (Arudo et al., 2003). Furthermore, analysis of the fifty deaths captured by both systems showed no correlation in reported causes of death between passive and active surveillance, except for weak correlation for malaria death (Arudo et al., 2003).

However, more recent studies that aimed to link records from the two different systems have shown how record linkage could be facilitated (Joubert et al., 2014; Kabudula et al., 2014; Rentsch et al., 2018). For instance, using deterministic and probabilistic techniques with the Agincourt HDSS demonstrated that 61% of deaths within the HDSS could be individually matched to the CRVS (Joubert et al., 2014). This technique seems to be a feasible option for linking CRVS and HDSS data and could provide empirical evidence about the quality and utility of CRVS data (Joubert et al., 2014). As lessons learned, Joubert et al. reported that accurate place name reporting during death reporting, place name consistency across data sources, and alignment of study-site and official boundaries are essential for proper matching of CRVS and HDSS/SAVVY data (Joubert et al., 2014). The WHO has alternatively suggested the use of unique ID systems to enable record linkages between sample vital registration systems and available CRVS records (World Health Organization, 2014). Either option will, however, also raise ethical concerns due to the use of personal records; each therefore requires the establishment of a formal partnership between the two systems guaranteeing confidentiality (Joubert et al., 2014).

By comparing the causes of death recorded in both systems, the Agincourt HDSS study found cause agreement of 15%–23%, depending on which cause list the researchers used (Joubert et al., 2014). Using VA diagnoses as a reference, the study examined misclassification patterns for selected causes, sensitivity, and positive predictive value (Table , Table) (Joubert et al., 2014). Again, these results could be used to identify specific weaknesses in the CRVS system (or HDSS system).

With the increasing use of VA in CRVS systems, and the potential collaboration of HDSS/SAVVY 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.

Table 5. Misclassification pattern for the selected cause/cause group in the Agincourt HDSS study site, 2006-09 (Joubert et al., 2014)

	Civil Registration diagnoses	Verbal Autopsy diagnoses																	
		Diarrhoea	Tuberculosis	HIV disease	Remaining infectious & parasitic disease	Neoplasms	Diabetes	Meningitis & meningococcal infection	Hypertensive disease	Remaining heart disease	Cerebrovascular disease	Acute lower respiratory infections	Other respiratory disease	Symptoms & ill-defined conditions	External causes	Remaining natural causes	CR total	Positive predictive value %	95% Confidence Interval
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15			
1	Diarrhoea	20	47	163	23	16	3	10	3	7	10	21	3	10	8	21	365	5.5	3.4 to 8.3
2	Tuberculosis	4	124	139	21	9	2	9	1	7	4	15	0	11	11	11	368	33.7	28.9 to 38.8
3	HIV disease	2	36	73	6	4	0	9	2	1	3	8	0	1	2	9	156	46.8	38.8 to 54.9
4	Remaining infect. & parasitic disease	4	6	17	13	3	0	3	1	1	1	3	0	2	5	6	65	20.0	11.1 to 31.8
5	Neoplasms	1	4	10	10	28	0	0	0	4	3	1	0	3	1	7	72	38.9	27.6 to 51.1
6	Diabetes	3	4	4	2	1	15	0	1	2	7	1	1	1	0	3	45	33.3	20.0 to 49.0
7	Meningitis	2	4	21	4	0	2	15	1	2	1	0	1	1	0	2	56	26.8	15.8 to 40.3
8	Hypertensive disease	7	4	7	6	6	2	4	4	9	4	7	1	1	0	2	64	6.3	1.7 to 15.2
9	Remaining heart disease	4	10	18	7	4	3	0	4	10	8	6	0	4	1	5	84	11.9	5.9 to 20.8
10	Cerebrovascular disease	2	3	10	14	5	3	5	10	4	34	10	1	7	0	3	111	30.6	22.2 to 40.1
11	Acute lower respiratory infections	10	44	118	20	9	2	14	7	7	8	21	1	10	7	15	293	7.2	4.5 to 10.7
12	Other respiratory disease	0	6	31	6	1	1	2	4	1	4	3	4	1	2	6	72	5.6	1.5 to 13.6
13	Symptoms & ill-defined conditions	4	13	15	11	4	1	5	0	3	4	8	0	4	3	4	79	5.1	1.4 to 12.5
14	External causes	1	2	2	1	1	0	4	0	2	2	0	1	7	96	4	123	78.0	69.7 to 85.0
15	Remaining natural causes	5	22	44	15	7	2	4	5	15	6	10	2	5	7	35	184	19.0	13.6 to 25.4
	VA total	69	329	672	159	98	36	84	43	75	99	114	15	68	143	133	2137		
	Sensitivity %	29.0	37.7	10.9	8.2	28.6	41.7	17.9	9.3	13.3	34.3	18.4	26.7	5.9	67.1	26.3			
	95% CI lower level	18.7	32.4	8.6	4.4	19.9	25.5	10.4	2.6	6.6	25.1	11.8	7.8	1.6	58.8	19.1			
	95% CI upper level	41.2	43.2	13.5	13.6	38.6	59.2	27.7	22.1	23.2	44.6	26.8	55.1	14.4	74.8	34.7			

8. Sharing expertise and skills among CRVS and HDSS/SAVVY

The effective and continuous collaboration of CRVS and HDSS/SAVVY systems would provide an excellent platform for technical exchange and data sharing between the two systems. Connecting demographic and analytic expertise between the HDSS/SAVVY and CRVS communities will be mutually supportive, and should lead to greater confidence in CRVS data and its eventual use. This requires, however, the development of careful operating protocols to guarantee confidentiality of findings (e.g., develop joint protocols for data sharing) and to ensure good long-term working relationships between the sites, the CRVS authorities, and other stakeholders. 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.

HDSS/SAVVY sites could help to build CRVS systems by providing experience in vital event registration operational techniques (Ye et al., 2012). This could include capacity training on technical skills, such as data collection, management, quality control, archiving and retrieval, data analysis, evidence generation, and dissemination (Ye et al., 2012). HDSS/SAVVY experience with tablet-based VA could inform the integration of VA in routine CRVS systems. The culture of data use and evidence-based decision making from HDSS/SAVVY sites could likewise be transferred to the CRVS system by improving capacities in data dissemination and use at the national level (Ye et al., 2012). Furthermore, such collaboration could both facilitate the use of HDSS/SAVVY data at the national level and enhance networking among national experts who work on similar issues but who approach their work from different perspectives (Ye et al., 2012). 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 (SAVVY) or the whole country (Lopez et al., 2013). Here, HDSS/SAVVY staff members acted as master trainers of VA supervisors and interviewers as the VA intervention was extended nationally. Thus, there is great benefit in promoting the transfer of the enhanced skills developed in the HDSS/SAVVY sites to routine CRVS systems (Lopez et al., 2013).

Piloting CRVS interventions in HDSS/SAVVY sites. As CRVS system improvement interventions are developed and applied (e.g., new vital event notification methods or integrating VA methods), they could be first demonstrated and evaluated cost-effectively in the HDSS/SAVVY sites. Their effects thus would be best monitored from such sites. HDSS/SAVVY sites would also be ideal for cost-effective, head-to-head comparisons of VA methods so that INDEPTH HDSS sites have access to the latest experience of automated VA.

9. Ways forward

Thus far, this Guidance Document has provided practical guidance, illustrated with actual experiences, on a variety of ways in which population and health observatories and CRVS could collaborate. Consideration should also be given to the degree (and periodicity) of linkage between the two systems. If HDSS/SAVVY sites routinely implement VA, which then feed into the CRVS system, a comparison of CSMF (Section 6) and data linkage for mortality cause concordance (Section 7) becomes redundant. Also, if HDSS/SAVVY sites continuously deliver CRVS service (registration and certification of all deaths and birth), analyses as suggested in sections 4 to 7 would not be possible since the HDSS/SAVVY system would be evaluating its own performance rather than the CRVS as it runs elsewhere in the country.

A WHO technical meeting held in 2014 recommended that the SAVVY approach should be modified and implemented using the civil registration administrative structure as the sampling frame for the introduction of true sample vital registration—as opposed to enumeration—systems along with verbal autopsy to determine cause of death (World Health Organization, 2014). The meeting participants argued that such a system would have the strengths of SAVVY, in terms of active case finding and the application of verbal autopsy, while simultaneously providing the framework on which a functional CRVS system could be constructed and then gradually extended nationwide (World Health Organization, 2014). Again, such a system would lose the ability to evaluate the performance of the CRVS system as described in Sections 4 to 7.

So what are some of the steps that can be taken to bring the enterprises of CRVS and HDSS/SAVVY closer together?

1) **HDSS/SAVVY 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 (Justice, Interior, Local Government, Bureaux of Statistics, Health, etc.) who are concerned with CRVS. One of these ministries is always the health ministry. The health ministry in many low and middle-income countries chairs sub-committees of the CRVS steering committee that are devoted to births and deaths. It would be important that experts from the HDSS/SAVVY systems are represented on the National Mortality Sub-Committee or Mortality Surveillance Committee. This committee will play a major role in improving the quality of medically certified causes of deaths from hospitals, but are also in supporting and monitoring pilot and demonstration efforts to add automated verbal autopsy to CRVS (de Savigny et al., 2017). Obtaining membership on such committees is a key to all subsequent linkage projects described in this document.
2) **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 HDSS/SAVVY area simply by comparing dated events captured in both systems over a recent one year period. This will provide important feedback to the performance of CRVS in the frequently remote or underserved populations where HDSS and SAVVY usually work, and

will start to provide the personal collaborative connections between the systems as a working foundation. This will naturally lead to some ideas for annual supplementation of missed births and deaths back into the CRVS system, which will be seen as a positive support for CRVS (see Section 4).

3) **Adding context to completeness of CRVS births and deaths data**. Once it is possible to know who is missed out by CRVS, the HDSS/SAVVY is in an excellent position to characterize the individual determinants of non-registration (age, education, civil status, socio-economic status, etc.) since this information is already available in the HDSS/SAVVY data set for each individual. This again is highly valuable to the development of CRVS and provides young researchers in sites with important publishable research findings (see Section 5).
4) **Comparing and assessing 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. The easiest of these will be to compare cause-specific mortality fractions seen in CRVS with those seen in the HDSS/SAVVY (see Section 6). Likely there will be important differences given that the CRVS will be biased towards deaths that occur in health facilities, and be subject to idiosyncrasies of how physicians assign cause of death, particularly when causes may be associated with stigma. HDSS VA data will likely have a greater representation of deaths that occur in the community in the absence of physician attendance. Ideally these comparisons will benefit from and depend on careful mapping of ICD-10 codes for the underlying causes of death, both in the CRVS system, and in the HDSS VA target cause lists. Sharing and working with such data will be an important endeavour for the national mortality sub-committee and will lead hopefully to original thinking on how to combine analyses of facility and community deaths to better understand national patterns and trends. Once interest and trust develops with such comparative studies, joint teams could then go on to the more difficult tasks of data linkage to compare individual cause of death assignments in the two systems (see Section 7).
5) **Sharing and building 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. The most obvious opportunity is the sharing of verbal autopsy expertise from HDSS/SAVVY sites with CRVS implementations that are beginning to integrate VA as part of CRVS. Many CRVS systems are now embarking on significant re-engineering of processes and are exploiting new technologies. HDSS/SAVVY sites provide excellent proving grounds to evaluate new CRVS interventions (e.g. digital vital event notification systems) (See Section 8). Also mutual access across the community of demographers, epidemiologists, statisticians, information and communication technology developers, biometrics and identity specialists, and many other specialists, managers, and planners can only be beneficial, and lead to co-membership on important committees and fora that can shape the way forward.

10. Conclusion

Population and health observatories (HDDSs 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 (Hill et al., 2007). To maximize synergies of effort, it is important that population and health observatories do not function entirely separately from existing civil registration systems (Lopez et al., 2013). Such HDSS and SAVVY 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.

This report provides practical, step-wise, illustrated guidance for how population and health observatories and CRVS can collaborate. It shows how systems like HDSS and SAVVY can augment the CRVS system and contribute to the long-term goal of generating timely and high quality vital statistics derived from civil registration with high coverage and reliable causes of death (MEASURE Evaluation & International Programs Center, 2007). 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. Therefore, population and health observatories should be seen as stepping stones to better vital event monitoring and a fully functioning, high performance CRVS in low- and middle-income countries (Health Metrics Network, 2008; MEASURE Evaluation & International Programs Center, 2007; Ye et al., 2012).

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