

A call to action for cause-of-death reporting in South Africa: An assessment of cause-of-death data for public health use.

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Accurate cause-of-death (COD) data provides insight into the reasons that people die and contributes valuable information to enable the government and communities to prevent premature deaths. In South Africa, cause-of-death information is inaccurate and often incomplete. Furthermore, there are challenges with underreporting of deaths. This makes it difficult to use the information to improve health services (such as maternal and child health), respond to public health concerns (such as infectious disease outbreaks) and identify disease prevention and health promotion priorities. Recently, a rapid assessment was conducted on the national cause-of-death data to investigate problems with the collection and use of cause-of-death statistics in South Africa. In this policy brief we share findings from the assessment and suggest how policy makers and government officials could address the highlighted problems to ensure that the country can use the information to improve population health and respond to public health needs.

Introduction

Accurate cause-of-death (COD) data provides insight into the reasons that people die. This data is essential to inform public health policy, plan health services and improve interventions that address pressing public health challenges. A well-functioning Civil Registration and Vital Statistics (CRVS) system is the preferred source of valid and reliable COD information. This is particularly important for monitoring Sustainable Development Goals as they enable smaller area surveillance to ensure that no one is left behind.

The primary function of civil registration systems is to create and maintain legal documents proving the identity of individuals. Since these systems also provide official records of births and deaths, the statistics they produce are essential for understanding health status in countries and how it is changing.¹

South Africa has a well-established CRVS, but there are indications that the quality of COD data is poor. Of concern is the misclassification of HIV/AIDS deaths as other causes, the inaccuracy of injury-related deaths ² and the extent of unusable codes which does not provide sufficient information about the underlying cause of death. The COVID-19 pandemic profoundly highlighted shortcomings of the current CRVS system, which could not provide timely COD information, with limited access by the Department of Health to enable public health follow-up actions.

A recent study conducted by researchers from the South African Medical Research Council's Burden of Disease Research Unit, undertook a rapid assessment to identify the current challenges related to the collection, reporting, and use of COD statistics in South Africa to identify how these may be addressed.³

KEY FINDINGS

Completeness of death registration in South Africa has improved since 1994 with the proportion of unregistered deaths being reduced, however, in past 10 years, there has been no further improvement in completeness and no improvement in the quality of COD information collected.

Death registration needs to be digitised to improve quality and timeliness.

Failure to address the current challenges and implement a digital system will leave South Africa unable to use COD information to respond to epidemics (as experienced during COVID 19 pandemic), accurately measure the burden of disease, conduct epidemiological research, monitor health inequities and allocate resources efficiently.

CALL TO ACTION

Urgent action is needed to **improve the accuracy of COD data** and ensure that it is used for effective public health responses.

Cooperation and coordination between the government departments Health, Home Affairs and Stats SA is needed to identify and implement business process improvements. Establishing a high-level national CRVS committee may be useful.

Digitisation of the death registration process will provide opportunities for the country to harness COD death information for public health in a timely fashion.

System integration/interoperability is critical when designing a new system with collaboration required between all role-players, Information Technology experts, and researchers.

Methodology for the rapid assessment

Why did we conduct the study?

The study was conducted to assess the quality of COD data in South Africa, identify its' strengths and weaknesses, and gather qualitative insight from key stakeholders to inform future planning within the CRVS system.

How was it conducted?

The rapid assessment was designed as a first step to consolidate information to be used to inform a joint planning initiative. It comprises a desktop review of grey and published literature to identify strengths and weaknesses. This was followed by qualitative interviews with key stakeholders to describe current challenges within CRVS and secondary analysis of COD data to assess the quality and completeness of COD statistics.

Where was the research conducted?

The study was conducted in South Africa and involved key stakeholders within the CRVS system i.e., Department of Home Affairs, National Department of Health, Statistics South Africa, National Institute for Communicable Diseases and the South African Medical Research Council.

Where did we get the data and how was it analysed?

We analysed mortality data from 2000 to 2017 from Statistics South Africa for completeness and compared it to the National Population Register data. We assessed the trends in COD and unusable codes by age, sex and province. The quality of COD data was evaluated using an assessment framework recommended by the World Health Organization (WHO).¹ Interviews with key stakeholders were conducted using semistructured interviews and themes were identified through an inductive data analysis process.

Findings

Scientific literature reflects some improvement but challenges remain

The review found an extensive body of literature reporting on strengths and weaknesses of the CRVS system in South Africa and its ability to provide accurate and timely COD information.

Highlights include:

• South Africa has a well-developed CRVS system which showed significant improvements post 1994.^{4,5} By 2007, the completeness of death registration was over 90%, with no further improvement thereafter.⁴

Concerns include:

- Vital Statistics Performance Index (VSPI),⁶ an indicator based on six dimensions (i. completeness of death registration, ii. quality of cause-of-death reporting, iii. quality of age and sex reporting, iv. internal consistency, v. level of causespecific detail, and vi. data availability and timeliness), found improvement up until 2009; however, the VSPI declined between 2009 and 2012, mainly associated with the increasing delays in reporting.
- Except for the Western Cape Mortality Surveillance Project ⁷ in the early 2000's, the current system fails to provide information for public health actions such as identifying outbreaks of diarrhoeal disease in children. Since the 2014 regulation that amended the death notification form, identifiable COD information has become inaccessible to the Department of Health, preventing its use for public health actions.

Evaluation of cause-of-death statistics

This assessment highlights that in many respects, the COD statistics in South Africa are good, and that there have been improvements in areas such as the completeness of death registration. However, the quality of the COD information is still suboptimal:

• The quality of COD information has not improved in the last 10 years (see Figure 1). Nearly a third (32%) of all deaths in 2017 were identified as unusable COD (i.e., with insufficient information about the underlying COD), raising questions around the quality of reporting cause-of-death by the certifying doctors. WHO recommends that unusable codes, excluding the insufficient category, should account for <5% of deaths under-65 years and <10% of deaths 65+ years.

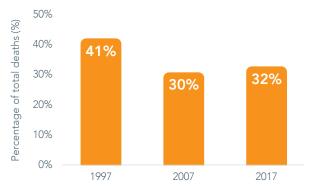
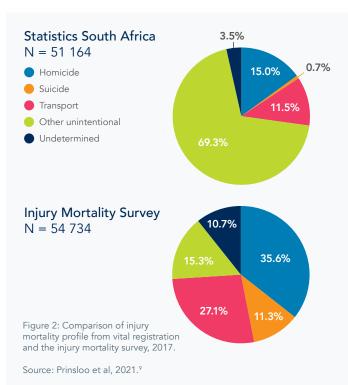


Figure 1: Trend in the proportion of unusable codes 1997, 2007 and 2017.

- Symptoms, signs and ill-defined conditions accounted for 13.4% in 2017, above the ideal level of below 5%. This is problematic as these cases have no information about the underlying disease/conditions that led to the death and therefore cannot contribute towards identifying health needs.
- Inaccurate information about causes of injury-related deaths occur due to the lack of a field for the manner of death to be captured on the death notification form. Despite legislation requiring all unnatural deaths to be processed by forensic pathology services, incomplete information is obtained from the certifying forensic pathologist because the death notification form does not include the necessary fields. This is highlighted by the stark differences seen in Figure 2 between the COD profiles obtained from the national statistics based on the CRVS compared to the information obtained from the 2nd Injury Mortality Survey, a study that obtained data from a representative sample of the forensic pathology mortuaries. The main reason for the difference is due to the fact that the manner of death (homicide, suicide, or accident) is generally not reported on the death notification as there is no field for this information. Inclusion of the manner of the death on the death notification is recommended by the WHO and would permit accurate coding of external causes of injury deaths.8



 Concerning is the reporting lag which appears to be increasing as shown by steady increase in production time (Figure 3). Setting an ambitious target of releasing the statistical report within 12 months of the reference period,¹⁰ it has clearly not been possible to meet this target. The COVID-19 pandemic highlighted the need for near to real-time COD information.

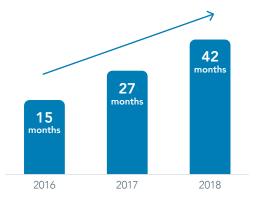


Figure 3: Production time for annual cause of death report.

Perceptions of key role-players

The role-players who were interviewed described a range of practical challenges that they face with the current system. These are summarised below:

Challenges related to cause of death information identified by CRVS key stakeholders.

Themes	Challenges
Human resources	Staff retention and staff shortages are experienced across all responsible departments.
Quality concerns	All departments expressed concerns about the quality of information about causes of death.
Delays in processing data	Delays in data processing was raised by users, and the particular challenges of getting resolution of forensic pathology services cases was highlighted by DHA and Stats SA.
Relationships between key departments	There is a need to strengthen the inter- departmental relationships, especially those affected by loss of institutional knowledge because of staff turn-over.
Access to information	COVID-19 has demonstrated faults in CRVS such as access to COD information and lack of mechanisms to share and link data in the CRVS system. All departments agree that the lag in annual mortality statistics needs concerted intervention.
Registration of stillbirths and perinatal deaths	Possible disincentives by the family to register perinatal deaths was mentioned. Distinguishing stillbirths and live births affects the numbers in the young age groups.
Accessibility of DHA offices	Challenges arising from the inadequate distribution of DHA offices.

Pragmatic and feasible way forward (as outlined by one of the key stakeholders):

- Develop a re-engineered framework for implementation that is signed off by all the stakeholders.
- Craft an action plan with clearly defined goals and roles and responsibilities by different stakeholders.
- Implement an integrated technology solution.
- Train officials on the rationale, process, technology and integration.
- Implement a proof of concept in one province.
- Communicate and share lessons learnt.
- Scope a national roll-out plan with clear accountability for action.

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