

# Rapid assessment of cause-of-death data collection and public health use in South Africa



LITERATURE  
REVIEW



DATA  
ANALYSIS



KEY  
INFORMANT  
INTERVIEWS



FINDINGS

**SAMRC Burden of Disease Research Unit**  
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## ABBREVIATIONS AND ACRONYMS

<b>ACME</b>	Automated Classification of Medical Entities programme
<b>AFRO</b>	Regional Office for Africa (WHO)
<b>AIDS</b>	Acquired immune deficiency syndrome
<b>ANACONDA</b>	Analysis of National Causes of Death for Action
<b>APAI-CRVS</b>	Africa Programme for Accelerated Improvement of Civil Registration and Vital Statistics
<b>CDC</b>	Centers for Disease Control and Prevention
<b>CHIP</b>	Child Healthcare Identification Programme
<b>COD</b>	Cause of death
<b>COVID-19</b>	Coronavirus disease
<b>CRS</b>	Civil Registration System

<b>CRVS</b>	Civil registration and vital statistics
<b>DBE</b>	Department of Basic Education
<b>DHA</b>	Department of Home Affairs
<b>DNF</b>	Death notification form
<b>DOJ&amp;CS</b>	Department of Justice and Correctional Services
<b>DSD</b>	Department of Social Development
<b>FPS</b>	Forensic Pathology Services
<b>GCP</b>	Good clinical practice
<b>GP</b>	General practitioner
<b>HANIS</b>	Home Affairs National Identification System
<b>HIV</b>	Human immunodeficiency virus
<b>HPCSA</b>	Health Professions Council of South Africa
<b>ICD-10</b>	International classification of diseases and related health conditions, 10th edition
<b>ID</b>	Identity number
<b>IRIS</b>	Automatic system for coding multiple cause of death and selection of underlying cause of death
<b>IT</b>	Information technology
<b>MCCOD</b>	Medical Certification of Causes of Death
<b>MOU</b>	Memorandum of understanding
<b>NBD</b>	National burden of disease
<b>NDOH</b>	National Department of Health
<b>NCODVP</b>	National cause of death validation project
<b>NICD</b>	National Institute for Communicable Diseases
<b>NPR</b>	National Population Register
<b>PEPFAR</b>	President's Emergency Plan for AIDS Relief
<b>PPIP</b>	Perinatal Problem Identification Programme
<b>RMS</b>	Rapid mortality surveillance
<b>SA</b>	South Africa
<b>SA NBD</b>	South African National Burden of Disease Study
<b>SAMRC</b>	South African Medical Research Council
<b>SARS CoV-2</b>	Severe acute respiratory syndrome coronavirus 2
<b>SD</b>	Standard deviation
<b>SDG</b>	Sustainable Development Goals
<b>Stats SA</b>	Statistics South Africa
<b>SMS</b>	Strengthening mortality surveillance
<b>TB</b>	Tuberculosis
<b>UCOD</b>	Underlying cause of death
<b>UCT</b>	University of Cape Town
<b>UNECA</b>	United Nations Economic Commission for Africa
<b>UNFPA</b>	United Nations Population Fund
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNICEF</b>	United Nations Children's Fund
<b>VA</b>	Verbal autopsy
<b>VR</b>	Vital registration
<b>VSPI</b>	Vital statistics performance index
<b>WHO</b>	World Health Organization





# EXECUTIVE SUMMARY

## Background

South Africa has a well-established civil registration and vital statistics (CRVS) system with notable improvements in the registration of births and deaths since the early 2000s. However, improvement in the quality of cause-of-death information remains a challenge. In addition, the SARS CoV-2 pandemic has highlighted the shortcomings of the current CRVS in providing timely cause-of-death information, information about deaths occurring outside of health facilities, and the National Department of Health's access to identified cause-of-death information to enable public health response.

## Aim

The overall aim for appraising the rapid assessment of cause-of-death data collection and public health use, including monitoring HIV/AIDS and TB, in South Africa was to identify the current challenges related to the collection, reporting, and use of cause-of-death statistics in South Africa and how they might be addressed.

## Method

The rapid assessment comprised a desktop review of reports and publications to identify strengths and the current understanding of challenges related to the collection, reporting and public health use of cause-of-death statistics in South Africa. This analysis of the cause-of-death data from the period 2000–2017 was performed to assess the quality of these data. After sharing the literature review and results from the data analysis with stakeholders, key informant interviews were conducted to collect additional information on the perceptions of challenges and plans to improve the reporting of deaths that are already underway by government departments involved in CRVS. A grounded theoretical approach was used to analyse the qualitative data. The interviews were independently analysed by two researchers using an inductive data analysis approach. Eleven themes were jointly identified and summarised under two groupings. Firstly, the various challenges were described with information relating to the nature of the problem. The responses were very consistent and are summarised in Table 1. The second grouping comprises ideas about how the country can move forward to overcome these challenges and to integrate these into recommendations.

Key findings have been drawn from the three assessment elements (i.e., the desktop review, the analysis of the cause-of-death data, and the qualitative interviews) with the lead researchers using these to identify steps that might be taken to improve the CRVS system.

## Findings

The literature review found an extensive body of literature describing the strengths and weaknesses of the CRVS system in South Africa and its ability to provide accurate and timely cause-of-death information. Highlights include:

- South Africa has a mature CRVS system which showed marked improvements post-1994.<sup>i,ii</sup> By 2007, completeness of death registration was estimated to be over 90%.<sup>i</sup>
- Assessments of cause-of-death data have found the following problems with medical certification:
  - a high proportion of deaths due to ill-defined causes ~ 13%,<sup>iii</sup>
  - a high proportion of deaths attributed to a cause of death considered unusable ~ 32%,<sup>iv</sup>
  - extensive misattribution of HIV-related deaths to other causes,
  - extensive misclassification of injury-related deaths due to the lack of a field for the manner of injury on the death notification form (DHA-1663).
- International agencies have developed numerous tools for improving CRVS which have informed the Africa Programme for Accelerated Improvement of Civil Registration and Vital Statistics (APAI-CRVS) led by the African Union.
- Cause-of-death data from CRVS in South Africa are not adequate for serving public health needs. Timely and accurate information about numbers and causes of death as well as identifiable information to ensure appropriate public health response are necessary. The need for such information has been exacerbated during the SARS-CoV-2 pandemic.
- A comprehensive assessment of CRVS was conducted by the South African Government in 2014/15. While the report of findings remains to be finalised and developed into a strategic improvement plan, important preliminary observations include:
  - South Africa does not have a high-level committee for CRVS coordination.
  - There is no provision for linking or integration of CRVS with other departmental systems, although there are some arrangements for data sharing.
  - In terms of management and operations, the assessment highlighted gaps and proposed mechanisms for improving performance of CRVS. Delays in transmission of death notification forms (DNFs) and a loss of documents in the transfer were identified in terms of production of cause-of death statistics.
  - In terms of data base management that considered storage and archiving of records, data sharing and transmission of records highlights the practical challenge of managing large numbers of paper records.

i Bradshaw D, Dorrington RE, Laubscher R. Rapid mortality surveillance report 2011. Cape Town: South African Medical Research Council, 2012. ISBN: 978-1-920618-00-1.

ii Nannan N, Dorrington R, Bradshaw D. Estimating completeness of birth registration in South Africa 1996-2011. Bull World Health Organ 2019 97(7): 468-76.

iii Pillay-van Wyk V, Bradshaw D, Groenewald P, Laubscher R. Improving the quality of medical certification of cause of death: The time is now! S Afr Med J 2011; 101(9): 626.

iv Oluwatoyin A, Nojilana B, Maqungo M, Groenewald P, Nannan N, Morof D, Rao C, Bradshaw D. Report on the quality of Physician Reviewed Verbal Autopsies cause-of-death data using ANACONDA for the South African National Cause-of-Death Validation Project. Cape Town: South African Medical Research Council, December 2020.

- In considering the public demand for registration of deaths, long distances to the Department of Home Affairs (DHA) offices and long queues demotivate people.
- The production of vital statistics falls under the two separate divisions in Stats SA, the National Statistics Office - corporate data processing and health and vital statistics – which may not be optimal.

Our analysis of the cause-of-death data from 2000-2017 identified some missing information about the characteristics of deaths with an increase in missing geographic information in 2017, but an improvement in the completeness of information about population group since 2004. However, there has been little change in the quality of the cause-of-death information between 2000 and 2017. The late transfer of forms from DHA to Stats SA by DHA leaves the most recent year of data in 2017, short of about 13,000 deaths.

**Table 1: Challenges related to cause of death information identified by CRVS key stakeholders.**

Themes	Challenges
Human resources	<ul style="list-style-type: none"> <li>– DHA, Stats SA - challenges regarding staff turn-over and shortages;</li> <li>– NDOH has a shortage of senior managers and no dedicated CRVS staff.</li> </ul>
Quality concerns	<ul style="list-style-type: none"> <li>– “Many hands touch the form” making quality assurance of the entire process very difficult;</li> <li>– Other role players (funeral parlors and private doctors) are involved in the process of determining community deaths;</li> <li>– Poor practices of certifying doctors and improvements in ICD coding.</li> </ul>
Delays in processing	<ul style="list-style-type: none"> <li>– Stats SA, Health - delay in COD information needs to be addressed;</li> <li>– Forensic pathology cases take longer to come through the system;</li> <li>– High-level committee comprising DHA, NDOH and Stats SA is needed to debate the matters and resolve.</li> </ul>
Relationships between key departments	<ul style="list-style-type: none"> <li>– Memorandum of Understandings in place between Stats SA and DHA, allowing partners to arrange meetings as needed;</li> <li>– Stats SA has no relationship with NDOH regarding COD statistics;</li> <li>– Loss of institutional knowledge impact on inter-departmental relationships within the CRVS community.</li> </ul>
Access to information	<ul style="list-style-type: none"> <li>– COVID-19 demonstrated faults such as access to COD information and lack of mechanisms to share and link data in the CRVS system;</li> <li>– NDOH, DHA, NICD and Stats SA agree that the lag in annual mortality statistics needs concerted intervention.</li> </ul>
Registration of stillbirths and perinatal deaths	<ul style="list-style-type: none"> <li>– Possible disincentives to register perinatal deaths;</li> <li>– Distinguishing stillbirths and live births correctly affect numbers in age groups</li> </ul>
Accessibility of DHA offices	<ul style="list-style-type: none"> <li>– DHA has an inadequate footprint even after extension of mobile units</li> <li>– DHA are in constant negotiations with NDOH for more offices</li> </ul>

DHA (Department of Home Affairs); NDOH (National Department of Health); CRVS (Civil Registration and Vital Statistics); Stats SA (Statistics South Africa); ICD (International Classification of Diseases) COD (cause-of-death).



## Way forward:

- South Africa may benefit from making use of the 2014/15 government assessment as well as this rapid assessment to develop a country plan that will address the challenges in the quality of cause-of-death information. The APAI-CRVS improvement framework recommends establishing a high-level national CRVS committee with resources to sponsor a business process evaluation and act on its results.
- Digital solutions would be ideal. Informants concurred that the current paper-system could make use of modernisation and digitisation to generate real-time data essential for public health and mortality surveillance. There was consensus that it is opportune timing. The possibility of electronic registration could be considered as a mechanism to enhance the quality and timeliness of cause-of-death information and ensure that the public health needs are met.
  - Roles and responsibilities could be clearly defined. It was suggested that these could be delineated by thorough review of each departments' responsibility and agreement between stakeholders. It was noted that the National Department of Health is best positioned to take a leadership role in using the data.
  - System integration/interoperability. Collaboration between all role-players, including IT experts and researchers, is suggested when designing the new system. Joint custodianship/stewardship of the COD information between Health and DHA could be a possibility.
- A complimentary solution was to consider improved collection of COD information in health facilities and to improve mortality surveillance at the community level through the implementation of Community Oriented Primary Care. Healthcare workers, looking after neighborhoods and sets of households, would be well placed to capture information about who has passed on.
- Informants from one of the institutions suggested a pragmatic and feasible way forward that could include:
  - a) Creating a high-level CRVS committee of all stakeholders
  - b) Developing a re-engineered framework for implementation that is agreed to by all stakeholders
  - c) Crafting an action plan with clearly defined goals and roles and responsibilities
  - d) Implementing an integrated technology solution
  - e) Training on the rationale, process, technology and integration
  - f) Implementing in the proof of concept in one province
  - g) Marketing and sharing lessons learnt; and
  - h) Scoping a national roll-out plan with clear accountability for action.

# 1. Background

The President's Emergency Plan for AIDS Relief (PEPFAR) works through South African partners and in collaboration with the National Department of Health to prevent new HIV infections, link people living with HIV to lifesaving antiretroviral treatment, and ensure they stay on treatment. This includes strengthening health information for monitoring these goals, including tracking numbers of deaths.

South Africa has a well-established Civil Registration and Vital Statistics (CRVS) system, having made considerable progress with strengthening its death registration system; however, the quality of cause-of-death (COD) data remains a challenge, particularly the underreporting of HIV/AIDS deaths<sup>1</sup>.

The National Cause-of-death Validation (NCODV) project,<sup>2</sup> funded by PEPFAR through the United States Centers for Disease Control and Prevention (US CDC), aims to validate the causes of death reported in the official statistics against verbal autopsy and medical records in order to derive best-estimates of cause-specific mortality patterns in South Africa for 2017. It aims to provide correction factors that can be applied to the cause-of-death profiles to improve estimates of the cause-specific mortality, and to monitor HIV and TB mortality. The SARS-CoV-2 pandemic has raised concerns that people living with HIV (PLHIV) would be more susceptible to severe disease and mortality from COVID-19. Preliminary data suggested that HIV and TB could be risk factors for COVID-19 mortality<sup>3</sup>. The pandemic has also highlighted shortcomings of the current CRVS system in providing timely cause-of-death information, particularly for deaths occurring outside of health facilities, and limited access by the Department of Health to identify COD information to enable public health follow-up actions<sup>4</sup>.

These challenges create an opportunity to identify longer term solutions that could improve the CRVS system and follow-on from a previous interdepartmental assessment of the CRVS system conducted in 2014/15, which highlighted some areas for improvement<sup>5</sup>. The first objective of the Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB and COVID-19 in South Africa project will be to undertake a rapid assessment of the COD data collection and use in South Africa, and thereby help to identify issues and strengthen the country's reporting of births and deaths. This project was supported in part by PEPFAR through the CDC under the terms of Cooperative Agreement: CDC-RFA-GH19-1911-03CONT21 between the South Africa Medical Research Council (SAMRC) and the CDC South African Country office.

# 2. Aims and Objectives

## 2.1 Aims

The overall aim of the assessment of COD data collection and use in South Africa, including monitoring HIV/AIDS and TB, is to identify the current challenges related to the collection, reporting and use of cause-of-death statistics in South Africa and to identify how they might be addressed.

## 2.2 Objectives

Specific objectives include:

1. Review documented strengths and weaknesses of national cause-of-death data in South Africa.
2. Review the quality of cause-of-death data in SA.
  - a. Describe completeness of cause-of-death statistics from 2010-2017 relative to numbers on the National Population Register and estimates based on demographic assessment.
  - b. Describe consistency in trends in total numbers of deaths by age, sex, and province.
  - c. Describe the trend in unusable codes in cause-of-death data for 2000-2017.
3. Describe current challenges within the CRVS system perceived by key stakeholders (National Department of Health (NDOH), Stats SA, DHA, National Institute for Communicable Diseases (NICD) and SAMRC).
4. Identify possible medium term and long-term strategies for South Africa to strengthen cause-of-death data.

## 2.3 Purpose of this report

This report outlines the rapid assessment methodology and presents key findings from the literature review and the analysis of 2000-2017 COD data. It also reports on the interviews conducted with key informants in the CRVS system. This consolidated information could assist the country with further efforts to strengthen the production of cause-of-death statistics.

# 3. Method

The CRVS assessment methodology, developed by World Health Organization and the accompanying rapid assessment tool<sup>6,7</sup>, as well as the shorter rapid assessment tool developed for the African region (personal communication with WHO AFRO), outlines a systematic approach for a country to undertake a comprehensive standards-based assessment. These are important tools that can be used to facilitate an inter-departmental process of joint planning. This rapid assessment, however, is designed as a preliminary step to consolidate information to be used to inform a joint planning initiative and the analysis steps are independent of any data analysis tools incorporated in any of the two WHO rapid assessment tools. The assessment was comprised of a desktop review of grey and published literature to outline the strengths and weaknesses of national cause-of-death statistics in South Africa, including the interdepartmental assessment conducted in 2014/15, plus secondary analysis of cause-of-death data and qualitative interviews with key stakeholders in the CRVS system.

## 3.1 Study population

The review of cause-of-death statistics focused on the period 2000-2017. There were approximately 600,000 deaths in 2010 which declined to about 520,000 by 2017. The study population for the semi-structured interviews were senior government officials directly involved in CRVS.

## 3.2 Study procedures

A phased approach was adopted to facilitate engagement with stakeholders. In the first phase, a desktop review was undertaken to consolidate information about the strengths and weaknesses of the data collection and use of cause-of-death data. After considering the importance of CRVS, it sought to outline the development of CRVS in South Africa and describe how the system functions. The findings of assessments of CRVS and cause-of-death statistics were consolidated and experiences of the public health use of the data were reviewed. Secondary analysis of national cause-of-death statistics was undertaken, with a focus on the availability and quality of cause-of-death data including an assessment of the completeness of official death data compared with the NPR and the proportion of ill-defined causes of death. The findings of the literature review and the analysis of cause-of-death data were shared with stakeholders before setting up interviews. The second phase sought to elucidate current strategies underway to respond to the challenges. Eight key informants were identified based on their areas of work responsibility in the CRVS system, targeting managers in the respective government departments.

## 3.3 Data collection

Public domain anonymised unit record data on COD reported on death notifications were obtained from Statistics South Africa for the period 2000-2017. For the second phase of the project, senior key personnel, selected based on their experience in CRVS, were invited to participate in the study. Invitees were asked to complete an informed consent form (Appendix 1.1) and the following four questions, adapted from the planned interview schedule (Appendix 1.2), were shared with the respondents for consideration once the respondent reached a decision to participate in the study:

1. Having worked extensively with death registration in South Africa, what do you feel are the current challenges and does your institution/department have plans in place to address them?
2. Are you aware of any challenges with the quality of the COD information and does your institution/department have any plans to improve what would be required?

3. COVID-19 has highlighted the importance of the Department of Health having real-time access to the cause-of-death information provided by doctors on the DHA-1663. What are the main reasons why this information cannot be provided to the Department of Health?
4. In the short-medium term, do you have any suggestions about how the Department of Health can obtain the information on causes of death in a timely manner?

The lead researcher set up TEAMS meeting slots for the interviews between 20 July and 30 September 2022. These were conducted in English and lasted approximately 45 to 60 minutes. At the beginning of the interview, permission was sought to record the interview and a full transcription of the interview was prepared using the transcription created by TEAMS. This was reviewed by the interviewer and errors in the transcription were corrected within 3 days after the interviews were completed. Two respondents provided written responses, which had been completed by more than one person from the respective institution.

### 3.4 Data analysis

To support an assessment of the cause-of-death data using the WHO 2007 framework developed by Mahapatra and colleagues<sup>8</sup>, secondary analysis of the Stats SA COD data were undertaken using Stata 16.0 (Stata Corp, College Station, Texas) and Microsoft Excel:

- Numbers of deaths from the Stats SA mortality data were compared with numbers of deaths on the SAMRC database created from deaths registered on the NPR to complement published estimates of completeness of death registration.
- The completeness of data elements available for each death was described for 2017 as well as the completeness trend since 2000 for key data elements (age, sex, and district as the lowest level geographic information).

The quality of cause-of-death data was assessed by reviewing trends in the 2000-2017 cause-of-death data by ICD-10. The Analysis of Causes of National Deaths for Action (ANACONDA)<sup>9</sup> was used to identify the extent of biologically implausible codes. ANACONDA is an electronic tool that assesses the accuracy and completeness of mortality and cause of death data by checking for potential errors and inconsistencies. The extent of garbage (ill-defined) codes was assessed using five types of unusable codes as defined by the Global Burden of Disease<sup>10</sup>.

In the case of the qualitative data, the transcribed interviews were reviewed by two researchers independently to understand the responses and identify codes towards a thematic analysis. A total of eight responses were analysed using an inductive data analysis approach under the guidance of an experienced qualitative researcher. The two researchers reviewed and discussed their interpretation of the interviews and agreed on suitable themes to report the findings. The themes were summarised under two groupings. Firstly, the various challenges are described with information relating to the nature of the responses. The second grouping comprises ideas about how the country can move forward to overcome these challenges.



# 4. Results

## 4.1 Literature review

The main purpose of the literature review was to identify strengths and weaknesses of the national cause-of-death statistics in South Africa. The following sections summarize the literature review findings, starting first with some background on the importance of CRVS, followed by a brief overview of the development of CRVS in South Africa and how the CRVS system works. Next sections will consider evaluation frameworks and consolidate the findings of various evaluations, including the inter-departmental assessment that was done in 2014/15. The final section considers the public health use of cause-of-death information.

### 4.1.1 Recognition of the importance of CRVS

A major conclusion at the end of The United Nations Millennium Development Goal project was that low-and middle-income countries face severe challenges measuring important health indicators due to inadequate CRVS systems<sup>11</sup>. This led to the establishment of the Monitoring Vital Events writing group, 'Who Counts?' in November 2007, which in turn led to a series in The Lancet in October 2015 on the status of country and global efforts to register every birth and death, and to certify every cause-of-death<sup>12</sup>. The 'Counting Births and Deaths' series explored how vital statistics are essential to health policy formation in both the developed and developing world and proposed ways forward for countries regarding their civil registration systems.

Civil registration and the resulting vital statistics constitute a continuous source of monitoring births and deaths over time and provides critical demographic and health information that have the potential to form the backbone of the public health surveillance system<sup>13</sup>. Apart from generating infant and maternal mortality rates and cause-of-death statistics, a well-developed registration system can be used to monitor teenage fertility rates, low birth-weight rates and the variations in trends between geographical regions<sup>14</sup>. These data are ideal because annual estimates provide a good source of recent levels and trend information and hence permit the monitoring of short and long-term demographic trends<sup>13</sup>. The usefulness of vital registration data, however, depends on the quality of the information<sup>8</sup>. Notwithstanding the importance of this information for the purposes of demographic analysis and for key functions in population health, these data often suffer from coverage errors where a birth, death, or both can simply go unrecorded; or in the case of death, errors in reporting the age at death may occur. Timeliness of the information, from the processing-stage to publication, is also challenging for many developing countries; however, despite the data imperfections, their utility lies in the fact that even where data are in some manner defective, the possibility exists to adjust and correct the data using alternative data sources such as censuses and surveys<sup>15</sup>.

CRVS are the preferred source of data to monitor many Sustainable Development Goals (SDGs)<sup>16</sup> that have been set globally for the period 2015-2030, which include a wider range of health-related indicators such as suicide rates and premature mortality from non-communicable disease. In addition, the focus of the SDGs on inequalities highlights the importance of full coverage of the CRVS. The WHO General Programme of Work 13 for 2019–2023<sup>17</sup>, focussing on universal health coverage, health emergencies and health promotion, also stresses the critical importance of measuring cause-specific mortality for a broad range of health conditions.

Experience in other low and middle-income countries shows that countries have benefited from the application of process management in CRVS systems to improve stakeholder understanding of the system<sup>18</sup>. Process management is a tool used in enterprise architecture to describe and analyse the working architecture of a system by capturing the complexity of multiple interactions of different stakeholders. The first step in process management is the development

of a process map. A process map is a visual representation of the end-to-end description of the activities, stakeholders and requirements of a process that can be useful to help identify issues and areas of improvement.

Another initiative to assist countries in strengthening CRVS systems is the development of the ten CRVS milestones framework, aiding policymakers, managers and development partners to better understand how CRVS systems function from start to finish and to distil complexity by focussing on ten milestones which must be achieved in any CRVS system<sup>19</sup>. The milestones framework has been particularly useful to align stakeholders' understanding of how the CRVS system operates and the need for standardisation procedures within and between institutions. It has also aided the design and integration of new interventions to improve CRVS performance and has been key in structuring the legal review some countries chose to facilitate mapping existing laws and regulations governing CRVS.

A recent initiative of the Africa Programme for Accelerated Improvement of Civil Registration and Vital Statistics (APAI) together with UN agencies and other partners have developed a CRVS Systems Improvement Framework<sup>20</sup> that aims to improve the processes to strengthen CRVS in the Africa region. The framework introduces an approach for improving CRVS by increasing system performance and service delivery to the population.

There are three stages to the framework:

- Stage 1: Assessment, analysis and redesign
- Stage 2: Development of the strategic action plan
- Stage 3: Implementation, monitoring and evaluation.

A critical factor for successful implementation of the framework, is a functional national high-level CRVS committee that is willing to sponsor a business process improvement effort and act on its results. However, if there is no national CRVS committee, efforts should be made to create such a committee to ensure that the framework is implemented effectively, and the overall CRVS system is well coordinated<sup>20</sup>.

## 4.1.2 Development of CRVS in South Africa

South Africa has quite an unusual past in the area of civil registration. Disjointed legislation affected administrative processes for capturing data, and undoubtedly compromised the quality of vital statistics for many decades<sup>21</sup>. Attempts were made at various historical stages to accommodate societal changes that only served to confuse and complicate the administrative notification process further. Only a brief account of the legislative landmarks leading up to the present day civil and vital registration systems, their requirements, and some reflection on the historical development is given here.

A variety of administrative records of population enumeration in forms such as colonial registers, diaries and journals since the mid-1600s have been used in the past<sup>22</sup>. Before the formation of the South African Union in 1910, the legislation relating to birth and death registration was different for each of the four colonies, and consequently each geographic territory produced, compiled and published separate reports<sup>23</sup>.

The establishment of a national statistics office in 1914, however, resulted in a more centralised approach to the collection of vital statistics, with the Births, Deaths and Marriages Registration Act of 1923 going further to ensure a more uniform approach to the registration of vital events. Although the act required compulsory registration for all races in the urban areas and for Africans living in rural areas (where the majority of Africans resided at the time) it was left up to the individual to decide whether to 'volunteer' this information<sup>22</sup>.

Apartheid legislation from around 1948 sought to formalise the idea of separate development. During this period, several Acts which affected demographic statistics were passed. Principally, the Population Registration Act of 1950 and the Native Laws Amendment Bill of 1951<sup>24</sup>. These two pieces of legislation aimed to compile a register of the population of the Union for purposes of issuing identity cards. However, another key feature of Population Registration Act is that it had the fundamental effect of removing a great deal of the individuals' agency about how they chose to present and interpret their identity in relation to power<sup>25</sup>.

This and other legislation fragmented the collection of vital statistics along the lines of race, and urban and rural residence, and contributed to what Bah refers to as the "stunting of the development of vital statistics among Africans"<sup>23</sup>. In addition, the creation of the four independent Homelands and six self-governing territories during the 1970's further stifled the way demographic information was collected.

A computerised population register established in 1972 recorded the details of Whites, Coloureds, and Indians and maintained a continuous source of records in the database. Attempts to improve the coverage and content of the population register occurred in three ways. First, in 1986 the registration of Africans through the issuing of uniform identity documents, and subsequently the “Population Registration Act Repeal Act” of 1991 and the “Births and Deaths Registration Act” of 1992 were amended to facilitate more accurate registration of all deaths with the Department of Home Affairs. The repeal of the Population Registration Act in 1991 effectively meant that the Department was no longer required to capture vital events classified by race; however, the act did require the registration of all deaths using the death notification form (DNF) B-1663 including medical certification of the cause-of-death. In settings where no medical practitioner was available for certification purposes, a headman could complete a death report form (BI-1680).

With transition towards democracy in the early 1990's, civil registration experienced major legislative and policy changes<sup>14</sup>. Structurally, the adoption of the South Africa Constitution in 1996, which served to frame the country into one geographic entity, demarcated into nine provinces, facilitated a standardised CRVS system. The introduction of the Births and Deaths Registration Act of 1992<sup>26</sup> removed registration based on racial classification and rural residence. Lastly, a collaborative initiative between strategic stake holders, Department of Health, Department of Home Affairs, Statistics South Africa and users of the data, help focus these groups on improving the vital statistics system<sup>27</sup>.

A variety of activities aimed at improving birth and death registration processes and the quality of vital registration data followed. Among these are the introduction of a new death notification form complying with WHO standards; establishment of provincial task teams to assist with implementation of the new death notification form; dissemination of ICD coding manuals explaining completion of the death certificate and classification of the cause-of-death and guidelines on the completion of birth and death registration<sup>14</sup>. In addition, relevant guidelines and new procedures were issued to registered doctors; and birth registration forms were made available at health facilities so that trained health workers could assist mothers to complete and submit the forms<sup>14</sup>. Stats SA also began skills development programs for their staff to improve processing and production of vital statistics<sup>14,27</sup>.

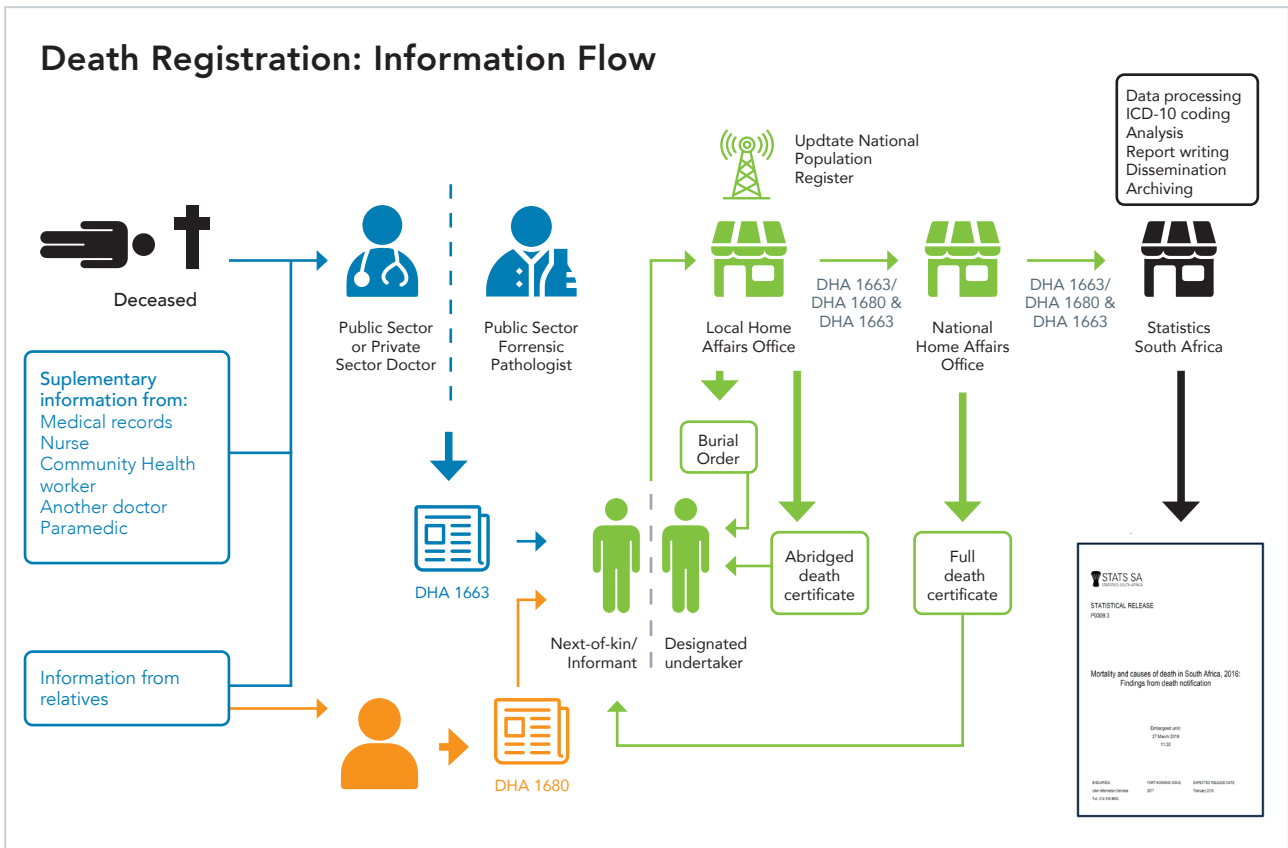
The result of inter-departmental initiatives since the mid-1990s achieved marked improvements in the completeness of both death<sup>28</sup> and birth registration<sup>29,30</sup>; however, despite interventions aimed at improving the quality of cause-of-death information directed at certification conducted by clinicians<sup>31</sup>, challenges around the quality of cause-of-death information remain<sup>32,33</sup>.

Strengths of the CRVS system include the attributes of collection, coordination, and publication of information that can be aggregated at district, province, and centralised to national level. South Africa has three government departments with national reach to report on an annual basis, provide civic documentation to the citizenry, and collect and transfer the information onto the government departments responsible for collation and dissemination of vital statistics. These are the Department of Home Affairs, Statistics South Africa and the Department of Health.

### 4.1.3 CRVS

CRVS in South Africa occurs within the framework provided by the Births and Deaths Registration Act (Act no 51 of 1992)<sup>26</sup>. The act requires all deaths and stillbirths to be notified to the Department of Home Affairs (DHA) on the official death notification form, Form DHA-1663, which includes the 2010 revision of the WHO international form of the Medical Certificate of Cause of Death<sup>34</sup> to be completed by a medical practitioner registered with the Health Professional Council of South Africa (HPCSA).

Figure 1 provides a schematic of the flow of information in the death registration process. A medical doctor or forensic pathologist is required to complete and sign the form. All deaths arising from unnatural (non-natural) causes must be referred to forensic pathology services for certification. In areas with poor access to medical practitioners, notice of a death may also be given via the Death Report (DHA-1680) provided that the death was due to a natural cause. The latter may be filled by authorised traditional leaders/headmen, members of the South African Police Service, and undertakers designated by the DHA.

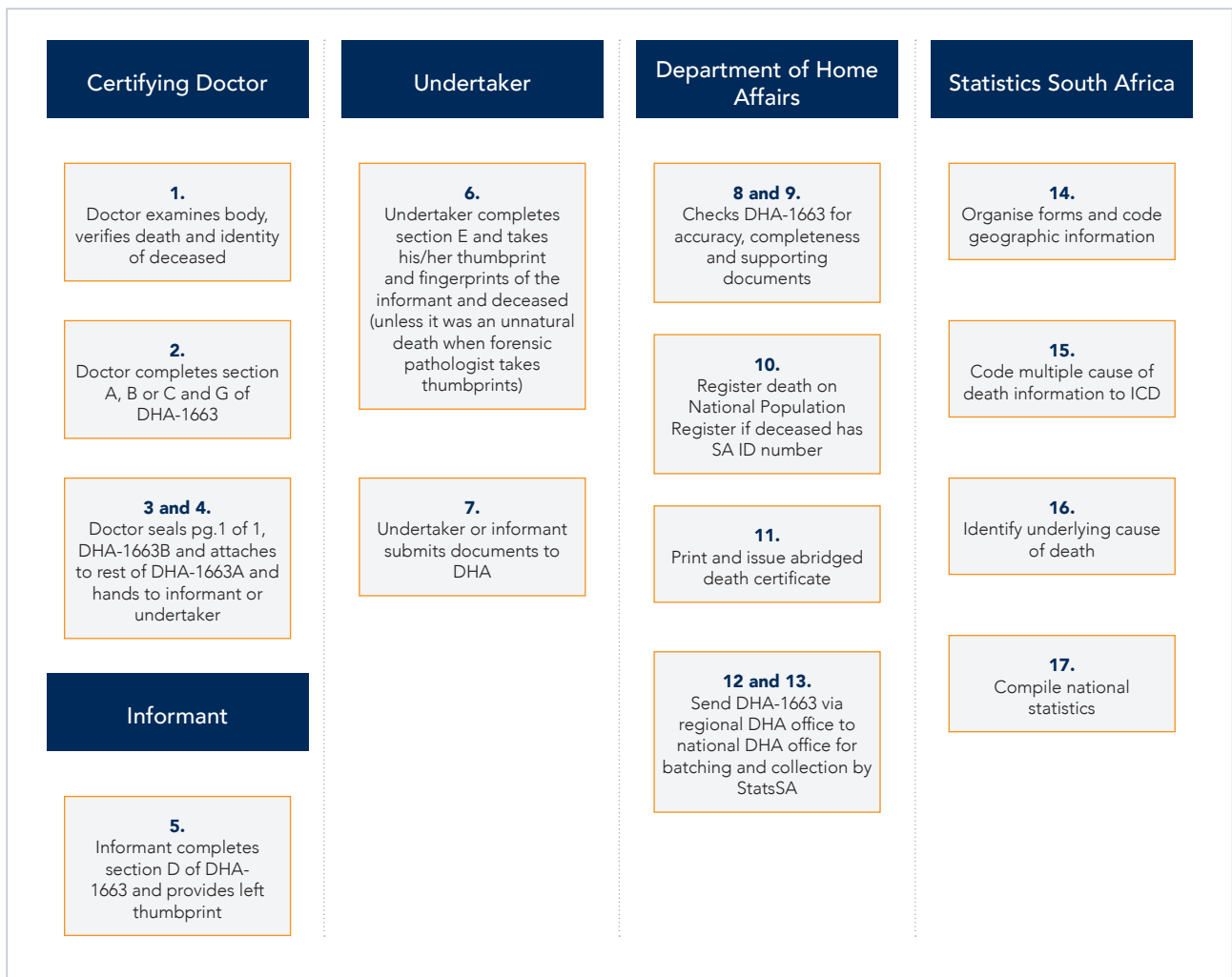


**Figure 1: Schematic of information flow for death registration in South Africa**

Source: Bradshaw et al (2020)<sup>2</sup>

#### 4.1.3.1 Completion of DHA-1663

The paperwork in the process of death registration begins with a certifying doctor completing relevant sections of the DHA-1663 (Appendix 1.3), sealing part B, which details the underlying cause-of-death, attaching part B to part A and handing these forms to the informant, most often a family member or handing them to the undertaker when delegated by the deceased’s family. The undertaker (or certifying forensic pathologist) completes section D of the DHA-1663 and provides a left thumbprint as verification of the information given on behalf of the deceased. The processes and responsible persons are schematically shown in Figure 2.



**Figure 2: Schematic of completion and processing of death notification forms in South Africa**

DHA-1663: Death notification form; Stats SA: Statistics South Africa  
 Source: Statistics South Africa (2012)<sup>35</sup>

#### 4.1.3.2 Funeral undertaker – process of death registration

A funeral undertaker may be designated by DHA to facilitate the registration of death on behalf of the family. Designated undertakers are issued with blank death notification forms (DHA-1663 with serial numbers) and may collate the documentation required for registration and take the fingerprints of the corpse. The completed DHA-1663 is taken to the local DHA office who will issue the death certificate. Alternatively, an informant may report the death for registration directly to the DHA office. The burial order is issued once registration has been completed. In the case of a home death, the corpse may be transported to a hospital for certification, or the undertaker may take the corpse to a mortuary and arrange for a medical practitioner to complete the medical section of the DHA-1663.

#### 4.1.3.3 Department of Home Affairs - process of death registration

The DHA maintains the computerised NPR. It comprises administrative details of all persons who have been issued with a South African identity document with a unique identity (ID) number. Eligibility for a South African ID number is based on South African citizenship or permanent residency from age 16 years or older. Death details are also included on the population register. This database provides information on the age and sex of deceased individuals who were on the population register.

The latest amendment to the Births and Deaths Registration Act of 1992 applicable to the registration of deaths replaced the previous DNF, BI-1663, with a longer form, DHA-1663, in 2009<sup>36</sup>. The new form is three pages instead of one and requires more information, but similar to the previous form, the last page contains demographic details and the causes



of death information. The DHA-1663 form is marked "Confirmation for Medical and Health use Only (After completion seal to ensure confidentiality)" and currently may only be accessed by Stats SA. In the case of minors (children under age 18), the details of the deceased child and the mother are included in this section.

The DHA captures personal and basic demographic information of the deceased on the Population Register, including whether the death was natural or non-natural (unnatural). A medical physician in the case of a natural COD carries out medical certification of causes of death included on the DNF. However, in rural areas where often no medical physician is available, a headman, or a member of the SA police service or a designated undertaker may complete a DHA-1680, also referred to as a death report. In the case of a non-natural (unnatural) cause of death, an inquest (required under the Inquests Act No. 58 of 195937), which is subject to medico-legal investigation. The results of the inquest are then sent to the DHA, which issues the final death certificate (which means that these take slightly longer to issue than for natural deaths). Some forensic pathologists feel that Section 20(4) of the Inquest Act prohibits them from reporting the manner of death, but others do report the manner of death.

In the case where an individual died before the birth is registered, the details of the death are not captured on the register because issuing the identification number is dependent on the notification of the birth. In such instances, neither the events of birth nor death are captured on the population register. A record of these events is maintained by DHA, but details of these events do not seem to be publicly available. Since entry of the decedent's details on to the NPR depends on a record of the individual's birth on the NPR, a key feature of these data therefore is large under-reporting of deaths of young children who died in the early hours, days, weeks and months of life.

#### 4.1.3.4 Statistics South Africa - reporting of death statistics

Part 1 of the DNF captures details of the death such as age at death, province of death and information related to the person who registered the death. Part 2 provides cause-of-death information consisting of three lines for the "immediate" cause-of-death, the "consequential" causes of death leading up to the immediate cause and the "underlying" cause-of-death. In the case of children, Part 2 also contains information about the mother, documenting her previous pregnancy outcome, antenatal treatment, and further important details of the deceased child such as birthweight.

Once entered on the Population Register, the DHA sends the forms to be recaptured by Stats SA head office in Pretoria where nosologists (mortality medical coder) classify all causes reported after which an underlying cause of death is selected using IRIS coding software and is checked against that selected by the Automated Classification of Medical Entities (ACME) programme. The cause-of-death information is coded according to the ICD-10 coding standards to single causes of death (4-digit codes). The underlying cause-of-death data are reported at a 3-digit code level.

In terms of the processing of vital statistics, late registrations refer to deaths that were registered later than the year in which they occurred. Although Stats SA aims to publish an annual statistical release on mortality and causes of death (series P0309.3) registered in the previous calendar year, the time taken to produce the report varies. Prior to 2010, this report typically took 24 months to publish<sup>38</sup>. The release of the 2010 annual report was published 14 months after the end of 2010; and the turnaround time to publication for the 2013 data was reduced to 11 months. As with the birth register, the database of deaths is updated with late registrations, but the timeliness differs from that of births<sup>39</sup>. In recent years, the time taken to report on mortality and causes of death has increased considerably, taking approximately 15 months for the 2016 data<sup>40</sup>, 27 months for the 2017 data<sup>41</sup> and 29.5 months for the 2018 data<sup>42</sup>. A probable reason for this delay could be changes to the working environment during the COVID-19 pandemic.

#### 4.1.4 Frameworks and criteria to evaluate cause-of-death statistics

There has been an evolution of the criteria for evaluation of the quality of cause-of-death statistics. In a seminal paper on the importance of "counting the dead", Mathers et al<sup>43</sup> conducted a global evaluation of cause-of-death data considering timeliness of reporting, completeness and coverage of registration, and the proportion of deaths assigned to ill-defined causes. Using completeness of death registration and the proportion of causes attributed to ill-defined causes to assess quality of cause-of-death statistics, the data prior to 1999 for South Africa fell below the threshold of both criteria, placing South Africa in the low-quality category.

In 2009, Stats SA initiated an assessment of South Africa's Health Information System which included vital statistics using a standards-based tool developed by the Health Metrics Network<sup>44</sup>. The tool was customised to the South African setting, i.e., ensuring that the selection of relevant questions and the standards were meaningful. A consultative workshop was held in March 2009 to obtain input from a wide range of role-players. The development of a standards-based tool focused on the processes involved in setting up and maintaining an HIS, e.g., human resources, indicators, data management, and included CRVS as one of the population-based data sources. The evaluation tool included benchmarks that were designed to provide guidance towards developing a strategic plan. However, it is not clear how the findings were utilised by the government.

Building on a more extensive conceptual framework for evaluation of cause-of-death data developed by Rao et al (2005)<sup>45</sup>, Mahapatra et al (2007)<sup>8</sup> outlined a more detailed set of criteria to evaluate the quality of data. In a global assessment of cause-of-death data, they also rated South Africa as having poor quality data.

Joubert et al (2012)<sup>28</sup> evaluated the quality of the cause-of-death statistics for the period 1997-2007 using the framework proposed by Rao and colleagues<sup>45</sup>. Of the nine criteria, two were rated as being unsatisfactory, six as satisfactory and one could not be evaluated:

1. Coverage	- satisfactory
2. Completeness	- satisfactory
3. Epidemiological Consistency	- could not be assessed
4. Temporal Consistency	- satisfactory
5. Content Validity	- unsatisfactory
6. Use of Ill-defined and Non-specific Causes	- unsatisfactory
7. Use of Age- and Sex-improbable Classifications	- satisfactory
8. Timeliness	- satisfactory
9. Sub-national Availability	- satisfactory

By 2007, there had been impressive improvement in the completeness of registration. However, major deficiencies relating to certification were the high proportion of deaths with ill-defined causes (13%), and an additional 13% having a cause-of-death which is not valid as an underlying cause in 2016<sup>40</sup>. The misattribution of HIV-related deaths to the opportunistic infections or pseudonyms for HIV leading to profound under-reporting has been extensively documented in South Africa<sup>46,47</sup>. It has been reported that a major obstacle to providing relevant public health information on injury-related deaths is their misclassification, largely due to lack of a field for the manner of injury on the death notification form<sup>48</sup>. Currently, the absence of the manner of death for an injury results in inaccurate national injury statistics, particularly for homicides, suicides, and transport accidents. A comparison of injury-related deaths recorded in the vital registration system<sup>49</sup> with deaths from post-mortem investigation found that homicides accounted for 10% of injury deaths according to Stats SA while they accounted for 36% of injury deaths according to the Injury Mortality Survey for 2009. Similarly, transport accidents accounted for 11% of injury deaths according to Stats SA and 34% according to the Injury Mortality Survey. In addition, forensic pathologists are reluctant to report the manner of death for injuries on the death certificates for fear of pre-empting the inquest findings. Compounding this problem is the ICD coding standard which rules that unspecified injuries should default to accidents.

The Global Burden of Disease team have developed a composite index of the quality of cause-of-death data, the Vital Statistics Performance Index<sup>50</sup> (VSPi). An overall score between 0 and 1 is based on a weighted combination of six dimensions: completeness of death registration, quality of cause-of-death reporting, quality of age and sex reporting, internal consistency, level of cause-specific detail, and data availability and timeliness. Mikkelsen et al<sup>50</sup> reported that South Africa had shown a substantial improvement during the 1990s, increasing from below 0.1 prior to 1995 to about 0.7 by 2010. However, the score dropped for the most recent period assessed (2010-2012) to below 0.5, which may be associated with timeliness which had begun to falter at that time, prior to an initiative by Stats SA to improve reporting times.

## 4.1.5 Assessment of CRVS 2014/15

The South African government undertook a comprehensive assessment of the CRVS system<sup>5</sup> between October 2014 and March 2015 with the overall aim of enhancing overall performance and providing the evidence required to prioritise interventions for strengthening the CRVS systems in the country. The CRVS assessment was undertaken by all entities involved in CRVS activities in the country, primarily the DHA, NDOH, Department of Justice and Correctional Services (DOJ&CS) and Stats SA. Other departments involved in the assessment included the Department of Basic Education (DBE), Department of Social Development (DSD) and The Presidency. Technical support was provided by: the United Nations Children's Fund (UNICEF), the United Nations Population Fund (UNFPA), the United Nations High Commissioner for Refugees (UNHCR), and the WHO.

The aim of the assessment was to identify strengths and weaknesses in the current system, drawing lessons from what has worked over time and to provide evidence of required interventions for strengthening CRVS. Specific objectives included:

1. To obtain information that will enhance overall performance of the CRVS system and influence the direction of development of the systems.
2. To establish an objective baseline that forms the basis for follow-up evaluations.
3. To build consensus around priority areas for CRVS system strengthening and mobilise technical and financial support for the implementation of a national strategic plan.
4. To assist the government and partners to distinguish key issues and increase the use of CRVS records.
5. To present exceptional learning from peers and clients/users from the self-assessment process.
6. To develop a costed National Strategic Plan for CRVS.

Data collection tools were developed with technical advice from United Nations Economic Commission for Africa (UNECA) and NICEF. Data collection was undertaken from 3 to 14 November 2014 in 21 selected areas in nine provinces. Two areas were selected within each province, and for Eastern Cape and KwaZulu-Natal, three areas were selected. The selection criterion for DHA and health facilities was based on well performing offices, facilities with known challenges, hard to reach areas, and the presence of special groups, e.g., people with disability. Interviews were also conducted with traditional leaders in Mpumalanga, Eastern Cape, North West, KwaZulu-Natal and Northern Cape. In Western Cape and Gauteng, focus group discussions were held with Muslim religious leaders. Funeral undertakers and individuals from Health and Demographic Surveillance Sites and five Medical Universities were also interviewed.

The findings of the investigation have been reported in the broad areas of policy and legislative environment, management and operations, resources for CRVS, registration operation – processes and practices, data management, demand creation for registration, monitoring and evaluation. An overview of the findings in each broad area are presented below with further details given in Appendix 2. However, it appears that it remains for the government to respond to the information gathered and develop a costed strategic plan.

### i) Policy and Legislative Environment

This section reflects on existing legislation and considers suggested amendments for the registration of vital events, production of vital statistics and the management, coordination and linkages of systems in CRVS. The section was largely done through desk review by a legal team from the three stakeholder departments. It was concluded that South Africa has a comprehensive legal framework governing civil registration processes and operations and that the laws are updated periodically with new regulations to accommodate changing environments. However, there are numerous issues that could be given more attention. Key observations include:

- Although the different entities work with each other, there is no high-level committee in place for coordinating activities with respect to CRVS. Coordination is currently ad hoc and takes place when the need arises. Entities within the CRVS system regularly work together. A high-level coordination committee was established for this assessment (Steering committee). It is envisaged that this committee will become a permanent structure.

- No medium or long term integrated CRVS strategic plan exists. Each entity has its own costed strategic plan. The country should consider the development of a comprehensive plan based on the outcome of the assessment.
- Civil registration laws in South Africa currently do not have provision for linking or interfacing with the national statistical system, identity systems, passport issuing, population register, or any other systems.
- The law does not specify the coordination mechanism among stakeholder agencies. However, the death registration process links to the health system by implication, this is through the collection of causes of death through the DHA-1663 Form. In addition, there are several examples of cooperation and data sharing between government departments e.g., data from the NPR is linked with the Department of Social Development systems for the purposes of payment of social grants.
- Innovations introduced in civil registration such as mobile and hospital units and SMS notifications are not documented in legislation.
- Specifically, in relation to the production of vital statistics there is no clear provision in the Statistics Act for the following:
  - The collection of causes of death data for statistical purposes.
  - The transmission and processing of the notice of death form to Stats SA.
  - The use of civil registration process for producing statistics on vital events is only implied for deaths because of section B of the DHA 1663, but there is no clear provision in the Act.
- Several specific gaps in the legislation were identified, including definitions and processes around data collection, production of vital statistics and linkages of the systems in CRVS (see Table A2.2 in Appendix 2).

## ii) Management and operations

This section evaluated the management and operations of CRVS in the country. It covered the processes, roles and responsibilities of several government departments and other stakeholders such as traditional and religious leaders and funeral undertakers. The assessment highlighted many gaps and suggested mechanisms for improving performance of the structures responsible for CRVS and accessibility of service points. Examples are shown in Table A2.4 in Appendix 2. In terms of data use, it was noted that:

- Various role players in the CRVS system have operational arrangements in the form of Memorandums of Understanding and Service Level Agreements that allow cooperation and data sharing between the entities. An example of this is between Stats SA and DHA regarding acquisition of forms and data by Stats SA for statistical purposes.
- Academic institutions and other researchers indicated that they use mortality and cause-of-death data for research purposes, i.e., estimation and trend analysis and that there are strategies for deaths statistics. Only the birth and death data are currently being used to check the accuracy of data against other data, mainly census data.

## iii) Resources for civil registration

This section reviewed the availability, quality and adequacy of CRVS resources. Resources covered were infrastructure, human resources, budgets and forms and other materials. It was noted that questions on infrastructure, and budget for CVRS were poorly answered. Key observations include:

- In relation to infrastructure, there seems to be some unhappiness about the working environment by office personnel as well as poor quality of resources such as computers, printers and telephones.
- The most consistent issue brought up by DHA clients was around the shortage of staff in offices, and the length of waiting time related to DHA services such as obtaining documents.

- Responses obtained from managers indicated a lack of common standards of what constitutes adequate storage for forms in facilities across DHA and how they should be stored.
- Two managers suggested improving timely registration of births by moving all birth registrations to hospitals with dedicated personnel for that service.

#### iv) Registration operation - processes and practices

This section reviewed the registration processes and procedures as per the department/institution for births, deaths, marriages and divorces. This assessment revealed that all institutions responsible for CRVS have a Standard Operating Procedure (SOP) to facilitate registration and revealed that there is generally good understanding of processes, procedures and documents required for registering. However, some officials felt there was a lack of public education about procedures and necessary documents for registering events. For instance, most clients visiting the DHA offices had incomplete documentation and some traditional leaders indicated that in their community no documentation is needed because people bury in their own family graveyards. Respondents were also assessed on both formal and informal (verbal autopsy) processes and procedures related to death and the impact of cultural and social factors affecting registration i.e., children born out of wedlock, resulting in late birth registration.

#### v) Database management

This section considered the storage and archiving of records, data, information sharing, and transmission of records. All processes are done manually and electronically. Even though the Act that regulates the storage and archiving of data provides for the proper management and care of public and non-public records, there is no standard and clear procedure for storage and transmission of vital records in regional offices. Issues concerning modernising and digitising DHA offices were highlighted as most offices use computers, but not all.

- There seems to be no clear procedures for handling and storage of records - some offices do not have acceptable facilities for record storage while some indicated that these facilities were not adequate. Most DHA offices did not have electronic storage, nor a systematic way of record keeping or method for checking accuracy and backup systems. Although most offices allocated only a few personnel access to records and storage for security purposes, some did not have lockable storage facilities to protect records.
- In relation to information sharing and transmission, the following issues were raised:
  - There is delay in acquisition of the death notification forms by Stats SA. Highlighted in other sections, there seem to be a lack of understanding of the importance of timely record transmission.
  - Delayed registrations being treated differently from timely registrations, and not being transferred to the vital statistics system, interrupting collection and data processing.
  - Loss of documents between transfer of the information from civil registration agencies to the vital statistics system, e.g., DHA 1663 without page 1 of 1 resulting in increase of ill-defined causes of death.
  - Failure to transmit information that arrived after a scheduled transmission period.
  - Failure to transmit information on forensic cases once they have been resolved and returned to the civil registration system.
  - Violation of confidentiality. The level of security provided during preparation and transmission of forms is minimal and, in most cases, the information is accessed by people who are not entitled to do so, resulting in many certifiers reluctant to write some causes of death such as HIV infection and AIDS.
  - High cost involved in preparation and transmission of records, such as costs for courier services, transportation of forms from DHA to Stats SA and back, packaging materials and photocopy of requests by DHA when forms are at Stats SA.
- It was suggested that many of these issues could be resolved through automation – scanning forms and transferring images from point of origin (at DHA) to the statistical point (at Stats SA) where capturing from images will be done. Introducing an audit system that will clearly outline responsibilities for logging all registration events sent to Stats SA and for recording what is received from local offices.



## vii) Demand creation for registration

This section evaluated respondents' understanding of the importance of registering vital events. The findings revealed that there is good understanding and appreciation of the importance of registration and the documentation emanating from the process. There is also awareness of the challenges that hinder registration as perceived by the respondents. Culture plays a large role in registering or not registering vital events.

For deaths, the issues of the effect of culture, on lack of registration of stillbirths were highlighted by respondents, as was death registration in rural areas not occurring because burials take place on family grounds. Long distances travelled to the DHA offices and long queues also de-motivated some people and bringing services closer to the people and hiring more staff would improve the registration.

## viii) Monitoring and evaluation for civil registration

The structures and procedures for supervising the production of vital statistics falls under the Stats SA divisions responsible for Corporate Data Processing and Health and Vital Statistics. It was noted that there is a need to publish vital events more regularly, such as on a quarterly basis to better inform relevant policy.

### 4.1.6 Public health use of cause-of-death data

#### 4.1.6.1 Rapid mortality surveillance

Since 1999, the South African Medical Research Council has developed a database comprising the deaths registered on the NPR that is updated every month with basic demographic details for each death. These data were valuable for monitoring trends in adult mortality<sup>51</sup>, during a period when Stats SA were unable to provide current information due to delays of up to six years in the processing and reporting of cause-of-death statistics.

The NPR data represent a precursor subset of the vital registration data, which particularly under-represent deaths of children due to the dependence of the capture of deaths on the NPR on prior registration of births. Deaths of children that are registered by DHA will not be added to the NPR unless the birth has already been registered. However, such deaths should eventually be captured in the vital registration data.

An annual Rapid Mortality Surveillance (RMS) Report, based largely on this SAMRC database, has been produced for the years since 2011 to provide empirically based estimates of key childhood and adult mortality indicators<sup>52</sup>, and more recently, indicators of adolescent mortality and mortality related to non-communicable diseases<sup>53</sup> for monitoring purposes. Initially, the reports were used by the Health Data Advisory and Coordination Committee to monitor progress on key mortality indicators<sup>54</sup> but the reports have been used more widely since then.

Since March 2020, the DHA have provided the SAMRC with death data from the NPR on a weekly basis, which has enabled the RMS to track excess deaths weekly<sup>55</sup>. Excess deaths have been monitored provincially and in the eight metropolitan districts and by whether the cause was natural or unnatural (non-natural). This has made it possible to provide near to real time estimates of the numbers of death and the excess deaths from natural causes and has provided the country with an essential quantum on the impact of SARS CoV-2 pandemic<sup>4</sup>.

#### 4.1.6.2 Local level mortality surveillance

A unique district level mortality surveillance system was set-up in the early 2000s between the Health Department of the City of Cape Town, the University of Cape Town, and the SAMRC to provide information from the DNF at local Department of Home Affairs offices prior to the forms being sent to the national statistics office for processing COD information<sup>56</sup>. City of Cape Town health officials were given copies of the DNFs at local Home Affairs offices and the data were captured by Health Information officers. Additional information about the underlying cause-of-death was obtained from forensic mortuaries to reduce the proportions of 'unspecified' in injury mortality data, and for the presentation of the cause-of-death profiles, ill-defined causes were proportionately redistributed to defined causes. In 2009, the Western Cape Department of Health joined this collaboration and expanded the local-level surveillance to the entire province.

Due to the surveillance system capturing subdistrict cause-of-death data, the utility for public health was immense. The data were used for decision-making at the smallest units of health management. Processing the deaths of children was prioritised and each year, these data were used to identify the geographic areas affected by diarrhoeal deaths so that environmental health officers could target areas for interventions. The project focused on the presentation of the data and for the first time described extreme health inequalities across the city and demonstrated that mortality surveillance could identify the leading causes of premature mortality and provide useful data for monitoring the effectiveness of programmes and interventions and reduce inequalities. This Western Cape initiative, illustrates how a local mortality surveillance system can improve the quality of cause-of-death statistics, while also providing essential information for public health action, programme monitoring and evaluation, and health policy and planning<sup>57</sup>.

After the production of provincial mortality reports from 2008 onwards<sup>58</sup>, an amendment to the South African Births and Deaths Registration Act was implemented in 2014 that introduced a new format of the DNF, making the fourth page (medical certificate of cause-of-death identified as Page 1 of 1) self-sealing, and stated that the page may only be opened by an official of Statistics South Africa. The desired effect of the amendment was to ensure confidentiality and thereby encourage more accurate description of COD information. However, this effectively halted effort to strengthen local mortality surveillance, provide statistics for small areas and enable data linkage to provide information for public health actions. Although COD information is confidential, public interest requires that it be available to NDOH to perform its functions, and to others such as health researchers and other scientists to undertake crucial scientific research. International experience has led countries such as Australia, Britain, and the USA to recognise the need for a careful balance between protecting individual patient confidentiality and enabling effective public health intelligence to guide activities toward the national good<sup>59</sup>.

#### 4.1.6.3 Verbal autopsy

Verbal autopsy is a method to ascertain a probable cause-of-death based on an interview conducted with the next of kin or caregiver of the decedent about the illnesses and circumstances leading to death. South Africa conducted a national cause-of-death study in 2017 to validate COD information from vital statistics with COD information collected from verbal autopsies<sup>2</sup>. The purpose of this study was to derive correction factors to adjust cause-specific mortality data from CRVS based on the reference diagnoses at national, provincial, and district levels. The study also aimed to design and test a standardised methodology for verbal autopsy for deaths occurring outside health facilities, with a view towards broader implementation in the routine processes of death registration.

The results of the study demonstrated that collecting national COD data using verbal autopsy was achievable and could provide good quality COD information. In particular, there appears to be improved accuracy in the proportion of deaths due to HIV/AIDS and the profile of injury-related deaths<sup>2</sup>. It is anticipated that verbal autopsy could provide useful information for deaths that occur outside of health facilities. The full analysis of the national cause-of-death validation project is underway as well as a pilot study of tele-VA in collaboration with the Western Cape DOH during the third wave of the SARS CoV-2 pandemic.

#### 4.1.6.4 Burden of disease analysis

Differential under-reporting of deaths by age, the high proportions of "garbage" causes including ill-defined signs and symptoms, the misclassification of HIV/AIDS deaths, insufficient detail relating to the manner and cause of non-natural deaths and the non-medical certification of deaths by headmen in rural areas based on informant information, have all necessitated the undertaking of burden of disease studies to ascertain coherent estimates of the levels and causes of mortality through the analysis and synthesis of several data sources.

The Initial National Burden of Disease Study for South Africa, centred on the year 2000, revealed a unique quadruple burden of disease comprising the broad cause-groups HIV/AIDS and TB, non-communicable diseases, poverty related conditions including maternal and child health, nutrition and other infections and injuries<sup>60</sup>. The second National Burden of Disease Study, covering the period 1997-2012, highlighted the beginning of the reversal of several epidemics and demonstrated stark provincial and population group differentials in mortality<sup>47</sup>. The implications of less than perfect cause-of-death data for public health actions, make a National Burden of Disease study an essential contribution to describing trends in the causes of death and ensuring internal consistency across causes and geographical regions.

Despite the inadequacies of cause-of-death statistics, the information from the CRVS system also displays strengths. The analysis of district level data has proven useful not only in terms of identifying issues of quality and systems failure when investigating the data but also for presenting mortality profiles simply by adjusting for ill-defined causes for 52 health districts i.e., a partial burden of disease approach. These profiles have been incorporated into the District Health Barometer to assist with the process of district health planning<sup>61</sup>.

## 4.2 Analysis of cause-of-death data

Based on the literature review, it was decided to use the framework by Mahapatra et al<sup>8</sup> shown in Table 2 to consolidate the observations made in the rapid assessment. The framework considers the accuracy, relevance, comparability, timeliness, and accessibility with a focus on cause-of-death statistics. It distinguishes between the general vital statistics that would arise from the registration process maintained by DHA and the cause-of-death statistics that are produced by Stats SA.

**Table 2: Assessment framework for vital statistics from civil registration systems**

	General vital statistics	Cause-of-death statistics
<b>Accuracy</b>		
Coverage	% of population living in areas where CRS is functional	% of population covered by medical certification of cause-of-death
Completeness	% of events contributing to fertility/mortality statistics	% of deaths with medically-certified cause-of-death
Missing data	% of key variables with response not stated	% of cause-of-death reports for which age/sex data are missing
Use of ill-defined categories	Not applicable	% of deaths classified under various miscellaneous and ill-defined categories
Improbable classifications	Not applicable	Number of deaths assigned to improbable age or sex categories per 100 000 coded deaths
Consistency between cause-of-death and general mortality	Not applicable	% of cause-of-death data points deviating more than 2 (or 3) SDs from general mortality based predictions
<b>Relevance</b>		
Routine tabulations	By sex and 5-year age groups, based on place of usual residence. Deaths in children under 5 years tabulated by 0 and 1–4 year age-group	By sex, and at least by eight broad age groups—namely, 0, 1–4, 5–14, 15–29, 30–44, 45–59, 60–69, and 70+ years
Small area statistics	Number of general vital statistics tabulation areas per million population	Number of cause-of-death tabulation areas per million population
<b>Comparability</b>		
Over time	Stability of key definitions over time	Consistency of cause specific mortality proportions over consecutive years
Across space	Uniformity of definitions across areas	ICD to certify and code deaths. revision used and code level to which tabulations are published
<b>Timeliness</b>		
Production time	Mean time from end of reference period to publication	Mean time from end of reference period to publication
Regularity	SD of production time	SD of production time
<b>Accessibility</b>		
Media	Number of formats in which data are released	Number of formats in which data are released
Metadata	Availability and quality of documentation	Availability and quality of documentation
User service	Availability and responsiveness of user service	Availability and responsiveness of user service

Source: Mahapatra et al, (2007)<sup>8</sup>.

## 4.2.1 Accuracy: Coverage and completeness of death registration

The number of deaths reported by Stats SA increased from just over 400,000 in 1997 and peaked at 614,412 in 2006, gradually declining to 446,546 in 2017. With the constitutional consolidation of all regions of the country in 1994 described in Section 4.1.2 of this report, it is considered that the CRS covers the whole population of South Africa, i.e., that coverage of death registration is 100%. However, not all deaths in the country are registered. A multistep approach has been used to estimate the completeness of death registration for the second South African National Burden of Disease study<sup>47</sup> and updated for the annual Rapid Mortality Surveillance Reports<sup>62</sup>, for three age groups as shown in Table 3.

**Table 3: Estimates of completeness of death registration by age group**

Age group	Methodology	Completeness
Under-5 years	Comparison of child mortality rate with survey and census--based estimates	72%
5-19 years	Smooth transition between Under-5 and the 15+	Linear interpolation between 72% and 92-93%
20+ years	Demographic methods comparing the deaths with population census	92-93%

Source: Dorrington et al (2020)<sup>62</sup>.

Dorrington et al<sup>4</sup> have undertaken a detailed analysis of the completeness of registration of adult deaths (15+ years) according to the date of release. "Late registrations" are added to the data as they become available to Stats SA for inclusion<sup>4</sup> arising from delays in registration of the deaths as well as delays in the transfer of documents within the system (i.e., "late processing"). The completeness increases over time as "late registrations" of deaths from previous years are added. Figure 3 shows the completeness of registration of adult deaths based on the published vital registrations for each calendar year against time between the end of the year of death and the date of release of each report. For example, the completeness of reporting of deaths that occurred in 2013 increases as the "late registrations" are added: the initial report on these deaths was released 0.92 years after the end of 2013, at which point 85.7% of the estimated true number of deaths for the year were reported. The next report on deaths was released a year later, at which point, the deaths reported for 2013 had increased to 88.6% of the estimated true number of deaths, the next report was released a further 1.25 years later, etc., until the most recent report, some 5.33 years after the initial report, with completeness plateauing slightly above 89%.

While the initial release of the report took about 2 years during the period 2008-2010, the completeness was higher than in subsequent years, running between 93-94% and increasing by a further percentage point over time. The initial release was reduced to about 18 months for deaths in 2012, but completeness fell below 89% increasing over time to 91-92%. Completeness of death registration was at its lowest for 2013, starting at 85.5% and reaching 89%, however, there is some evidence that the estimates should be 1% higher due to a possible overestimate of the true number of deaths in 2013. For the period 2014-2015, the levels of completeness reached 91%. The initiative to speed up the reporting of cause-of-death statistics introduced with the report on 2012 data has affected completeness, and the completeness cannot be assumed to be constant over time. The completeness in death registration in 2017 was just below 87%, this is comparable for the first release of 2014-2015 data, but low for a duration of 2 years for the report to be released.

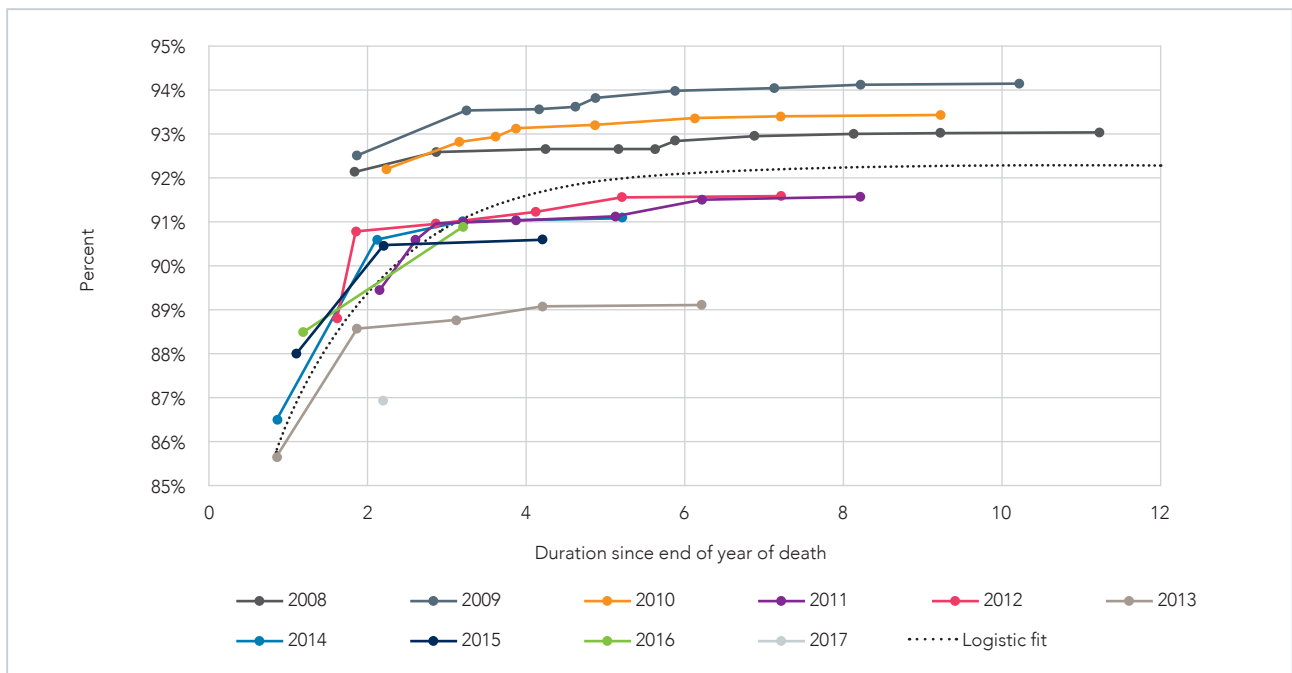


Figure 3: Completeness of registration by time since death on average for annual releases of the cause-of-death data

Source: Dorrington et al. (2021)<sup>4</sup>.

#### 4.2.2 Comparison of number of deaths from NPR and Vital Registration

Since only deaths of people with a South African ID number are included on the NPR, the number of deaths from VR should be higher than the number on the NPR. It has been found that close to 100% of death notifications of people aged (25+), and between 90% and 95% for the age groups 1, 2-14, 15-19, and 20-24 years are recorded on the NPR<sup>62</sup>. The proportion is about 56% for children who die within the first year of life. The ratios of broad age-groups under-15 years, 15 to 59 years and above 60 years for males and females are shown in Figure 4. Close to 100% of death notifications of people aged 60 and above, and between 90% to 98% of people aged 15-59 years were on the NPR. Between 2010 and 2016, females above 60 years exceed 100%. The uptick in 2017 is due to missing late registration of 2017 deaths, which missed the cut-off date for inclusion into the 2017 report. The proportion of people under-15 years on the NPR increases with time, and in 2017 exceeded 70% (also due, in part to missing late registrations). Late registrations are mostly due to delay in the transfer of forms between offices and less due to the result of the difference between the occurrence of death and registration of death (personal communication, Stats SA).

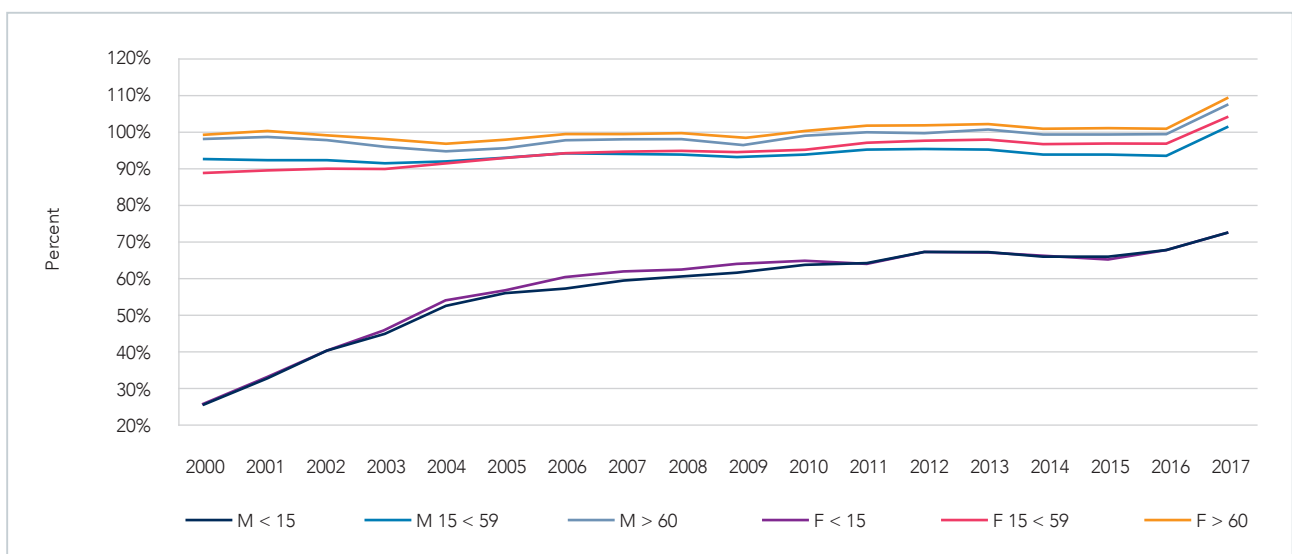
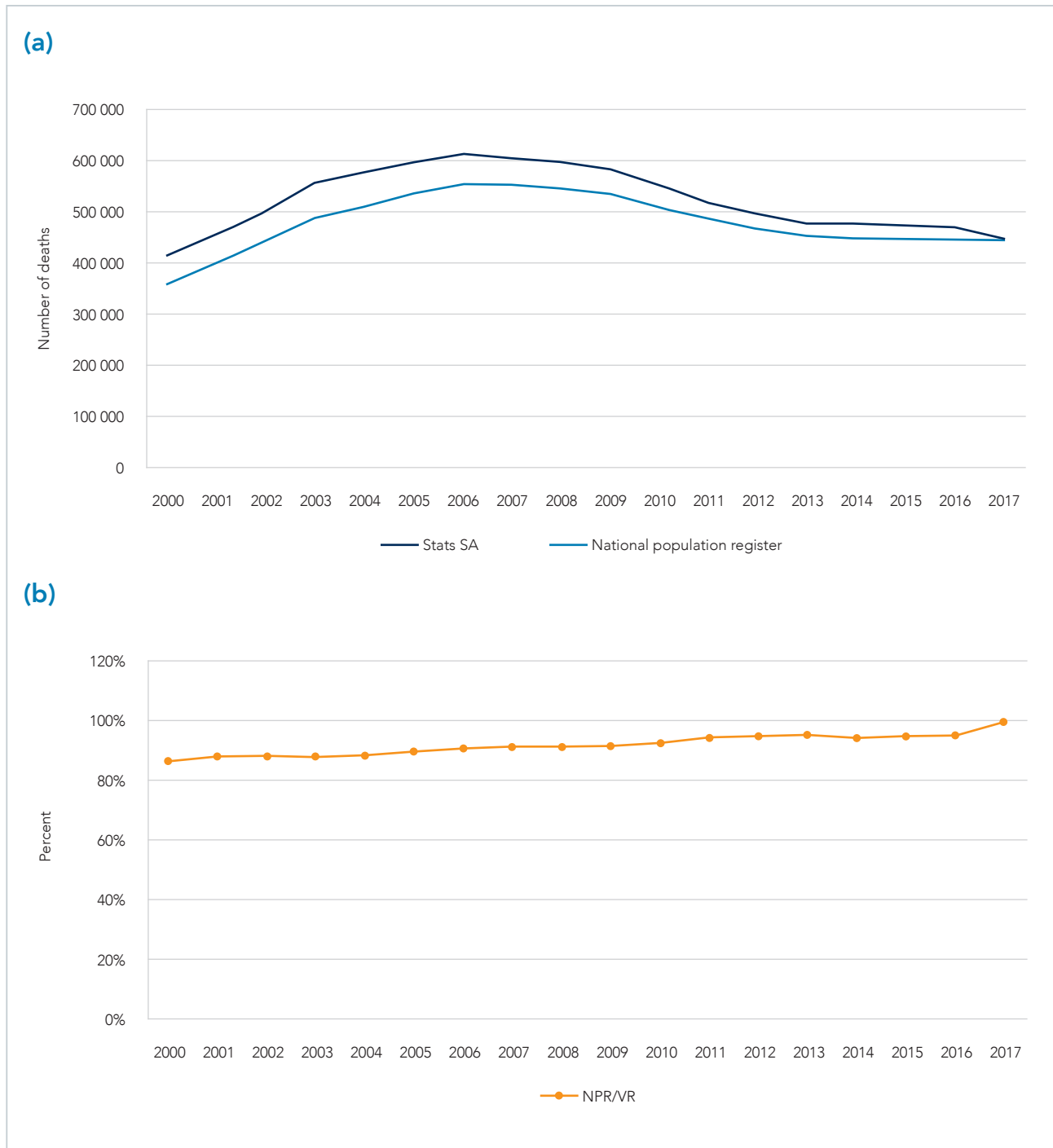


Figure 4: Ratios of National Population Register (NPR) deaths relative to Stats SA (VR) deaths by age-sex categories, 2000-2017

Figure 5a shows that the number of deaths in the NPR are slightly lower than those reported to VR throughout the period peaking in 2006 (N=555,708); however, the difference began to decline around 2011. The narrowing of the difference between NPR data and VR data indicates improvement in birth and subsequent Identification Document (ID) registrations. However, the noticeable narrowing of the gap in 2017 suggests a delay in transfer of death notifications for the latest year. Another way of assessing the changes is shown by the ratio of the total number of deaths recorded on the NPR as a proportion of deaths reported by Stats SA is shown in Figure 5b. This highlights a steady increase in this proportion from 86% in 2000 to 95% in 2016, indicating improvement in the birth and subsequent Identification Document (ID) registrations, and the abrupt increase to 99% in 2017 associated with late transfer of forms between DHA and Stats SA.



**Figure 5: Total numbers of National Population Register (NPR) and Stats SA deaths (VR) (a) and proportion of NPR to VR (b), South Africa 2000-2017**

### 4.2.3 Number of deaths by province

It is challenging to compute the completeness of death registration by province due to inter-provincial migration of the population. For the second National Burden of Disease Study<sup>63</sup>, estimates were derived for infants, children 1-4 years, and adults 15+ years up to the year 2010. The estimates of completeness used in the 2<sup>nd</sup> National Burden of Disease Study are shown in Table 4.

**Table 4: Estimates of provincial completeness in 2010-2012 by age group, 2nd National Burden of Disease Study**

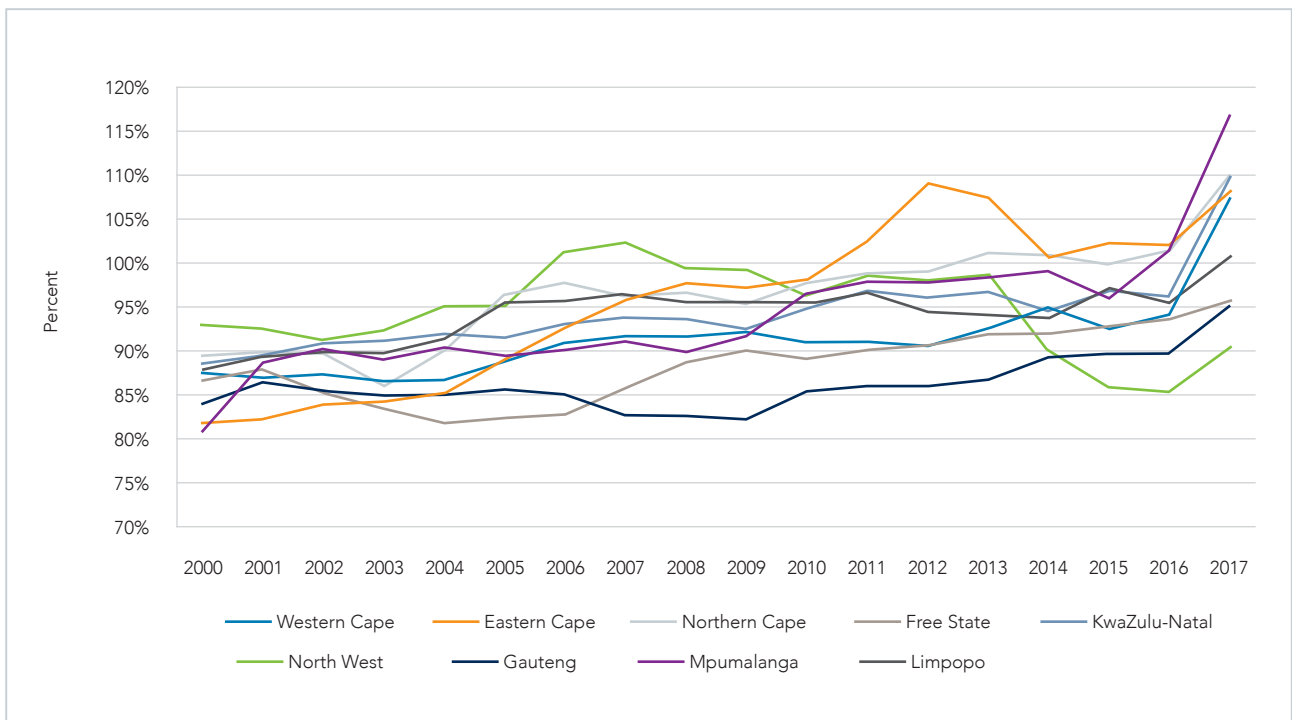
Province	Infants (%)	1-4 years (%)	15+ years (%)
Eastern Cape	48.1	50.8	87.4
Free State	124.5	83.9	107.7
Gauteng	121.9	66.4	95.0
Kwa Zulu-Natal	61.4	44.8	83.4
Limpopo	86.3	99.1	107.3
Mpumalanga	70.7	66.8	88.6
Northern Cape	123.8	101.4	111.4
North West	110.2	80.9	92.1
Western Cape	121.5	53.5	100.4
South Africa	85.0	64.1	93.0

Source: Adapted from Pillay van-Wyk et al<sup>63</sup>.

In this assessment, we consider the numbers of deaths on the NPR relative to the number reported by Stats SA to better understand the shortage of deaths in the VR data for 2017. The numbers of deaths reported to Stats SA by province and year are shown in Appendix 3. Few deaths are recorded for the "Unknown" and "Outside of South Africa" for the period 2000 to 2005. Substantive fluctuations in both categories are recorded thereafter up to 2016. In 2017, 17,213 deaths were recorded with province as being "Unknown". No deaths were recorded as being from "Outside of South Africa". The reason for these fluctuations is unclear.

Compared with the number of NPR deaths, the Stats SA data show the general trend of an increase in the number of NPR deaths captured by vital registration in all provinces (Figure 6). In 2000, the proportion ranged from 81% Mpumalanga (MP) to 93% North West (NW) and in 2016 the proportion ranged from 85% (NW) to 102% Eastern Cape (EC). The sharp increase in the ratio between 2016 and 2017, can be seen in all provinces, and is due to the late registration of deaths that occurred towards the end of 2017, and therefore not captured by the Stats SA official statistical release cut-off date, which is usually the end of March of the year after registration, (although this sometimes changes). Aside from the ratios presented for the last year, the North West, Eastern Cape and to a lesser extent the Northern Cape experienced periods where the ratio exceeded 100%. None of the other provinces ever attain 100% of NPR deaths captured onto the VR system. For example, Gauteng (dark blue), Free State (yellow) and Western Cape (light blue) show steady increases in the ratio from about 85% at the beginning of the period to between 90%-95% in 2016. It is, however, important to note that the NPR data are categorised by the province where the office of registration is located and not by province in which the death occurred and this is likely to account for some of the difference in the ratios.





**Figure 6: National Population Register (NPR) deaths as a proportion of Stats SA (VR) deaths by province, South Africa 2000-2017**

#### 4.2.4 Missing data

Elements of missing data for 2017 presented in Table 5 are the categories “Don’t Know”, “Unknown” and “Unspecified” summed to “Total missing” and the last column showing the proportion of total missing. While Table 5 highlights problems with completion of some of the fields, there have been improvements over time. The introduction of the new DNF in 1998 brought improvements in reporting on some important variables. For example, there was a marked reduction in the proportion of ‘population group’ missing from 60% in 1998 to 24% in 2010 and further reductions to 12% missing in 2017. Completion of the province of residence also showed improvement from 19% missing in 1998 to just over 1% in 2017. Proportions of deaths missing age and sex variables have been very low throughout the period. Other important variables for the study of mortality have been added to the data set such as the collection of ‘occupation group’ in 2006.

**Table 5: Missing data, Stats SA 2017 (N = 446,546)**

Data field	Don't know	Unknown	Unspecified	Total missing	Proportion of total missing
Next of kin smoker	0	0	446,366	446,366	100.0%
Province of birth	0	230,067	0	230,067	51.5%
Education	0	25,131	181,149	206,280	46.2%
Smoker	24,209	0	135,241	159,450	35.7%
Ascertainment	0	344	148,586	148,930	33.4%
Place of death	0	647	109,005	109,652	24.6%
Relationship	0	0	86,562	86,562	19.4%
Marital status	0	0	78,255	78,255	17.5%
Pregnancy	0	2,108	54,436	56,544	12.7%
Population group	0	0	54,927	54,927	12.3%
Occupation group	0	0	50,674	50,674	11.3%
Death district	0	0	17,213	17,213	3.9%
Death province	0	17,213	0	17,213	3.9%
Citizenship	0	342	12,288	12,630	2.8%
Residential province	0	5,145	0	5,145	1.2%
Residential country	0	0	5,145	5,145	1.2%
Day of birth	0	0	1,347	1,347	0.3%
Month of birth	0	0	1,347	1,347	0.3%
Age in years	0	0	1,342	1,342	0.3%
Sex	0	27	313	340	0.1%

## 4.2.5 Cause-of-death data

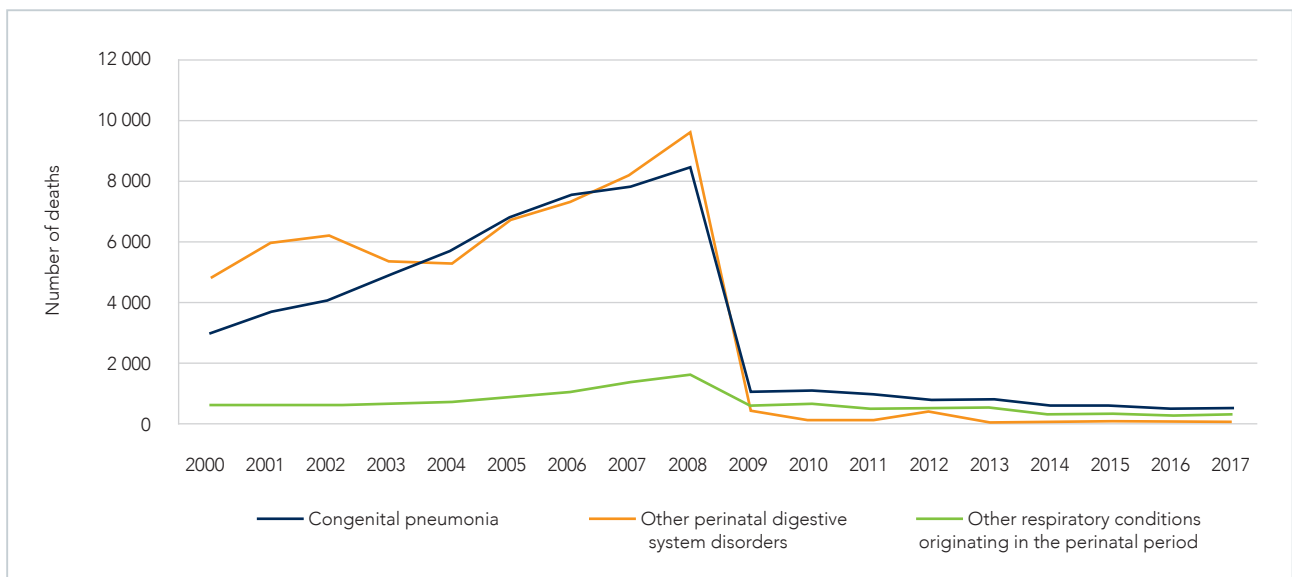
The cause-of-death data reported by Stats SA is obtained from the submitted death notification forms, mostly completed by a medical practitioner. The information about the medical cause-of-death is manually coded to ICD-10 by trained coders in Stats SA and the underlying cause-of-death is identified using IRIS and checked against ACME. Experienced coders review the cases that are rejected by the automatic systems and manually identify the underlying cause.

### 4.2.5.1 Consistency in use of codes

A broad overview of the trends in the numbers of deaths by ICD chapter (shown in Appendix 4) reveals a changing pattern in the causes of death over time. The impact of the HIV epidemic is seen in several ICD chapters including the infectious and parasitic diseases, respiratory diseases, and ill-defined conditions with increasing numbers that peaked around 2006. Maternal conditions peaked in 2012 and musculoskeletal conditions peaked in 2008. The numbers of deaths from circulatory conditions, cancers and endocrine conditions followed an increasing trend over the period 2000-2016. They all dropped off in 2017 in line with the all-cause number of deaths.

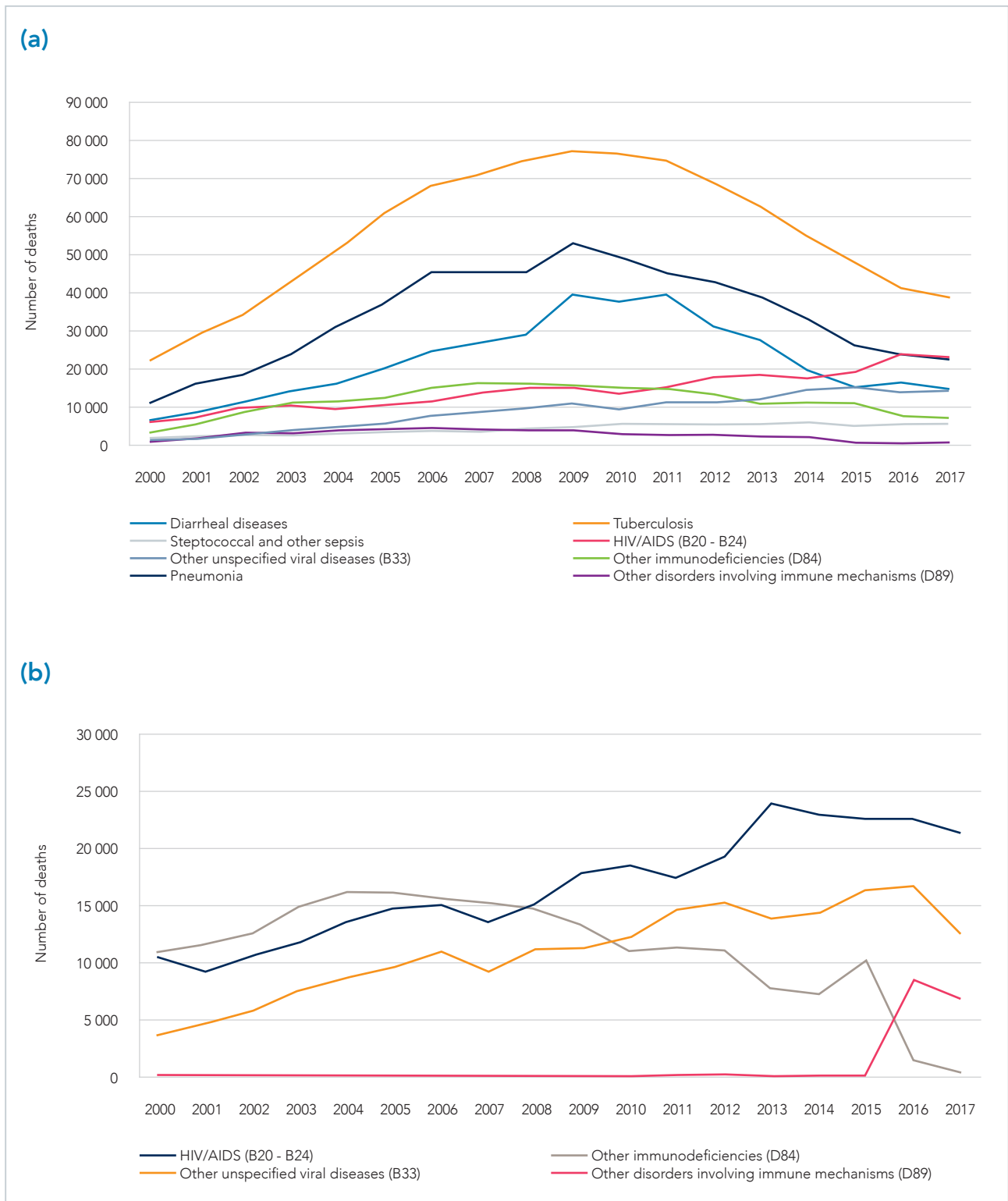
The trends in numbers of deaths also revealed some changes in coding practice. Stats SA's coding rule is to "code what you see". Figure A4.2 shows a change in coding practice in 2006 that resulted in a substantial drop in deaths from perinatal conditions, with a correction of the incorrect coding of post-neonatal deaths to this chapter. Between 2000 and 2005, there was a systematic miscoding of the cause-of-death for infants, shown in Figure 7 for selected perinatal codes. For most children dying before their first birthday, the cause-of-death was miscoded to a perinatal code or P-code, which are causes 'originating in the first week of life'. For example, the death of an 8-month-old infant from pneumonia would have been incorrectly coded to the code for congenital pneumonia. Consequently, the majority of infant deaths were attributed to conditions originating in the perinatal period even if the death occurred in the post-neonatal period.

This coding practice was corrected after 2005, but for the period prior to 2005, resulted in a substantial inflation in the numbers of perinatal conditions, and a corresponding under-recording of true underlying causes of death for infants.



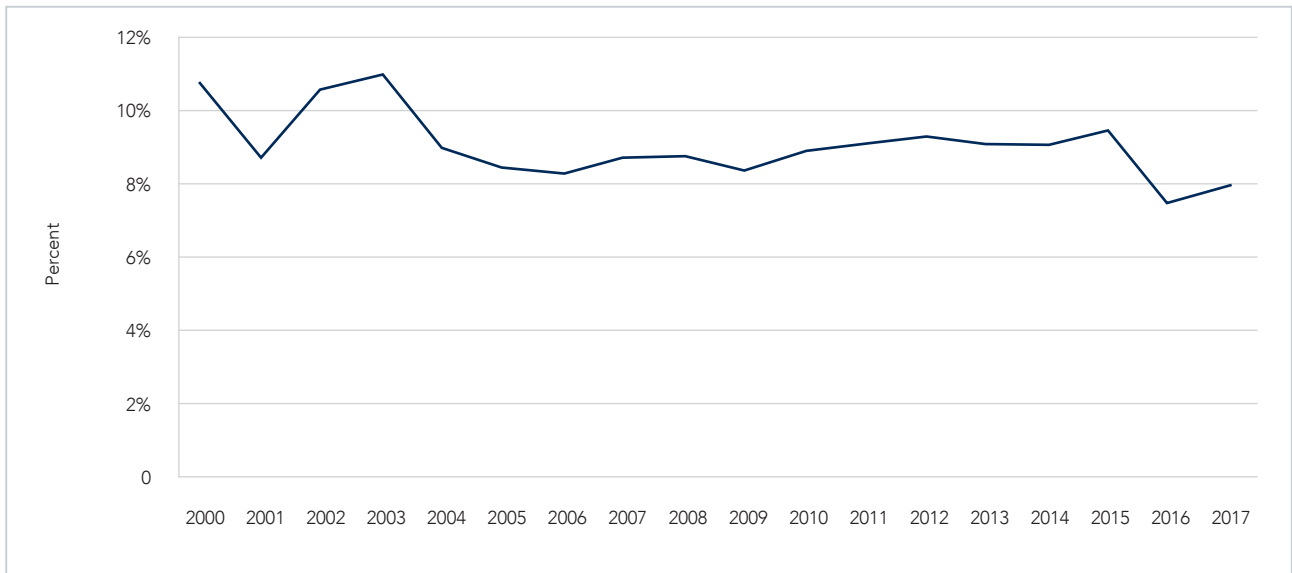
**Figure 7: Trend in selected perinatal codes, South Africa 2000-2017**

HIV-related causes of death are shown in Figure 8. From Figure 8a, it can be seen that tuberculosis, pneumonia, diarrhoeal diseases, other immunodeficiencies, and pneumocystosis all display a trend related to the South African HIV epidemic<sup>46,51</sup> although the latter two causes of death have much smaller numbers. The deaths coded to HIV/AIDS (yellow) and other viral diseases (light blue) steadily increase throughout the period. The codes for other disorders involving immune mechanism (dark grey) increase sharply in 2015. Streptococcal and other sepsis (light grey) increase slightly over the period. The trends suggest that HIV-related deaths have been recorded according to the opportunistic infection that was the immediate cause-of-death, without indication that HIV was the underlying cause. Figure 8b shows HIV/AIDS and pseudonyms related to HIV and highlights a change in coding practices that occurred between 2015 and 2016. Stats SA uses strict coding rules of what you see, hence the codes to pseudonyms.



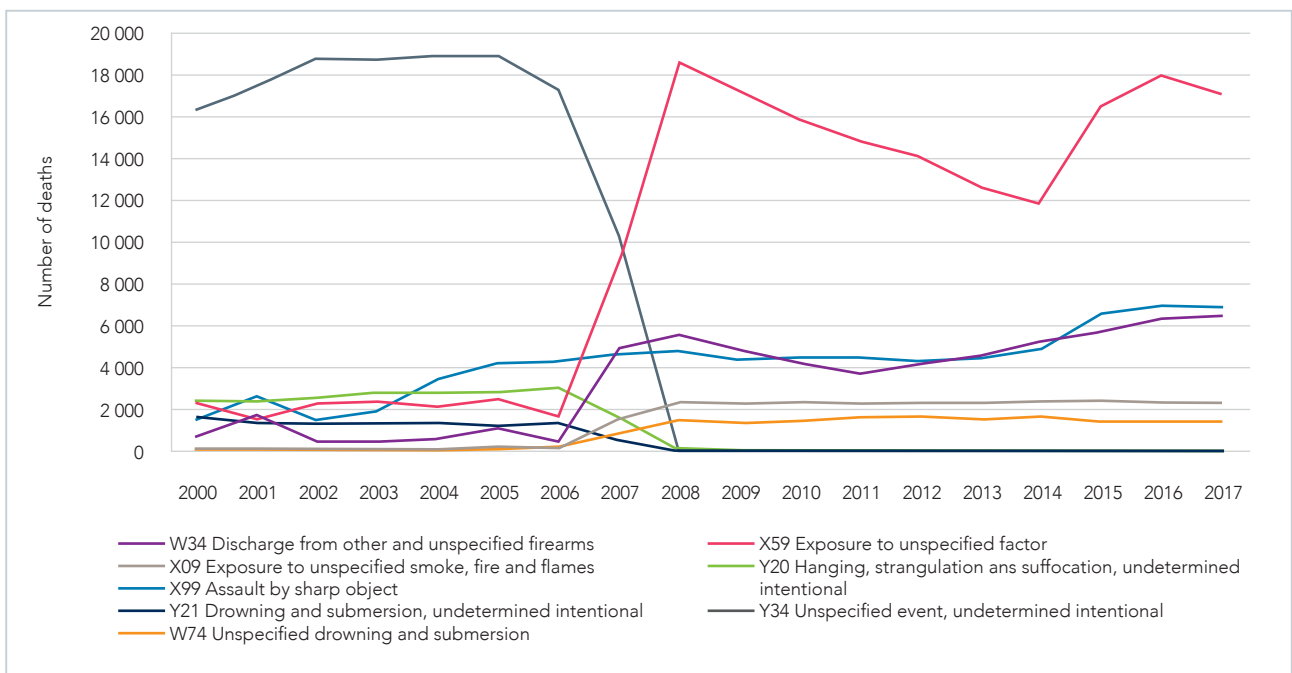
**Figure 8: HIV/AIDS-related codes (a) and HIV/AIDS and related pseudonyms (b) South Africa 2000-2017**

Malignant neoplasm without specification of site (C80) as a proportion of all neoplasms (Figure 9) shows that between 2003 and 2015 there is a gentle rise in the proportion of neoplasms without specification of site. However, this dropped in 2016 and remained at the lower proportion in 2017. The provinces with the highest proportions of unspecified site of neoplasms were Gauteng (25.4%), Western Cape (20.6%), KwaZulu-Natal (17.0%) and Eastern Cape (13.8%).



**Figure 9: Proportion of neoplasms without specification of site (C80), South Africa 2000-2017**

It can be seen from Figure 10, that the coding practice regarding selected injuries changed between 2006 and 2008. The deaths classified as Y34 unspecified event undetermined intent, in large numbers, and deaths from Y20 hanging, strangulation and suffocation, undetermined intent in lower numbers, were reclassified to X59 exposure to unspecified factor and W34 discharge from other and unspecified firearms. Without a field for the manner of death on the death notification form, many cases do not have adequate information for specific coding of the injuries.



**Figure 10: Annual number of deaths from selected injury codes, South Africa 2000-2017**

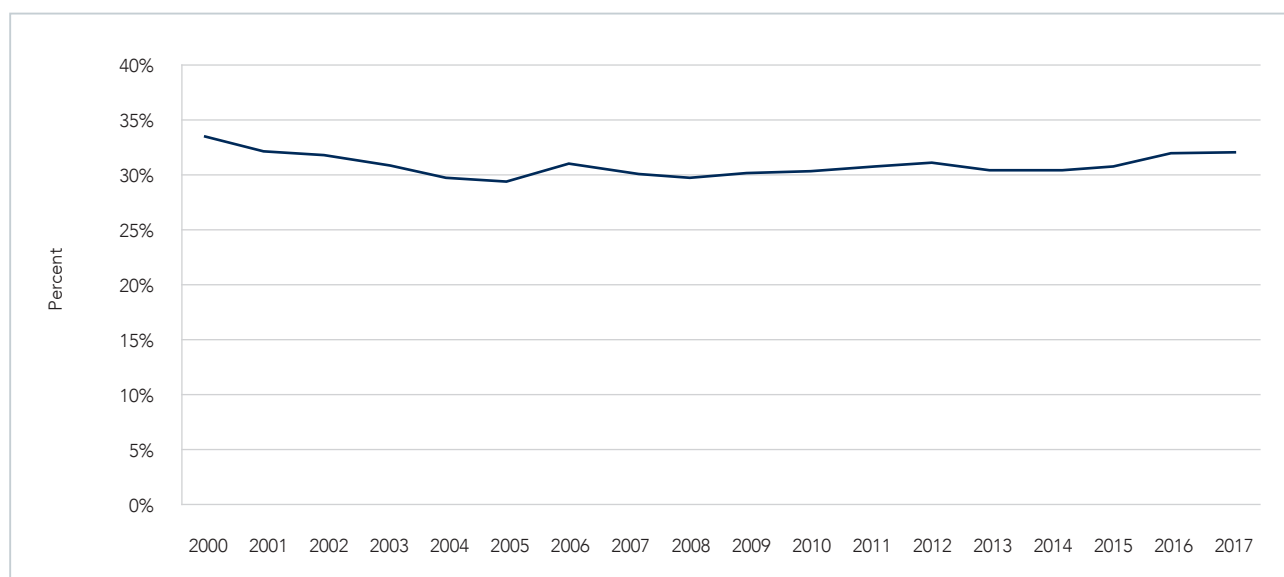
#### 4.2.5.2 Unusable codes

The 2010 Global Burden of Disease Study<sup>10</sup> developed a classification of “garbage codes” to allow comparability across ICD revisions (Appendix 5). These codes include any code that cannot or should not be an underlying cause-of-death, such as septicaemia, senility or headache, a cause that belongs in some other part of the morbid sequence of events leading to death, such as an intermediate or immediate cause, or causes of death that are insufficiently specified and have become known as unusable codes<sup>64</sup>. The four types of “garbage” or “unusable codes” have been extended into five categories of unusable codes in the ANACONDA tool by separating the Ill-defined symptoms and the Impossible causes of death into two separate categories as listed in Table 6<sup>64</sup>. The current analysis does not use ANACONDA, but presents the authors own calculations of the categories of unusable codes based on Naghavi et al (2010)<sup>10</sup>.

**Table 6: Categories of unusable codes for underlying cause-of-death**

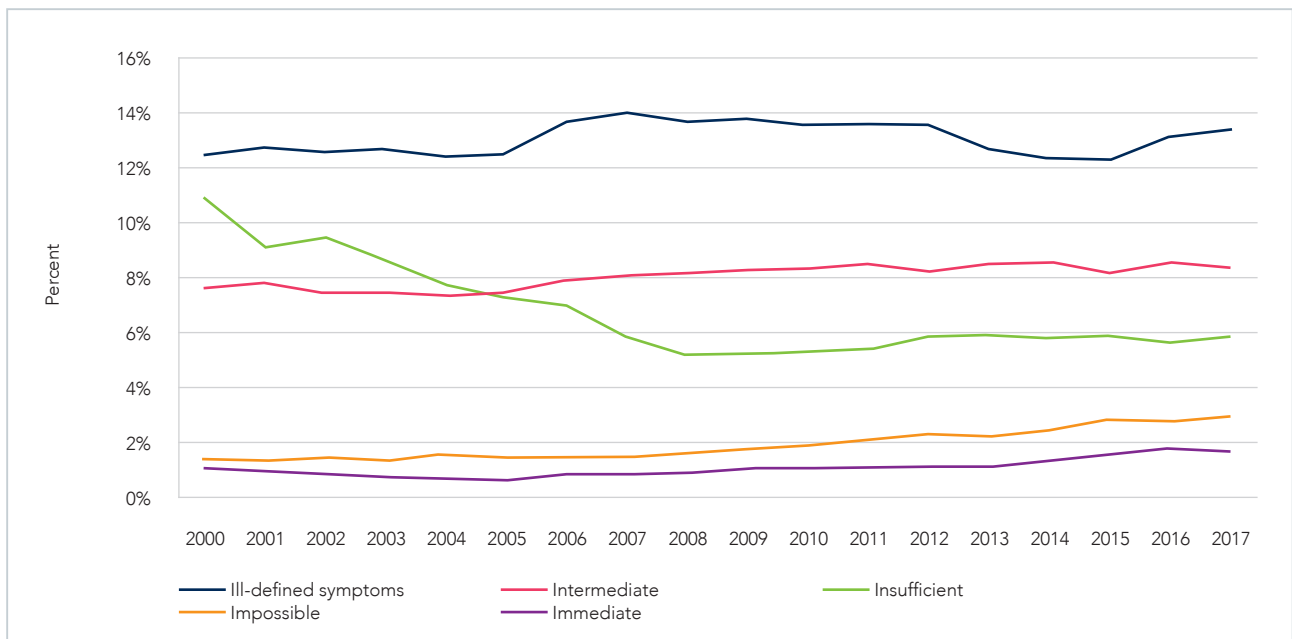
Category	Description
1. Ill-defined symptoms	Ill-defined symptoms (R00-R99) are causes that cannot or should not be considered UCODs
2. Impossible as underlying causes of death	These are defined conditions which should not be considered as an UCOD. These include:- codes used to describe health services 'essential primary hypertension' (which should be considered a risk factor) 'atherosclerosis' causes described as long-term sequelae (e.g. paraplegia, or complications of pregnancy and childbirth)
3. Intermediate causes of death	Intermediate causes include conditions such as: heart failure septicaemia peritonitis osteomyelitis pulmonary embolism
4. Immediate causes of death	Immediate cause-of-death, such as cardiac arrest and respiratory failure are not usable for public health policy.
5. Insufficiently specified causes	Insufficiently specified causes, although these may not be important for assessing aggregate causes for a category, the lack of the site of the cancer or the factor that caused the injury, for example, make them useless for public health preventions.

Figure 11 shows the trend in the overall proportion of unusable codes between 2000 and 2017. Approximately 31% of the South African deaths were coded to unusable codes over the period. Following a slight decline from 34% in 2000, the proportion was about 30% from 2004 until 2015, increasing to 32% in 2016 and 2017.



**Figure 11: Proportion of all deaths with unusable codes, South Africa 2000-2017**

Proportions of the five categories of unusable codes are shown in Figure 12. Causes of death coded to ill-defined symptoms have the highest proportion of between 12% and 14% throughout the period. Intermediate causes of death account for about 8% of deaths and are consistent over time. Intermediate COD cannot be an underlying COD and immediate COD are both less than 2% in 2000 but increase to 3% and 2% respectively in 2017. Deaths coded to 'insufficiently specified within ICD chapters', decreases from 11% to 5% between 2000 and 2008, remaining stable up until 2017 at 6%. The drop in the overall proportion of unusable codes between 2000 and 2005 is related to the changes in this category while the slight increase in the overall proportion since 2015 has resulted from small increases in all types, with the possible exception of intermediate causes.



**Figure 12: Causes of death by garbage type, South Africa 2000-2017**

Further investigation into the marked drop in the proportion of unusable codes in the category of insufficiently specified within ICD chapters between 2000 and 2008 (Appendix 6) reveals that it is largely related to the drop in the proportion of deaths due to injuries during this period as they had an extremely high proportion of unusable codes of this type (Figure A6.1). In addition, the change in coding practice between 2006 and 2008 reduced the proportion of insufficiently specified codes among the injuries, and further reduced the overall proportion of unusable codes in this category.

#### 4.2.6.3 Unusable codes by province

Proportions of unusable codes by province (Figure 13) show a range from 26.6% in the Western Cape to 35.4% in the Eastern Cape over the period 2000-2017. The comparatively lower level of unusable codes in the Western Cape across the whole period could be attributed to better access to health services. The profile of the garbage type in each province is shown in Figure 13. Limpopo stands out with a high proportion of ill-defined causes and the Western Cape with a high proportion of insufficiently specified causes.





**Figure 13: Proportion of all deaths with unusable codes (a) and distribution of garbage type (b) by province, South Africa 2000-2017**

Examination of provincial trends in ill-defined symptoms (Figure 14) range between 5% and 21% throughout the period with considerable year to year fluctuations. Western Cape was relatively stable with an increase between 2005 to 2008 and showed a steady decrease thereafter. Using local level mortality surveillance data and monitoring of ill-defined causes and training of public sector doctors in medical certification of death since 2008 the Western Cape Department of Health have been able to reduce the proportion of ill-defined causes. Gauteng was also relatively stable, with an increase over the period from about 11% to about 15%. Limpopo and Eastern Cape had the highest proportions of ill-defined and were both erratic over the period. The Northern Cape had a marked increase from just over 5% in 2000 to nearly 20% in 2011, and then reverted to about 8% by 2014. While the proportion of deaths due to garbage resulting from the immediate cause-of-death has increased slightly over the period, the proportions in Gauteng and Northern Cape increased considerably in 2016 and 2017.

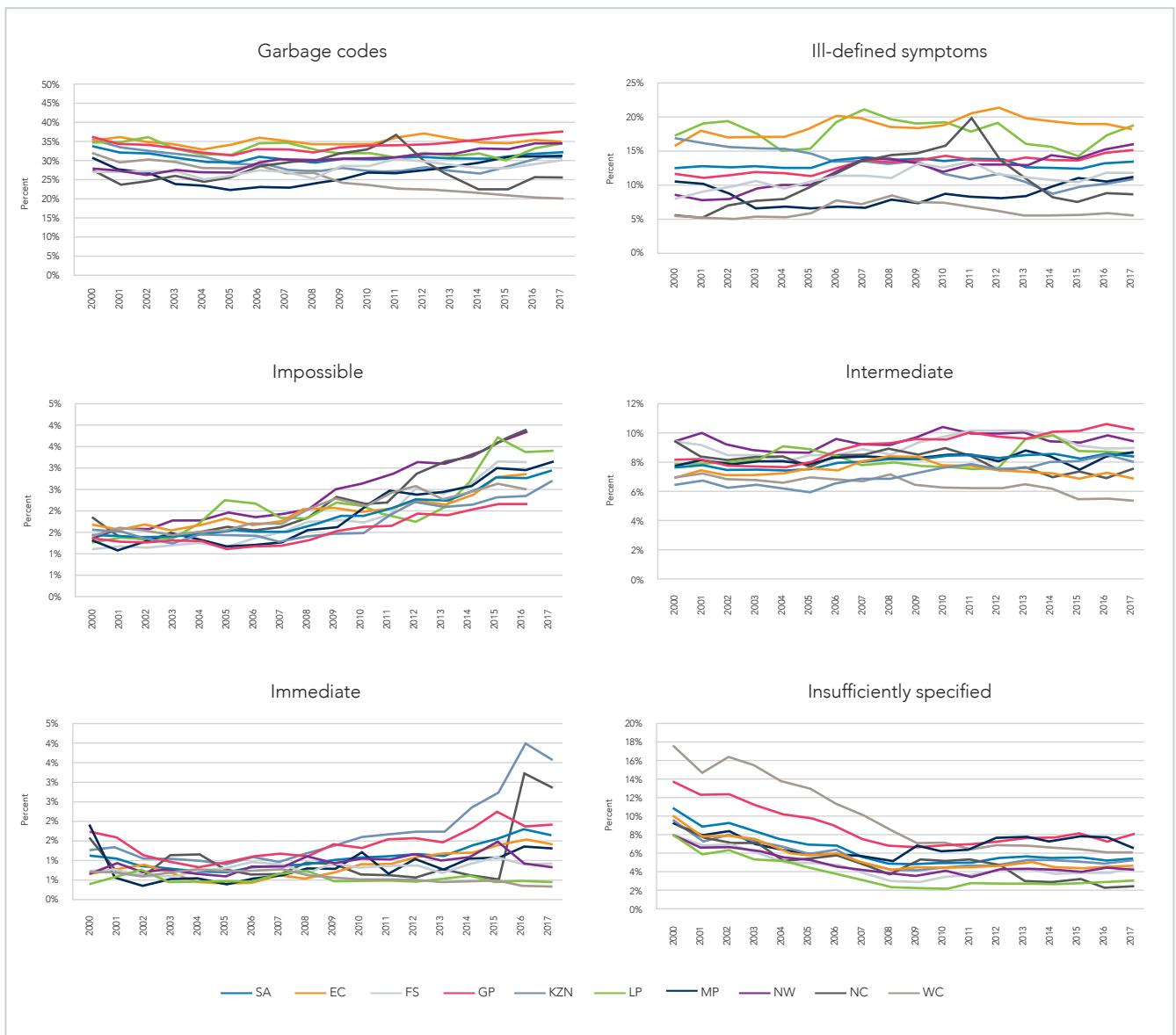


Figure 14: Proportion of all deaths that are garbage by type and province, South Africa 2000-2017

## 4.3 Semi-structured interviews with key informants

Two researchers reviewed the eight transcripts independently and used an inductive data analysis approach. Several meetings were held to discuss interpretations of the responses and eleven themes were jointly identified. These are summarised, in no particular order, under two groupings. Firstly, the various challenges are described with information relating to the nature of the problem. The second grouping comprises ideas about how the country can move forward to overcome these challenges.

### 4.3.1 Current challenges in the CRVS system

#### Human resource issues

Several aspects related to human resource challenges were identified. Both Department of Home Affairs (DHA) and Stats SA reported that they face challenges regarding staff turn-over and staff shortages. While CRVS management structures in DHA were resolved during 2022, respondents indicated that the whole department is significantly understaffed. Two senior management posts within the Medical Certification of Causes of Death (MCCOD) division have been vacant for about two years, although Stats SA is currently in the process of filling these posts. In terms of processing the Death Notification Forms (DNF), Stats SA experiences staff shortages with coders. Currently their capacity is between 25% to

50% below optimal. There is also lack of capacity among data-capturers; however, Stats SA indicates that there are plans to train an additional thirty data-capturers starting in 2022.

The National Department of Health (NDOH) appears to face different challenges regarding CRVS. They have no role in the day-to-day activities and do not have staff dedicated to CRVS. However, they are expected to play a strategic role, and capacity issues makes it difficult for senior managers in NDOH to engage with CRVS as they have multiple responsibilities and are thinly stretched. In general, the NDOH has a shortage of senior managers and programme managers have large portfolios. Overall expertise is lacking with limited appreciation of the role or importance that cause of death data plays in public health surveillance and mortality surveillance. Opinions of fellow NDOH health personnel included those of frustration. For instance, a senior researcher in public health and mortality surveillance commented that the NDOH does not appear to understand the importance of mortality data or how the process works. "I don't know that they are thinking at a population, public health level and how these interventions can be put in place as soon as we know about it, instead of waiting for like 5 years down the line when everything's out of date and we've got a different set of problems."

### Quality of information

An informant from Stats SA explained that "many hands touch the form", making it difficult to ensure quality. Concerns about quality of the certification and quality of other information on the DNF were noted by several informants, and the fact that each stakeholder has specific input into the form gives the impression that each is concerned with their specific section and not the entirety of the information. Problems include, missing information, errors on the form which are only corrected later in the process and which require the form to be physically located and retrieved. An informant from DHA said: "Sometimes the DHA-1663 is not fully completed and there is a need to retrain officials and undertakers".

In other situations, such as when deaths occur in the community, other role players in death registration include undertakers, traditional leaders, and private medical practitioners. DHA does engage with undertakers about the importance of ensuring quality of information i.e., completeness of the information. Another issue mentioned was that there are also poor practices by certifying doctors and improvements in ICD coding would be beneficial to the quality of information. However, it was also noted that fragmentation of care in the public health sector makes it difficult for a certifying doctor who does not have the full medical history. Furthermore, they are often very short of time to be able to do this systemically in a manner that is needed.

A clinician who had been through medical internship mentioned that while there are trainings in medical certification for doctors, nothing was specifically targeted to training interns or community service doctors, who are often required to certify deaths, in CRVS. It was also considered that limited time and competing tasks for overstretched doctors to complete the DNF in health facilities might impact the quality of information.

### Delays in processing

The current process to collate, code, and capture the information from DNFs is intensive and delays occur at various stages in the process. Informants from Health and Stats SA believed that the delay in processing COD information needs to be addressed.

From the user perspective, it is not clear why it takes so long for the death notification forms to be processed. Some specific issues on this included a delayed transfer of DHA-1663 forms from DHA regional offices to Head Office for collection by Stats SA in any given processing year. Also, Forensic Pathology Service (FPS) cases take a long time to come through the system. There are specific challenges with external causes of death which are more delayed than natural causes of death. This includes that NDOH cannot access the FPS system and in addition the challenge of delays when Home Affairs submits the autopsy results. Resolution of this could be obtained with the establishment of a tripartite decision and a high-level committee to debate the reason for delays and to devise ways of shortening the period to get results.

NICD reported that they require mortality data for disease and mortality surveillance. Access to as close as possible real-time data has been their biggest challenge. During 2020, the NICD tested a COVID mortality surveillance system in 4 health districts to overcome this challenge. However, they did not make use of the DNFs.

Also mentioned was the issue of other stakeholders, in the context of the lag in reporting national statistics. “What about other stakeholders in health information such as parliamentary MECs, health portfolio committee etc. are they aware of the lag in national COD statistics?”

## **Relationships between Departments**

MOUs are in place between Stats SA and DHA and these partners arrange meetings as the need arises. There is more frequent engagement with lower-level staff than with senior managers of the different partners; however, Stats SA report they do not have an established relationship with NDOH in terms of COD data.

Historically, there has been some co-operation between NDOH and DHA with offices being opened in selected hospitals. There is also a good working relationship between Stats SA and DHA officials, but staff turnover/death has interrupted this. It is suggested that the current working relationship be revived and solidified.

Loss of institutional knowledge and its impact on inter-departmental relationships and cooperation was also noted among stakeholders.

## **Access to information and data sharing**

The COVID-19 pandemic clearly demonstrated limitations in the CRVS system. All respondents agreed that access to information is extremely problematic. Two health officials mentioned that to address the issue immediately, a copy of the DNF could be made but, the issue of the form only being accessed by a Stats SA official would have to be addressed by changing or amending the legislation. Electronic transfer would likely assist with this matter; however, the system needs to be re-designed.

Respondents reported that the lag in the annual mortality statistics clearly needs concerted intervention. There was also concern about the lack of district level information since 2016. While the country is organised into health districts, the lack of district level information limits public health surveillance and mortality surveillance.

NDOH and NICD spoke about the major obstacle of access to mortality data from the death notification process. NICD has requested mortality data since 2017, without success.

One of the provinces mentioned that they can only access death data from some hospitals.

## **Registration of Stillbirths, Perinatal and Infant deaths**

One health programme manager was particularly concerned about perinatal deaths, noting possible disincentives to register deaths. The manager was concerned about whether stillbirths and live births are correctly distinguished. Certification of early neonatal deaths can be problematic because sometimes it is logistically easier for the family to register a stillbirth particularly if the mother is young. It is then the responsibility of the DOH to incinerate the fetus rather than the responsibility of the family to bury an early neonate. This obviously affects the accuracy of deaths in this age group.

## **Accessibility of Department of Home Affairs offices**

The DHA indicated that it has an inadequate geographic representation through their fixed offices and have therefore extended services in the form of mobile units which are inadequate in some areas. Officials from DHA considered that it would be helpful if space could be provided in public health facilities for DHA offices to enable wider access and that funding for after-hours services could also help.

## 4.3.2 Improving CRVS

### Digital solutions would be ideal

All participants support modernisation, real-time data digitization. However, it was acknowledged that this would necessitate a review of legislation to ensure no gaps and a thorough review of each departments' responsibility and agreement between stakeholders. One respondent noted however that depending on the point of electronic transfer of COD information, there may be overlap or duplication with the registration of the fact of death actioned by Home Affairs.

Recognising that the current system is paper-based, modernisation and digitisation of CRVS are envisioned routes to generate real-time data which are essential for mortality surveillance. A rapid system could allow data to be analysed even before processing the registrations. "We can process this information electronically and in the manner that is in line with various legislation, that is POPIA<sup>v</sup> compliant but, most importantly, in a manner that is safe and credible." However, this would necessitate review of legislation to ensure no gaps and a review of the responsibility of each department and the role they should take to ensure the protection of personal information would be needed.

Real-time data are essential for NDOH and NICD to meet their mandates. The obstacles to access data, such as legal limitations and lack of MOUs can be removed through ensuring steps in data governance and digitisation. With some tweaks, there could be good and prompt COD data which can be used for a very clear value proposition with a proposal, but a big push at a higher coordinating level may be possible. All respondents thought it was opportune timing but that political buy-in and strategic communications are essential.

### Roles and responsibilities

During the COVID-19 pandemic, the SAMRC used the NPR data for surveillance of excess deaths. However, this provided no information on causes of death. More timely access to the information documented on the DNFs would require cooperation from three stakeholders.

A current limitation within the system is lack of legislated coordination mechanisms across key entities involved to improve efficiency and close loopholes. High level traction is suggested between major stakeholders in order to coordinate these activities. During the 2<sup>nd</sup> Conference of African Ministers for CRVS, stated that countries should assess the state of CRVS and develop plans to improve. The Conference recommended the formation of a CRVS steering committee. All respondents agreed that the formation of a CRVS steering committee to take concerns of improvement forward is urgent.

Participants at the conference expressed concerns about the role of the NDOH. It was considered by one informant that NDOH should be making the case for access and questioned "does NDOH understand the role of mortality data in public health surveillance?" They further suggested that NDOH take a leadership role in using the data.

### System integration/interoperability

It was mentioned that all role-players including Information Technology experts and researchers need to collaborate in designing a new system. Joint custodianship/stewardship of mortality data between NDOH and DHA could be a possibility.

"System integration" with proper rules could be valuable. "You may also look at the database of all the doctors that are certifying on the HPCSA database and try and integrate it with the NPR HANIS (Home Affairs National Identification System) and all those other databases that are relevant to the project that you are running".

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<sup>v</sup> Protection of Personal Information Act (POPIA). To promote the protection of personal information processed by public and private bodies. <https://popia.co.za/act/>.

In the context of system integration for the country, the following were suggested:

- a. Implement an integrated technology solution
- b. Train on the rationale, process, technology, and integration
- c. Implement in the proof of concept in one province
- d. Market and share lessons learnt, and
- e. Scope a national roll-out plan with clear accountability for action

NDOH has developed the Perinatal Problem Identification Programme (PPIP) and the Child Healthcare Identification Programme (CHIP) <sup>65</sup> to monitor facility deaths; focus on quality of care and provide added value due to the identification of avoidable factors.

PPIP and CHIP have grappled with the conceptual issue of the causal sequence of death, e.g., the role of HIV and malnutrition in child deaths. Mention was made of development of mobile device APPS which make use of familiar terminology for cause of death. In terms of the process, the paper-based system is a problem. It would be ideal to link the electronic medical record with submission of the fact of death to DHA. This would be relatively easy to implement by making use of a common serial number.

Informants from one of the institutions articulated the following pragmatic and feasible elements to ensure an appropriate mortality surveillance system for the country:

- a. High-level committee
- b. Developing a re-engineered framework for implementation that is signed off by all the stakeholders
- c. Crafting of an action plan with clearly defined goals and roles and responsibilities
- d. Implement an integrated technology solution
- e. Training on the rationale, process, technology and integration
- f. Implement in the proof of concept in one province
- g. Market and share lessons learnt
- h. Scope a national roll-out plan with clear accountability for action

### **Improve collection of COD in health facilities and with Community Oriented Primary Care**

Respondents expressed concerns about the quality of cause of death information for the deaths occurring outside of health facilities. Implementation of community oriented primary care could improve mortality surveillance at the community level, with healthcare workers looking after neighbourhoods and sets of households and capturing information about who had died.

# 5. Key findings

## 5.1 Findings from the literature

This review has 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 mature CRVS system which showed marked improvements post 1994. By 2007, completeness of death registration was over 90%, thereafter plateauing.
- Evaluation of cause-of-death data, however, has found the following problems with medical certification:
  - a high proportion of deaths were due to ill-defined causes ~ 13%
  - a high proportion of deaths were attributed to a cause of death considered unusable ~ 32%
  - extensive misattribution of HIV-related deaths to other causes, predominantly infectious conditions such as diarrhoea and TB; and
  - extensive misclassification of injury-related deaths due to lack of a field for the manner of injury on the death notification form.
- Vital Statistics Performance Index found improvement up until 2009; however, the index declined between 2009 and 2012, mainly associated with the increasing reporting delay.
- CRVS has been highlighted as a preferred source of data for monitoring SDGs and international agencies have developed tools for improving CRVS. The APAI-CRVS improvement framework is process-centric and has three stages:
  - Stage 1: Assessment, analysis and redesign.
  - Stage 2: Development of the strategic action plan.
  - Stage 3: Implementation, monitoring and evaluation.



- A critical factor for successful implementation of the vision towards the improved CRVS system is a functional high-level national CRVS committee with resources to sponsor a business process improvement effort, to act on its results and to ensure that the overall CRVS system is well coordinated.

## 5.2 Findings from the Government 2014/15 assessment

A detailed assessment of CRVS was conducted by the government of South Africa in 2014/15<sup>5</sup> which remains to be finalised and developed into a strategic improvement plan. The assessment found that:

- South Africa did not have a high-level committee for CRVS co-ordination.
- The legal framework for death registration had some gaps and does not make provision for linking or integration with other departmental systems, although there are some arrangements for data sharing.
- In terms of management and operations, the assessment highlighted gaps and proposed mechanisms for improving performance of CRVS. It was noted that the production of vital statistics falls under two separate divisions in Stats SA (Corporate data processing and Health and vital statistics) which may not be optimal.

In terms of data base management, storage, and archiving of records, data sharing and transmission of records highlighted the practical challenge of managing large numbers of paper records. Although the Act that regulates the storage and archiving of data<sup>66</sup> provides for proper management and care of public and non-public records, there is no standard and clear procedure for storage and transmission of vital records in regional offices. Delays in transmission of DNFs from DHA to Stats SA were noted as well as the occurrence of a loss of documents in these transfers.

In considering the demand for registration, it was noted that long distances to DHA offices and long queues demotivate the public.

There was no national strategic plan for strengthening CRVS.

## 5.3 Assessment of cause-of-death statistics in South Africa

The current status of the quality of COD statistics in South Africa is presented in Table 7 based on the analysis that has been undertaken in combination with information from the literature review. The assessment highlights that in many respects, the COD statistics in South Africa are good, and that there have been improvements in some areas such as the completeness of death registration. However, the quality of the COD information is still suboptimal. Symptoms, signs and ill-defined conditions accounted for 13.4% in 2017, above the ideal level of below 5%<sup>43</sup>. Together with high proportions of “intermediate causes” and “insufficiently specified causes”, nearly a third (32%) of all deaths in 2017 were identified as unusable COD. This raises questions around the quality of MCCOD as well as some structural issues in the registration process such as the lack of a field for the manner of death for injury related deaths. Another concern is the 2-3-year lag in reporting which appears to be increasing (Table 7). Timeliness ‘production time’ has increased from 15 months for the 2016 data to 27 months for 2017 data and 42 months with 2018 data. Production time is affected first, by delays in the transfer of DNFs from DHA to Stats SA and second, by delays in processing COD information.

**Table 7: Quality of cause-of-death statistics in South Africa**

Criteria	General vital statistics	General vital statistics Status	Cause-of-death statistics	Cause-of-death statistics Status
<b>Accuracy</b>				
Coverage	% of population living in areas where CRS is functional	CRS is functional across the country. 317 DHA offices accept death registrations. No information regarding the spread of the offices and whether functional access is equitable.	% of population covered by medical certification of cause of death	Unclear which areas use the DHA-1680 form (also called death report) completed by headmen and SA police service where certification by a medical practitioner is not possible.
Completeness	% of events contributing to fertility/mortality statistics	Completeness of VR in 2017 = 87%. Completeness by age and province differs (see Table 3).	% of deaths with medically-certified cause of death	Unknown
Missing data	% of key variables with response not stated	Improvement in % of some fields of missing data since 2000 (see Table 4).	% of cause-of-death reports for which age/sex data are missing	2017: Missing age/sex: 0.33% district: 3.9% population group: 12.3%
Use of ill-defined categories	Non applicable	Non applicable	% of deaths classified under various miscellaneous and ill-defined categories	Symptoms, signs and ill-defined conditions: 13.4%. See provincial differences in Figure 14. In 2017, 32% of the codes were considered unusable when considering all the garbage codes.
Improbable classifications	Non applicable	Non applicable	Number of deaths assigned to improbable age or sex categories per 100 000 coded deaths	2017: 0.013% of all deaths with improbable age or sex
Consistency between cause-of-death and general mortality	Non applicable	Non applicable	% of cause-of-death data points deviating more than 2 (or 3) SDs from general mortality based predictions	Not evaluated as HIV/AIDS has not been included in the general mortality models used to evaluate this.
<b>Relevance</b>				
Routine tabulations	By sex and 5-year age groups, based on place of usual residence. Deaths in children under 5 years tabulated by 0 and 1–4 year age-group	Annual report 2017: National meets standard - number of deaths by sex and 5-year age groups and children by 0 and 1-4 years.	By sex, and at least by eight broad age groups—namely, 0, 1–4, 5–14, 15–29, 30–44, 45–59, 60–69, and 70+ years	Annual report 2017: By province, age and sex 0, 1-14, 15-44, 45-64, 65+ for the ten leading underlying natural causes of death. Unit record data available for further analysis.

Criteria	General vital statistics	General vital statistics Status	Cause-of-death statistics	Cause-of-death statistics Status
Small area statistics	Number of general vital statistics tabulation areas per million population	52 municipalities and 59.31 million people = 0.88 per million population; Uneven distribution - metro municipalities are densely populated.	Number of cause-of-death tabulation areas per million population	0.88 per million population.
<b>Comparability</b>				
Over time	Stability of key definitions over time	No obvious changes in definitions.	Consistency of cause specific mortality proportions over consecutive years	Section 4.2.5.1 highlights occasional changes in coding practice to correct for previous incorrect use of codes.
Across space	Uniformity of definitions across areas	Boundary changes have from time to time impacted on provincial and lower-level area demarcations. However, data from 1997 – have been updated to 2011 boundaries.	ICD to certify and code deaths. Revision used and code level to which tabulations are published	ICD 10 3-digit codes.
<b>Timeliness</b>				
Production time	Mean time from end of reference period to publication	Non applicable	Mean time from end of reference period to publication	Increasing over recent years, e.g., 2016 data = 15 months 2017 data = 27 months
Regularity	SD of production time	Non applicable	SD of production time	6.5 months
<b>Accessibility</b>				
Media	Number of formats in which data are released	Non applicable	Number of formats in which data are released	<ul style="list-style-type: none"> <li>– print report</li> <li>– electronic unit record data</li> <li>– internet unit record data</li> </ul>
Metadata	Availability and quality of documentation	Non applicable	Availability and quality of documentation	Complete documentation available.
User service	Availability and responsiveness of user service	Non applicable	Availability and responsiveness of user service	Available.

Source: Mahapatra et al, 2007 <sup>8</sup>.

In 2017, the overall completeness of vital registration was 87%; however, this masks substantial age and provincial differences shown in Table 4. More rural provinces, Eastern Cape, Kwa Zulu-Natal and Mpumalanga require targeted interventions to improve death registration, particularly in children under-five years of age. Comparison of the VR data with the NPR data indicates improvement in birth and subsequent ID registrations. However, the noticeable narrowing of the gap in 2017 suggests a delay in transfer of death notifications for the latest year and higher numbers on the NPR than in the VR data indicate that not all the DNFs are reaching Stats SA for processing.

Although South Africa does well in terms of availability of information required for the assessment framework (Table 7), further data are needed to inform important equity-related questions. For instance, the indicator 'coverage', shows that although the civil registration system has 317 DHA offices across the country, there is no information regarding

the distribution of offices and whether functional access is equitable across rural and urban areas. Similarly, it is rural areas that use the DHA-1680 where a headman and the police service are able to certify deaths because certification by a medical practitioner is not possible. The geography of these death notifications would be useful information for interventions to improve quality of cause-of-death information in rural areas. The indicator of completeness of medically certified deaths could be assessed by identifying the proportion of DNFs with an HPCSA number, however, this field is not made available for analysis.

Comparability 'across space', considers ICD to certify and code deaths and the level of coding. Currently 3-digit codes are used, but 4-digit coding could be considered to improve the detail of the available information.

## 5.4 Public health use of cause-of-death data

Cause-of-death data from CRVS cannot be considered fit for purpose in terms of serving public health needs. Timely and accurate information about numbers and causes of death as well as identifiable information to ensure appropriate public health response are necessary and the need for such information has been exacerbated during the SARS-CoV-2 pandemic.

The Western Cape mortality surveillance, set up by the Provincial DOH, provided useful information to health managers for planning health interventions, for public health response (e.g., diarrhoea outbreaks) and for monitoring health programmes down to sub-district level. Close engagement of DOH in the production of mortality statistics appears to have contributed to an improvement in the quality of cause-of-death data and a reduction in the unusable codes. The surveillance system halted in 2014 due to the amendment to the DNF<sup>67</sup> and DOH could no longer access the information on the DNF.

It has been possible for research institutions to overcome delays in reporting by making use of the NPR to give annual estimates of mortality indicators and weekly deaths to track the impact of COVID-19. However, the SARS-CoV-2 pandemic has highlighted the urgency of timely access to cause-of-death information.

Various analytical approaches are used to derive robust estimates of the burden of disease and the national cause-of-death validation project is underway to validate the cause of death information on death notifications and derive correction factors that can be used to obtain improved COD profiles. The study has found that verbal autopsy produces more realistic information on HIV/AIDS and injury-related deaths.

A critical component in the redesign to a modern CRVS system is to ensure that the legal framework supports all stakeholders.

## 5.5 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 include issues around human capacity and were experienced by all the role-players in the responsible departments. Issues around the quality of information were raised by all departments. Delays in processing data were raised by the users and the challenges of getting resolution of FPS cases was highlighted by DHA and Stats SA. There appears to be an opportunity to strengthen the relationship between departments especially those which suffered from the loss of institutional knowledge because of staff turn-over. Users of data reflected on the challenges of access to information and data sharing, and expressed concern about the registration of stillbirths, perinatal, and infant deaths. The inadequate distribution of DHA offices was perceived as a challenge for DHA.

Solutions, put forward by the respondents to address the perceived challenges, included digitization of death registration, legislated coordination mechanisms across key entities, system integration between key role players to design a new system, and implementation of community oriented primary care to improve the quality of COD information.

# 6. Way forward

- South Africa could make better use of the 2014/15 assessment as well as the rapid assessment to develop a country plan that will address the challenges in the quality of cause-of-death information.
- The APAI-CRVS improvement framework provides a comprehensive process-centric approach involving all stakeholders and recommends that a critical factor for successful implementation of an improved CRVS system is a functional high-level national CRVS committee with resources to sponsor a business process improvement. It recommends that if there is no national CRVS committee, efforts should be made to create a committee to ensure that CRVS improvement efforts are well coordinated with clearly defined roles of all key stakeholders.
- The committee could provide a vision for the system that will meet the needs of all stakeholders. The possibility of electronic registration could be considered as a mechanism to enhance the quality and timeliness of cause-of-death information and ensure that the public health needs are met. Ideally, a secure electronic registration system could be designed to enable doctors to complete page 1 of 1 of DHA 1663B online and for the registration to be completed by the other parties online. This would allow the information on cause-of-death to be accessed by Stats SA and the Department of Health in a timelier manner. The obstacles to access to data, such as legal limitations and lack of MOUs could be removed through ensuring steps in data governance and digitisation.
- More timely access to the information documented on the DNFs is essential and this requires cooperation and coordination from three stakeholders through legislated mechanisms to improve efficiency and close loopholes.
- Strengthening quality assurance processes for the reporting of births and deaths and making use of evaluation expertise beyond Stats SA such as UCT's Centre for Actuarial Research<sup>vi</sup> and SAMRC Burden of Disease Research Unit<sup>vii</sup> could be an option for improved data.
- Improvement and monitoring of quality of cause of death information include the following:
  - Consider including online training as a requirement for registration with HPCSA similar to GCP training.
  - Providing immediate access to cause of death information will provide NDOH an opportunity to audit MCCOD and respond immediately when problems are identified.
  - Design a new system utilising system integration of databases across entities such as DOH and DHA, governed by agreed rules to streamline the collection of information.

vi <http://www.care.uct.ac.za>

vii <https://www.samrc.ac.za/research/intramural-research-units/BOD>



# 7. Appendices

## APPENDIX 1: DATA COLLECTION

### Appendix A1.1 Informed consent for key stakeholder

#### CONSENT FORM

**TITLE OF THE RESEARCH PROJECT:** Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB in and COVID-19 in South Africa

**ETHICS REFERENCE NUMBER:** EC005-2-2021

**PRINCIPAL INVESTIGATOR:** Pam Groenewald

**CO-INVESTIGATORS:** Nadine Nannan, Debbie Bradshaw, Ian Neethling

**ADDRESS:** Burden of Disease Research Unit, South African Medical Research Council, Francie Van Zijl Drive, Parow Valley 7500, Cape Town

**CONTACT NUMBER:** Nadine Nannan 021 938 0953

Dear Sir / Madam

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate.

Your participation will take the form of a semi-structured interview conducted by one of the project investigators. The interview will be conducted at your convenience, and permission requested to record a video interview or teleconference on a digital platform. It can be expected to last between 1 and 2 hours.

Please note that participation is entirely voluntary, and you are free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Ethics Committee of the South African Medical Research Council (SAMRC) and will be conducted according to the ethical guidelines and principles of the Department of Health: [Ethics in health research: principles, processes and structures, second edition, 2015](#) and the Declaration of Helsinki (2013).

### **What is this research study all about?**

This study seeks to conduct a rapid assessment of cause-of-death statistics by reviewing cause-of-death data at a national level between 2010 to the current period.

### **Why have you been invited to participate?**

You have been identified to participate in this study as a key informant on the basis of your work responsibility in the Civil Registration and Vital Statistics system. The study is targeting the managers in the respective government departments.

### **What will your responsibilities be?**

Your responsibility will be to respond to the semi-structured interview to be conducted by one of the investigators.

### **Will you benefit from taking part in this research?**

There is no personal benefit in this study. However, participating in this study will help to inform future decision making about improving the availability and quality of cause- of-death data for health planning in South Africa.

### **Are there any risks involved in taking part in this research?**

There should be no risks involved in taking part in this research.

### **If you do not agree to take part, what alternatives do you have?**

You are free to decide whether or not to participate in the study, and to withdraw from the study at any point. No information obtained from you will be included in the study records or in any report if you choose not to participate in the study.

### **Who will have access to your personal information?**

The information collected in this study will be treated as confidential and protected. Responses will remain confidential and will not be shared with anyone, except in the form of summarised themes that emerge from the interviews with key informants which will be presented in a publication or report.

### **Is there anything else that you should know or do?**

You will receive a copy of this information and consent form for your own records.

Participants are welcome to contact the Chair of the SAMRC Ethics Committee if there are any queries or problems.

Contact details of the Committee:

Prof Danie du Toit (telephone 021 938 0687. email [adri.labuschagne@mrc.ac.za](mailto:adri.labuschagne@mrc.ac.za)).



## DECLARATION BY PARTICIPANT

By signing below, I ..... agree to take part in a research study entitled “Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB in and COVID-19 in South Africa”.

I declare that:

- I have read or have been read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- Informed consent has been explained to me by the investigator.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

Signed at (*place*) ..... on (*date*) .....

Signature of participant

Signature of witness

## DECLARATION BY PARTICIPANT ON AUDIO RECORDING

By signing below, I ..... agree that my verbal inputs to the research study entitled “Strengthening Mortality Surveillance (SMS) for improved monitoring of HIV/AIDS, TB in and COVID-19 in South Africa” may be audio recorded.

Signed at (*place*) ..... on (*date*) .....

Signature of participant

Signature of witness

## DECLARATION BY INVESTIGATOR

I .....declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I explained to ..... that the interview to be conducted with her/him would be audio recorded only if he/she had given permission for this to be done.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ..... on (*date*) .....

Signature of investigator

Signature of witness

## Appendix A1.2: Rapid assessment of cause-of-death statistics interview structure

### Strengthening Mortality Surveillance

Thank you for agreeing to answer these questions. This interview is part of a study to improve South Africa's cause-of-death information to support planning and monitoring health services. The objective of the survey is to help develop interventions to improve the quality and timeliness of mortality data for public health surveillance. Please express your opinion honestly. Your responses will remain confidential and will not be shared with anyone, except in a consolidated form. We appreciate your assistance and co-operation in completing this study.

#### Semi-structured interview

- **Do I have your permission to record this interview?**
  - **Have you read the information sheet about the project or would you like us to go through it now?**
1. **Having worked extensively with death registration in South Africa, what do you feel are the current challenges and does your institution/department have plans in place to address them?**

*Probe - what are*

- *general challenges and barriers*
- *specific challenges resulting from COVID-19*
- *future plans*

2. **Are you aware of any challenges with the quality of the COD information and does your institution/department have any plans to improve what would be required?**

*Probe - what are*

- *general challenges and barriers*
- *specific challenges*
- *human resources*

3. **COVID-19 has highlighted the importance of Department of Health having real-time access to the cause-of-death information provided by doctors on the DHA-1663. What are the main reasons why this information cannot be provided to the Department of Health?**

*Probe for*

- *legislation*
- *logistical/technical barriers*
- *confidentiality of informant details*
- *ownership of data on medical certificate*
- *human resources*

4. **In the short-medium term, do you have any suggestions about how the Department of Health can obtain the information on causes of death in a timely manner?**

*Probe for*

- *Provincial Department of Health to obtain copies of DNF*
- *Provincial Department of Health to obtain contact detail of informant*

# Appendix A1.3: DHA-1663 pages 1-4

G.P.-S. 09/09

DHA-1663 A  
Page 1 of 3

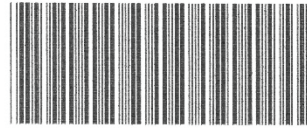


REPUBLIC OF SOUTH AFRICA  
DEPARTMENT OF HOME AFFAIRS

## NOTICE OF DEATH / STILLBIRTH

[Births and Deaths Registration Act 51 of 1992]

[Regulations 11 and 14]



1663F632561

To be completed in full and submitted at the Department of Home Affairs office by the informant or authorised funeral undertaker. The form to be completed in **BLACK INK** with **BLOCK LETTERS**. Please mark with  the CORRECT box, where required. **All fields are COMPULSORY. Incomplete applications and applications that are not legible may be considered invalid.** (Note: The fingerprints of the deceased, the informant and the undertaker must be taken by the undertaker)

### A. PARTICULARS OF THE DECEASED

**Instructions:** Section A to be filled out by **Authorised Medical Practitioner / Professional Nurse**, who is responsible for examining the body to determine the cause of death. The **Informant must** verify, and where necessary, complete in full the personal particulars and other information of the deceased below.

1. Was this a death or a stillbirth?  1.1 Death  1.2 Stillbirth

2. Identification of the deceased (tick one box):

2.1 The deceased was identified with an ID document / passport (if foreigner) produced by the family

2.2 Stillborn child

2.3 The features of the deceased do not seem to match the features on the ID document or passport of deceased

2.4 ID document or passport of the deceased was not presented. The deceased was identified through word of mouth

2.5 The deceased was already buried prior to the completion of this form

2.6 The deceased was unidentifiable:  2.6.1 Burnt  2.6.2 Decomposed  2.6.3 Other (specify) \_\_\_\_\_

2.6.4 DNA samples retrieved for identification purposes  2.6.5 Dental records taken for identification purposes

3. Date of Death / stillbirth

Y Y Y Y M M D D

4.1 Place of Death/stillbirth (City/Town/Village)

4.2 Province of Death/stillbirth

5. Place of Registration of Death / stillbirth

6. If death occurred within 24 hours after birth, number of hours alive

7. Home telephone no.

8. Identity No. (Passport No. if foreigner)

9. Age at last birthday if DOB is unknown

10. Date of Birth if there is no ID number

Y Y Y Y M M D D

11. Gender

11.1 Male

11.2 Female

11.3 Indeterminable

12. Surname

13. Previous / Maiden Surname

14. Forenames

15. Usual\* Residential Address:

Street

Town

Province

Postal code

16. Citizenship

16.1 Place of Birth (City / Town / Village)

or Country of Birth, if abroad

16.2 Province of Birth

17. Marital Status of the deceased

17.1 Single

17.2 Married

17.3 Widowed

17.4 Divorced

18. Education level of deceased, (Specify only the highest class completed)

None

Gr R

Gr 1

Gr 2

Gr 3

Gr 4

Gr 5

Gr 6

Gr 7

Gr 8 Form 1

Gr 9 Form 2

Gr 10 Form 3 NTC 1

Gr 11 Form 4 NTC 2

Gr 12 Form 5 NTC 3

Univ Tech

Un-Known

(mark with a )

19. Usual occupation of deceased (type of work done during most of working life)

20. Type of business / industry: (mark with a )

1. Agriculture, hunting, forestry and fishing	2. Mining and quarrying	3. Manufacturing	4. Electricity, gas and water supply	5. Construction	6. Wholesale and retail trade; repair of motor vehicles, motor cycles and personal and household goods; hotels and restaurants	7. Transport, storage and communication	8. Financial intermediation, insurance, real estate and business services	9. Community, social and personal services	10. Private households, extraterritorial organisations, representatives of foreign governments & other activities not adequately defined
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21. Was the deceased a regular\*\* smoker five years ago? (mark with a )

21.1 Yes

21.2 No

21.3 Do not know

21.4 Not applicable (minor)

\*When the deceased had no next of kin \*\*Smoker tobacco or opium

Left thumbprint of deceased

Right thumbprint of deceased





REPUBLIC OF SOUTH AFRICA  
DEPARTMENT OF HOME AFFAIRS  
**NOTICE OF DEATH / STILLBIRTH**  
[Births and Deaths Registration Act 51 of 1992]  
[Regulations 11 and 14]



1663F632561

To be completed in full and submitted at the Department of Home Affairs office by the informant or authorised funeral undertaker. The form to be completed in **BLACK INK** with **BLOCK LETTERS**. Please mark with  the CORRECT box, where required. **All fields are COMPULSORY. Incomplete applications and applications that are not legible may be considered invalid.** (Note: The fingerprints of the deceased, the informant and the undertaker must be taken by the undertaker)

**E. PARTICULARS OF FUNERAL UNDERTAKER**

**Instructions:** Section E to be completed by **Funeral Undertaker**. The undertaker must take his or her finger print, the finger print of the deceased and the informant. **Authorised Funeral Undertaker or Informant** may submit the completed form to the nearest Home Affairs office.

47. Name of Funeral Parlour

48. DHA Designation No.  49. Company Reg. No.

50. SARS Reg. No. (Income tax reference no.)

**Details of Funeral Undertaker or Authorised Representative**

51. Identity No. (Passport No. if foreigner)

52. Surname

53. Forenames

54. Business Address Street

Town

Province  Postal Code

Telephone No. (Office)

Cellphone No.

55. Date of collection of corpse

56. Date of Cremation (if applicable)

57. Place of Burial (City / Town / Village)

Province

58. Date of Burial

59. Grave No. (if available)

Place signed

Date signed  Signature



Left thumbprint of funeral undertaker

**Name of person who collected the deceased:**

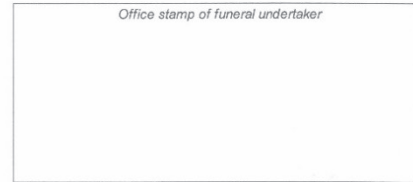
60. Identity No. (Passport No. if foreigner)

61. Surname

62. Forenames

Place signed

63. Date signed  Signature



**F. FOR OFFICIAL USE ONLY**

Registration of death approved, DHA-1663 received by (particulars of DHA official):

64. Surname

65. Forenames

66. Persal No.

- Documents included with this notice:
- Copy of the deceased's ID
  - Copy of ID document of the informant
  - DHA - 6 (if applicable)
  - DHA - 1680 (if applicable)
- DHA-1663 was submitted by:
- Informant
  - Funeral Undertaker





NOTICE OF DEATH / STILLBIRTH

Confirmation for Medical and Health use Only

To be completed in full and submitted at the Department of Home Affairs office by the informant or authorised funeral undertaker.

The form to be completed in BLACK INK with BLOCK LETTERS. Please mark with [X] the CORRECT box, where required.

All fields are COMPULSORY. Incomplete applications and applications that are not legible may be considered invalid.

(Note: The fingerprints of the deceased, the informant and the undertaker must be taken by the undertaker)



1663F632561

This page must be sealed after completion to ensure confidentiality

FOLD TO THIS POINT

FOLD TO THIS POINT

ID No. (Passport No. if foreigner) File no Date

DHA-1663 B Page 1 of 1

G. MEDICAL CERTIFICATE OF CAUSE OF DEATH

Instructions: Section G is to be filled out by Medical Practitioner / Professional Nurse / Forensic Pathologist, who has determined the cause of death

PARTICULARS OF DECEASED

67. Identifying No. (Passport No. if foreigner)
68. Gender
69. Surname
70. Forenames
71. Population Group
72. Place of Death
73. Name of Health Facility/Practice
74. Facility Contact Telephone No. incl. Area Code
75. Patient File No.
76. Contact Person at Facility: Surname, Forenames, Role/Rank

G.1 FOR DEATHS OCCURRING AFTER ONE WEEK OF BIRTH

Instructions: Section G.1 is to be completed for all deaths that occurred after one week of birth

77. CAUSES OF DEATH

Part 1 Enter the disease, injuries or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock or heart failure. List only one cause on each line. IMMEDIATE CAUSE, Underlying Cause, Part 2 Other significant conditions contributing to death but not resulting in underlying cause given in Part 1

78. If a female, was she pregnant at the time of death or up to 42 days prior to death? (X) 82.1 Yes 82.2 No

79. Method used to ascertain the cause of death (tick all that apply):

79.1 Autopsy 79.2 Post mortem examination 79.3 Opinion of attending medical practitioner 79.4 Opinion of attending medical practitioner on duty 79.5 Opinion of registered professional nurse 79.6 Interview of family member 79.7 Other (specify)

G.2 FOR STILLBIRTHS AND DEATHS OCCURRING WITHIN ONE WEEK OF BIRTH (PERINATAL DEATHS)

Instructions: Section G.2 is to be completed for all stillbirths and deaths that occurred within one week of birth (perinatal deaths)

Mother: 80. Identifying Number, 81. Date of Birth, 82. Age of last birthday/DOB unknown, 83. Number of previous pregnancies resulting in: 83.1 Live births, 83.2 Stillbirths, 83.3 Abortions, 84. Outcome of last previous pregnancy (tick one): 84.1 Live birth, 84.2 Stillbirth, 84.3 Abortion, 85. Date of last previous delivery, 86. First day of last menstrual period, 87. Method of delivery: 87.1 Spontaneous, 87.2 Forceps delivery, 87.3 Forceps and rotation, 87.4 Vacuum extractor, 87.5 Caesarean section, 87.6 Other (specify), 88. Antenatal care two or more visits: 88.1 Yes, 88.2 No, 88.3 Unknown
Child: 89. Type of death: 89.1 Stillbirth, 89.2 Live birth, 90. Birth weight (in grams), 91. This birth was: 91.1 Single birth, 91.2 First twin, 91.3 Second twin, 91.4 Other multiple, 92. If still born, heartbeat ceased: 92.1 Before labour, 92.2 During labour but before delivery, 92.3 Before delivery but not known whether before or during labour, 93. If death occurred within 24 hours after birth, number of hours alive, 94. Attendant at birth: 94.1 Physician, 94.2 Trained midwife, 94.3 Other trained person (specify), 94.4 Other (specify)

95. CAUSES OF DEATH

a. Main disease or conditions in foetus or infant
b. Other diseases or conditions in foetus or infant
c. Main maternal disease or condition affecting foetus or infant
d. Other maternal diseases or conditions affecting foetus or infant
e. Other relevant circumstances

96. Autopsy information (X) 96.1 Certified cause of death has been confirmed by autopsy 96.2 Autopsy information may be available later 96.3 Autopsy not performed



## APPENDIX 2: CRVS ASSESSMENT BY STATS SA

Additional information relating to specific aspects of the 2014/15 CRVS assessment are provided in Tables A2.1 – A2.4.

**Table A2.1: Details of respondents in CRVS assessment**

A total of 786 questionnaires were completed in the field and 22 via email (Total =808). Of those 729 questionnaires were valid.

A total of 222 interviews were conducted within DHA offices which included 21 regional office managers, of these eleven reported on the mobile unit operations in their offices and 8 on the hospital units operated by their offices. 19 DHA supervisors completed questionnaires and 79 clerical staff completed self-assessment questionnaire.

Twenty CEOs and 15 clinical managers from health facilities answered questions on operations related to deaths and certification of death. Self-assessment questionnaires were completed by 80 certifiers, of which 42 were medical practitioners, 12 forensic pathologists, 10 medical specialists, 7 were a combination of interns and professional nurses.

Within Stats SA, three managers responsible births and deaths, marriage and divorce statistics and mortality data processing manager completed a questionnaire each. Sixteen personnel responsible for data processing, mortality and cause-of-death ICD coding and data analysis completed self-assessment questionnaires.

Also included were interviews with 27 traditional and 12 religious leaders. About 63 funeral undertakers participated in the assessment.

**Table A2.2: Identified gaps in legislation**

Some aspects of the definition of births and deaths in the current legislation need to be revised to be in line with international definitions

- The Births and Deaths Act does not specify the mechanisms for enforcement in cases of non-compliance.
- The Births and Deaths Act does not provide for registration of birth without a name or insertion of a name after a specified period, the insertion of this provision in legislation will accommodate cultural practices of naming, improve registration of events within the 30 days.

In relation to the production of vital statistics there is no clear provision in the Statistics Act for:

- The collection of causes of death for statistical purposes,
- The transmission and processing of the notice of death form (DHA1663 B Form) to Stats SA.
- The use of civil registration process for producing statistics on vital events is only implied for deaths because of section B of the DHA 1663, but there is no clear provision in the Act.

In relation to the management, coordination and linkages of systems in CRVS:

- The law does not prescribe linkages in the CRVS systems.
- Innovations introduced in civil registration such as mobile and hospital units and SMS notifications are not documented in legislation.

**Table A2.3: Recommendations concerning data management**

Ways of improving efficiency, timelines etc. of the operations for deaths recommended include:

- Automation of coding of causes of death using international standards such as IRIS
- Automated processing of causes of death (e.g. scanning)
- Streamlined processes of collecting death notification forms from all registration centres through all DHA processes up to Stats SA
- Linking of systems or provision of processed data from DHA to avoid duplication of data processing
- Use of standard place names in all databases
- Improved quality assurance systems

Recommended measures to enhance vital statistics processes and products include:

- Preparation or updating of standard operating procedures
- Automated system of preparing tables and graphs for each release
- Regular review of the contents of the products
- Production of detailed thematic reports
- Use of ancillary data sources to complement data from civil registration
- Use of different data dissemination platforms for all products

**Table A2.4: Recommendations concerning management and operations**

Mechanisms for improving the performance of the structures responsible for CRVS included suggestions about the content of the DHA-1663 form and if it contains all the information required for mortality indicators.

“A second sealable copy of the form should be addressed to the Department of Health.” This is the sealable envelop that goes to Stats SA from the DoH. The follow-up question asked users why they wanted the questions they proposed added. The former user said: “Currently the statistics on unnatural deaths are incorrect and/or incomplete due to doctors not writing this information on the form, and the ICD coding rules that are followed.”

“So that injuries can be coded to ICD-10 accurately. SA has a very high burden of injuries and it is essential that these be classified accurately to assist with raising awareness of the extent of the problem and for planning interventions to reduce these injuries.”

On the question of confidentiality of data, two users indicated a need for DoH to access ICD-10 codes of cause-of-death of all persons in order to have accurate and internationally comparable cause-of-death statistics for planning and service improvements.

“The department of health should have access to cause-of-death information of all persons in order to:

1. Monitor and evaluate quality of death certification
2. To query the cause with certifier if an invalid or ill-defined cause-of-death is reported
3. For surveillance purposes in order to follow up diarrhoea and pneumonia deaths in children for example
4. To provide insight into what training certifiers require.”

## APPENDIX 3: PROVINCIAL NUMBERS OF DEATHS

Table A3.1: Numbers of deaths reported by Stats SA by province by year, 2000-17

	Western Cape	Eastern Cape	Northern Cape	Free State	KwaZulu-Natal	North West	Gauteng	Mpumalanga	Limpopo	Unknown	Outside SA	Total
2000	38,532	62,174	11,078	34,138	96,842	30,748	84,015	28,185	31,459	36	204	417,411
2001	41,080	67,854	11,780	36,917	106,968	34,689	90,179	31,235	35,408	39	335	456,484
2002	43,593	75,006	12,698	40,970	118,889	38,552	99,465	35,280	38,760	38	341	503,592
2003	44,603	83,576	13,717	45,898	131,581	43,195	109,573	41,150	44,913	48	426	558,680
2004	44,273	88,919	14,542	49,245	134,615	43,228	113,583	43,151	46,389	68	633	578,646
2005	45,596	93,835	14,350	50,467	141,556	43,558	115,326	46,322	48,132	80	632	599,854
2006	44,710	92,060	15,128	52,409	140,317	43,026	120,072	48,838	53,178	2,386	2,288	614,412
2007	46,894	88,235	15,079	51,062	137,001	43,220	119,100	48,541	53,058	2,264	2,005	606,459
2008	47,108	85,555	15,262	49,534	133,493	43,168	118,892	47,868	53,484	2,343	1,783	598,490
2009	46,195	85,514	15,252	47,962	129,866	41,044	116,599	46,210	53,628	1,076	928	584,274
2010	46,211	83,339	15,288	45,262	117,845	40,354	106,693	42,119	50,569	65	4,075	551,820
2011	46,535	77,129	14,880	41,402	107,466	38,175	102,215	38,540	48,001	121	3,471	517,935
2012	47,554	69,050	14,081	35,584	103,287	36,186	99,486	36,896	49,920	2,214	1,278	495,536
2013	46,507	67,338	13,757	34,043	95,099	35,679	98,866	35,736	48,030	1,505	902	477,462
2014	46,602	70,392	14,112	33,312	91,877	35,412	99,682	35,225	48,667	1,058	1,145	477,484
2015	50,793	70,352	13,792	32,441	89,122	35,178	99,160	34,655	47,523	401	758	474,175
2016	50,245	68,743	14,005	32,224	90,243	35,712	98,645	33,575	46,171	585	251	470,399
2017	45,715	65,162	12,638	31,209	76,605	32,473	92,524	29,300	43,707	17,213	0	446,546
<b>Total</b>	<b>822,746</b>	<b>1,394,233</b>	<b>251,439</b>	<b>744,079</b>	<b>2,042,672</b>	<b>251,439</b>	<b>693,597</b>	<b>1,884,075</b>	<b>702,826</b>	<b>31,540</b>	<b>21,455</b>	<b>9,429,659</b>

## APPENDIX 4: TRENDS IN DEATHS BY ICD-10 CHAPTER, 2000-2017

The following three graphs show trends in the numbers of deaths by ICD chapter, divided according to the numbers of deaths. Figure A4.1 displays the largest chapters (ranging from 40,000 to 160,000) including Infections and parasitic diseases, Circulatory system, Respiratory system, Ill-defined and Injuries. This reveals the profound impact of the HIV epidemic on the numbers of deaths, affecting several chapters. While there are some fluctuations in the numbers of deaths each year, deaths from circulatory system show an unexpected decline in 2017.

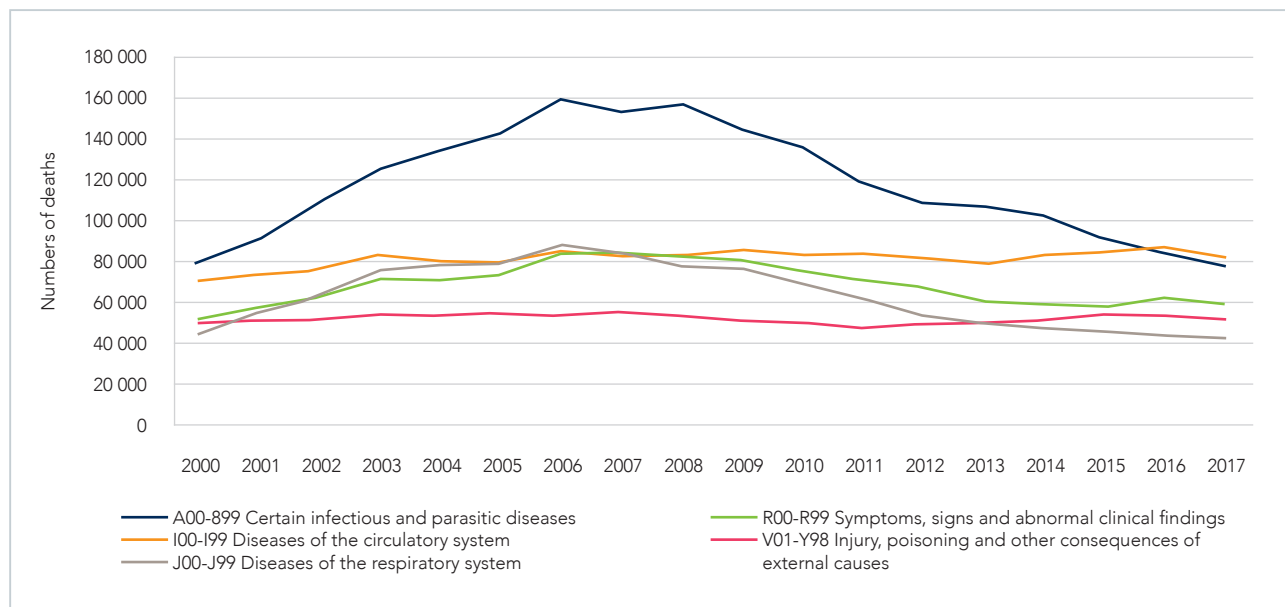


Figure A4.1: Trend in selected ICD chapters with highest numbers of deaths, 2000-2017

Figure A4.2 displays the chapters with mid-range numbers (from 5,000 to 40,000) including Cancers, Endocrine, nutritional and metabolic diseases, Perinatal conditions, Digestive system, Blood and blood-forming organs, Nervous system and Genitourinary system. The figure reveals increasing numbers of deaths from cancers and endocrine, nutritional and metabolic diseases, as well as a major shift in coding practice of Perinatal conditions between 2005 and 2006. From 2006 onwards, deaths during the neonatal period have been coded to this chapter compared with deaths under the age of 1-year for earlier years.

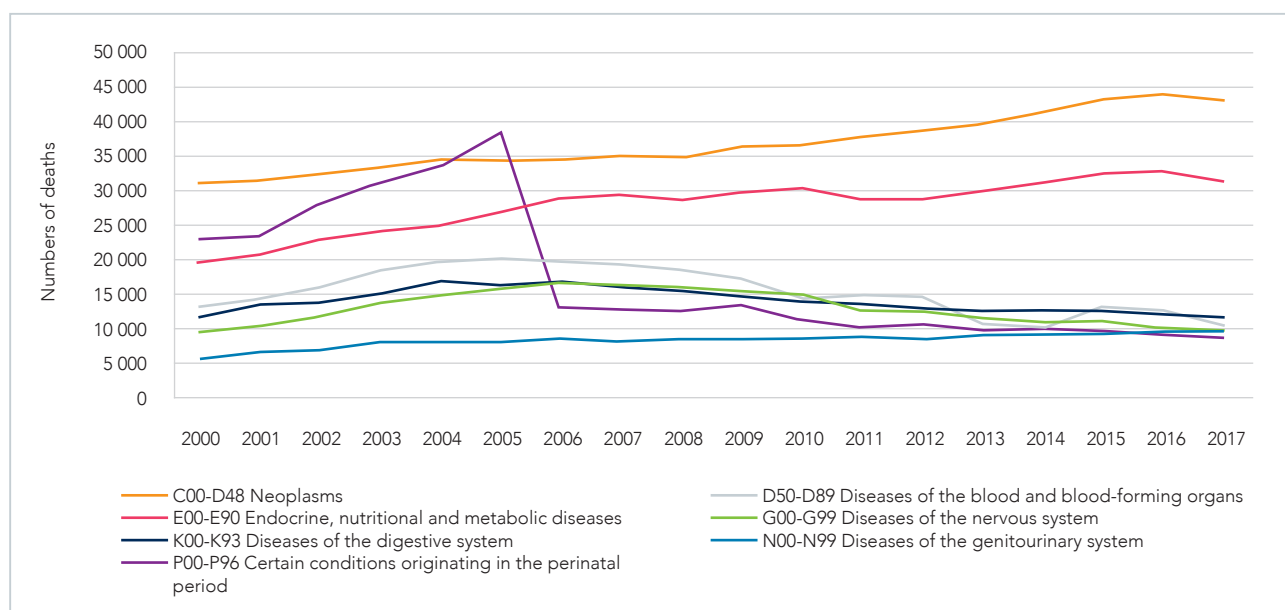


Figure A4.2: Trend in selected ICD chapters with mid-range numbers of deaths, 2000-2017

Trends in numbers of deaths by ICD chapter are shown in Figure A4.3 for the least common causes of deaths (numbers below 2,500 per years). These include Mental, behavioural and neurodevelopmental, Musculoskeletal system and connect tissue, Disease of the skin and subcutaneous tissue, Pregnancy, childbirth and puerperium, Ear and mastoid, and Eye and adnexa. Codes related to pregnancy, childbirth and puerperium (the period of about six weeks after childbirth) show a sustained increase up until 2012, followed by a decrease, and in 2016 begin to increase again. Musculoskeletal conditions show a similar pattern, with an earlier peak in 2008. The majority of deaths contributing to the chapter H00–H59 ‘Diseases of the eye and adnexa’ and the chapter H60–H95 ‘Diseases of the ear and mastoid process’ (Figure A4.3) are based on fewer than 100 deaths per year.

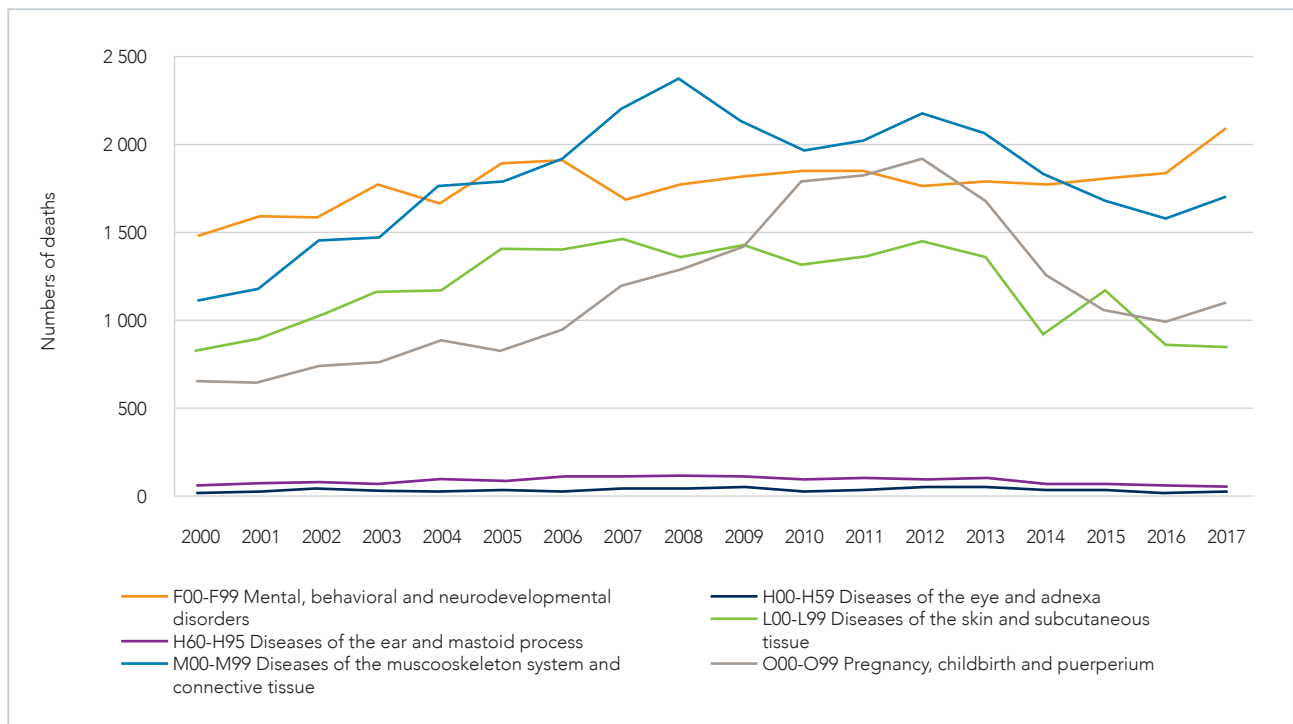


Figure A4.3: Trend in selected ICD chapters with lowest numbers of deaths, 2000-2017

## Appendix 5: Garbage codes by type and ICD-10 code

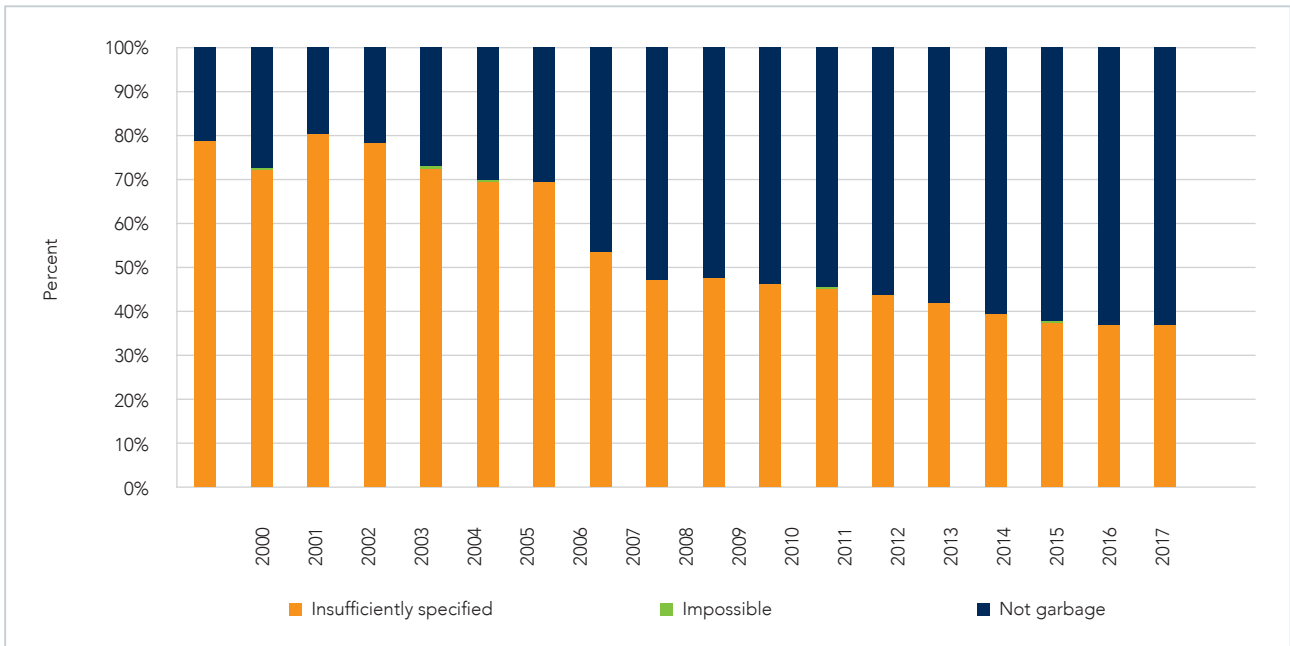
The list of garbage codes identified for the 2010 GBD study <sup>10</sup> are shown in Table A5.1.

Table A5.1: Garbage codes by type and ICD-10 codes	
Type	ICD-10 Codes
Type 1 Ill-defined symptoms	A31.1, A59, A60.0, A71-A74, A63.0, B00.0, B08.1, B08.8, B30, B35-B36, F32-F33.9, F40-F42.9, F45-F48.9, F51-F53.9, F60-F98.9, G43-G45.9, G47-G52.9, G54-G54.9, G56-G58.9, H00-H04.9, H05.2-H69.9, H71-H80.9, H83-H93, J30, J33, J34.2, J35, K00-K11.9, K14, L04-L08.9, L20-L25.9, L28-L87.9, L90-L92, L94, L98.0-L98.3, L98.5-L98.9, M03, M07, M09-M12, M14-M25, M35.3, M40, M43.6-M43.9, M45.9, M47-M60, M63-M71, M73-M79, M95-M99, N39.3, N40, N46, N60, N84-N93, N97, Q10-Q18, Q36, Q38.1, Q54, Q65-Q74, Q82-Q84, R00-R99, B94.8, B949.9, G80-G83, Y86, Y87.2, Y89, I10, I15, I70
Type 2 Intermediate COD	A40-A41, A48.0, A48.3, E85.3-E85.9, E86-E87, G91.1, G91.3-G91.8, G92, G93.1-G93.6, I26, I27.1, I44-I45, I49-I50, I74, I81, J69, J80-J81, J86, J90, J93, J93.8-J93.9, J94, J98.1-J98.3, K65-K66, K71-K72 (except K71.7), K75, K76.0-K76.4, K92.0-K92.2, M86, N14, N17
Type 3 Immediate COD	D65, I45-146, J96
Type 4 Insufficiently specified causes within ICD chapters	C80, C26, C39, C57.9, C64.9, C76, D00-D13, D16-D18, D20-D24, D28-D48, A49.9, B83.9, B99, E88.9, I51, I99, X59, Y10-Y34

Source: Naghavi et al., 2010 <sup>10</sup>.

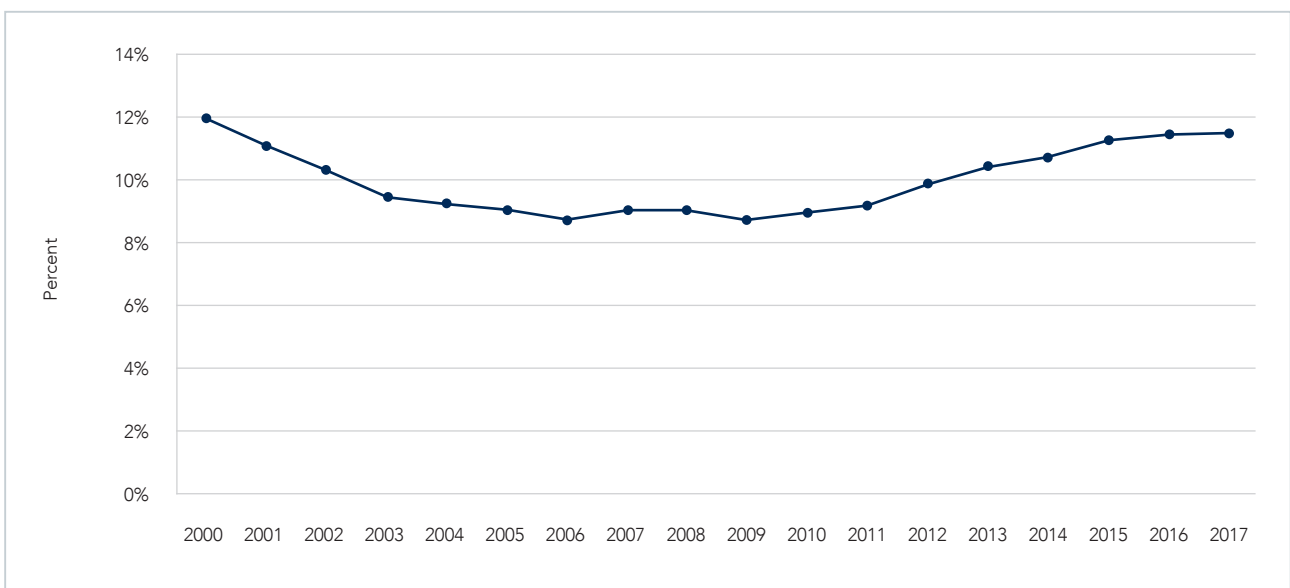
## APPENDIX 6: GARBAGE CODES AMONG INJURY DEATHS

As shown in Figure 13 in Section 4.2.4, the data regarding the external cause-of-death for injuries has considerable quality issues. This relates to the lack of a field to specify the manner of death on the death notification form and results in considerable garbage codes among the injury deaths (Figure A6.1). The major type of garbage is insufficiently specified causes with an ICD chapter. It can also be seen that there have substantive changes over time from 80% in 2000 to 37% in 2017 that mostly occurred in 2007 and 2008. This change in proportion lines up with the change in coding practice for injuries that occurred between 2006 and 2008 (Figure 13) resulting in a decreased in the group of undetermined intentional injuries (Y10-Y34), coinciding with an increase in the injury code (X59) 'exposure to unspecified factor'.



**Figure A6.1: Proportion of injury deaths coded to garbage type and not garbage, 2000-2017**

The annual number of injury deaths has remained fairly static between 2000 and 2017 at about 50,000-55,000 deaths per year, yet the injury chapter has accounted for differing proportion of the total deaths due to the large changes in the numbers of deaths from natural causes (Figure A6.2). In 2000, the proportion of deaths due to injuries was 17% and this declined to a low of around 9% from 2006 till 2014. In 2015, the proportion increased to 10% and continued to increase slightly in the last 2 years.



**Figure A6.2: Proportion of total deaths caused by injuries (V01-Y98), 2000 – 2017**



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