



Technical Landscape Analysis for Electronic Medical Certification of Cause of Death

South African Medical
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INTRODUCTION: CAUSE OF DEATH DATA IN SOUTH AFRICA

Introduction

Previous research^{1,2,3} has documented persistent challenges with mortality data in South Africa, including a range of factors spanning the quality of data, usability of data for research and public health surveillance, and the timeliness and efficiency of the death reporting process.

Briefly, the current paper-based process requires actions from multiple stakeholders across many departments, introducing many potential inefficiencies and delays. For example, the medical practitioners who begin the process when a person dies may have limited time and knowledge of the person's clinical history, yet must hand write the medically certified cause of death (MCCD) information on a death notification form and often capture the same information in various other clinical and administrative systems. The medical practitioners often record only the immediate Cause of Death (CoD) rather than detailing the underlying conditions, which significantly limits understanding of the true CoD. Further limiting the clarity of these data, cultural stigmas around HIV and suicide can lead medical practitioners to use euphemisms that result in under-reporting and misclassification of deaths from stigmatized diseases like these. Beyond these challenges of death reporting in health facilities, a large number of deaths occurring outside facilities are not medically certified at all, introducing high numbers of unknown and "other" classifications of CoD.

Challenges also arise after medical practitioners enter data into the form. Statistics South Africa (Stats SA) is the entity responsible for publishing vital statistics. Stats SA receives the MCCD data entered by the medical practitioner after it has been processed by the Department of Home Affairs (DHA) and follows a process to code causes and underlying causes of each death. Given limitations in the access to health system data, this coding process is not informed by potentially relevant clinical information that could inform CoD analysis, resulting in missed opportunities to improve the quality of mortality data and understanding of mortality causes in South Africa.⁴

Finally, the current paper-based process is governed by regulations that further limit the usability of mortality data by health researchers and health policy decision makers. A regulation to the Births and Deaths Act introduced in 2014 requires that only representatives from Stats SA gain access to the individually identifiable MCCD information in the official Notification of Death Form. This prevents public health specialists and health researchers from accessing mortality data until the official statistics have been reported, introducing a **lag time of over two years**.⁵

¹ Nannan N, Bradshaw D, Laubscher R, Mazinu M, Nkwenika T, Neethling I, Awotiwon O, Glass T, Groenewald P. Rapid assessment of cause-of-death data collection and public health use in South Africa. Cape Town: South African Medical Research Council, 2022.

² Pillay-van Wyk V, Msemburi W, Laubscher R, Dorrington RE, Groenewald P, Glass T, et al. Mortality trends and differentials in South Africa from 1997 to 2012: second National Burden of Disease Study. *Lancet Glob Health*. 2016 Sep;4(9):e642-53. doi: 10.1016/S2214-109X(16)30113-9

³ Groenewald P, Azevedo V, Daniels J, Evans J, Boulle A, Naledi T, Bradshaw D. The importance of identified cause-of-death information being available for public health surveillance, actions and research. *S Afr Med J*. 2015 Sep 21;105(7):528-30. doi: 10.7196/SAMJnew.8019

⁴ Interviews from Rapid Assessment Interviews (on-going)

⁵ Statistics South Africa. Mortality and causes of death in South Africa: Findings from death notification 2018. Pretoria: Statistics South Africa, 2021.

These data are anonymized and cannot be linked to individual clinical records by the National Department of Health (NDoH) and researchers.

Together, these challenges significantly limit the ability of mortality data to inform health policy and planning. In the interest of enabling health programming to be more responsive to mortality data in South Africa, the South African Medical Research Council (SAMRC) has undertaken a scoping study to evaluate the feasibility of an electronic MCCD (eMCCD) system in South Africa. An eMCCD system would capture only MCCD information, in contrast to an electronic Death Registration System (eDRS) that would capture all of the information collected during death registration in South Africa. The focus on eMCCD in this scoping study is an entry point for connecting health systems and NDoH stakeholders to the death registration process, with a vision of eventually extending to an eDRS system.

Given this context, this evaluation begins by mapping the current death registration process, recognizing there is currently no involvement of NDoH, and no linkage between health systems and the mortality data recorded on the official death registration form and analyzed by Stats SA. In order to consider the potential for an electronic system that better connects health information and stakeholders to the process, the evaluation then turns to the existing landscape of health and demographic information systems that could be integrated into an eMCCD or eDRS system in the future. Finally, the evaluation proposes a possible model for an eMCCD system and an eDRS system that has potential to streamline, improve the quality of, and accelerate the availability of MCCD information.

METHODS

This technical evaluation was informed by desk research as well as key informant interviews. Desk research focused on understanding the current processes and systems involved in death registration, as well as the data schema of existing health information systems (HIS). Key informants were selected for their expert knowledge and experience within the relevant sectors, and interviews were conducted to validate and flesh out information gathered from desk research. Informants included representatives from provincial health departments, the Department of Home Affairs (DHA), and practitioners familiar with the HIS identified for the evaluation. Interviews were conducted virtually using open-ended questions that explored details of the current process of death registration, strengths and weaknesses of existing HIS with relevant health and mortality data, and perspectives on future models of death reporting in South African context.

STRUCTURE OF REPORT

Section 1 begins by documenting the existing death reporting process, beginning with an individual death, and following the process through to DHA, Stats SA, and the eventual availability of CoD data to public health researchers such as the SAMRC. It lists existing challenges with mortality data and identifies corresponding opportunities for an electronic MCCD (eMCCD) system.

Section 2 then considers existing HIS that currently capture mortality data in the South African landscape yet are disconnected from the death registration process. With a view of potential

integration of HIS with a future eMCCD or eDRS, it reviews a subset of health and demographic systems in light of their coverage, data quality, consideration for linkage, and relevance of data for eMCCD.

Section 3 analyzes the underlying structure of the data captured by the HIS systems identified in Section 2. It details the specific data elements that make up the current MCCD form and compares coverage of these elements by the HIS.

Section 4 brings together the existing process and landscape of health and demographic systems to propose two general models for a future eMCCD system. Each model presents a hypothetical, high-level design for an eMCCD system and considerations for the opportunities and challenges of each model. This section discusses high level requirements and processes for an eMCCD or eDRS system.

Section 5 summarizes the forward-looking visions and strategies of the key institutions involved in MCCD and death registration. It discusses the opportunity for mobilizing stakeholders around a future electronic system given the political priorities and outlook of relevant institutions.

Section 6 identifies near-, medium-, and long-term next steps to advance actions towards an eMCCD system. This section provides initial considerations for moving forward with design, formal requirements gathering and documentation, and implementation of an eMCCD system.

SECTION 1: CURRENT HEALTH SYSTEM PROCESSES FOR MCCD

The current death registration process is governed by the DHA and involves multiple stakeholders in the process of recording and submitting information on the official Notification of Death/Stillbirth Form, DHA-1663, and the Death Report by Authorized Person Form, BI-1680. The current process requires each stakeholder to fill one or more sections of the forms, which, when complete, are submitted to DHA and passed on to Stats SA.

In most cases, each individual or organization engages with some electronic tools for storing data relevant to each part of the process, e.g., medical practitioners may have electronic hospital systems or patient files where a patient death is noted; the DHA manages the National Population Register to record deaths; and Stats SA uses a variety of electronic tools to capture and code CoD information. However, the current death registration process is largely paper based, with little or no electronic data exchange between stakeholder platforms.

In preparation for the death registration process, DHA distributes copies of the official forms for death registration. Health facilities receive batches of DHA-1663 forms, in which Notice of Death is captured in Sections A-F, and MCCD is captured in Section G, a one-page Annex known as DHA-1663B, or “page one of one.” Outside of medical facilities, village headmen receive copies of BI-1680 for deaths that occur in the community without a medical practitioner present to certify the death.

Each form has a barcode and serial number that can be used to track and trace their distribution from DHA headquarters to provincial offices and subsequent distribution points. The presence of a uniquely identifying barcode on each page of the form also enables distinct pages of the

forms to be matched and for the entire form, theoretically, to be tracked by DHA from distribution to return.

The death registration process is triggered when a person dies, and it can follow one of several paths depending on whether there is a medical practitioner available to certify the death.

[Appendix 1](#) details the flow of information in the current death registration process. As detailed in the rows of the diagram, the current process involves multiple individual and organizational actors, including both individual and institutional actors, each with a distinct role in the process. The relevant system databases for each actor are shown in the column on the right side of the diagram, indicating a potential source of relevant data that is siloed from other stakeholders and parts of the death registration process.

For simplicity, the diagram in Appendix 1 is broken down into smaller sections to accompany the narrative below.

Certification by a Medical Professional or Forensic Pathologist (Figure 1)

When a person dies in a facility or in a community with access to a general practitioner, a **medical practitioner** (usually a physician, but may also be a registered nurse in some contexts) fills out section A of DHA-1663 (Particulars of the Deceased), aided by an **informant**, usually a family member of the deceased. The practitioner also fills out section B to certify whether it is a natural or unnatural death. The practitioner may also fill out other paper or electronic patient records that must be completed upon a patient's death.

The **medical practitioner** must complete Section G, a separate 1-page MCCD annex that contains CoD information, as well as repeated Particulars of Deceased fields. The medical professional completes this section with a clinical description of the immediate and underlying causes of death. Once complete, Section G of the form is sealed by the medical practitioner, following the Births and Deaths Registration Act⁶ regulation passed in 2014, and returned to the informant.⁷ As noted in Step 1, medical practitioners may also record CoD information in other hospital systems and patient notes.

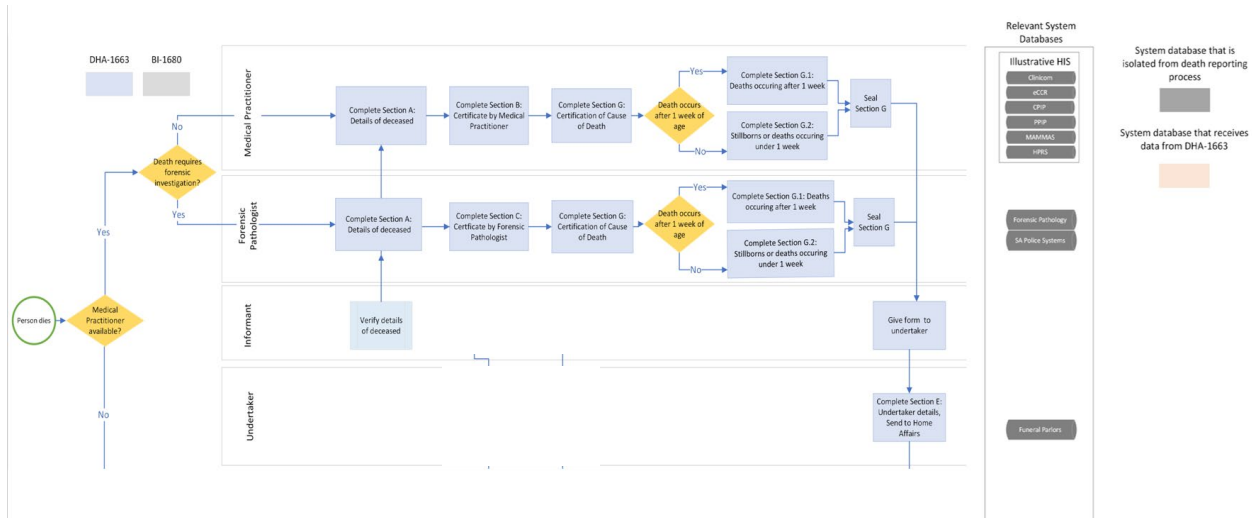
Alternatively, if a person dies in ways that cannot be certified as natural, a forensic investigation may be needed. In these instances, a **forensic pathologist** fills out Section A, Section C, and Section G.

The informant takes the form to a **funeral undertaker**, who enters their details in section E and submits the form to the local Home Affairs office. Alternatively, individuals may take the form directly to a local DHA office (DHA Front Office).

⁶ Births and Deaths Registration Act: Regulations. 2014;70.

⁷ While the intention is for this information to be unaltered until received by Stats SA, there are anecdotal reports of informants opening the envelope and sometimes changing the contents to prevent potentially stigmatizing CoD determinations from going forward. In addition, there are also reports that DHA-1663B does not, in practice, get sealed.

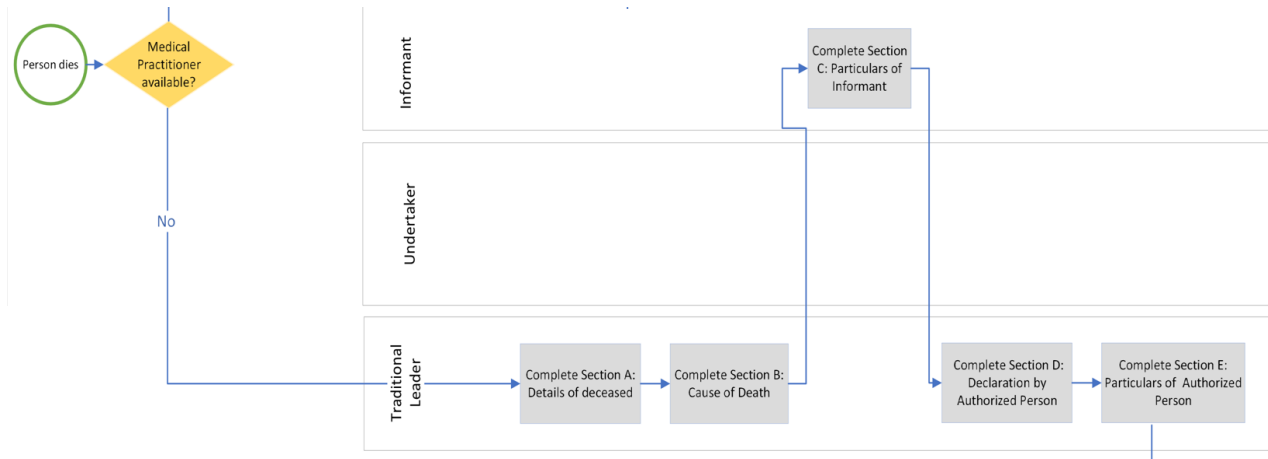
Figure 1 – Certification by Medical Practitioner or Forensic Pathologist



Death Notification by Traditional Leaders or Police Officers (Figure 2)

Alternatively, if a person dies where no medical practitioner is available to certify the death, a traditional leader or police officer is authorized to fill out form BI-1680⁸, which includes the details of the deceased and a description of CoD. This information is currently not verified by a medical practitioner, and the form is passed on to funeral undertakers or Home Affairs (Figure 2).

Figure 2 – Notification by Headmen or Police Officers



⁸ Department of Home Affairs - Death Certificates [Internet]. [cited 2022 Oct 25]. Available from: <http://www.dha.gov.za/index.php/civic-services/death-certificates>

DHA and Stats SA Process (Figure 3)

DHA Front Office verifies the identity of the deceased and informant from the National Population Register (NPR), as well as the identity of physician and undertaker. DHA Front Office updates the NPR with the fact of death, date of death, and whether the death was natural or unnatural. If the deceased was not a South African citizen, DHA will issue a paper death report. There is no electronic file or any digital record for deaths of non-South African citizens or South African citizens who were not issued a national identification number.⁹ DHA will also issue abridged death certificates and burial orders before sending the DHA-1663 forms in batches to the National DHA Office (DHA Back Office).

DHA Back Office collates batches of forms and sends these by courier to Stats SA to conduct official coding and produce official death statistics. DHA will also issue full death certificates upon request, for a fee.

Stats SA unseals Section G of Form DHA-1663B and completes ICD-10 coding based on the information entered by the medical practitioner. Stats SA receives all DHA-1663 and BI-1680 forms, regardless of citizenship of the deceased, and creates one dataset for death notifications. The underlying cause-of-death is identified using IRIS ICD10 Coding tool¹⁰ and checked against the Automated Classification of Medical Entry tool (ACME).¹¹ Subsequently, Stats SA's editing program, as well as two WHO-developed tools (Analyzing mortality levels and causes-of-death [ANACoD], version 2.0 and CoDEdit, version 1.0) are used to check accuracy and flag implausible causes of death for investigation.¹² Stats SA then publishes aggregate mortality data and analyses in the annual "National Statistical Release of Mortality and Causes of Death in South Africa,"¹³ as well as anonymized, line-level data per death.

Once Stats SA prepares official statistics, the **aggregate mortality data is available** to public health researchers via the statistical release. Deidentified individual data is also made available to public health specialists and researchers by Stats SA, with a similar multi-year time delay from the year of death.

⁹ The proportion of deaths occurring where there is no SA ID number was not easily discoverable through this process. Deaths of this sort would include non-South African citizens who die in South Africa, babies that die before an SA ID number is registered, and potentially others for whom the SA ID number is not reported at time of death.

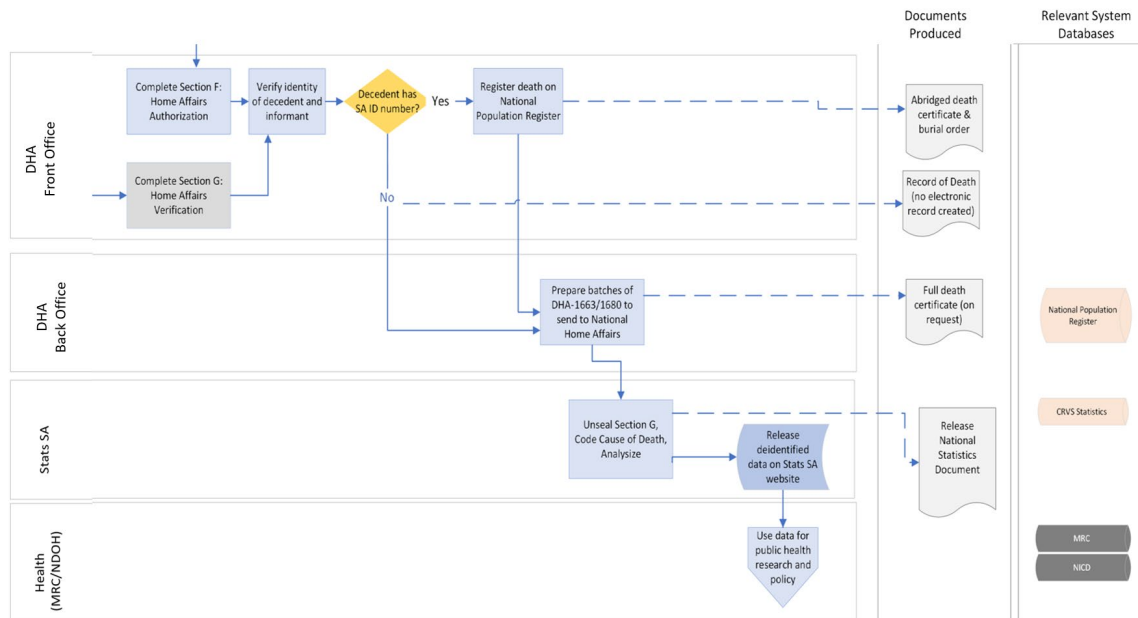
¹⁰ Iris Institute [Internet]. [cited 2022 Oct 11]. Available from: <https://www.dimdi.de/dynamic/en/classifications/iris-institute/>

¹¹ Lu TH. Using ACME (Automatic Classification of Medical Entry) software to monitor and improve the quality of cause of death statistics. *Journal of Epidemiology & Community Health* [Internet]. 2003 Jun 1 [cited 2022 Oct 11];57(6):470–1. Available from: <https://jech.bmj.com/content/57/6/470>

¹² The Analysis of Causes of National Deaths for Action (ANACONDA) tool is not referenced as a tool used by Stats SA. (Mortality and causes of death in South Africa: Findings from death notification report.)

¹³ Mortality and causes of death in South Africa: Findings from death notification report. Stats SA [Internet]. 2018. [cited 2022 Oct 11]. Available from <https://www.statssa.gov.za/publications/P03093/P030932018.pdf>

Figure 3 – DHA and Stas SA Process



The current process of death registration enables the following:

- Certification of CoD by a medical practitioner.¹⁴
- Provision of death certificates (abridged and unabridged) and burial orders for citizens.
- Provision of a record of death for non-citizens and other decedents without a South African ID number.
- Registration of deaths of those with South African National Identity Numbers in the NPR.
- Provision of national CoD statistics by Stats SA.

¹⁴ The medical practitioner's professional certification is not routinely checked via HPCSA.

However, previous research has identified, and informant interviews have reiterated, numerous challenges in the quality of mortality data captured through the MCCD process, the timely use of mortality data by public health researchers and policymakers for data-driven policy and planning, as well as the overall efficiency across NDoH, DHA, and Stats SA systems.

Rapid Mortality Surveillance

SAMRC set up a process of Rapid Mortality Surveillance (RMS)^a, involving a near to real-time feed of fact and nature of death information from the DHA NPR. These data have been used to produce the RMS Report which has been in place since 2012 and provides high-level mortality estimates. These data have also been used as part of an ethics-approved collaborative project, “A linked data base (registry) of South African COVID-19 related deaths,” which involved linking deaths reported from the NPR with Covid-19 case information collected by the National Institute for Communicable Diseases (NICD), NDoH, and the Western Cape Department of Health (WCDOH), using the SA ID Number. Mortality data from the NPR excludes the deaths of those not registered in the NPR (those lacking birth certificates or identity documents) but were used to identify deaths in the Western Cape PHDC that had not been previously recorded by the health system. Linkage was restricted to only those with SA ID Numbers that had a confirmed Covid-19 episode. WCDOH sends a list of SA ID Numbers for all Covid-19 cases where the patient has not been identified as dead to the MRC on a weekly basis. The MRC links these SA ID numbers to the RMS extract and returns the list of ID numbers for which a death from natural causes has been recorded in the NPR. These deaths are then used for restricted Covid-19 excess death analyses and are not updated in the patient clinical records.

a Rapid Mortality Surveillance Report 2019 & 2020 [Internet]. South African Medical Research Council. 2021 [cited 2022 Oct 17]. Available from: <https://www.samrc.ac.za/reports/rapid-mortality-surveillance-report-2019-2020>

Challenges & Opportunities in the Current Process

The complexity of the current process and involvement of many stakeholders contributes to a range of challenges in quality, usability, and system efficiency that stem from different points in the process. These are detailed below in Table 1.

Table 1 – Summary of Challenges with Mortality Data Capture and Reporting in South Africa

Data Quality Challenges	
1	Incomplete CoD data: Information on underlying conditions is missing or partially recorded on the death registration form. Medical practitioners may not have access to full record, have limited time to record it by hand, and little incentive to do so.
2	Incorrect coding of CoD: Limited information in handwritten CoD information, coupled with lack of access to clinical history of the deceased, contributes to incorrectly coded causes of death.

3	Loss of clinically relevant information: The collapsing of written CoD information into ICD-10 codes can result in a loss of clinical information that would be of value to the health sector.
4	Underreporting of HIV-related deaths: Stigma around HIV often results in HIV being recorded with euphemisms, e.g., retroviral disease.
5	Incomplete tracking of Death Registration forms: Paper forms can fall out of the system between origination and final transfer to Stats SA.
6	Incorrect injury classification: Incomplete understanding of injury related deaths and the lack of a “manner of death” field on the form leads to injury misclassification. Homicides, suicides, and traffic accidents are underreported as manner of death is not specified, forensic pathologists are reluctant to influence investigations, and suicides are underreported due to stigma.
7	Lack of medically certified CoD information for deaths occurring without involvement of a medical practitioner: Traditional leaders and police officers are authorized to complete forms yet do so without formal medical training.
8	Inconsistent geographic coding: Capture of geographic data during death registration is inconsistent and follows magisterial district boundaries using the provided address information. Stats SA uses a different set of boundaries from their ‘place names’ dictionary.
Usability of CoD death for research, planning, and policy	
9	Delay in availability of CoD data to public health specialists and researchers (2+ years): Release of mortality data by Stats SA is delayed, with the “Mortality and Causes of Death in South Africa” report taking approximately 27 months. Data cannot be used for epidemic response (e.g., Covid-19).
10	Anonymized CoD Data: CoD data that are made available by Stats SA are anonymized and unable to be linked to patient clinical records. This limits the usefulness of the information for research and public health decision making.
11	Lack of data flow back to practitioners: Currently the practitioners that enter CoD data do not have access to official CoD recording that could inform quality improvement, as well as administrative or clinical reporting.
12	Lack of data on persons not registered in the NPR: The fact and nature of death for persons without a South African identity number (non-SA citizens, unregistered South Africans, stillbirths, or children who die before birth registration) are not available to research institutions or DoH via the routine RMS extract from the NPR and cannot be used for excess death analysis.
System Efficiency	

13	Burden on medical practitioners: Filling out paper death registration form in addition to other clinical documentation requirements takes extra time and may contribute to quality issues.
14	Data silos across systems: Currently, many systems collect patient-level medical information, including underlying conditions that may contribute to understanding the CoD. Medical practitioners are unable to link these records to deaths in order to inform CoD reporting. Conversely, CoD cannot be linked back to clinical records to inform burden of disease and epidemiological analysis.
15	Logistics: The current process necessitates the need for storage and transportation of large volumes of paper forms, which is increasingly infeasible.
16	Data Capture: Data needs to be manually transcribed into the Stats SA electronic system from the paper forms, introducing delays to the coding process.

Opportunities of an Electronic System

Many of these challenges have potential to be improved by the introduction of an electronic system for capturing CoD information, and further, by integrating existing health information from across the existing landscape. Specific opportunities to improve quality, usability, and efficiency are as detailed below and summarized along with contributing factors in [Appendix 2](#).

Opportunities to Improve Quality

An electronic system for **recording** MCCD would provide several opportunities to improve data quality:

- Implementation of validation and skip-logic to ensure forms are filled in correctly with a minimum of free-text entry.
- Provision of job aids to assist practitioners in determining immediate and underlying CoD (informed by clinical logic).
- Secure access control to CoD information, ensuring CoD is only accessible by authorized users and limiting access by informants or other actors in the death registration process. This electronic privacy capacity may encourage medical practitioners and forensic pathologists to provide true CoD information, rather than euphemistic or incorrect causes.¹⁵
- Visibility of medical records of the deceased, if these exist in an online system (e.g., Western Cape Single Patient Viewer¹⁶) and data governance policies are in place to allow access.
- Potential for the CoD information to be populated automatically by external electronic systems (e.g., an existing hospital discharge summary containing the correct information).

¹⁵ Groenewald P, Azevedo V, Daniels J, Evans J, Boule A, Naledi T, Bradshaw D. The importance of identified cause-of-death information being available for public health surveillance, actions and research. *South African Medical Journal*. 2015 Sep 21;105(7):528-30. doi: 10.7196/SAMJnew.8019

¹⁶ Foster R, Heekes A, Hussey H, Smith M, Mutemaringa T, Phelanyane F, et al. Beyond interoperability with the single patient viewer: A clinical portal to access integrated patient records. *International Journal of Population Data Science* [Internet]. 2020 Dec 7 [cited 2022 Oct 6];5(5). Available from: <https://ijpds.org/article/view/1614>

An electronic system for **sharing** MCCD information across stakeholders presents additional opportunities to improve the coding of CoD data.

- Providing Stats SA access to more complete medical information to verify and extend what is recorded in the clinical description.
- Automatically generating and checking the validity of ICD-10 mortality coding based on clinical description through integration with online tools, such as ACME, IRIS and ANACOD, earlier in the registration process.

Opportunities to Improve Usability of CoD Data

An eMCCD system offers multiple opportunities to address challenges of the timely usability of CoD data.

- Electronic capture of CoD information during the death registration process will create an electronic MCCD record available to NDoH stakeholders immediately.
- An eMCCD record containing demographic data would allow linkage to patient clinical records even where there is no robust unique identifier such as the South Africa ID Number (SA ID). This would enable reporting of fact and CoD of deceased people who are not in the National Population Register (and are not present in the RMS extract).
- Availability of CoD data to medical practitioners would complete a feedback loop to those entering the data and may encourage greater use of mortality data for quality improvement.

System Efficiency

Finally, an eMCCD offers several opportunities to improve the overall **efficiency** of the death registration process and eliminate redundant data capture across the landscape.

- An eMCCD that is fully or partially integrated across NDoH, DHA, and Stats SA stakeholders could allow each stakeholder to enter data once and have those data be immediately available to all authorized stakeholders. For medical practitioners in particular, this efficiency could save time and have a positive influence on the quality of information entered.
- Reduced storage and logistics requirements. Electronic systems would lessen the volume of paper forms moving through the system and requirement storage.
- Reduced manual capture and interpretation of handwritten CoD data by Stats SA.

Limits on the Opportunities of eMCCD

An eMCCD will likely not address all challenges currently in the system. Non-digital solutions such as workforce training, increased capacity, and policy change are necessary and complementary interventions. Specifically, an eMCCD system may not improve:

- Intentional use of incorrect codes or euphemisms to describe deaths from HIV due to persistent stigmatization.
- Late registrations of death.
- Lack of “manner of death” field on DHA forms (its inclusion in any eMCCD system is a policy rather than technical decision).

- Reluctance of forensic pathologists to specify unnatural causes of death.¹⁷
- If there remains any paper component of the death registration process, paper forms may still be lost in the process.

Additionally, introducing a new electronic system into the landscape can raise new risks. These include introducing dependencies on new equipment, as well as requirements for electricity and connectivity. While systems can be designed to allow for offline data capture with upload to an online platform when connectivity is available, availability of internet connection and electricity remain a concern in many parts of South Africa. In addition, digital tools often require investments in digital literacy and training. Finally, introducing a new system will require investment in a change management process across individuals and entire organizations. There may be an extended period where both the existing paper process and a new electronic process are in use. These risks will be considered in the context of potential models for an electronic system introduced in **Section 4**.

SECTION 2: LANDSCAPE OF HIS SYSTEMS

One major advantage of an eMCCD is the ability to leverage existing electronic health information to enrich the MCCD data captured in the death registration process. Data including immediate CoD and underlying conditions are captured in numerous existing HIS in South Africa. A future eMCCD system could access these data through system integrations and data sharing to enable medical practitioners to have access to more complete patient data to inform completion of the eMCCD. Eventually, such integrations may enable key elements from existing systems to automatically populate fields of an eMCCD. This section details existing HIS that capture data relevant to a future eMCCD.

Health Information Systems

This landscape review considered ten systems existing in the HIS landscape in South Africa (Table 2). These systems include national and provincial systems dealing with longitudinal clinical patient records, as well as disease-specific systems, such as TIER.net for HIV and TB and Maternal Morbidity and Mortality Audit System (MAMMAS) for maternal mortality. Data considerations were informed by review of data schemas, electronic forms, and expert interview.

¹⁷ Some FPs are reluctant to report unnatural causes of death out of concern that doing so could interfere with an inquest and incur a fine. See Nannan et. al., 2022 for additional detail.

Table 2 – Existing Health Information Systems with Relevant Data for Mortality and Underlying Condition Data

System	Description	Relevant Data Elements
Child Problem Identification Program (Child PIP) ¹⁸ Organization: Provincial DoH	Hybrid paper and digital system used by hospitals to report child CoD and modifiable conditions. Paper data collection forms are aggregated and entered online and submitted twice annually to higher levels (e.g., provincial Child PIP). Data considerations: Data initially entered by hand; accurate but uses a bespoke coding scheme (not ICD-10) Coverage: Facility based, mostly in Western Cape but anecdotally in other provinces Unique Identifier: Folder number	CoD (for children)
Perinatal Problem Identification Program (PPIP) ¹⁹ Organization: Provincial DoH	Hybrid paper and digital system that hospitals use to report perinatal CoD and modifiable conditions. Paper data collection forms are aggregated and entered online, submitted twice annually. Data considerations: Data initially entered by hand; accurate but uses a bespoke coding scheme (not ICD-10) Coverage: Birthing centers, mostly in Western Cape Unique Identifier: Variable, data capture form includes open field for “identification” without restricting to a specific type	CoD, stillborn
Maternal Morbidity and Mortality Audit System (MAMMAS) ²⁰ Organization: National Committee for the Confidential Enquiry into Maternal Deaths	Electronic system for storing and collating maternal death forms filled out as part of the Confidential Enquiry into Maternal Death process. Data are collected on paper at facilities, then reviewed through an audit system before being entered into MAMMAS. Data from MAMMAS are used to compile the Saving Mothers Reports every three years. Data considerations: Data goes through expert audit process before entry; available at provincial level within 6 months of end of year Coverage: Facility based, national Unique Identifier: Anonymized identifier	CoD, maternal mortality
Notifiable Medical	Web and mobile app-based system to enable labs, physicians, and health schemes to notify NICD of suspected cases of notifiable medical conditions (NMC), which they are legally required to report. Reports mortality if occurs but does not routinely aggregate all deaths from a particular condition. Death is often ascertained as part of the	CoD, if occurs from legally notifiable condition*

¹⁸ The Perinatal Problem Identification Programme. [Internet]. [cited 2022 Oct 6]. Available from: <https://www.up.ac.za/centre-for-maternal-fetal-newborn-and-child-healthcare/article/2871749/the-perinatal-problem-identification-programme>

¹⁹ Child PIP DATA COLLECTION. University of Pretoria [Internet]. [cited 2022 Oct 6]. Available from: <https://www.up.ac.za/centre-for-maternal-fetal-newborn-and-child-healthcare/article/2868032/child-pip-data-collection>

²⁰ Moodley J, Fawcus F, Pattinson R. Improvements in maternal mortality in South Africa. South African Medical Journal. 2018 Mar 2;108(3a):s4–8.

<p>Conditions (NMC App)²¹</p> <p>Organization: NICD</p>	<p>follow-up process for each NMC case.</p> <p>Data considerations: Incomplete reporting; app initially had poor interface and could not handle large volumes of reports; there is a (mis)perception reporting will require data which limits its use</p> <p>Coverage: National, but receives limited use by medical practitioners</p> <p>Unique Identifier(s): SA ID number, passport number, or patient demographics</p>	
<p>Three Interlinked Electronic Registers (TIER.net)</p> <p>Organization: NDoH</p>	<p>The TIER.net database contains information on clinic visit attendance, laboratory results and medicine dispensing records for public sector patients on ART and TB treatment.</p> <p>Data considerations: Potentially low-quality mortality data; patients are sometimes marked as dead to improve loss-to-follow-up indicators</p> <p>Coverage: HIV and TB public sector patients only</p> <p>Unique Identifier(s): SA ID, ART Number, Folder number, Clinicom number</p>	<p>HIV related deaths; HIV as an underlying condition</p>
<p>DATCOV²²</p> <p>Organization: NICD</p>	<p>Covid-19 case reporting system for public and private Covid-19 reporting. Public and private hospital reporting (admission, discharge, death), as well as positive Covid-19 laboratory tests from private and public sector laboratories, and some community information (deaths, where possible). Planned to be decommissioned December 2022.</p> <p>Data considerations: High quality mortality data but only for Covid-19 deaths</p> <p>Coverage: National</p> <p>Unique Identifier(s): SA ID number, Hospital ID, HPRN, other demographics</p>	<p>Covid-19 deaths only</p>
<p>DHIS National Health Information Repository and Data Warehousing (NHIRD)</p> <p>Organization: NDoH</p>	<p>DHIS1.4 and DHIS2 are used throughout South Africa as a Health Management Information System for aggregate indicator information, including the National Indicator Data Set²³ (NIDS)</p> <p>Data considerations: Good quality data but aggregated to facility level (age/sex disaggregation); minimal CoD data</p> <p>Coverage: National</p> <p>Unique Identifier: N/A</p>	<p>National mortality aggregate indicators</p>

²¹ National Health Act: Regulations: Surveillance and control of notifiable medical conditions [Internet]. 2022. Available from: <https://www.gov.za/documents/national-health-act-regulations-surveillance-and-control-notifiable-medical-conditions-15>

²² Jassat W, Cohen C, Kufa T, Goldstein S, Masha M, Cowper B, et al. DATCOV: A sentinel surveillance programme for hospitalised individuals with Covid-19 in South Africa, 2020. Covid-19 Spec Public Health Surveill Bull. 2020 Jun 10;18(1):1–15.

²³ National Department of Health Data Dictionary [Internet]. [cited 2022 Oct 12]. Available from: <https://dd.dhmis.org/>

<p>WC Health Information System²⁴</p> <p>Organization: Western Cape Provincial Dept. of Health</p>	<p>The WC DoH Hospital information system is built on Clinicom supplied by Intersystems.²⁵ It is used in all Western Cape Public hospitals and includes admission, visit and discharge data, as well as mortality information if the death occurs in hospital. The client registration component is used across all provincial health facilities, and every beneficiary of the WC Public health system is allocated a unique identification number.</p> <p>The Electronic Continuity of Care Record (eCCR) is a module of the Clinicom hospital system where additional patient information can be entered when a patient is discharged from hospital. It includes patient outcomes and primary discharge ICD codes. If a patient dies in a hospital using eCCR, the CoD data is captured in the structured format required for the death notification form.</p> <p>The Provincial Health Data Center (PHDC) ingests information from multiple disparate health data sources, including but not limited to the NHLS, multiple disease specific systems, emergency services and community health platforms, and links these data using the Clinicom number. Access to the records is provided via the Single Patient Viewer (SPV) web application.</p> <p>Data considerations: High quality clinical record or care Coverage:</p> <ul style="list-style-type: none"> • Clinicom: All Western Cape Hospitals (Client Registry at all PHC clinics) • eCCR: A subset of Western Cape hospitals • PHDC/SPV: Full provincial coverage <p>Unique Identifier: Clinicom Folder Number</p>	<p>Underlying conditions, CoD (if death occurs in hospital), demographics</p>
<p>Health Facility Registry</p> <p>Organization: NDoH</p>	<p>The NDoH maintains a registry of all public sector health facilities. This contains unique identifiers for the facility, the name of the facility and some geographic information and contact details.</p>	<p>Facility identifiers, contact number, geolocation</p>
<p>DHIS2 Tracker</p>	<p>DHIS2 Tracker supports WHO CRVS modules,²⁶ which are not used in South Africa. A CoD module using ICD-10-SMoL has now been discontinued. Other programs use DHIS2 Android for capture of data in communities and in clinics, e.g., Mothers2Mothers for HIV and TB programs.</p>	<p>n/a</p>

The current landscape of HIS in South Africa is highly fractured. Existing systems have varying levels of data quality, with only a small number having achieved national coverage. While there are numerous systems containing relevant health and mortality data, this subset reflects a larger trend of decentralization within the health system, where most HIS operate at provincial or

²⁴ Boulle A, Heekes A, Tiffin N, Smith M, Mutemaringa T, Zinyakatira N, et al. Data centre profile: The Provincial Health Data Centre of the Western Cape Province, South Africa. IJPDS [Internet]. 2019 Nov 20 [cited 2022 Sep 14];4(2). Available from: <https://ijpds.org/article/view/1143>

²⁵ HealthShare [Internet]. US Corporate. [cited 2022 Oct 12]. Available from: <https://www.intersystems.com/interoperability-platform/>

²⁶ Metadata Package Downloads - DHIS2 [Internet]. [cited 2022 Oct 12]. Available from: <https://dhis2.org/metadata-package-downloads/#crvs>

metro level, or lower. Of the subset of public HIS reviewed as part of this landscape, many of those with high quality health and mortality data are concentrated in the Western Cape. Additional research is needed to identify systems in other provinces and metros. Where electronic medical records systems are used, there are likely to be elements that could contribute to an eMCCD system. As electronic medical records (EMRs) are adopted across provinces and achieve greater scale, the opportunity for an online MCCD to further enrich and be enriched by health system data will also grow. The technology introduced as part of the National Health Insurance²⁷ implementation will strengthen and centralize demographic and clinical information systems and contribute to this opportunity.

This landscape also highlights the diversity in unique identifiers used across various HIS. Linkage of patient records will be a critical part of enabling data exchange between these systems and an eMCCD. While the master patient index in Western Cape makes it most feasible there, the potential for such exchange will grow as the health system works toward adoption of a unique patient ID such as the health patient registration number (HPRN).

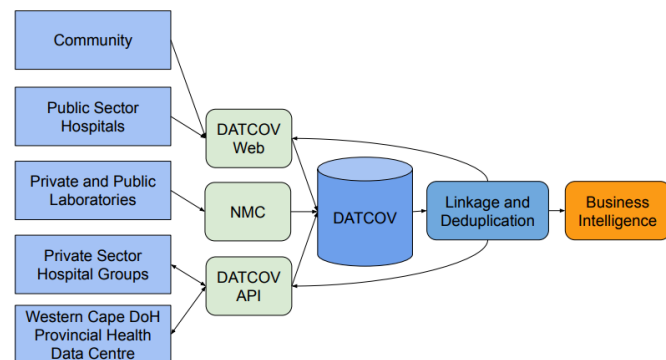
Learning from DATCOV: Opportunities and best practices

In March 2020, the National Institute for Communicable Diseases (NICD) began implementing a surveillance platform for Covid-19. Although the Notifiable Medical Conditions App was available to medical practitioners for reporting, it was not widely used nor ready for large volumes of case reports. NICD instead initiated a new standalone emergency system known as DATCOV to capture Covid-19 statistics at hospitals.

NICD worked with Microsoft to implement a platform to capture hospital admissions, daily updates, and discharges within a matter of days. Without a mandate to engage in national surveillance, DATCOV started small. By April 2020, eight public sector hospitals had implemented DATCOV and were electronically submitting data via a web application and receiving reports. Subsequently, all Western Cape private sector hospitals began sharing data with the system electronically, followed by the Western Cape public hospitals. The Western Cape DoH chose to submit a daily export of data from the Provincial Health Data Center (PHDC) via File Transfer Protocol (FTP) and subsequently an API interface. The PHDC covers all WC public sector hospitals, and this electronic process relieved the public hospitals in the province from implementing manual data capture.

Figure 4 – DATCOV Data Flow

The National Health Laboratory services, covering all public sector testing as well as most private sector labs, integrated with DATCOV via the Notifiable Medical Condition (NMC) surveillance system²⁸, and submitted all positive Covid-19 test results daily. Other private hospital groups joined, followed by public hospitals in other provinces with support from the NDoH. DATCOV quickly became a surveillance system ingesting data from all labs and hospitals in South Africa and providing reports via NICD dashboards and data via API feeds to various subscribers. NICD implemented patient linkage and deduplication to



²⁷ Motsoaledi DA. National health insurance for South Africa; Toward universal health coverage. Government Gazette [Internet]. 30 June 2017 [cited 2022 Oct 11]. Available from https://www.gov.za/sites/default/files/gcis_document/201707/40955gon627.pdf

²⁸ NOTIFIABLE MEDICAL CONDITIONS [Internet]. NICD. [cited 2022 Nov 1]. Available from: <https://www.nicd.ac.za/nmc-overview/>

aggregate records from various systems and then used data for research to inform epidemic response. (Figure 4)

DATCOV also relied on a robust network of data capturers to facilitate data submission through the platform. While this increased cost of the platform, it enabled data to be reported at national scale quickly. Because it is a stand-alone emergency response platform, DATCOV is set to be decommissioned in December 2022. However, it serves as a proof of concept for successful data integration across public, private, hospital, lab, and community stakeholders. The DATCOV experience offers several lessons that can inform future online systems integrating health information across the landscape:

1. **Capture the minimum data set.** Reducing the number of fields captured over time to the minimum needed enhanced feasibility of reporting.
2. **Minimize entry of free text.** Using drop down lists, check boxes, and job aids for coding can significantly improve data quality.
3. **Minimize manual capture of data.** Enabling automatic data sharing from other systems through an API based data exchange or data export helped to lessen burden and minimize potential for error.
4. **Create a feedback loop.** Enabling those submitting data to access the daily reports for their own use created additional incentive to report timely, high-quality data.
5. **Prioritize a simple user interface.** Investing in an interface that was clean and easy to use lowered barriers to adoption.
6. **Start small and build momentum for scale by delivering value early.**
7. **Invest in champions.** DATCOV benefited from the engagement of provincial and hospital-level information managers to drive the effort locally.

Demographic and Biometric Information Systems

The landscape also considered multiple systems relevant to storing and linking individual data across NDoH, DHA, and Stats SA. These systems contain demographics and unique identifiers for individuals that could be used to link health data across disparate systems in a future eMCCD (Table 3). Data considerations were informed by review of data capture schemas and expert interview.

Table 3 – Demographic Systems for Linking Individuals across Health Systems

System	Organization	Description	Relevant Data Elements
National Population Register (NPR)	DHA	<p>DHA system that tracks the demographics of all South Africa Citizens. Responsible for issue of SA ID numbers. The NPR holds basic demographic details for all SA citizens, including date of birth, death, gender, marriage, etc.</p> <p>System considerations: Identity data of record for most South Africans and central to death registration process.</p> <p>Coverage: National</p> <p>Unique Identifier: SA ID number</p>	<p>Details of deceased</p> <p>Verification of identity of informant, medical practitioner, funeral undertaker</p>

Home Affairs National Identification System (HANIS)²⁹	DHA	<p>The HANIS database stores the photos and fingerprints of each South African citizen registered in the NPR. The HANIS database allows biometric identity verification (via fingerprint) of the deceased and links to the NPR but does not store the demographic details and fact of death. HANIS is set to be replaced by ABIS (below)</p> <p>System considerations: Relevant for biometric verification of identity, currently being transitioned to ABIS. Coverage: National Unique Identifier: Biometric (fingerprint)</p>	Verification of identity of deceased, informant, medical practitioner, funeral undertaker
Automated Biometric Identification System (ABIS)³⁰	DHA	<p>An in-progress IT system to replace HANIS. Envisioned to integrate with other DHA systems to serve as a single source of biometric authentication for both South African citizens and non-citizens. It integrates with the financial system, SA police system, and border control authorities among others.</p> <p>System considerations: Unestablished in health sector, still in roll-out phase Coverage: Not yet accessible to health sector Unique Identifier: Biometric (fingerprint)</p>	Verification of identity of deceased, informant, medical practitioner, funeral undertaker
National Health Patient Registration System (HPRS)	NDoH	<p>National patient registration system intended to biometrically verify patients against their fingerprint in HANIS/ABIS during registration. Issuing of unique HPRN to link the patient to his/her electronic records, and support tracking of service delivery through facilities.</p> <p>System considerations: High level NDoH support for national-level patient identifier Coverage: Eventually national Unique Identifier: Primary: HPRN, Secondary: SA ID number, Passport Number</p>	Patient identification details including SA ID number or passport number if provided.

Of demographic databases, the NPR remains the system of record for DHA, which is in the process of updating the biometric verification system from HANIS to ABIS. Within the health sector, the HPRS has potential be a unifying identifier across systems.

²⁹ Verify identity online. South African Government [Internet]. [cited 2022 Oct 12]. Available from: <https://www.gov.za/services/verify-identity-online>

³⁰ Department of Home Affairs - ABIS [Internet]. [cited 2022 Oct 12]. Available from: <http://www.dha.gov.za/index.php/civic-services/abis>

SECTION 3: MORTALITY DATA ACROSS THE HIS LANDSCAPE

One opportunity of an eMCCD system, regardless of the model it takes, is to both enhance the quality of MCCD data by enabling the medical practitioner to access a more complete patient record, and potentially, to minimize the number of fields that must be entered by a medical practitioner. The current death registration process uses nearly forty individual data fields to capture medical certification of CoD. The full list of data elements in Section G of DHA 1663-B is documented in **Table 4**, below.

Current MCCD Data Model

This section maps data elements in the subset of systems described above to the data elements from DHA-1663 Section G that are relevant to the eMCCD process. Data elements from Section G that may be found in or informed by similar data in existing HIS systems are marked with a tick. Data elements were identified from publicly available copies of data collection forms, relevant publications for each system reviewed, or from data supplied by informants.

Of the data elements currently captured in Section G of the DHA-1663 form, there is highest coverage by HIS in the fields for CoD and underlying conditions. While these systems do not necessarily have “other significant conditions” specific to CoD, they contain data on health conditions that could inform the selection of “other significant conditions” by a medical practitioner in the context of MCCD. For example, TIER.net can provide insight into HIV and TB status, and hospital information systems such as Clinicom will have clinical records. Several systems contain mortality data only for a certain subset of deaths, such as DATCOV for Covid-19 deaths and MAMMAS for maternal mortality. Notably, there are fewer systems that capture elements of pregnancy history, which are intended to be collected in DHA-1663B Section G.2, detailing the number of previous pregnancies, pregnancies that ended in live births, miscarriage, stillborn or abortion, as well as whether an attendant was present.³¹

³¹ It is unclear how this information is used by Stats SA in coding as it does not appear in the electronically available data files.

Table 4 – eMCCD Data Model and Potential HIS System Integrations

Data Element in DHA-1663B (Section G)	Data in Existing Demographic and Health Systems										
	NPR	HPRS	NMC	HFR	eCCR	Clinicom	TIER.Net	Child PIP	PPIP	MAMMAS	DATCOV
Identity number (SA ID)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Gender	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>
Surname	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Forenames	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Population Group			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>
Place of Death					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					
Name of Health Facility			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		
Facility Contact Number				<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>			
Patient file number					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					
Contact person at facility					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					
Immediate COD					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Condition leading to COD					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Underlying Cause					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Other significant conditions			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Pregnancy status at time of death					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Method of ascertaining COD									<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Mother (of stillborn) identity number	<input checked="" type="checkbox"/>										
Mother's DOB	<input checked="" type="checkbox"/>										
Age at last birthday									<input checked="" type="checkbox"/>		
No. previous pregnancies resulting in live birth											
No. of previous pregnancies resulting in still birth											
No. of previous pregnancies resulting in abortion											
Outcome of last pregnancy											
Date of last previous pregnancy											
Date of last menstrual period											
Method of delivery					<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>	
Antenatal care two or more visits									<input checked="" type="checkbox"/>		
Type of death (live/stillbirth)					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		
Birth weight					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		
Type of birth (single, twin, multiple)									<input checked="" type="checkbox"/>		
If stillborn, heartbeat ceased before or during labour									<input checked="" type="checkbox"/>		
No. of hours alive											
Attendant at birth											
Main disease or condition of foetus or infant									<input checked="" type="checkbox"/>		
Other diseases or conditions of foetus or infant									<input checked="" type="checkbox"/>		
Main maternal disease affecting foetus or infant									<input checked="" type="checkbox"/>		
Other maternal disease affecting foetus or infant									<input checked="" type="checkbox"/>		
Other relevant circumstances									<input checked="" type="checkbox"/>		
Autopsy information											

Note: Red coloring notes data elements not readily found in data schema reviewed.

The HIS reviewed in this landscape analysis are a subset of those across South African, yet within this sample there are numerous systems that could provide relevant data as to the underlying and other significant conditions leading to death, as well as CoD.

As more provinces and the NDoH adopt electronic medical records and data exchange capabilities in the future, the potential to leverage data from HIS to augment eMCCD data entry is high.

Among systems with coverage in multiple provinces, the Child PIP, Perinatal PIP, and MAMMAS systems capture mortality data for mothers, children, and perinatal deaths. While currently reported in aggregate, there are individual level identifiers assigned at collection that could potentially allow linkage and usability of individual level mortality data through a data exchange.

HIS Integration considerations

Terminology Services, Data Exchange, and Messaging Standards

While there is overlap of data elements across the multiple systems mentioned above, data are coded and stored in different formats which are not easily exchanged across the systems. Each system may also have different methods to produce and consume data from other systems. These common interoperability challenges are solved by using terminology services, international health messaging standards, and interoperability architectures.

Terminology services³² enable codes from one system to be mapped to another and, ideally, to a canonical source coding system. The International Classification of Diseases 10th Revision³³ (ICD-10) is one such system developed by the WHO as the main coding system for disease reporting across care levels, and for CoD statistics. Systems such as LOINC³⁴, SNOMED³⁵, ATC³⁶ and many others are used to code various clinical questions and answers, covering a plethora of terminologies including for clinical procedures, laboratory tests and results, and drug classifications. Many of the HIS in South Africa use one or more of these coding systems, e.g., hospital information systems commonly use ICD-10 diagnosis codes and Current Procedural Terminology³⁷ (CPT) procedure codes, and many use their own proprietary coding, e.g., CHIP and PIPP use proprietary codes for CoD and underlying conditions. To interoperate and exchange data, all these codes need to be mapped to one another to produce homogeneous data resources. A terminology service is commonly used as part of a health information exchange to enable these mappings.

A standard messaging format for data exchange is also necessary. Implementing standards such as HL7 V2³⁸ or HL7 FHIR³⁹, in conjunction with known terminologies enables disparate systems to talk to each other. The NDoH is the custodian of these standards and terminologies in South Africa and has published the Health Normative Standards Framework (HNSF)⁴⁰ detailing how to apply them in the health system. This is described further in Section 5.

Identification and Linkage

A common problem across information systems is the unique identification and linkage of individuals. While each South African citizen is allocated a 13-digit identification number by the DHA, this is not reliably captured in health information systems. Those who are not citizens may be identified by their passport number or refugee id number or may not have any unique identification number. HIS use multiple identification numbers for patients, including the HPRN

³² OpenHIE Terminology Service (TS) [Internet]. [cited 2022 Oct 12]. Available from: <https://guides.ohie.org/arch-spec/openhie-component-specifications-1/openhie-terminology-service-ts>

³³ WHO ICD-10 User Guide [Internet]. [cited 2022 Oct 11]. Available from: <https://icd.who.int/browse10/Help/en>

³⁴ What LOINC is [Internet]. LOINC. [cited 2022 Oct 12]. Available from: <https://loinc.org/get-started/what-loinc-is/>

³⁵ SNOMED - Home | SNOMED International [Internet]. [cited 2022 Oct 12]. Available from: <https://www.snomed.org/>

³⁶ Anatomical Therapeutic Chemical (ATC) Classification [Internet]. [cited 2022 Oct 12]. Available from:

<https://www.who.int/tools/atc-ddd-toolkit/atc-classification>

³⁷ Dotson P. CPT® Codes: What Are They, Why Are They Necessary, and How Are They Developed? *Adv Wound Care* (New Rochelle). 2013 Dec;2(10):583-587. doi: 10.1089/wound.2013.0483. PMID: 24761332; PMCID: PMC3865623.

³⁸ Learn About HL7 International [Internet]. [cited 2022 Oct 12]. Available from: <https://info.hl7.org/learn-more>

³⁹ Index - FHIR v4.3.0 [Internet]. [cited 2022 Oct 12]. Available from: <https://hl7.org/fhir/>

⁴⁰ Motsoaledi DA. National Health Normative Standards Framework for Interoperability in eHealth in South Africa. [Internet]. 30 June 2017 [cited 2022 Oct 11]. Available from <https://www.colleaga.org/sites/default/files/attachments/hnsf-complete-version%201.pdf>

allocated by HPRS and facility-based folder numbers. To link individuals across these disparate systems, a robust client registry (CR), or master patient index, is necessary. The CR should have the ability to link patients according to a set of rules and algorithms, either deterministically or probabilistically. Health records lacking the SA ID will need to be linked to NPR records using other data points, typically demographic information including DOB, first and last name, sex, and geographic information. Linkage through demographic data necessarily depends on sharing these demographic fields. The linkage can often include a level of uncertainty, especially where first name and last name combinations are very common. Several referenced information systems include the capability to link client records, notably the PHDC, HPRS and DATCOV.

Security, Authentication, and Authorization

Ensuring that data are secure in the CRVS, and health system environments will be an important requirement for an eMCCD system. To interact and exchange data with core DHA and NDoH processes and systems, each external system would need to be certified and verified, from a technology and data perspective, by the NDoH and the DHA. Each would need to implement normative security standards to ensure data remain private and that users are authenticated against relevant user registries and authorized to view or submit data.

The existing paper death notification system does not involve electronic data exchange and the DHA and Stats SA information systems are secured within respective private networks. Implementing data exchange between these systems and other external systems containing clinical or demographic information will require communication between the secure private networks, adding a level of complexity not present in the existing process. The protocols for data exchange must ensure that data are encrypted and protected at rest and during transfer.

SECTION 4: MODELS FOR AN eMCCD SYSTEM

Considering the current death registration process and health system landscape, an eMCCD system could take several possible models. For this landscaping, two hypothetical models have been developed to illustrate how the current process might be designed as an electronic system and, further, how it could leverage existing data captured within health information systems in the landscape. Opportunities, risks, and limitations are explored for each model.

Model 1: A hybrid paper-electronic system for eMCCD only.

Model 2: A full eDRS with tightly integrated systems across the NDoH, DHA, and Stats SA.

Model 1: Hybrid Paper-Electronic System for eMCCD

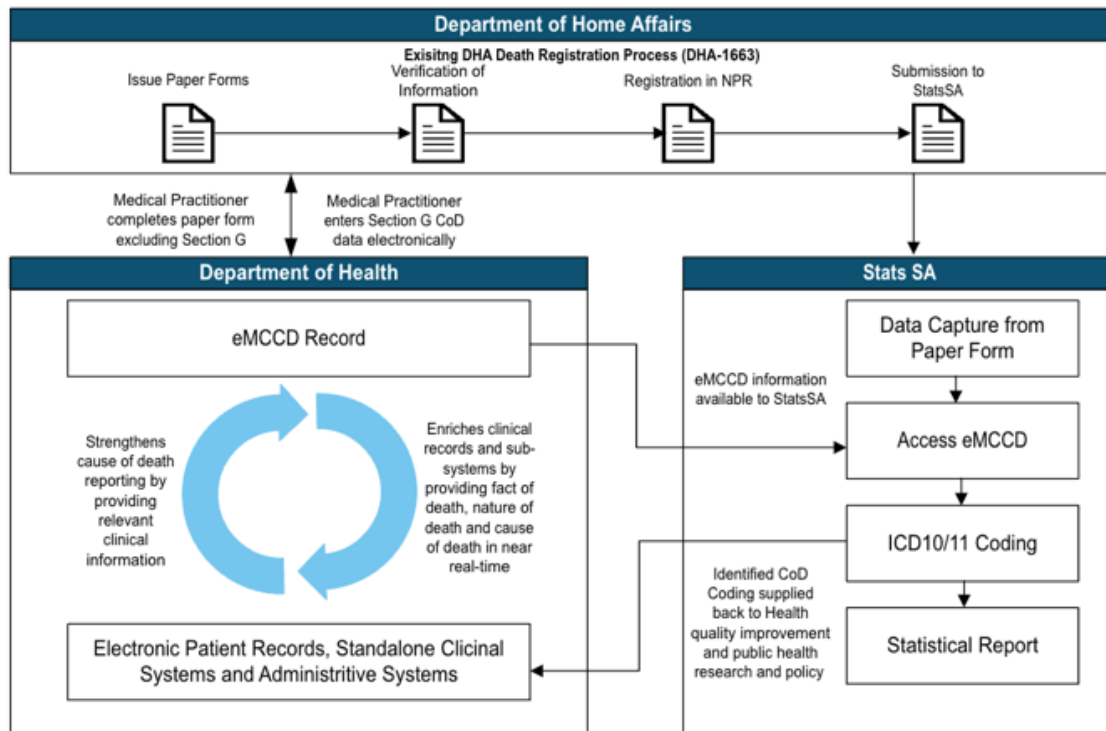
Model 1 proposes an electronic system for only the CoD information entered into Section G of DHA-1663 and Section B of BI-1680. [Appendix 3](#) contains a detailed process flow for this proposed model. In this model, the medical practitioner, and Stats SA coders engage with the online system, while the paper DHA-1663 BI-1680 continues to go through the current paper process. To begin the eMCCD process, a medical practitioner would create a new death record in the online system by scanning the barcode of the existing DHA-1663 form. They would then enter the data currently handwritten into Section G into an online form and leave Section G form fields blank. When the online form is completed and saved, the practitioner could write the generated eMCCD reference number into Section G and subsequently seal it. This would allow Stats SA to cross-check the DHS-1663 form with the eMCCD system using the reference number as well as the barcoded number. The electronic record would then be saved into the

eMCCD system and become available immediately, while the paper form continues through the usual process for registration of the death by DHA. The medical practitioner would be registered as a user of the eMCCD application and would be authenticated and authorized to enter MCCD data. Each would be verified against respective authorities, either the Health Professionals Council of South African (HPCSA)

After completion of the eMCCD data, the paper process of DHA-1663 through DHA remains the same. When Stats SA receives the forms for ICD-10 coding, coders then access the electronic system using the reference number provided in Section G, or simply using the barcode on the form. Stats SA coders would be registered as users of the eMCCD system.

Changes to the process of data entry for Section G should not affect DHA processes as DHA does not have access to the sealed Section G. This hybrid paper-electronic model allows for the MCCD information to move from NDoH to Stats SA and back without changing or relying upon DHA processes. (Figure 5)

Figure 5 – Schematic of Electronic Flow of MCCD Data



Although this system requires minimal to no change to the DHA process, it would necessitate organizational and individual change management for the medical practitioners and traditional leaders who are responsible for entering CoD information into the paper form and the Stats SA administrators, clerks, and coders who would be retrieving CoD information from an online system.

Linkage between the paper forms and the digital system would be maintained bi-directionally, with the electronic system capturing the serial number of the associated paper form, and the electronic CoD reference number provided by the platform being written or printed and pasted as a barcode or QR Code, into section G before the page is sealed (in the case of DHA-1663).

While there is potential for this system to include a similar process for the BI-1680 form used by traditional leaders to enter CoD information (albeit not medically certified), it would present several additional challenges. Because the CoD data is not isolated into a self-sealing form on the BI-1680, the form would still need to be completed as per current process, with Section A and B data either manually entered into the digital platform (duplicate data entry) or with a digital scan or photo of the form captured in the platform. Traditional leaders would need access to digital tools and sufficient digital literacy to fill in the form. In addition, the authorization of the traditional leader would require validation against a DHA system, rather than a system of accreditation that exists within the health sector. While more complicated, this model would enable CoD information originating from traditional leaders to be identifiable and differentiated from MCCD information originating from registered medical practitioners. Details of this process would need to be further developed during a formal requirement gathering process.

The inclusion of the CoD information from DHA-1663 and potentially BI-1680, along with the nature of death and the demographic information required for linkage, into an eMCCD solves several of the issues identified in the current process, as detailed below in Table 5.

Table 5 – Benefits of Model 1: eMCCD

Benefits of Model 1: eMCCD	
Quality	<ul style="list-style-type: none"> ● Structured data entry: Electronic data capture reduces free-text entry and errors by providing structured data entry options (e.g., drop-down lists, checkboxes), data validation and skip logic. ● Job aids built into the eMCCD would guide users through the process of providing comprehensive CoD information. ● Access to clinical history: Integrating HIS systems with the eMCCD provides medical practitioners with access to patient clinical records to improve their visibility into underlying conditions and improve accuracy of CoD information. ● Higher quality CoD for coding: Similarly, providing Stats SA with CoD data informed by clinical records can improve their official ICD-10 coding. ● Medical Practitioner Verification: Enables online verification of users of the system against demographic registries, including HRH, HPCSA etc., and rapid iteration to investigate anomalies in CoD information. ● Auditability: Death notification forms have linked eMCCD records can provide additional mechanisms to audit the flow of data between stakeholder systems. ● Confidentiality: CoD data is not entered into the paper Section G in this model and, therefore, is more secure and less accessible to informants. Medical practitioners can be confident that the information they provide is confidential. ● Quality Feedback: Users who enter CoD information into the eMCCD can be provided with reports on the volume and quality of the data entered. ● Geographic information: Place of death would be selected from drop-down lists, ensuring that the various locations such as hospitals, facilities, towns, and suburbs can be captured correctly.

Usability	<ul style="list-style-type: none"> • Accelerated access by NDoH: The NDoH will have immediate access to eMCCD records, with the potential for linkage to clinical records. The existing extract from the NPR via RMS would be replaced by an expanded dataset including deaths of those not in the NPR (non-SA citizens, stillbirths, and perinatal child deaths), containing CoD information. • Actionable patient level mortality data: Connecting NDoH and Stats SA through an eMCCD systems enables potential to share identified CoD records between Stats SA and NDoH.
Efficiency	<ul style="list-style-type: none"> • Potential to reduce workload for medical practitioners (if duplicate data capture is not necessary), and electronic entry automatically adds relevant information that would otherwise be repeated in every form (e.g., practitioner details). • Greater efficiency for Stats SA. Coders at Stats SA will have access to an electronic file with CoD data, providing more data that is clear, easy to read, and facilitates ICD 10 coding. • Potential to partially automate: Future integrations with source electronic clinical systems (e.g., hospital EHR/discharge summaries or clinical data warehouses) enable auto-population or enhancement of CoD information, where these data exist in the source systems. • Continuous update: Potential for other users (e.g., forensic pathologists) to integrate with clinical systems to routinely update fact, nature, and CoD.
Risks	
<ul style="list-style-type: none"> • Potential to introduce limited duplication in data collection during completion of death notification forms, if the same data needs to be entered on paper and electronically. • Insufficient investment in training and consideration for user design may lead to users abandoning or failing to use the system in favor of the paper form. • Change management of the migration from a paper to a digital system may result in limited-term increased burden on administrators and users. 	
Dependencies	
<ul style="list-style-type: none"> • Clarification on the legal position regarding access to identified CoD information by the National Department of Health is necessary to enable near-time sharing of CoD information between the three stakeholders. 	

Model 2: Fully Electronic Systems for eDRS

In this model, all data would be entered into a digital system and exchanged electronically. This would require interoperability between the digital systems in the NDoH, the DHA, Stats SA and

other registries via a data exchange platform. [Appendix 4](#) details the high-level process for an eDRS model.

This model builds off the integrations that are proposed in Model 1. Like the hybrid model, health information systems could be integrated with the eDRS such that clinical data from the HIS are available to the medical practitioners filling out MCCD data. These data, along with structured data entry and job aids would greatly increase the quality of CoD information.

Individuals involved in the death registration process would be registered as authorized users of the system, and credentials could be verified in various databases such as the Health Professionals Council of South African (HPCSA), Human Resources for Health Provider Registry (HRH) and NPR as appropriate. Undertakers and authorized traditional leaders should be authenticated from an electronic list. For each new record, health practitioners or traditional leaders enter relevant details into a fully online form. When done, the system would prompt the next user to fill in their relevant information via SMS or other mechanism. The eDRS would be able to query and write to the NPR and would be accessed by Stats SA for official coding and production of vital statistics. Like Model 1, the eDRS would provide Stats SA with structured and validated electronic CoD data that has been enriched by clinical information. The resulting CoD information would be shared back to health systems to improve fact, nature, and CoD linkage. Each stakeholder providing data would get feedback on volume and quality of the data they entered. There may be an opportunity to integrate with other systems including forensic pathology (part of the National Department of Health) and South African Police Services (SAPS) systems such as the nascent Investigation Case Management Docking System.⁴¹

This model requires more significant and widespread change to the current process, contingent on political buy-in across all stakeholders, and significant strengthening of digital system capacity across the country.

Additional Benefits Beyond Model 1	
Quality	<ul style="list-style-type: none"> ● Coverage: Electronic data capture expanded across all actors including informants, undertakers, headmen and forensic pathologists. ● User Verification: Rapid cross-referencing across the systems enables verification of users of the system against demographic registries, including HRH, HPCSA etc., and rapid iteration to investigate anomalies in CoD information.
Usability	<ul style="list-style-type: none"> ● Accelerated access by NDoH and Stats SA: The near real-time exchange of data will allow Stats SA to receive and code data more quickly and enable analysis and provision of statistics in the shortest possible time.
Efficiency	<ul style="list-style-type: none"> ● Capture once: Data need only be entered into the system once, including details of each actor which will be entered once when registering as a data provider (e.g., medical practitioner, undertaker), and need not be entered for each individual form.

⁴¹ SAPS is transitioning to a new information system known as the Investigation Case Management Docking System. It's role out is one of the priorities listed in the 2020/2021 Strategic Plan.
https://static.pmg.org.za/200710SAPS_Addendum_to_the_SP_APP_-_8_July_2020.pdf

	<ul style="list-style-type: none"> ● Paperless system: No need for storage and transport of paper records.
Risks	
<ul style="list-style-type: none"> ● National implementation of digital systems across multiple government stakeholders is complex and expensive in the short term. ● Electronic health information systems retain a number of limitations and will not necessarily have perfect clinical data. Continued strengthening of health information systems concurrent to the development of an eDRS would further improve quality.⁴² 	
Dependencies	
<ul style="list-style-type: none"> ● A robust enabling environment needs to be in place, with all actors digitally literate with access to digital devices and connectivity. ● Mature electronic information systems need to be in place and able to exchange data between NDoH, DHA, and Stats SA. ● Organizational capacity to transition from paper based to electronic systems across all system actors. 	

Summary

The two models presented above offer starting points to design an eMCCD system that would enhance the quality of CoD information, make CoD information available to NDoH stakeholders and researchers more quickly, and take steps to simplify and strengthen the death registration process.

The most significant difference between the two models is the extent to which DHA processes change. The hybrid paper-electronic eMCCD model keeps most of the existing DHA process, including use of forms DHA-1663 and BI-1680, intact, and creates a complementary electronic system for capturing MCCD data, making it more readily available. The fully electronic eDRS model extends the electronic system across the entire death registration process and is a much more significant change to the current system. Model 2 will require full buy-in across NDoH, DHA, and Stats SA stakeholders, and may be a significantly longer endeavor given the level of digital capacity it requires of all parties.

Importantly, the two models are not mutually exclusive. Supporting Model 1 by focusing first on an eMCCD system may be a feasible goal in the near term that will improve a subset of MCCD data, as well as produce useful lessons and position many stakeholders to better approach

⁴² Nicol E, Hanmer LA, Mukumbang FC, Basera W, Zitho A, Bradshaw D. Is the routine health information system ready to support the planned national health insurance scheme in South Africa? Health Policy and Planning [Internet]. 2021 Jun 1 [cited 2022 Oct 7];36(5):639–50. Available from: <https://academic.oup.com/heapol/article/36/5/639/6209444>

development of an electronic system for the full death registration process. Taking initial steps towards such integration within the health sector will require investments in complementary digital services to enable interoperability and data exchange between HIS and an eMCCD (see HIS Integration Considerations in Section 3). While this is presently most feasible in the Western Cape, the potential to scale such integrations will increase as other provinces increase use of electronic HIS and work towards interoperability, consistent with broader institutional strategies described below.

SECTION 5: STRATEGIC OPPORTUNITIES

An electronic eMCCD or eDRS will have implications for each of the institutions involved in the death registration process. This section reviews key objectives outlined in the strategic plans of each institution to inform the policy context in which an eMCCD or eDRS system would evolve, and possible pathways forward. Perspectives on several on-going or anticipated initiatives were further informed by interviewees consulted for this landscape analysis.

Department of Home Affairs

The DHA 2020-2025 Strategic Plan⁴³ clearly defines the need for digital systems. These include enhancement of the NPR and replacement of HANIS by ABIS. Over the next five years key elements of the new model will be phased in, such as fully digital processes for birth, marriage, and death. All these services will be accessed through an expanding number of channels, often involving partners such as public and private health systems for birth and death registration. The strategy declares that the NPR must be digital, integrated, and operate in the cyber environment using e-identity. There is an ongoing digitization project to digitize 350 million civic paper records relating to birth, marriages, deaths, and amendments that is scheduled for completion by 2026.⁴⁴ An eHomeAffairs⁴⁵ website already exists for online request, payment, and scheduling of appointments for South African National ID SmartCards and Passports. Use of these services is based on a biometrically verified NPR record. Together, these activities indicate strong alignment between the strategic goals of DHA and what would be needed for an eDRS system.

Informants from the DHA were not clear on the implementation timeline for the digitization (scanning of paper forms into digital format) and automation (migration to digital, paperless systems) processes for births, deaths, and marriages. Estimates ranged from the full automation of all processes being completed by the end of the 2023 financial year, to only digitization of birth and marriage records being completed by 2025. Other estimates indicated that a viable timeline for full automation would be 4-6 years.

⁴³ DHA Strategic Plan 2020-2025. [Internet]. [cited 2022 Oct 7]. Available from: http://www.dha.gov.za/images/FILES2/DHA_Strategic_Plan2020_25_WEB.pdf

⁴⁴ Home Affairs on progress of digitization project | South African Government [Internet]. [cited 2022 Oct 7]. Available from: <https://www.gov.za/speeches/verification-assessment-and-interview-candidates-dha-digitisation-project-underway-6-sep>

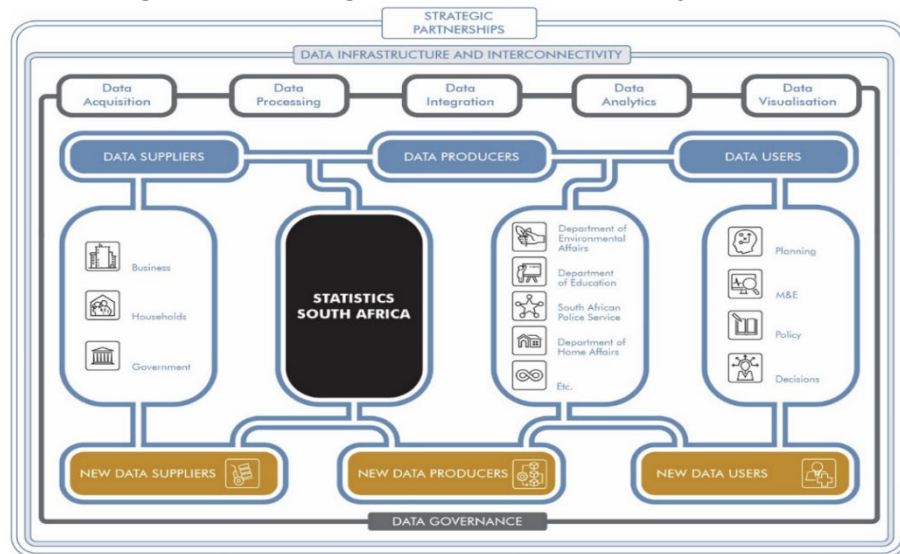
⁴⁵ DHA eHome Affairs. [cited 2022 Oct 7]. Available from: <https://ehome.dha.gov.za/ehomeaffairsv3>

Further, lack of clarity on implementation of ABIS⁴⁶ and criminal investigations into the IT contracting for both ABIS⁴⁷ the Electronic Document Management System (EDMS)⁴⁸ make it difficult to gauge the status of the digital transformation process of DHA. Given this complication, the feasibility of an eDRS is likely to be low in the near-term, though consistent with the future direction. In that respect, beginning with an electronic system that does not rely on DHA in the near-term may be a more viable approach.

STATS SA

The Statistics South Africa Strategic Plan 2020/2021-2024/2035⁴⁹ makes no specific mention of death registration or ICD-10 coding. A high-level strategic vision for the data ecosystem is presented, as seen in Figure 6. This ecosystem aligns with the DHA vision for a cyber-environment, and an integrated digital process to exchange data

Figure 6 – Strategic Vision for Data Ecosystem



between systems. Interviewees from Stats SA indicate there is appetite for digital exchange of data between DHA and Stats SA, and that the major bottleneck is the timeliness of DHA-1663 and BI-1680 forms arriving at the Stats SA Data Processing Center. Notably, Stats SA is still receiving BI-1663 forms which were replaced by the DHA-1663 form in 2009. While Stats SA is also broadly aligned in moving towards an electronic system, it will likely be a long-term goal to connect Stats SA and DHA in a fully electronic eDRS system.

⁴⁶ Burt C. South Africa still waiting for biometric system upgrade after spending whole budgeted amount | Biometric Update [Internet]. 2022 [cited 2022 Oct 11]. Available from: <https://www.biometricupdate.com/202207/south-africa-still-waiting-for-biometric-system-upgrade-after-spending-whole-budgeted-amount>

⁴⁷ Automated Biometric Identification System (ABIS) Forensic Investigation Report; with Ministry | PMG [Internet]. [cited 2022 Oct 11]. Available from: <https://pmg.org.za/committee-meeting/33021/>

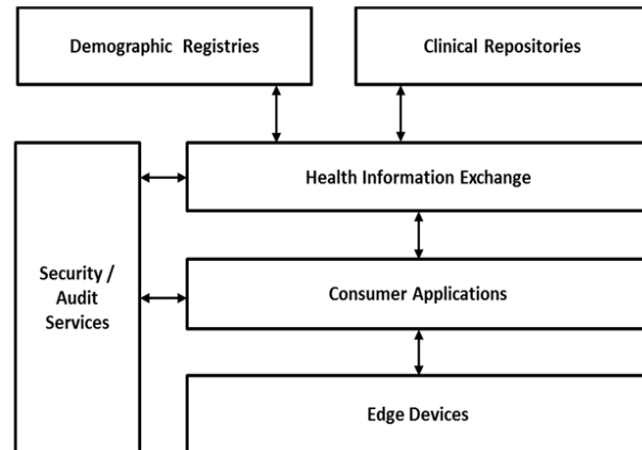
⁴⁸ Department of Home Affairs - The Minister of Home Affairs is ecstatic at the Constitutional Court judgment in the matter involving New Dawn Technologies and Valor IT over a contract for an Electronic Document Management System [Internet]. [cited 2022 Oct 11]. Available from: [http://www.dha.gov.za/index.php/statements-speeches/1504-the-minister-of-home-affai\[...\]over-a-contract-for-an-electronic-document-management-system](http://www.dha.gov.za/index.php/statements-speeches/1504-the-minister-of-home-affai[...]over-a-contract-for-an-electronic-document-management-system)

⁴⁹ Strategic Plan 2020/2021–2024/2025. Statistics South Africa [Internet]. 2020 [cited 2022 Oct 11]. Available from https://www.statssa.gov.za/strategy_plan/Stats%20SA%20Strategic%20Plan.pdf

National Department of Health

The NDoH Digital Health Strategy⁵⁰ does not prioritize mortality reporting and mentions mortality only in the context of infant mortality rate targets for the National Development Plan (NDP). However, the HNSF offers insights into technical priorities consistent with the needs of an eMCCD system. As noted above, it governs health data standards that will be relevant for integration of health systems into a future eMCCD or eDRS system. Further, it specifies the enterprise architecture and interoperability standards to be used in the health system, detailing a patient-centric approach to health information systems (rather than an aggregated indicator-based approach). The framework references a generic eHealth architecture, similar to the OpenHIE architecture specification,⁵¹ consisting of demographic registries and clinical repositories connected to consumer applications through an interoperability layer.

Figure 7 – Generic eHealth Architectural Components including Demographic Registry



Reproduced from NDoH Health Normative Standards Framework

The HPRS reviewed in this landscape was developed to fill the role of the core demographic registry for the South African public health system (Figure 7). Interviewees indicated that the NDoH was focusing on data standards and coding and is building a backbone framework that other health systems can interoperate with for the purposes of NHI. Together, this is consistent with the level of integration proposed within the models above.

Given the federated state of the health system, with each province implementing its own technologies and systems, provincial departments of health are also important stakeholders whose priorities will be relevant. There is a spectrum of electronic HIS maturity across provinces, and even at district and subdistrict level. The Western Cape is at the more advanced end of the spectrum, with the Western Cape PHDC and Single Patient Viewer providing a provincial patient clinical record. Pilots of the Single Patient Viewer and Public Health Data Center are ongoing in KwaZulu-Natal and are planned for Eastern Cape, suggesting that such integrations may be possible for more provinces soon, and increasing the ability to benefit from such integrations in an eMCCD model. Some governance barriers exist to accessing Client Registry information from HPRS and TIER.net data, which are controlled by the NDoH, and would need to be addressed through further stakeholder engagement.

⁵⁰ National Digital Health Strategy for South Africa, 2019–2024. National Department of Health South Africa [Internet]. 2019. [cited 2022 Oct 11]. Available from <https://www.health.gov.za/wp-content/uploads/2020/11/national-digital-strategy-for-south-africa-2019-2024-b.pdf>

⁵¹ OpenHIE Architecture Specification - OpenHIE [Internet]. [cited 2022 Oct 12]. Available from: <https://ohie.org/architecture-specification/>

Summary

This review of strategic plans suggests that a full eDRS system will likely be infeasible in the near term, though it is consistent with the long-term visions of many stakeholders involved. Focusing in the near term on an eMCCD system lead from the NDoH would be more achievable in the near term and still support moving in the direction of an eDRS in the longer term. There is an opportunity to create a shared vision across stakeholders that will not be in competition with an existing plan. This will require significant additional stakeholder engagement and mobilization.

SECTION 6: NEXT STEPS

This assessment summarizes the current system and opportunities to leverage CoD data from existing health and demographic data systems in the landscape. Additional areas that could be further explored to enhance understanding of current barriers and opportunities for integration in an online system are detailed below.

Near Term: Learning from Global Best Practices

The challenges and models developed through this landscape are informed by the South African context. However, multiple countries and states within countries around the world have electronic systems for death registration at various stages of development that could offer further insights into both the design of an eMCCD or eDRS system as well as the process through which systems were transitioned from paper to electronic. The SAMRC has planned activities to engage with global experts through an online workshop which will further inform the approach in South Africa.

Near Term: Stakeholder Engagement

Moving forward, engagement and buy-in from all the stakeholders that have a role in completing the Death Notification Form and compiling CoD data will be important. In the near term, developing buy-in and building relationships across the major institutional stakeholders of NDoH, DHA, and Stats SA can build necessary political will. Developing a shared commitment through a Memorandum of Understanding, Task Force or Steering Committee, will facilitate action to further develop an eMCCD model and guide a formal requirement gathering process.

Medium Term: Formal Requirements Gathering

This evaluation produced high level requirements of a potential eMCCD system, yet they must be further defined prior to development or implementation of any future system. Ideally, this can occur through a human centered design process involving all relevant actors. There are several parts of the current death registration process that need further investigation as part of such a user-centric requirements gathering process. In particular, the proportion of deaths lacking an SA ID number which therefore are not recorded in any electronic system is unknown. This contributes to uncertainty in causes of death for unregistered persons, including babies that die before a birth certificate is issued. Understanding this process will inform requirements development of an electronic system that does capture this population reliably, and allows for linkage of these deaths and their addition to the RMS.

The process and coverage of verification of fingerprints, captured as part of the paper process through, via HANIS and/or ABIS, is also unknown. Biometric verification could be added as a requirement for the eMCCD system.

Requirements related to integration of HIS can be further explored through review of additional clinical information systems, such as provincial and metro hospital systems, private sector General Practitioner practice management systems, Medical Aid administration schemes and private sector hospital systems.

Systems outside of the health sector should also be explored further and considered for potential integration with an eMCCD system. These include systems used by funeral undertakers if these exist, as well as those by forensic pathologists and SAPS given their roles in recording of unnatural and accidental causes of death. Their engagement will be important to understand user needs for the future eMCCD or eDRS system.

Medium Term: Exploring Supportive Technologies

An eMCCD system or eDRS will require supportive technologies to ensure the system is safe, secure, and reliable. Advancing the system design will require consideration for digital signing technologies, authentication, and authorization mechanisms for users of the system, reliable connectivity solutions, and secure data exchange. Development of these requirements, based on existing specification including the HNSF and South African Digital Health Strategy, global learnings from organizations such as OpenHIE and Digital Square⁵², and existing global and local health information exchanges (e.g., CareConnect in South Africa).

Medium-term: Developing an Implementation Approach

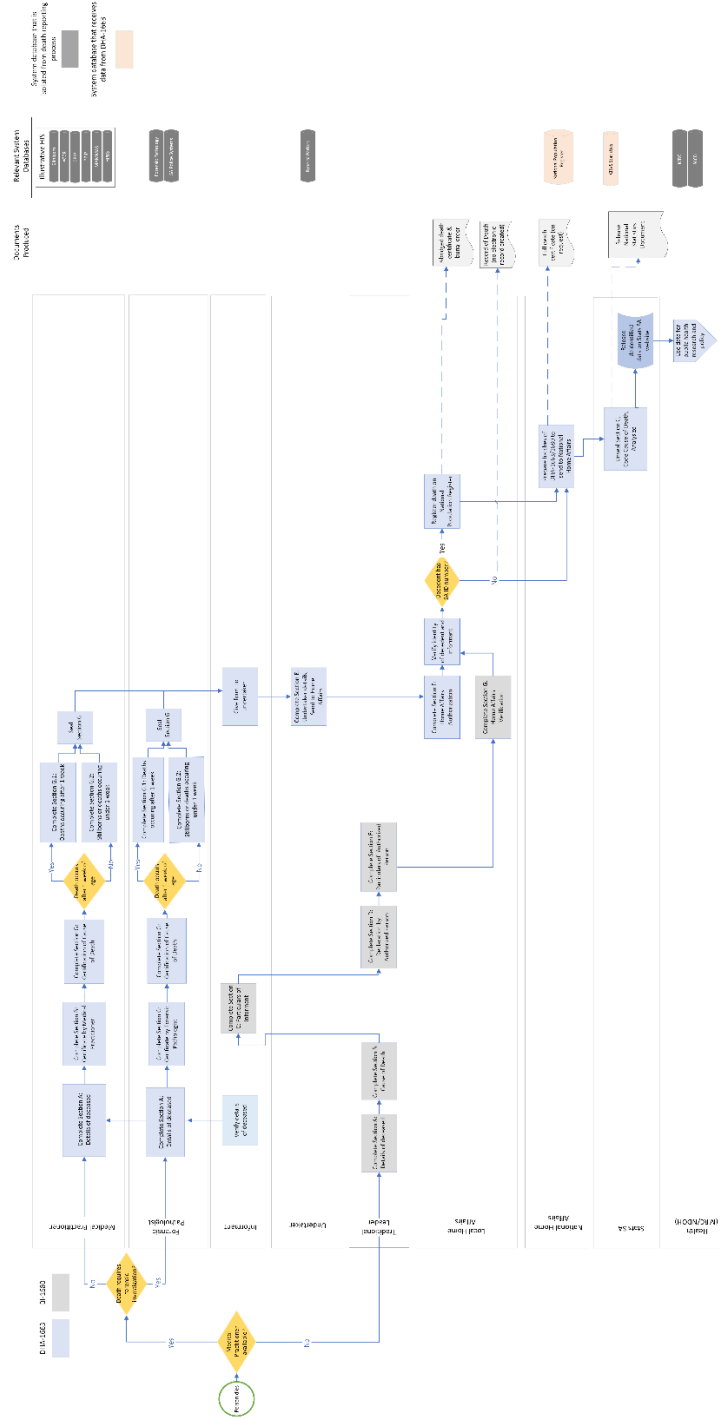
Implementing an electronic system will necessarily require more than technology. Introducing changes in the death registration process will involve significant commitments to change management within respective organizations. While the development and implementation of a system is a long-term objective, planning for change management activities as part of future projects may smooth its adoption. Choosing specific geographic regions for implementation of small pilots before a larger scale-up of the system nationally will offer opportunities for learnings which can be incorporated for the widescale roll out. As the transition to an electronic system will take time, there must be a migration strategy support both paper and electronic MCCD processes simultaneously.

The implementation of a national paperless eDRS model, such as the one presented here, will depend on changes to policy and legislation such as the Births and Deaths Act, which makes the paper DHA-1663 form a legal requirement. Planning and implementation of the eDRS will depend upon concurrent activities to change these policies and legislation to create an enabling environment that makes the move to an electronic system possible.

⁵² Digital Health Global Goods [Internet]. Digital Square. [cited 2022 Oct 13]. Available from: <https://digitalsquare.org/digital-health-global-goods>

APPENDICES

Appendix 1: Current Death Registration Process

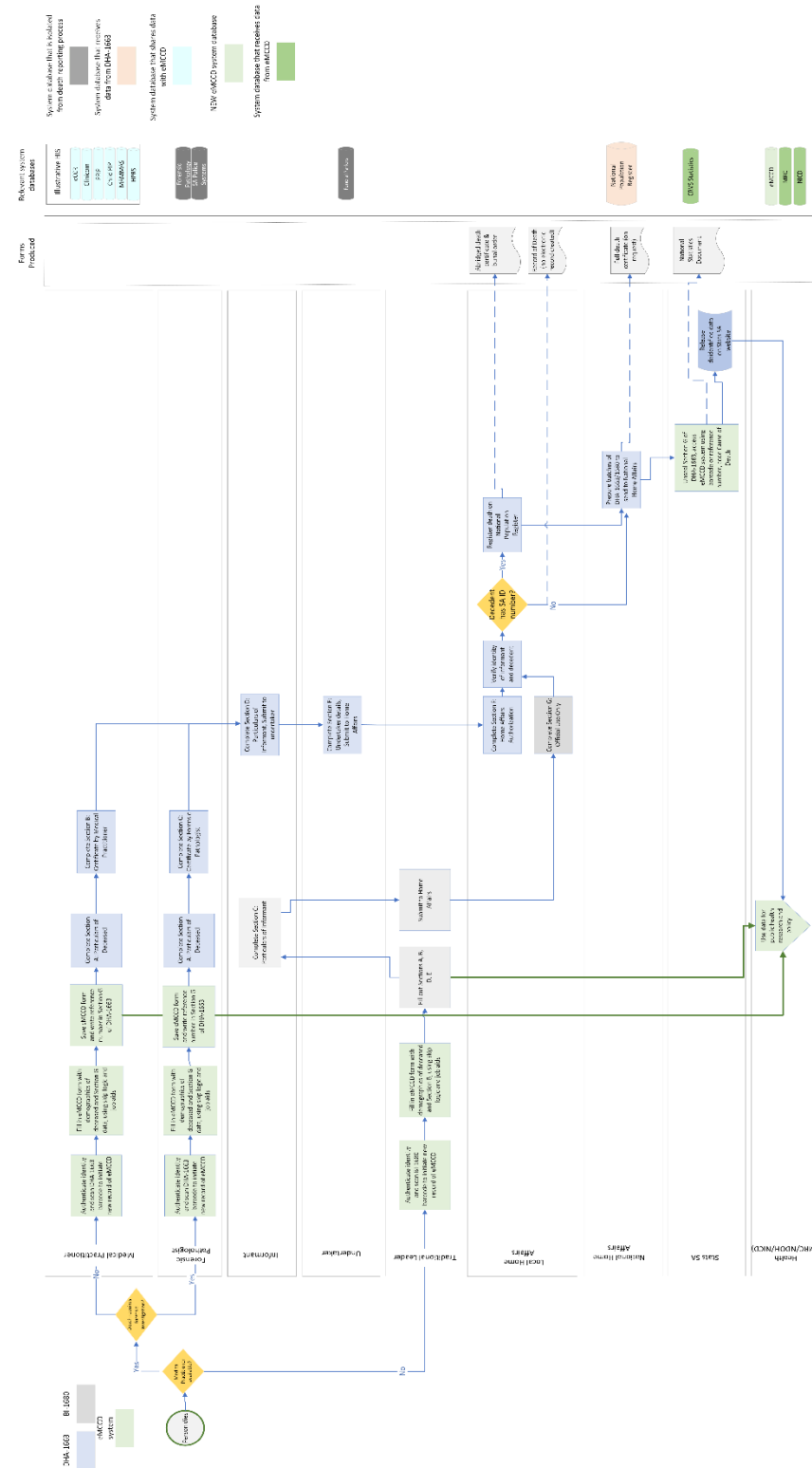


Appendix 2: Mortality Data Challenges and Digital Opportunities

Data Quality		
Challenge	Contributing Factors	Digital Opportunities
1. Incomplete CoD data	<ul style="list-style-type: none"> Limited time of MPs. Incomplete access to patient history by MP. Limited incentive. Normal human error. 	<ul style="list-style-type: none"> Implementation of validation and skip-logic to ensure forms are filled in correctly with a minimum of free-text entry. Provision of job aids to assist practitioners in determining immediate and underlying CoD (informed by clinical logic).
2. Incorrect coding of CoD	<ul style="list-style-type: none"> Limited access by Stats SA to patient medical history. Limited time to conduct coding (workforce capacity). Difficulty in reading handwritten causes of death. 	<ul style="list-style-type: none"> Linkage between NDoH system with patient information (e.g., Patient Viewer model) and Stats SA. Electronic capture of CoD information. Electronic exchange of CoD information with Stats SA systems.
3. Loss of clinically relevant information	<ul style="list-style-type: none"> Limited access by Stats SA to patient medical history when completing ICD-10 coding. 	<ul style="list-style-type: none"> Linkage between NDoH system with patient information (e.g., Patient Viewer model) and Stats SA.
4. Underreporting of HIV-related deaths	<ul style="list-style-type: none"> Desire by families to not have HIV deaths officially recorded due to stigma. 	<ul style="list-style-type: none"> Electronic Section G would not be accessible by informants or family members (though physicians ultimately determine what gets recorded).
5. Incomplete tracking of death notification forms	<ul style="list-style-type: none"> Normal human error/burden of paper-based system. 	<ul style="list-style-type: none"> Digital auditing and traceability system could easily link form number to record.
6. Incorrect injury classification	<ul style="list-style-type: none"> Lack of space on form to record manner of death. Potential legal consequences of determining manner of death ahead of inquest (current conflict with Inquest Act) even if space to record it. 	<ul style="list-style-type: none"> Electronic Section G could be made non-accessible by law enforcement, informants, or family members.
7. Lack of medically certified CoD information for deaths occurring without involvement of a	<ul style="list-style-type: none"> Limited access to medical practitioners. Preference to bury on private property without need of death certificate. 	<ul style="list-style-type: none"> eMCCD could be accessible to any authorized user and could identify records entered by authorized, non-medical practitioners for review.

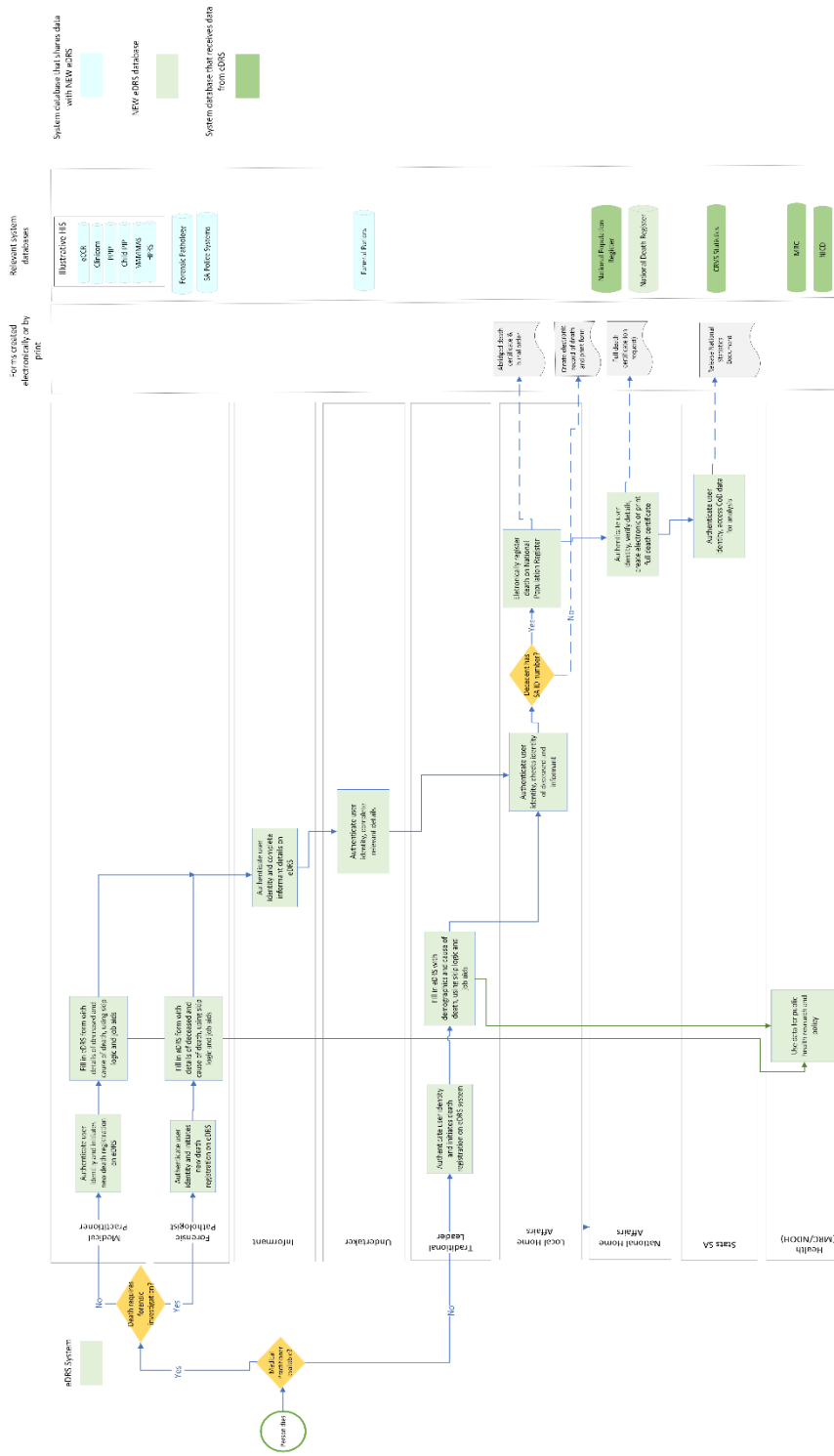
medical practitioner		
Usability of CoD data for research, policy, and planning		
Challenges in MCCD	Contributing Factors	Digital Opportunities
8. Delay in availability of CoD data to researchers (2+ years)	<ul style="list-style-type: none"> Legal regulation limiting access to CoD information to Stats SA only. Capacity of DHA and Stats SA to process and then code paper death registration forms. 	<ul style="list-style-type: none"> NDoH sets up system to capture COD data. NDoH contributes to development of integrated system to capture individual CoD data and make available from time of entry.
9. Anonymized CoD Data	<ul style="list-style-type: none"> Policy requirement allowing sharing only natural or unnatural CoD. Lack of system to securely link official CoD back. 	<ul style="list-style-type: none"> NDoH contributes to development of integrated system to capture individual CoD.
10. Lack of data flow back to practitioners	<ul style="list-style-type: none"> No mechanism for medical practitioners to access and use CoD data. 	<ul style="list-style-type: none"> Medical practitioners would have a feedback mechanism to retain MCCD data, in a POPI-compliant manner, for generation of mortality reports, e.g., CHIP, PIPP, facility/hospital mortality reports.
11. Lack of data on persons not registered in the NPR	<ul style="list-style-type: none"> No electronic information system for these data. 	<ul style="list-style-type: none"> Capture demographics of persons without SA ID for probabilistic linkage to clinical records.
System Efficiency		
Challenges in MCCD	Contributing Factors	Digital Opportunities to improve
12. Burden on medical practitioners	<ul style="list-style-type: none"> Requirements of current paper-based death notification process. 	<ul style="list-style-type: none"> Develop fully or partially integrated system to capture data once at time of entry and share across stakeholders.
13. Data redundancy across health systems	<ul style="list-style-type: none"> Siloed nature of systems within NDoH, DHA, Stats SA. 	<ul style="list-style-type: none"> Develop fully or partially integrated system to capture data only once, at time of entry, and securely share across systems and stakeholders.
14. Logistics	<ul style="list-style-type: none"> Paper-based system requires storage. 	<ul style="list-style-type: none"> Develop electronic system to eventually replace need for paper forms.
15. Data Capture	<ul style="list-style-type: none"> Handwriting is inherently time consuming to write and read. 	<ul style="list-style-type: none"> Develop electronic system to capture data electronically once.

Appendix 3: Future eMCCD Model



* In this eMCCD model, medical practitioners, nurses, and herbalists participate in entering data through the system needs identification for eMCCD (MHC, HRC, HRS, MRF).

Appendix 4: Future eDRS Model



* In this eDRS model, each user entering data through the system would authenticate via relevant repositories and registries (e.g. HFCSA, HPH, HPRS, NRP for medical practitioners). As similar systems for undertakers are developed, they could be integrated. Similarly, a registry of authorized traditional leaders would enable online completion of BI 1880 information.