

# Strengthening Mortality Surveillance

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## Scoping Study for Electronic Medical Certification of Cause of Death in South Africa

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# Aims and Objectives

**Aims:** This scoping study aims to assist South Africa to draw on international best practice and identify local requirements, opportunities and barriers towards developing an electronic death registration system.

**Objectives:**

1. To identify lessons from international initiatives to develop electronic death registration.
2. To conduct a technical evaluation of the CRVS and other existing systems for collecting cause of death information in South Africa.
3. To identify the requirements for an online system for certification of the medical cause of death in South Africa through review of systems in selected countries.
4. To explore the perception of users (doctors, funeral practitioners, government officials) and their views on acceptability and feasibility of a potential implementation of EDRS.
5. To conduct a review of the legislation regulating CRVS in South Africa to identify any opportunities or barriers to EDRS.



# The South African Context

- SA has a well-established CRVS system – death registration increased dramatically since 1994 (from 50% to more than 90% for adults)
- Quality of cause-of-death statistics is rated low
  - *Misclassification of HIV deaths to other causes (TB, Diarrhea etc.)*
  - *Injury mortality profile inaccurate*
  - *High proportion of ill-defined causes*
- Department of Health has no access to identifiable cause of death information
- Now a 5-year delay before DoH has access to de-identified cause of death data
- MRC receives mortality data from DHA National Population Register – rapid surveillance



# Importance of Mortality and Cause of Death Data

- **Fact of Death** needed to
  - correctly assess **excess deaths**
  - Address treatment interruption for HIV and TB patients (LTFU vs death) etc
- **Cause of Death** **INVALUABLE** for
  - **Epidemic Disease Response**
  - **Burden of Disease and other Epidemiological Research**
  - **Healthcare Funding and Resource Allocation**
  - **Highlight inequity in health services by socio-economic and geographic strata**



# Methods



Desktop review of EDRS international best practice and global EDRS initiatives

Participatory workshop/  
webinar



Technical review of current CRVS processes in SA



Technical review of international MCCD processes

Develop requirements



Acceptability and feasibility assessment



Review of legal framework

# 1. Lessons from international experience

- Literature review yielded limited and dated information  
=> arrange webinar to elicit lessons
  - Fourteen countries that have implemented or piloted EDRS were identified through WHO-FIC ITC committee and literature
  - Seven countries agreed to participate
  - Data collected through online survey and 2-hour webinar/workshop and analysed using the Nine Digital Principles framework
- Experiences emphasized that EDRS enhanced data availability, timeliness, and quality in mortality statistics.
- Key insights for implementation encompassed:
  - the significance of strong leadership,
  - legislative support for eMCCD utilization and data sharing, and
  - comprehensive stakeholder involvement from inception.
- Challenges encompassed legislative barriers, user acceptability issues, electronic system variations, and infrastructure inadequacies.



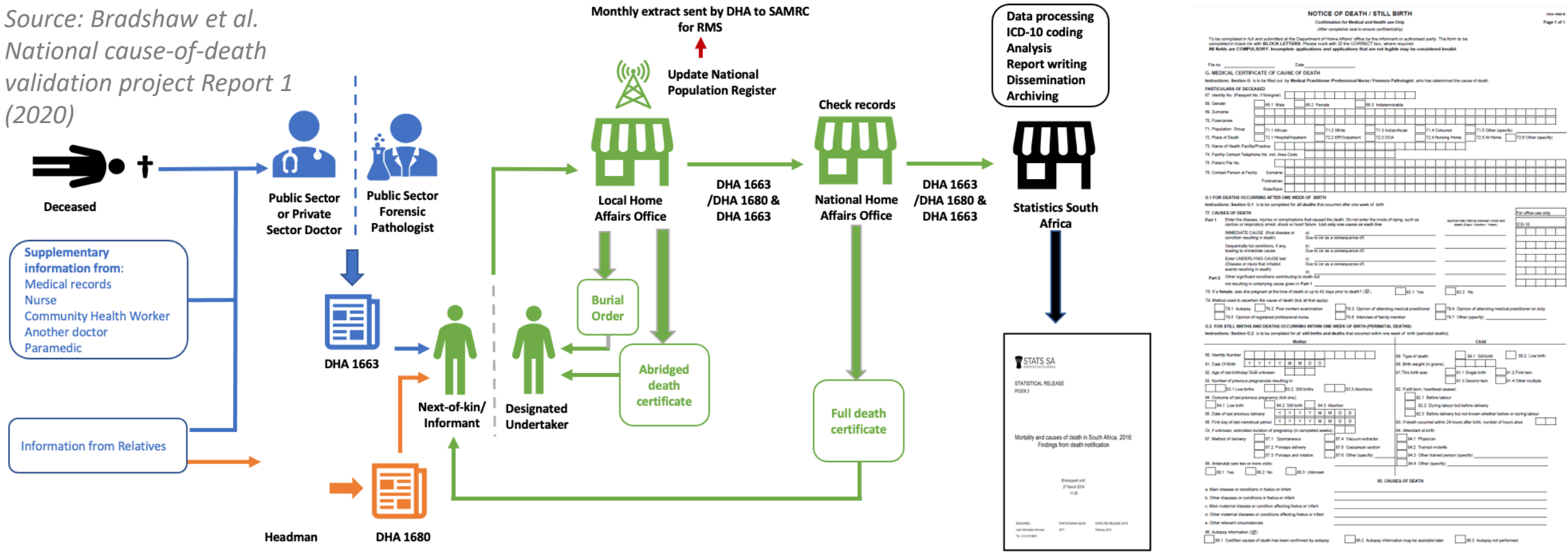
# 2. Technical review of current CRVS processes in SA

- Used an Enterprise Architecture approach to map as-is and potential to-be processes
- Analyzed successful mortality and CoD programs
  - E.g., MRC Rapid Mortality Surveillance & link with PHDC, DATCOV (COVID-19)
- Mapped data elements from Health Information Systems to DHA-1663 form
  - E.g., TIER.net, C/P PIP, HPRS, NMC app, DATCOV, NHIRD, eCCR, WC PHDC
- Highlighted challenges with the existing paper-based process
  - Data Quality
    - incorrect/incomplete data, stigma around HIV/suicide, geographic coding, injury classification & manner of death
  - Usability of CoD Data
    - Delayed, anonymized, only available for SA citizens, no feedback to medical practitioners
  - System Efficiency
    - Burden on medical practitioners, siloed data, logistics challenges with volume of paper, data transcription errors



# 2.1 Death Registration Process in South Africa

Source: Bradshaw et al. National cause-of-death validation project Report 1 (2020)



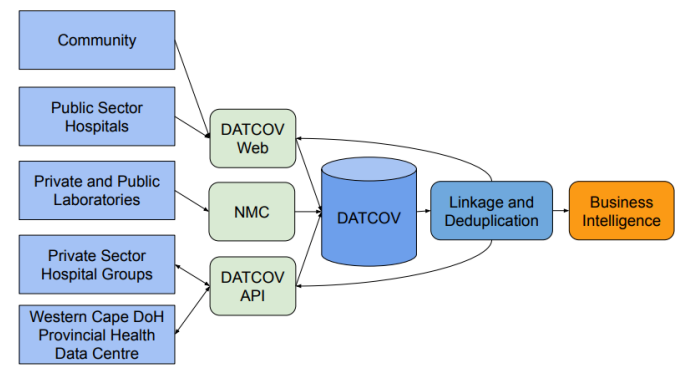
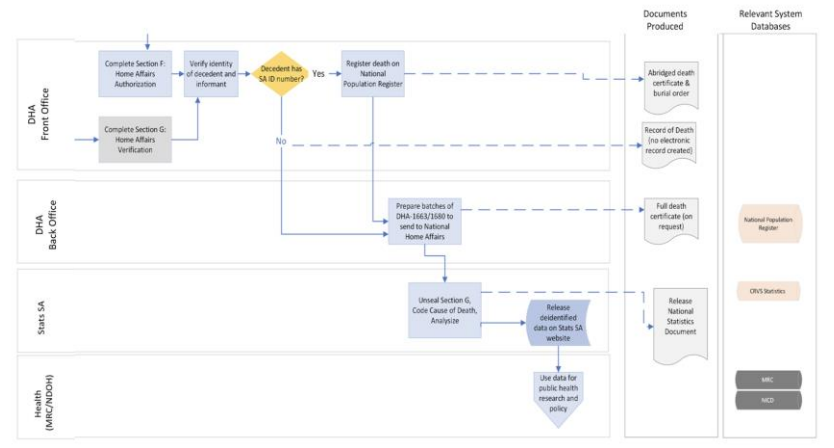
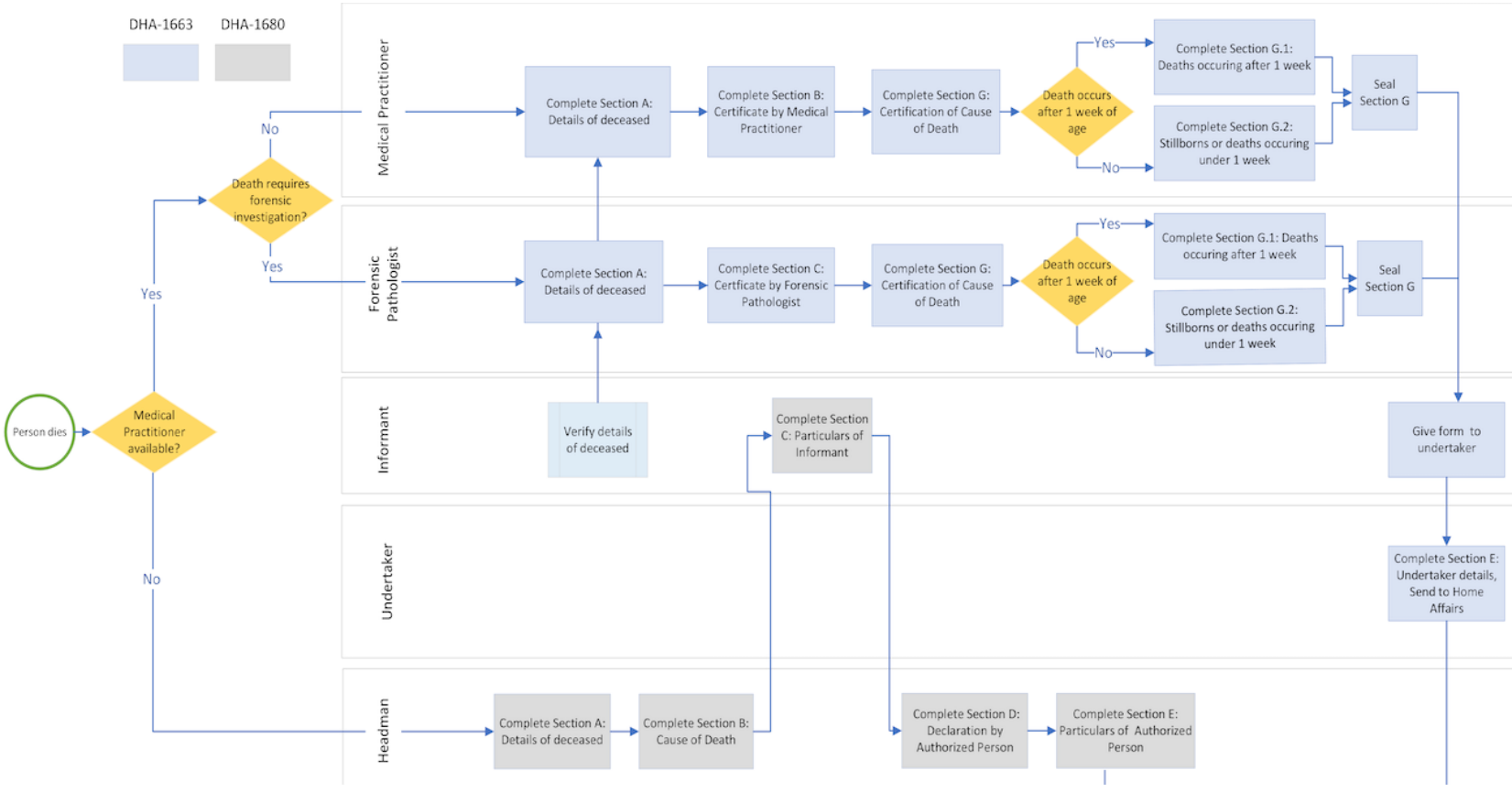
The form is titled "NOTICE OF DEATH / STILL BIRTH" and is used for medical and health purposes. It includes sections for:

- Particulars of Deceased:** Fields for sex, date of birth, race, and place of death.
- Part 1: Causes of Death:** Fields for immediate, underlying, and contributing causes.
- Part 2: Still Births and Deaths Occurring Within One Week of Birth:** Fields for mother and child details.
- Part 3: Cause of Death:** Fields for main disease, other conditions, and relevant circumstances.



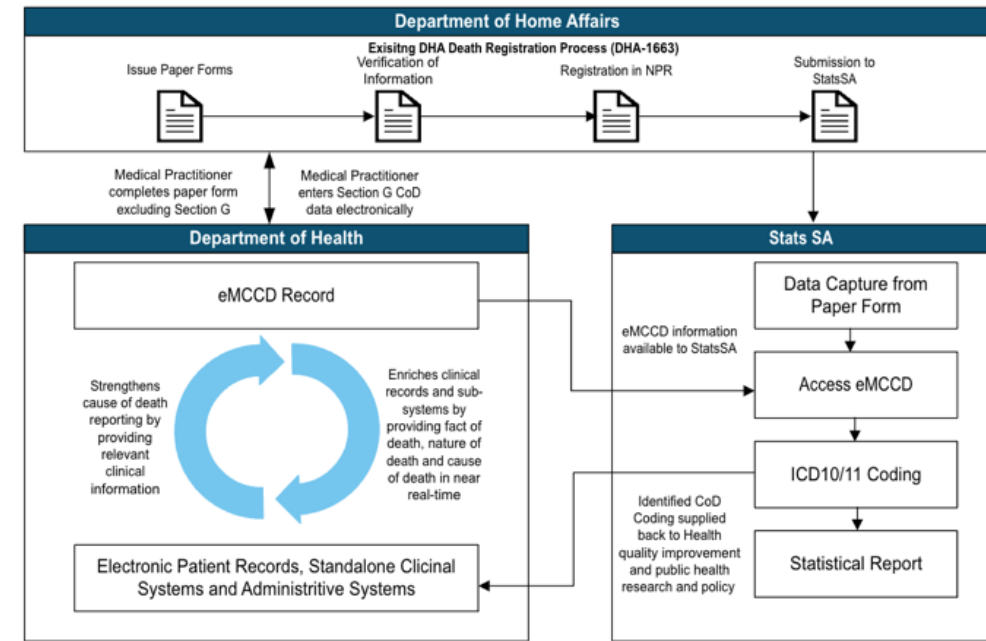


# 2.2 Business Process Mapping



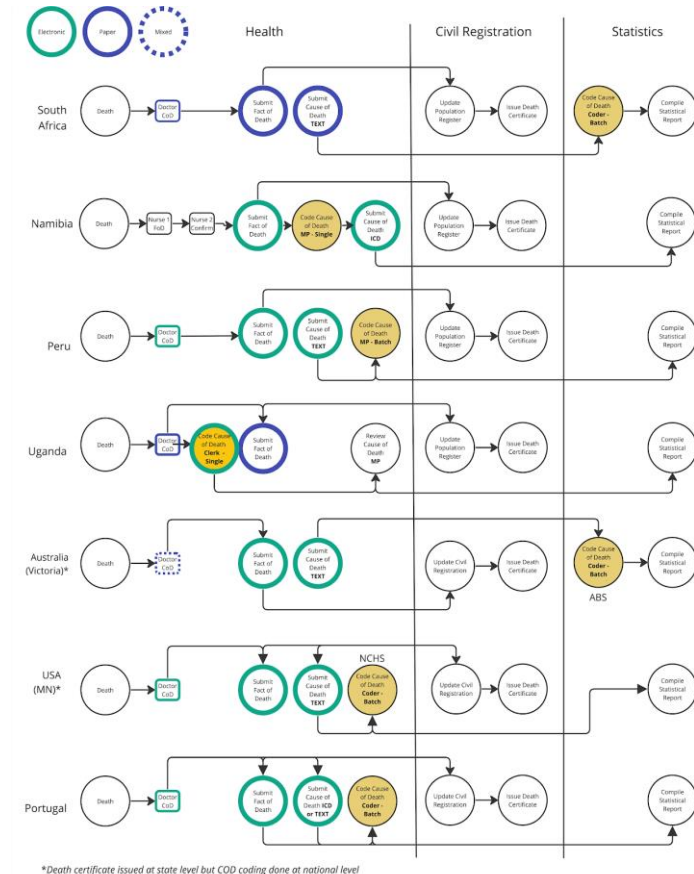
# 2.3 Recommendations

- Two models
  - Electronic MCCD only
  - Full electronic death registration
- DHA is currently digitizing forms and digitalizing birth and death registration
- Stakeholder collaboration, and governance and policy change necessary for success



# 3. Technical review of international eMCCD systems

- Six country examples, each one with very different processes
- CoD Entry and Coding was a key differentiator
  - Coding by Medical Practitioners
    - Namibia (required) & Portugal (optional)
  - Coding by Data Clerks
    - Uganda – from paper form
  - Coding by Nosologists
    - Portugal, Peru, USA, Australia
- Civil Registrar not involved/interested in CoD
- Responsibility for coding - MoH or Statistics
- Central-level coding give higher-quality data, can delay reporting



# 3. eMCCD Design Considerations

- Security
  - Mortality and CoD data are sensitive
  - Risk of security breach in electronic system higher
- Incentives
  - Where CoD is required for a death certificate or burial order, completion is higher
- Technology Specifications
  - Data hosted within government data centers
  - Mix of public sector and vendor solutions
- Training
  - ICD-coding is skilled work, and significant training required (6-12 months in some countries)
  - However, length and type of training differed significantly across countries



# 4. Acceptability and feasibility assessment

- Exploratory mixed methods study to investigate the feasibility and acceptability of an electronic solution for registering deaths (eMCCD).
- Twelve key informant interviews
- Online survey of potential users of the electronic solution to quantify these perceptions.
- Workshop to explore options for making cause of death data fit for purpose in South Africa. Data were collected during the workshop using interactive software.
- During an interpretation phase, qualitative and quantitative data were integrated according to key themes that emerged from the data.

## Findings

**COD data important for public health BUT data quality concerns**



Lack of MCCD training, stigmatized diseases, poor access to and quality of patient health information, and a high proportion of deaths occurring outside facilities

**eMCCD appeared to be acceptable and perceived as a means to strengthen the mortality information timeliness and quality**



A future eMCCD should include features such as built-in quality checks, simple design, accessibility across devices, and an integrated design and processes with other information systems in the country.

# 5. Legal framework

Two issues that might result in barriers to EDRS were investigated

- ***Inclusion of a field for manner of death on the death notification form***
  - Accurate coding of injury causes of death is not possible because manner of death is not required on form DHA-1663, contrary to international recommendations.
  - Nothing in legislative framework precludes the inclusion of manner of death on Form DHA-1663
- ***Data sharing***
  - Amendment to Regulations for Births and Deaths Registration Act promulgated by the **Minister of Home Affairs** in February 2014 requires that COD page of Form DHA-1663B be sealed and provided to Stats SA only.
  - Minister's regulation making powers cannot be used to **limit the DG's powers** which includes: "furnish[ing] any information in relation to a person submitted in terms of [the Registration] Act to ... any department of State, local authority or statutory body for any of the statutory purposes of that department, authority or body".
  - Form DHA-1663 as currently reads is not lawful, but until a court has pronounced on its lawfulness or it has been amended it remains in force.



# Conclusions/Way Forward

- International experience shows that:
  - implementing eMCCD with careful planning is strategic and feasible for South Africa.
  - Hybrid solutions (digital and paper) could work, possible to integrate eMCCD with other systems such as forensic pathology and emergency services
  - Best practice is to have the eMCCD system separate from, but interoperable with, the civil registration system
- South African research shows that:
  - Considerable scope to harness cause of death information obtained within the health sector
  - Most users in the study find eMMCD to be acceptable and perceived it as a means to strengthen the mortality information timeliness and quality.
- This empirical-derived knowledge will be instrumental in advancing South Africa's CRVS system through technology-driven enhancements
- Consideration for digital signing, user authentication, reliable connectivity, and secure data exchange needed
- Organizational change management will be essential for successful implementation (NDoH, DHA, StatsSA + NICD, MRC...)
- There is scope for additional operational research around approaches to improve quality of information and efficiency of different designs.

