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Fellowship report: Introducing routine verbal autopsy as part of the CRVS system in Rwanda

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Acronyms and abbreviations

CD	communicable disease
CRVS	civil registration and vital statistics
GBD	global burden of disease
HMIS	Rwanda Health Management Information System
ICD-10	10th revision of the International Statistical Classification of Diseases and Related Health Problems
MCCOD	medical certification of cause of death
MOH	Ministry of Health
NCD	noncommunicable disease
NISR	National Institute of Statistics of Rwanda
RBC	Rwanda Biomedical Center
RDHS	Rwanda Demographic and Health Survey
VA	verbal autopsy
WHO	World Health Organization

Summary

Background

Vital statistics on mortality data and cause of death (COD) are a cornerstone for gathering evidence-based information to guide policy, planning, resource allocation, program implementation, monitoring and evaluation. These data should be collected and disseminated by an effective civil registration and vital statistics (CRVS) program. Rwanda has a shortage of medical doctors to certify all deaths, and most deaths occur outside health facilities and are invisible in official records. Most deaths are therefore neither notified nor registered and are not counted by the Rwandan CRVS system. Verbal autopsy (VA) has become a primary source of information about CODs in countries lacking effective death registration and medical certification.

In 2017, Rwanda introduced a new cadre of health professionals, home-based care practitioners (HBCPs), whose tasks include the provision of care and support at the community level, with a focus on the prevention, screening and follow-up of patients with chronic (non-communicable) conditions and the provision of palliative and end-of-life care. As part of their responsibilities, the HBCPs have been trained to implement VA, a method designed to determine probable COD when deaths occur outside of medical facilities and in the absence of trained physicians able to complete a medical certificate of COD.

Study and report

The pilot phase was implemented in a sample of 100 cells (4.6 per cent of the total population of Rwanda). We conducted a quality assessment of the implementation of this phase, including:

- The impact of VA on overall HBCP workload
- Community acceptability of VA
- The effects on number of deaths notified and registered
- The plausibility of CODs from VA in comparison with other mortality datasets, including the Rwandan Health Management Information System (HMIS) and Global Burden of Disease (GBD) estimates.

Lessons learnt from these initial stages will be vital as Rwanda considers the next stage of roll out of the HBCP program and CRVS strategy.

The first part of this report describes the effects on the CRVS system of the introduction of new notification procedures and VA. It provides details of the population from the pilot region and changes observed in death notification and registration after the introduction of VAs. It also explores key challenges and the way forward.

The second part analyses the preliminary VA data and compares them with other sources of mortality data to assess plausibility and provides some interpretation and key considerations for the subsequent phases.

Findings

This evaluation found that HBCP-led VAs have been well accepted by the population of Rwanda. The program contributed to dramatic improvement in the CRVS system, with an increase in death notification and some improvement in death registration. VAs contributed to a threefold increase in the overall death notification in 2017 compared with death notification before VA (in 2016). Importantly, community deaths – which seem to be invisible in official records before the introduction of VA – were identified, notified and VAs were conducted to assign probable COD.

VAs produced plausible CODs consistent with HMIS data and GBD estimates. Differences mainly related to the different sources of data used by VA and comparators. The low numbers of children and neonates in the sample size hampered effective comparison or interpretation.

Recommendations

Overall, our study shows that the introduction of VA in Rwanda has achieved its goals. It also shows that the system could be improved and strengthened in several ways. Our key recommendations are that:

- The supervision, mentorship, monitoring and evaluation of the HBCP program should be improved (eg the status of completeness of death notification and plan for improvement should be included in monthly coordination meetings between HBCPs and managers).
- Collaboration mechanisms should be built between HBCPs and community health workers to share information on deaths occurring in their communities.
- Collaboration mechanisms between different sectors involved in registration – including local administration, the National Institute of Statistics of Rwanda and the health sector – should be improved.
- All potential barriers to registration should be studies to help plan evidence-based interventions to address those challenges.
- The development of a one-stop integrated system combining notifications and registration should be considered.
- The Ministry of Health and Rwanda Biomedical Center should review the classification of diseases and age categories to align them to International Classification of Diseases (ICD-10) standards.
- Other sources of information (eg HMIS and maternal death audits) should be used to complement VA data.
- The use of death registers and mandatory burial permits should be enforced.
- Further studies on larger sample sizes should be conducted to explore some of the findings of this study, including the CODs of children and the high 'undetermined' COD rate.

The findings also highlighted some key concerns relevant to health planning. Noncommunicable diseases (NCDs) are a growing concern, and the Government of Rwanda may need to improve efforts to control and reverse the burden of NCDs. At the same time, Communicable diseases (CDs) continue to be a threat to Rwandans, and CD prevention and control efforts must not be relaxed.

The Rwandan Government, partners, stakeholders and other countries can learn from the achievements of the pilot phase of the HBCP-led VA program to inform further implementation of the program and improvement of CRVS systems.

Fellowship report: Introducing routine verbal autopsy as part of the CRVS system in Rwanda

Introduction

Background

Reliable data on the number and distribution of deaths and cause of death (COD) are essential to understand the epidemiological profile of the population and to build a solid evidence base for health policy, planning, monitoring and evaluation. The most effective way of generating such data is through a functional civil registration and vital statistics (CRVS) system that registers all deaths and collects age, sex, location and COD information. Death is registered through medical certification by a physician, in alignment with World Health Organization (WHO) standards and the International Classification of Diseases (ICD-10).

Death registration is low, and few records have accurate information on cause of death.

Strengthening the CRVS system is among the priorities of the *Rwanda National Strategic Plan*, the *Economic Development, Poverty Reduction Strategy 2013–18*, and the Rwandan Vision 2020 program. However, a recent comprehensive assessment of the Rwandan CRVS system, conducted within the framework of the Africa Program on Accelerated Improvement of Civil Registration and Vital Statistics, found that death registration is low and that few death records have accurate information on COD. Most deaths occur at home and are neither registered nor associated with a medically determined COD. As a result, the Government of Rwanda does not have reliable information upon which to base health policy and planning.

Home-based care practitioners

In 2017, Rwanda introduced a new cadre of health professionals, home-based care practitioners (HBCPs), whose tasks include provision of care and support at the community level, with a focus on the prevention of, and screening for, chronic conditions and the provision of palliative and end-of-life care. The HBCP program aims to strengthen the country's response to the growing burden of noncommunicable disease (NCD) through prevention and follow up.

The home-based care practitioner program was developed to help address the growing burden from chronic diseases.

The program also aims to strengthen the CRVS system. As part of their responsibilities, the HBCPs have been trained to implement verbal autopsies (VA), a method designed to determine probable COD when deaths occur outside of medical facilities and in the absence of trained physicians able to complete a medical certificate of COD. This represents a highly innovative approach, because VA has hitherto been used mainly in research and demographic surveillance settings. Lessons learnt from these initial stages will be vital as Rwanda considers the next stage of roll out of the HBCP program and the CRVS strategy.

The HBCP program has been created through a collaboration between the Ministry of Health (MOH), Rwanda Biomedical Centre (RBC), National Institute of Statistics (NISR) and the Ministry of Education. The program also creates new jobs for youth to meet the aims of the Workforce Development Authority within the Ministry of Education: almost 4300 jobs will be created once the program is rolled out countrywide.

HBCPs are also involved in conducting verbal autopsies.

The pilot phase of the HBCP program was implemented in July 2017. In this phase, 206 HBCPs were employed in 100 cells from 40 health centres in the catchment areas of nine hospitals. Each cell has two HBCPs (a man and a woman), each with at least a basic secondary school education (A level). They receive intensive training in NCDs, palliative care and VA through technical vocational education and training.

Methods

Study objective

The objective of this study is to review, document and assess the initial phase of implementation of the HBCP-led VA. The three main components of the study are:

- Documenting and assessing routine VA implementation, including the impact on HBCP workloads, HBCP impressions of community perception of VA, costs, and potential for sustainability and scalability
- Documenting changes in numbers of deaths notified and registered following VA implementation
- Reviewing the plausibility of COD data from VA, and comparing the data with other sources of cause-specific mortality data such as the Rwanda Demographic and Health Survey (RDHS) and Health Management Information System (HMIS).

This report focuses on the second and third objectives.

The study aims to generate valuable lessons on the routine implementation of VA and to inform MOH/RBC, NISR and other stakeholders on the sustainability and scalability of the program.

Study design

This evaluation used a combination of quantitative and qualitative methods.

The quantitative analysis concerned death notification and registration and COD plausibility. This analysis used data from the CRVS database for comprehensive information on death notification and registration, and RDHS and HMIS data for complementary and comparative information on COD plausibility.

The qualitative assessment concerned the perceptions and experiences of the personnel engaged in the HBCP-led VA system in Rwanda. This analysis used data from interviews with HBCP personnel.

Study setting

This study was conducted in the five Rwandan hospitals that have HBCPs: Muhima, Ruhengeri, Kabutare, Rwamagana and Kibuye. The hospitals have been geographically stratified to provide representative samples countrywide. Each province was represented by one hospital.

The pilot phase was introduced in 100 of the 2148 cells of Rwanda. A 'cell' is an administrative structure of Rwanda, ranked second after the village.[1] According to the 2012 Census, the 100 cells involved in the pilot phase have a total population of 486 564. Assuming a two per cent growth rate, this population is projected to be 554 113 in 2017. This region represents five per cent of the total population of Rwanda.

1 National Institute of Statistics of Rwanda. Statistical Yearbook 2017. Available at: http://www.statistics.gov.rw/statistical-publications/subjects (accessed 4 March 2019).

Data variables

To assess the changes in numbers of deaths notified and registered following VA implementation, the study examined:

- Deaths notified and registered before VA implementation
- Deaths notified and registered after VA implementation
- Differences between HBCP-led VA regions and zones without HBCPs.

To review the plausibility of COD data emanating from VA implementation and compare it with other sources of cause-specific mortality data such as RDHS and HMIS, the study examined:

- The distribution of CODs from the VA database
- The distributions of CODs from different databases (CRVS, RDHS, HMIS)
- Differences between the distribution of CODs from VA and from other databases.

Data analysis

The data were analysed using Excel. The first step in data analysis was descriptive analyses, including frequencies, percentages and means for categorical data, and medians with interquartile ranges for continuous data. We analysed the numbers of deaths notified and registered before and after VA implementation, and used a sample t test to compare trends before and after VA implementation.

Limitations

Data may be incomplete in some areas. For example, registry offices at the sector level may not collect complete information for death registration, or the HMIS may have incomplete data because of poor reporting in the health system.

Also, the outcomes for number of deaths registered may be less than expected because the study has been conducted only six months after HBCP program implementation. However, we believe that the system will continue to improve, and a further study after a longer time frame should provide further positive results.

Ethics considerations

Ethics approval from relevant bodies

This study was conducted with RBC and NISR internal review and approval as part of HBCP program implementation, monitoring and evaluation.

Data confidentiality

Data from the RDHS, CRVS and HMIS did not bear any patient identifiers. Data were kept in a password-controlled file and only members of the study team were involved in data collection. For focus group discussion and interviews with key informants, groups were given IDs and no names of participants appeared anywhere. HBCP participation in the study was voluntary.

Dissemination of results

The fellowship findings and conclusions will be disseminated to partners and stakeholders of the CRVS system, MOH, RBC and NISR. Lessons learnt will also be shared through consultative meetings with high authorities, planners and policymakers, including the Ministry of Local Government's Ministry of Justice, National Identity Agency, Rwanda Law Reform Commission, and other partners and stakeholders.

Part I: Documenting the impact of verbal autopsy on death notification and registration completeness

Background

Estimated levels of mortality

Of the almost 77 000 deaths in Rwanda in 2017, just over 13 000 were registered.

In 2017, Rwanda had an estimated population of 11 839 420 people and a crude death rate of 6.5 deaths per 1000 population per year.[2] This indicates that the number of deaths expected in 2017 was 76 956. However, the data from CRVS show that most deaths are neither notified nor registered. In 2017, only 9173 deaths were notified and only 13 277 deaths were registered (Table 1). This shows that Rwanda lacks information on deaths and their causes. Such information is needed for planning, resource allocation, and monitoring and evaluation of public health and socioeconomic interventions aimed at reducing premature and preventable death and improving the quality of life of Rwandans.

Data from the HMIS show that only 13 320 deaths were reported in 2017, suggesting that most deaths occur in the community. This compounds the lack of data arising from underreporting of deaths occurring in health facilities.

Table 1 Estimated level of completeness of mortality data by source, 2017

Measures	CRVS death notifications	CRVS death registrations	HMIS data
Observed deaths	9 173	13 277	13 320
Derived crude death rate (per 1000 population per year)*	0.80	1.12	1.13
Completeness (%)	12.0	17.0	17.0

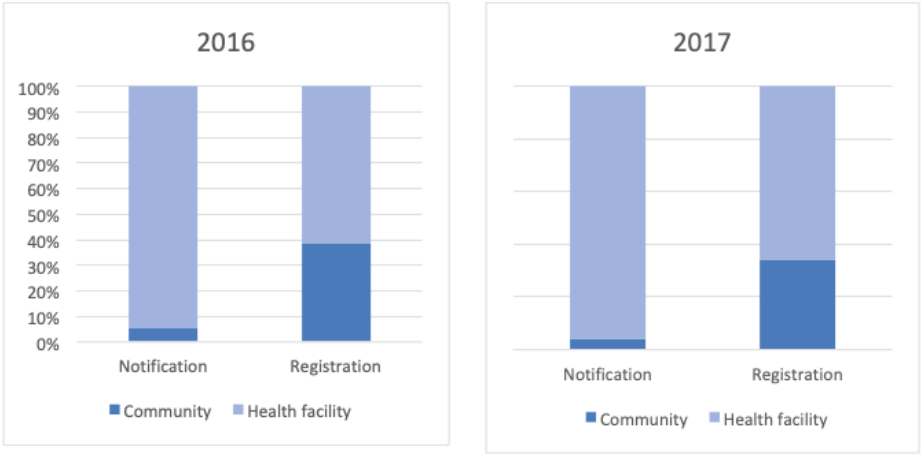
CRVS = civil registration and vital statistics; HMIS = health management information system
*Calculated based on a population of 11 839 420 and the number of observed deaths

Death notification and registration system

Before the introduction of the HBCP program, death notifications were only done by data managers from health facilities. Although most deaths occur in communities, 96 per cent of the deaths notified in 2017 occurred in health facilities – where data managers are based (Figure 1). The CRVS system captured some of the deaths occurring in the community, but the proportion is still below the number of deaths expected to be registered.

2 National Institute of Statistics of Rwanda. Population Projections. Available at: http://www.statistics.gov.rw/publication/rphc4-population-projections (accessed 4 March 2019).

Figure 1 Deaths notified and registered by place of death, 2016–17



Verbal autopsy implementation results

Number of deaths notified before and after verbal autopsy implementation

Before implementation of VA in 2016, the number of deaths notified in the 100 cells was 535, including 528 deaths occurring in health facilities and 7 occurring at home (Table 2). After VA implementation, notifications of community deaths increased from 7 to 897 (including 894 notified by HBCPs), or from around 1 per cent to 55 per cent of total deaths notified.

Table 2 Death notifications by place of death, 2016–17

Measures	2016	2017
Estimated population	539 892	554 113
Expected number of deaths*	3 509	3 602
Total number of death notifications	535	1 634
- Health facilities (%)	*528* *(98.7)*	*737* *(45.1)*
- Community (%)	*7* *(1.3)*	*897* *(54.9)*
Calculated crude death rate (per 1000 population)	1.0	2.9
Proportion of expected deaths notified (%)	15.0	45.0
Deaths notified by HBCP	0	894
Number of VAs conducted	0	780

HBCP = home-based care practitioner; VA = verbal autopsy
*Based on a crude death rate of 6.5 per 1000 population per year

VA contributed to an overall increase in notifications from 535 in 2016 to 1634 in 2017. This indicates that scaling up the VA program will help the country as a whole increase the number of death notifications. The proportion of expected deaths captured in death notifications also increased, from 15% in 2016 to 45% in 2017. The reported crude death rate increased from 1.0 to 2.9 deaths per 1000 population per year.

Number of deaths registered before and after verbal autopsy implementation

Following the introduction of the VA program, the national number of registered deaths also increased (Table 3).

This could be related to the fact that, as part of their responsibility for death notifications, HBCPs promote the benefits of registration by educating family members. Before VA implementation, the total number of deaths registered in 2016 in the 100 cells was 462. After VA implementation, deaths registered increased by 13 per cent, from 462 to 523. VA contributed to an increase of community deaths registered, from 210 in 2016 to 275 in 2017. The proportion of all community deaths registered also improved, from 45% in 2016 to 53% in 2017.

Table 3 Deaths registered by place of death, 2016–17

Registered deaths	2016	2017
Occurred in the community (%)	210 (45.0)	275 (53.0)
Occurred in a health facility	252	248
Total number of registrations	462	532

Conclusions

The introduction of VA seems to have increased the number of community deaths notified, and increased the number of registered deaths overall.

The introduction of VA in 100 cells dramatically increased the number of community deaths notified and increased the number of deaths notified overall. This is good news for the Government of Rwanda in planning the roll out of the VA program.

Although the data are promising, gaps remain. This could be related to difficulties in implementing the new program, or inaccuracies in estimations of the number of expected deaths. This was addressed by the introduction of medical certification of cause of death (MCCOD) at the end of 2017, introduction and distribution of death registries to be completed by local administrators at the cell level, and enforcement of mandatory burial permits. These strategies, in addition to strengthening the monitoring and evaluation of the HBCP program, will improve notifications in the future.

To further strengthen the program, we recommend that:

- The use of death registers and mandatory burial permits is enforced
- The supervision, mentorship, monitoring and evaluation of the HBCPs program are improved
- Reports on the status of completeness of death notification and plans for improvement are included in monthly coordination meetings between HBCPs and managers
- Collaboration mechanisms are built between HBCPs and community health workers to share information on deaths occurring in their communities.

Death notifications were dramatically improved after VA implementation, but increases in death registration were small. Although HBCPs can provide family education about death registration, they are some barriers to making registration more effective and complete that are beyond their control.

The main barrier is that notification and registration are done in different places: notification is done at health facilities or in the community by HBCPs, whereas registration is done at the administrative sector. Interviews with HBCPs showed that some families were reluctant to make another trip for registration unless they felt any direct benefit. Our recommendations include:

- A study of all barriers to registration should be made to help plan evidence-based interventions to address those challenges.
- Collaboration mechanisms between different sectors involved in registration – including local administration, NISR and the health sector – should be improved. For example, the civil registry officer could work in close collaboration with HBCPs and the data manager at the health-facility level to improve linkages between the community and registration office.
- A one-stop integrated system combining notifications and registration should be considered.

Part II: Assessing the plausibility of cause of death determined through verbal autopsy

Background

Cause of death data collected through a VA is less detailed than data collected through medical certification.

Why verbal autopsy data are different from other mortality data

VA data aims to understand the causes of out-of-facility deaths. It complements COD information from hospital deaths to provide better information on CODs of the whole population. However, VA COD data are different from COD data from hospitals gathered using MCCOD.

MCCOD will provide a detailed and legally recognised COD. The process involves a doctor and patient relationship and often diagnostic tests that allow more certainty and precision about the COD. Physicians can assign one of the thousands of causes available in the ICD-10 classification of COD.

For VA data, information on signs and symptoms of the deceased person before death is collected from a third party (a family member or caregiver) who may or may not be aware of all the relevant symptoms. The data usually do not include information from diagnostic tests. A computer algorithm uses VA information to come up with a 'probable' COD.

Limitations of verbal autopsy data and cautions for interpretation

Because the information available from VA is less detailed, the causes assigned will be limited to the main CODs of public health importance (see Appendix 1). They will also be less specific (eg stroke, not specified as ischaemic or haemorrhagic). Since VA can only assign COD for a limited number of causes, there will be a number of residual categories ('other NCDs', 'other cancers' etc) that will make up the other causes.

The primary purpose of VA is to provide the cause-specific mortality fraction, which is the fraction of the population dying from particular causes. Given the limitations of VA data, VA COD should not be directly compared with COD from hospital deaths. Patterns of disease should be compared between datasets to assess their plausibility. In general, VA data can provide information on broad disease patterns in the community, and hospital data from MCCODs can provide more detail within these categories.

Undetermined deaths and redistribution algorithm

Some deaths will not be able to have a cause assigned; these are referred to as 'undetermined'.

There will always be some deaths for which a cause cannot be assigned because of multiple competing symptoms or lack of information. VA data are particular susceptible to this because of the methodology (collecting signs and symptoms of the deceased from family members), which may fail to collect critical information for diagnosis. This method is also highly dependent on the quality of the interview, which may be affected by poor interviewer skill or reluctance on the part of the respondent to provide open and honest answers.

This can lead to a significant proportion of VA interviews being assigned an 'undetermined' COD. It is expected that around 10 per cent of CODs will be undetermined, particularly for deaths of older people, so a higher proportion than this may indicate a problem with the training, questionnaire translation or acceptability of the methods to the population.

To address the issue of 'undetermined' CODs, the SmartVA Analyze software uses a redistribution algorithm. First, the software looks at the current distribution of deaths from the VA sample and redistributes on that basis. Second, it will also partly redistribute based on the current Global Burden of Disease (GBD) estimates for the country.[3] In this study, comparisons with other data sources have used the cause-specific mortality fraction, which includes redistribution of 'undetermined' deaths.

Characteristics of verbal autopsy data in the pilot region

Deaths by verbal autopsy age group

In the VA pilot phase, 788 VAs were collected between July 2017 and January 2018. Adult deaths were common (80% of total deaths in this population) whereas neonatal deaths were infrequent (2% of all deaths) (Table 4).

The ratio male to female deaths was around 1 in all age groups, with a slightly higher death rate in males. This is consistent with GBD estimates.

Table 4 Number of verbal autopsies conducted, by age group and gender

Age group	Number of VAs conducted			Sex ratio (male/ female)
	Female	Male	Total (%)	
Adult (12+ years)	302	326	628 (79.7)	1.08
Child (29 days – 11 years)	70	72	142 (18.0)	1.03
Neonate (0–28 days)	9	9	18 (2.3)	1.00
Total	381	407	788 (100.0)	1.07

VA = verbal autopsy

Health facilities data show that neonatal deaths represent 29 per cent of all deaths occurring in health facilities. Rwanda has a high rate of facility-assisted births (97% of all births nationwide),[4] which could explain why most neonatal deaths occur in health facilities. In comparison, GBD estimates show that neonatal deaths represent 10 per cent of all deaths.

VA is a better source than the HMIS for data on deaths occurring in the community for adults and children aged over 28 days.

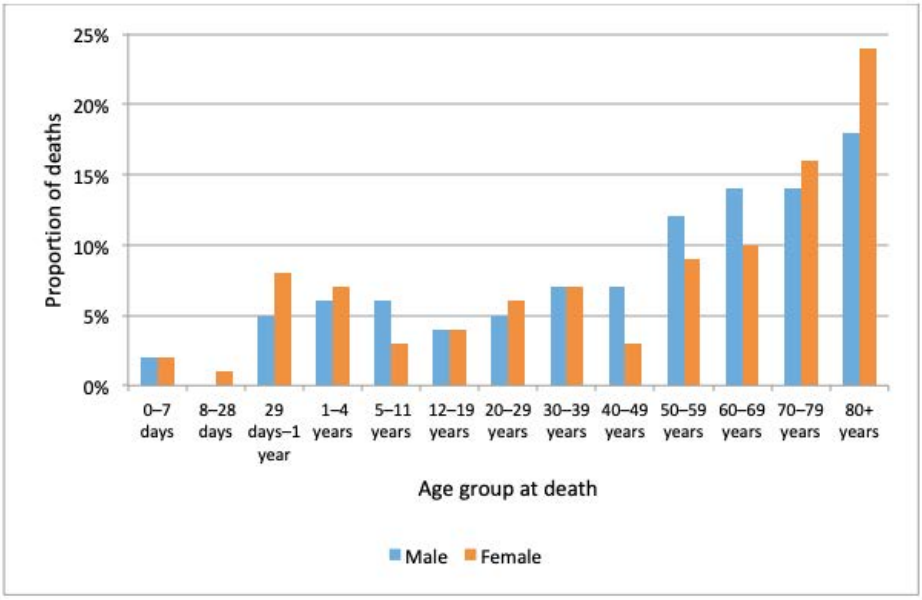
Deaths by age group and sex

In this population, many deaths occur at advanced ages (80+ years) (Figure 2). This is partly because the Government of Rwanda has successfully reduced premature deaths, and so people are living longer and dying at a late age. Generally, females live longer and die somewhat later than males. This is consistent with GBD estimates, which show that 14 per cent of female deaths occur after 80 years of age whereas for males it is 10 per cent.

3 The global burden of disease is an ongoing initiative that collects and collates information from a variety of sources to come up with best estimates for a variety of measures including causes of death. Available at: www.healthdata.org/gbd (accessed 17 December 2018).

4 Ministry of Health, *Annual health statistics booklet 2016*. Available at: www.moh.gov.rw/fileadmin/user_upload/HMIS/2016_Annual_Statistical_booklets_V9_08_03_2018.pdf (accessed 17 December 2018).

Figure 2 Verbal autopsies conducted by age group and sex, 2017–18



Comparison of verbal autopsy results to global burden of disease

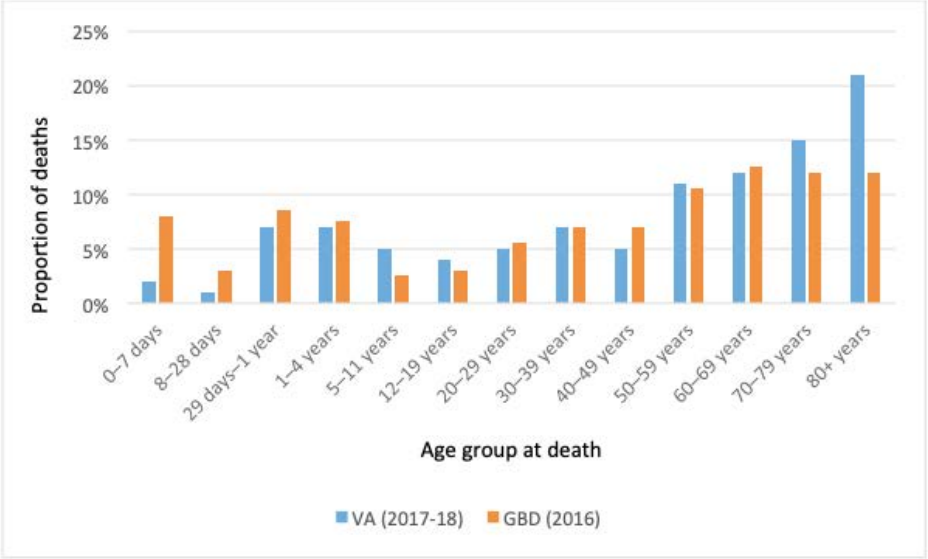
VA data is more likely to include deaths at much older ages.

For both sexes, GBD data show comparatively more deaths at very young ages (neonate and children aged under 5 years) whereas VA data show comparatively more deaths at much older ages (from 70+ years, but most pronounced in the 80+ category) (Figure 3).

The variation in age of death between GBD estimates and VA data is related to the different sources of data (community deaths only versus community and hospital deaths), and could be related to four factors:

- Elderly people probably consult health facilities less often than young people, which leads to a higher proportion of deaths in homes for older people.
- Older adults have a higher proportion of chronic conditions than young people, which could lead to more deaths in the community for older people.
- Young people use more modern medicines than older people, which leads to a higher proportion of deaths in health facilities for younger people.
- Community health workers manage illnesses in children, ensuring timely referrals and fewer deaths in the community for young people.

Figure 3 Comparison of age at death from VA and GBD data



GBD = global burden of disease; VA = verbal autopsy

Both VA and GBD data show that within the neonatal age category there is a high proportion of early neonatal death (0–7 days) compared with late neonatal death (8–28 days); 2 per cent versus 1 per cent (VA data) and 8 per cent versus 2 per cent (GBD data). The MOH could investigate the reasons behind the high mortalities in earlier neonates – especially looking at the quality of antenatal care services, maternity environment, neonatal and postnatal care services – and plan appropriate interventions to address the gaps identified.

It would be interesting to compare the age distribution of deaths in facilities with the VA data to see how they differ. However, HMIS data do not provide detailed age subcategorisations. A lack of standard age categories in data makes it difficult to assess trends in death and inform disease prevention and control.

Cause-specific mortality: adults

Adult deaths by broad disease group

The GBD study groups adult deaths into three broad disease groups (Figure 4). Grouping the VA data in this way and comparing them with the GBD estimates can act as an initial check for the plausibility of the data, especially when there are few data available.

The VA data show that NCDs are the most common COD, with more deaths than the other GBD disease categories combined (Figure 5). These data are consistent with GBD estimates. This suggests that VA can provide useful data for countries with low rates of medically certified death and poor notification and registration systems.

Figure 4 Distribution of adult deaths by broad GBD category from GBD estimates, 2016

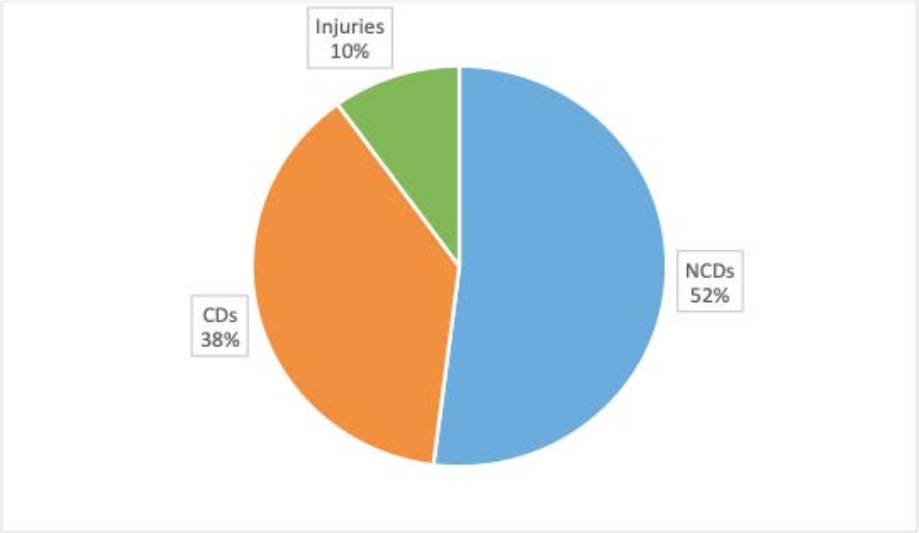
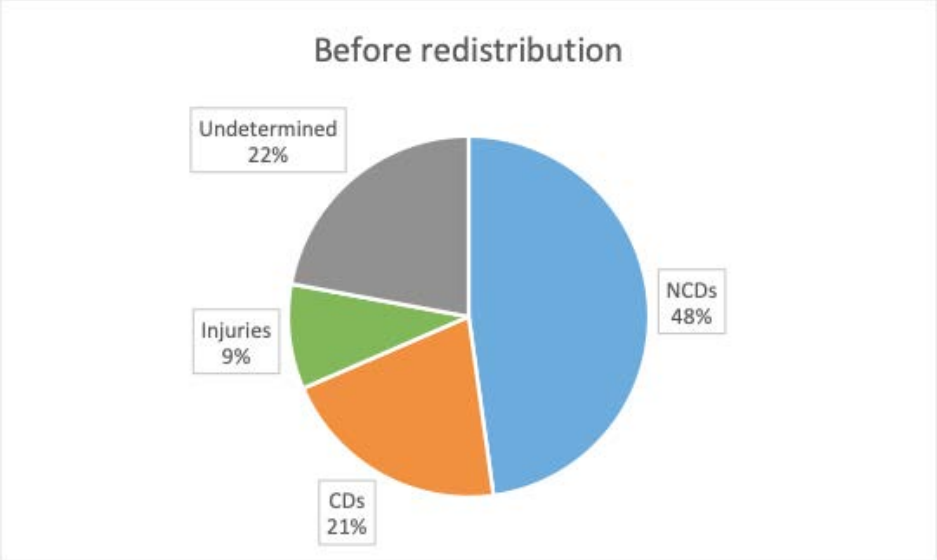
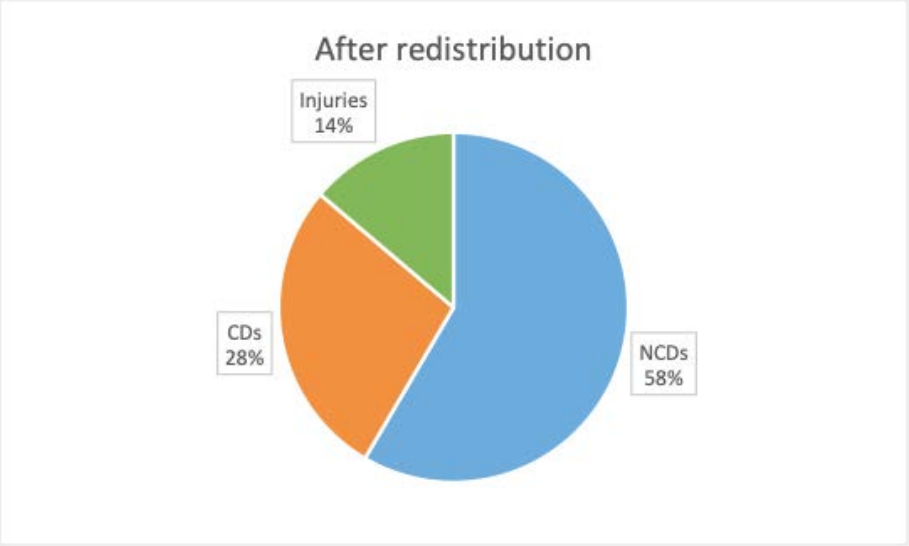


Figure 5 Distribution of adult deaths by broad GBD category from VA data, before and after redistribution, 2017/18





Sample size = 628
CDs = communicable diseases; GBD = global burden of disease; NCDs = noncommunicable diseases; VA = verbal autopsy

HMIS data show that NCDs account for around 35 per cent of all deaths occurring in health facilities. The high burden of NCDs compared with other diseases may be because of the efforts Rwanda has made to reduce the burden of communicable diseases (CDs), especially in children younger than 5 years. Economic growth and the subsequent adoption of unhealthy lifestyles by many people exposes more people to NCDs.

Both GBD estimates and VA data show a higher burden of NCDs compared with HMIS health-facility data because they consider deaths in the community. There may be several reasons for the higher rates of NCDs in the community.

People with NCDs may be more likely to die in the community compared with patients with other conditions. People with acute illnesses immediately consult health facilities for treatment, whereas patients with NCDs may tolerate the disease for many years without treatment.

VA data showed higher rates of deaths related to NCDs than data provided from the hospitals.

The higher rates of NCDs in the community could also show that, although Rwanda has made significant efforts to fight CDs, the capacity to diagnose and manage NCDs may have not improved at the same speed. Therefore, some people with NCDs may go undiagnosed and die from NCDs in community before they reach health facilities. For example, previous studies have shown that half of the patients with diabetes are undiagnosed.

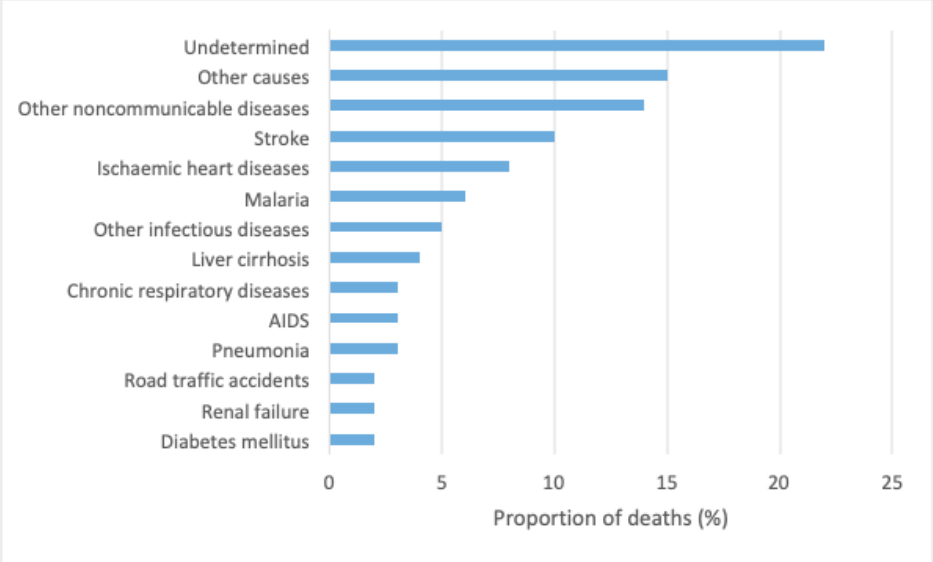
These findings suggest that the Rwandan Government should consider NCDs as a public health concern and improve efforts to control and reverse the growing burden of NCDs. This could be achieved through prioritisation of NCDs in planning and budget allocation. These plans should aim to:

- Improve health system capacity in NCD screening, early diagnosis and management
- Maximise the awareness of the general population of the prevention and early detection of NCDs
- Roll out the HBCP program nationally to help people in need of palliative care at home.

Adult deaths by cause of death

VAs assigned 22 per cent of CODs for adults as 'undetermined', and the next two categories of death were nonspecific ('other causes' and 'other noncommunicable diseases') (Figure 6). These designations provide only limited information on the mortality profile in Rwanda.

Figure 6 Leading causes of adult deaths from verbal autopsy data



VA data was consistent with GBD estimates for leading causes of death.

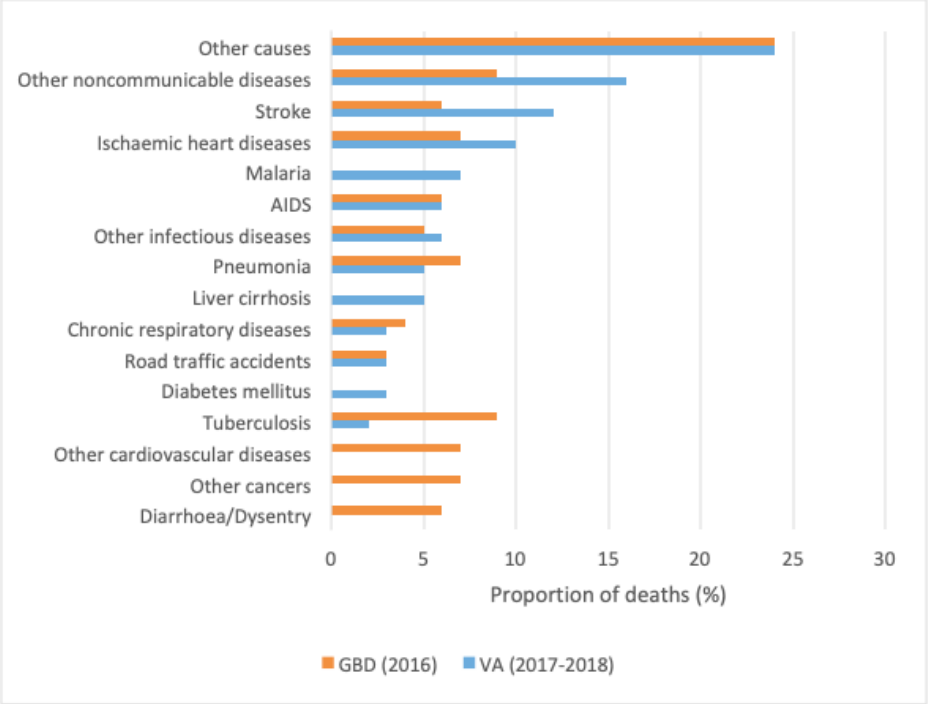
After redistributing these undetermined CODs, the leading CODs from VA data were compared with HMIS health-facility data and GBD estimates for Rwanda (Figure 7). VA data are consistent with GBD estimates in almost all of the top 10 CODs, suggesting that VA data provide reliable estimates of frequencies of CODs for deaths occurring in communities and so complement notifications from deaths occurring in hospital.

Stroke, malaria and ischaemic heart disease are the top three leading CODs in VA data, whereas for GBD estimates the top three are tuberculosis, pneumonia and ischaemic heart disease.

The ranking of CODs between VA and GBD estimates may differ because VA assesses only community deaths whereas GBD estimates incorporate both health facility and community deaths. In addition, the age distribution of VA deaths is older than that of the GBD estimates. Since older people more often of NCDs, this may account for some of the differences in the frequencies of the top causes.

The sample of 100 cells may also not be representative of the general population. Therefore, it is difficult to generalise these findings to all community deaths occurring in Rwanda at this pilot stage of the VA implementation.

Figure 7 Comparison of leading causes of adult deaths from VA data and GBD estimates



GBD = global burden of disease; VA = verbal autopsy

HMIS health facilities data show that pneumonias (combining acute respiratory infections and pneumopathies) are the top cause of hospital deaths (excluding neonates) (Table 5). However, pneumonia is also a concern in community deaths, as it is ranked 5th in VA data.

Table 5 Leading causes of death in health centres and district, provincial and referral hospitals, 2016 (all age groups excluding neonates)

Cause of death	Deaths	
	Number	%
Neonatal illness	2 094	16.2
Acute respiratory infection	1 351	10.5
Cardiovascular disease	921	7.1
Pneumopathies	560	4.3
Physical trauma and fractures	491	3.8
Asthma	366	2.8
HIV/AIDS opportunistic infections	354	2.7
Obstetrical problems	352	2.7
Diabetes	314	2.4
Congenital anomalies	294	2.3
Other listed diseases	5 807	45.0
Total	**12 904**	**99.8**

Tuberculosis was ranked 1st in GBD COD estimates, only 8th in VA data, and does not appear in HMIS data. There is strong support for tuberculosis control in Rwanda,[5] which may have dramatically reduced deaths from this cause compared with GBD estimates. The high antiretroviral therapy (ART) coverage in people with HIV/AIDS (83 per cent of estimated people with HIV in Rwanda are on ART drugs)[6] may also minimise the risk of tuberculosis as an opportunistic infection among people with HIV/AIDS.[7] More investigations are needed in this area to ascertain the real picture.

Deaths from diabetes, cirrhosis and malaria were ranked high in the VA data.

Deaths from diabetes, cirrhosis and malaria were ranked among the highest in VA data, but not in GBD estimates. This could be because diabetes and cirrhosis are more likely to occur in the community than in health facilities and thus become among the leading CODs in community. VA data are consistent with HMIS health-facility data, which ranks diabetes among the top CODs. However, cirrhosis and renal failure are only ranked in the top 15 CODs in HMIS data. The MOH has recognised that these causes are underreported and expect that, with improving diagnosis and reporting mechanisms, they will come higher on the list of the most common CODs.

Malaria was ranked 3rd in VA CODs, but does not appear in the top 10 CODs in GBD estimates or HMIS data. The VA result is surprising, given that Rwanda has made significant efforts to combat malaria, including increasing the capacity of health systems in malaria management, and training community health workers to diagnose and treat this condition and make timely referrals. However, the changes in the WHO malaria protocol[8] used in Rwanda mean that deaths in hospitals are only confirmed as malarial if they are confirmed by parasitological assessment. This could lead to underestimates of the number of malaria deaths reported in HMIS. It should be noted that malaria is still the 1st cause of hospitalisation in health facilities. More investigations are needed in this area.

5 Gasana et al. Tuberculosis in Rwanda: challenges to reaching the targets. Bulletin of the World Health Organization. 2007;85(5):383-384.

6 Ministry of Health. Annual health statistics booklet 2016. Available at: https://moh.gov.rw/index.php?id=390 (accessed 17 December 2018).

7 Elul et al. High levels of adherence and viral suppression in a nationally representative sample of HIV-infected adults on antiretroviral therapy for 6, 12 and 18 months in Rwanda. *PLoS One.* 2013;8(1) e53586.

8 World Health Organization. *Guidelines for treatment of malaria*, 3rd edition. Available at: who.int/iris/bitstream/10665/162441/1/9789241549127_eng.pdf (accessed 17 December 2018).

Other leading causes of death include AIDS, chronic respiratory diseases and road traffic accidents.

VA, GBD and HMIS all listed AIDS, chronic respiratory diseases and road traffic accidents among the top 10 CODs.

VA data show other infectious diseases and other NCDs in the top 10 CODs. This is a limitation of VA and means that only the major CODs of public health concern can be assigned. Other sources of mortality data (eg HMIS data or data from cancer registries or specific disease programs) could be used to get more information on the likely breakdown of these general categories in the VA data.

Health facilities data also show more gynaecological and obstetric problems, with maternal death accounting for 2.7 per cent of all deaths reported in health facilities.[9] The most common causes of these maternal deaths were postpartum haemorrhage (29 per cent), sepsis or postpartum infection (17 per cent), severe malaria (12 per cent), eclampsia (9 per cent), abortion (9 per cent), pulmonary embolism (8 per cent) and uterine rupture (6 per cent). The SmartVA software is currently only able to provide the broad category of 'maternal death', and HMIS data and maternal death audits reports could be used to disaggregate the VA data into more specific maternal causes for public health purposes.

In the VA data, reproductive death, cervical cancer and breast cancer could have been underestimated. An error in the prepopulation of sex data into the VA questionnaire would mean that most questions that would be useful for assigning such CODs were not asked of respondents. However, this issue has been resolved, and further analysis will provide more accurate assignment of these particular causes.

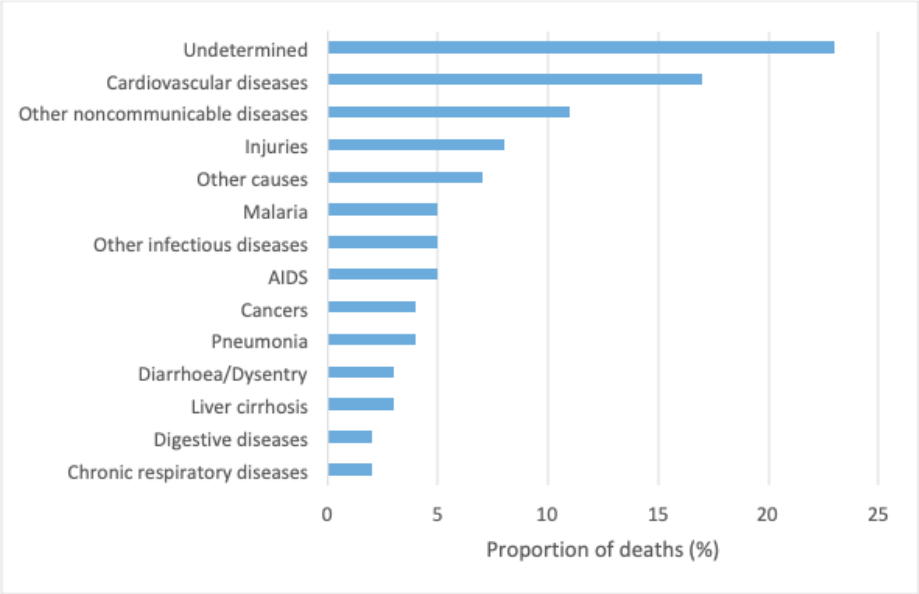
Adult deaths by leading causes of death

In addition to looking at the broad GBD disease groups (Figure 4), it may be useful to aggregate some of the VA data into broader disease groupings. These groupings show that cardiovascular disease, cancers and injury are some of the top CODs (Figure 8). This suggests that the Government of Rwanda may wish to focus resources on these areas, given the growing burden these diseases are posing to the country.

This also suggests that it will be important to strengthen monitoring and evaluation systems, including cancer and injury registries, to ensure all deaths are collected. Cancer and injury registries can use VA as a source of information.

9 Ministry of Health. Annual health statistics booklet 2016. Available at: https://moh.gov.rw/index.php?id=390 (accessed 17 December 2018).

Figure 8 Leading causes of death in adults from VA data



'Cancers' = breast cancer, cervical cancer, colorectal cancer, oesophageal cancer, leukaemia/lymphomas, lung cancer, prostate cancer, stomach cancer, other cancers; 'Cardiovascular diseases' = other cardiovascular disease, ischaemic heart disease, stroke; 'Injuries' = road traffic accident, bite of venomous animal, drowning, fall, fire, homicide, other injury, poisoning, suicide

Leading causes of death, female adults

A technical issue means that deaths from maternal causes, and breast and cervical cancer were under-counted in this data.

There are many similarities between VA and GBD estimates of many CODs for females; exceptions include chronic conditions such as cirrhosis, renal failure, diabetes and malaria (Table 6).

Unlike both GBD estimates and HMIS, VA does not rank maternal death among the top CODs. As noted earlier, maternal deaths and breast and cervical cancer will be underestimated for this VA cohort because of a technical issue that has now been resolved.

Table 6 Leading causes of death in female adults

VA data	Deaths (%)	GBD estimates	Deaths (%)
Other causes	21	Other causes	22
Other noncommunicable diseases	16	Other noncommunicable diseases	9
Ischaemic heart disease	13	Pneumonia	8
Stroke	13	Stroke	8
AIDS	6	Other cancers	8
Malaria	6	Ischaemic heart disease	8
Other infectious diseases	6	AIDS	7
Pneumonia	5	Diarrhoea/dysentery	7
Liver cirrhosis	4	Other cancers	7
Chronic respiratory diseases	4	Tuberculosis	6
Diabetes	3	Other infectious diseases	5
Renal failure	3	Chronic respiratory diseases	4
Tuberculosis	3	Maternal	4

GBD = Global Burden of Disease; VA = verbal autopsy

Leading causes of death, male adults

They are many similarities between VA and GBD estimates for CODs in males, except for malaria and cirrhosis (Table 7).

Chronic respiratory diseases are not ranked among the top CODs for males according to GBD estimates. We expect that VA data have the real picture on this condition, because they are consistent with HMIS data (asthma and chronic respiratory diseases), ranking them among the top 10 CODs.

Suicide in males appeared in the top CODs in VA data but not in GBD estimates or HMIS data, where it is ranked 20th. Suicide could be underreported in HMIS data; data from police (not collected in this study) may provide the real picture.

Table 7 Leading causes of death in male adults

VA data	Deaths (%)	GBD estimates	Deaths (%)
Other causes	26	Other causes	24
Other noncommunicable diseases	16	Tuberculosis	13
Stroke	10	Other noncommunicable diseases	9
Malaria	8	Other cancers	7
Ischaemic heart disease	7	Pneumonia	7
AIDS	6	AIDS	6
Liver cirrhosis	5	Ischaemic heart disease	6
Other infectious diseases	5	Chronic respiratory diseases	6
Pneumonia	5	Diarrhoea/dysentery	5
Road traffic accidents	4	Road traffic accidents	5
Diabetes	3	Stroke	5
Chronic respiratory diseases	3	Other infectious diseases	5
Suicide	3	Diabetes	3

GBD = Global Burden of Disease; VA = verbal autopsy

Comparison of leading causes of death by sex

When comparing the VA CODs of males and females, we can see that females have more stroke and ischaemic heart diseases than males (13 per cent and 12 per cent respectively for females and 10 per cent and 7 per cent for males). In GBD estimates, stroke and ischaemic heart diseases are 8 per cent and 7 per cent for females, and 5 per cent and 6 per cent for males.

The higher proportion of these conditions in females could be because females generally live longer than males, and so are more likely to eventually die from these conditions. Females may also experience more unhealthy lifestyles than males. This was shown in the 2012 risk factors STEP survey conducted in Rwanda, which found that the proportion of females who were overweight and who lacked physical exercise was higher than for males.

Males have more cirrhosis than females in VA data. This may be because alcohol abuse is more prevalent in males than females, as reported in STEP surveys, which showed that 30 per cent of males exhibit excessive alcohol consumption, compared with 17 per cent of females.

Chronic respiratory diseases in males seems to be underestimated in VA and HMIS data compared with GBD estimates. The reasons for this are unclear and need to be further investigated.

More deaths occur in males aged between 40 and 70 years compared with females, and more deaths occur in females aged more than 70 years compared with males (Table 8). For both males and females, stroke, ischaemic heart diseases and diabetes are frequent in advanced ages (70+). Cirrhosis deaths generally occur in people aged 40–69 years because this group is exposed to risk factors at earlier ages.

Males most commonly die between ages 40 and 70 years, compared with females, who most commonly die after age 70 years.

Females experience more traffic accidents at an earlier age compared with males. However, given the relatively small number of deaths in this VA sample, further analysis of more data is needed.

Table 8 Leading causes of death by sex and age group from verbal autopsy data

Cause of death	Proportion of female deaths (%)			Proportion of male deaths (%)		
	12–39	40–69	70+	12–39	40–69	70+
Stroke	29	34	3	4	39	57
Ischaemic heart disease	6	21	74	6	33	61
Malaria	18	24	59	17	39	43
Cirrhosis	11	78	11	13	60	27
Pneumonia	0	20	80	0	36	64
AIDS	67	33	0	18	82	0
Chronic respiratory disease	0	44	56	0	75	25
Diabetes	17	17	67	11	44	44
Renal failure	0	71	29	17	33	50
Road traffic accidents	75	0	25	38	50	13

Cause-specific mortality: children

Child deaths by broad disease group

Infectious diseases cause the highest number of deaths among children.

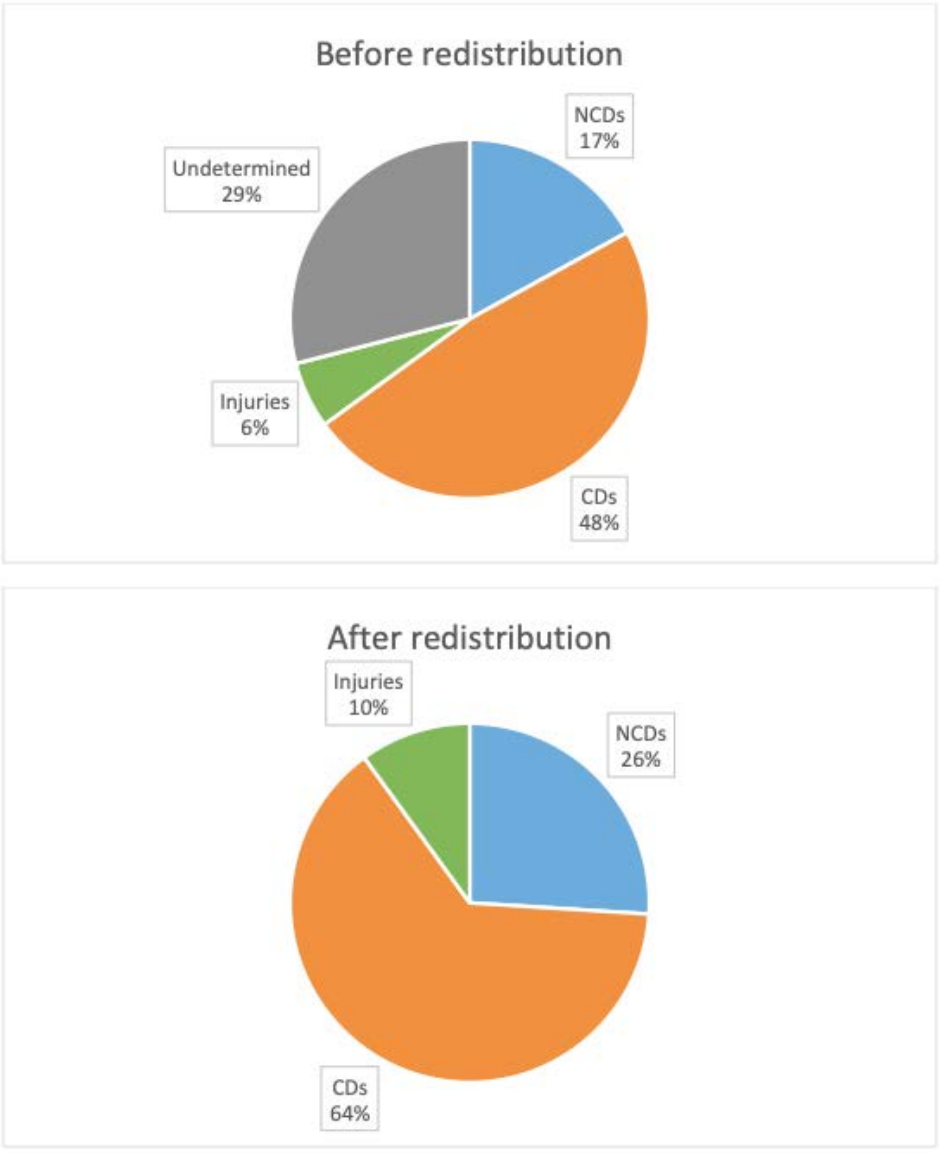
Unlike in adults, the highest category of CODs from GBD estimates in children is CDs (Figure 9).

Figure 9 Distribution of child deaths by broad GBD category from GBD estimates, 2016

CDs = communicable diseases; GBD = global burden of disease; NCDs = noncommunicable diseases

VA data are consistent with GBD estimates (Figure 10). However, the proportions of CD CODs are higher in GBD estimates (81 per cent) compared with VA data (64 per cent). This could be because the VA sample size was not large enough. Future evaluation of larger samples may provide more representative results.

Figure 10 Distribution of child deaths by broad GBD category from VA data, before and after redistribution, 2017/18



Sample size = 142
CDs = communicable diseases; GBD = Global Burden of Disease; NCDs = noncommunicable diseases; VA = verbal autopsy

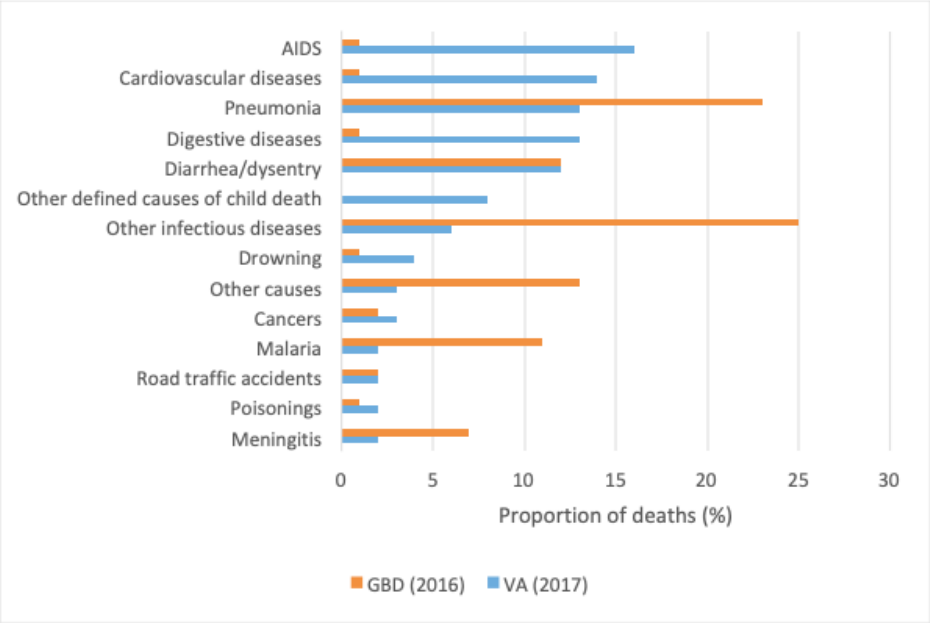
Leading causes of death

The leading CODs in adults are similar across the different data sources. For children, however, there are few similarities. This may be because there were few children in the VA sample; larger samples may provide more consistent results.

VA data show AIDS, cardiovascular diseases, and digestive diseases as the top three CODs for children. This does not reflect GBD estimates, and it is particularly unusual to have cardiovascular diseases as a leading COD in children (Figure 11). Conversely, malaria and meningitis are ranked high in GBD estimates but low in VA and HMIS data.

Diarrhoeal and digestive diseases and pneumonia were expected to be the leading CODs in VA data because they also ranked among the most common CODs according to HMIS (Table 9). It is not clear whether AIDS was also ranked highly in HMIS data because HMIS does not categorise data by the same age groupings. However, given that AIDS is ranked among the top CODs for children aged more than 5 years and that the HIV program evaluation report shows that a high proportion of children may have undiagnosed HIV, the VA results are plausible. HMIS data also show congenital anomalies and accidents among the top CODs, whereas they do not appear in VA or GBD estimates; this could also be investigated further in larger samples.

Figure 11 Leading causes of child deaths from VA data and GBD estimates, after redistribution



GBD = Global Burden of Disease; VA = verbal autopsy

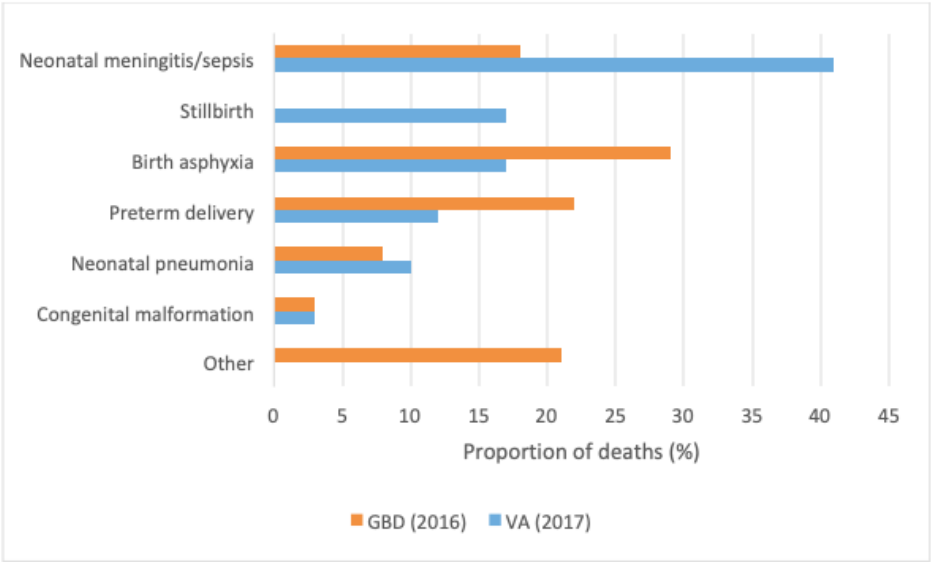
Table 9 Leading causes of death in health centres, and district, provincial and referral hospitals, 2016 (children younger than 5 years)

Cause of death	Deaths	
	Number	%
Neonatal illness	3735	50.5
Acute respiratory infection	2524	34.1
Congenital anomalies	588	8.0
Pneumopathies	233	3.2
Physical trauma and fractures	74	1.0
Diarrhoea	65	0.9
Burns	28	0.4
Cerebrospinal infections	28	0.4
Bone and joint disease	23	0.3
Gastrointestinal disease	19	0.3
Other diseases	77	1.0
Total	**7394**	**100.1**

Cause-specific mortality: neonates

The VA neonate sample was not large enough to analyse, with 28 per cent of deaths classified as undetermined. However, the available data show similarities in the rates of neonatal pneumonia and congenital malformation between VA data and GBD estimates (Figure 12).

Figure 12 Leading causes of neonatal deaths from VA data and GBD estimates



GBD = Global Burden of Disease; VA = verbal autopsy

Conclusions

Our study of the pilot HBCP program in 100 cells found that VA data are plausible for almost all CODs. These preliminary findings provide a promising indication that VA can be an appropriate source of information for community death to complement routine notification in Rwanda and other countries that have incomplete death notification and certification systems.

Some differences in the proportions of COD between VA data, HMIS data and GBD estimates were related to differences in the sources of data: VA considers only deaths in the community, HMIS considers deaths in health facilities, and GBD considers deaths in the community and health facilities.

The study findings show that NCDs are becoming a growing burden for Rwanda. The HBCP program is designed to start to address NCDs by supporting the follow up of NCDs in community and providing home-based palliative care. CDs also continue to be a threat to Rwandan, so efforts to addressing NCDs should not be at the expense of infectious disease control.

There were some limitations in the data, particularly because there were few children in the sample. Larger samples are needed to confirm that the CODs for children are plausible.

They are also some limitations in using VA as the only source of COD information. For example, VA does not collect information on different categories of maternal death. Other sources of information, such as HMIS and maternal death audits, can be used to complement VA data. In addition, VA will often classify COD as 'other NCDs' or 'other infectious diseases', which makes it difficult for countries to plan specific interventions. However, the data available for community death may still be sufficient to inform public health actions.

VA will produce some undetermined CODs, with a rate of 10 per cent considered acceptable. This study found a higher undetermined rate. This should be investigated in further studies, and more efforts should be made to minimise this rate when rolling out larger programs.

VA data were consistent with HMIS data; however, it is difficult to fully assess this consistency, because HMIS data does not use standard ICD-10 disease classifications or age categories. We recommend that MOH and RBC review the classification of diseases and age categories to align them to international standards. This will improve data collection and better support health planning and resource allocation.

Appendix 1 Cause list for SmartVA software with ICD-10 codes

VA cause	ICD-10 code	WHO ICD definition and comments
ADULT CAUSES		
GBD Cause Group A: Communicable, maternal, neonatal and nutritional disorders		
AIDS	B24	Unspecified human immunodeficiency virus [HIV] disease
Diarrhoea/dysentery	A09	Other gastroenteritis and colitis of infectious and unspecified origin
Malaria	B54	Unspecified malaria
Maternal	O95	Obstetric death of unspecified cause: Maternal death from unspecified cause occurring during pregnancy, labour and delivery, or the puerperium
Other infectious diseases	B99	Other and unspecified infectious diseases
Pneumonia	J22	Unspecified acute lower respiratory infection
Tuberculosis	A16	Respiratory tuberculosis, not confirmed bacteriologically or histologically
GBD Cause Group B: Noncommunicable diseases		
Acute myocardial infarction	I24	Other acute ischaemic heart diseases (as for WHO 2014)
Breast cancer	C50	Malignant neoplasm of breast
Chronic respiratory diseases	J44	Other chronic obstructive pulmonary disease
Cervical cancer	C53	Malignant neoplasm of cervix uteri (WHO VA has C55 for all female reproductive neoplasms)
Cirrhosis	K74	Fibrosis and cirrhosis of liver
Colorectal cancer	C18	Malignant neoplasm of colon
Diabetes	E14	Unspecified diabetes mellitus
Oesophageal cancer	C15	Malignant neoplasm of oesophagus
Leukaemia/lymphomas	C96	Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue
Lung cancer	C34	Malignant neoplasm of bronchus and lung
Other cardiovascular diseases	I99	Other and unspecified disorders of circulatory system
Other noncommunicable diseases	R100*	
Prostate cancer	C61	Malignant neoplasm of prostate
Chronic renal failure	N18	Chronic renal failure
Stomach cancer	C16	Malignant neoplasm of stomach
Stroke	I64	Stroke, not specified as haemorrhage or infarction
Other cancers	C76	Malignant neoplasm of other and ill-defined sites
GBD Cause Group C: Injuries		
Bite of venomous animal	X27	Contact with other specified venomous animals
Drowning	W74	Unspecified drowning and submersion
Falls	W19	Unspecified fall
Fires	X09	Exposure to unspecified smoke, fire and flames
Homicide (assault)	Y09	Assault by unspecified means
Other injuries	X58	Exposure to other specified factors
Poisonings (accidental)	X49	Accidental poisoning by and exposure to other and unspecified chemicals and noxious substances
Road traffic accident	V89	Motor- or nonmotor-vehicle accident, type of vehicle unspecified
Suicide (intentional self-harm)	X84	Intentional self-harm by unspecified means

VA cause	ICD-10 code	WHO ICD definition and comments
CHILD CAUSES		
GBD Cause Group A: Communicable, maternal, neonatal and nutritional disorders		
AIDS	B24	Unspecified human immunodeficiency virus [HIV] disease
Diarrhoea/dysentery	A09	Other gastroenteritis and colitis of infectious and unspecified origin
Encephalitis	G04	Encephalitis, myelitis and encephalomyelitis
Haemorrhagic fever	A99	Unspecified viral haemorrhagic fever
Malaria	B54	Unspecified malaria
Measles	B05	Measles
Meningitis	G03	Meningitis due to other and unspecified causes
Other infectious diseases	B99	Other and unspecified infectious diseases
Pneumonia	J22	Unspecified acute lower respiratory infection
Sepsis	A41	Other sepsis
GBD Cause Group B: Noncommunicable diseases		
Child cancers	C76	Malignant neoplasm of other and ill-defined sites
Child cardiovascular diseases	I99	Other and unspecified disorders of circulatory system
Other defined causes of child deaths	R101*	Other ill-defined and unspecified causes of mortality
Other digestive diseases	K92	Other diseases of digestive system
GBD Cause Group C: Injuries		
Bite of venomous animal	X27	Contact with other specified venomous animals
Drowning	W74	Unspecified drowning and submersion
Falls	W19	Unspecified fall
Fires	X09	Exposure to unspecified smoke, fire and flames
Poisonings	X49	Accidental poisoning by and exposure to other and unspecified chemicals and noxious substances
Road traffic accident	V89	Motor- or nonmotor-vehicle accident, type of vehicle unspecified
Violent death	Y09	Assault by unspecified means
NEONATE CAUSES		
Birth asphyxia	P21	Birth asphyxia
Congenital malformation	Q89	Other congenital malformations, not elsewhere classified
Neonatal meningitis/sepsis	P36	Bacterial sepsis of newborn
Neonatal pneumonia	P23	Congenital pneumonia/unspecified acute lower respiratory infection
Preterm delivery	P07	Disorders related to short gestation and low birth weight, not elsewhere classified
Stillbirth	P95	Fetal death of unspecified cause

*Non ICD-10 Code to signify other noncommunicable disease/other defined causes of child death not otherwise included in the SmartVA cause list.

Related resources and products

University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Library

https://crvsgateway.info/library

CRVS country overview: Rwanda. CRVS summaries.

Fellowship profile: Strengthening civil registration processes and improving vital statistics in Rwanda. CRVS country perspectives.

Improving vital statistics for informed policy: The importance of data quality. CRVS development series.

Intervention: Automated verbal autopsy. CRVS summaries.

Intervention: Improving registration practices. CRVS summaries.

Intervention: Medical certification of cause of death. CRVS summaries.

University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Learning Centre

https://crvsgateway.info/learningcentre

Topic 1: Introduction to CRVS.

Topic 4: Cause of death in CRVS.

University of Melbourne, D4H Initiative, CRVS Knowledge Gateway: Courses

https://crvsgateway.info/courses

Analysis of Causes of (National) Deaths for Action.

Medical certification of cause of death.

SmartVA.

Bloomberg Philanthropies DATA FOR HEALTH INITIATIVE

Australian Government
Department of Foreign Affairs and Trade

The program partners on this initiative include: The University of Melbourne, Australia; CDC Foundation, USA; Vital Strategies, USA; Johns Hopkins Bloomberg School of Public Health, USA; World Health Organization, Switzerland.

Civil Registration and Vital Statistics partners:

Vital Strategies

CDC Foundation
Together our impact is greater

THE UNIVERSITY OF MELBOURNE

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