



## Lessons learned about implementing Electronic Death Registration Systems (EDRS)

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**Abstract** South Africa's Civil Registration and Vital Statistics (CRVS) system has made considerable progress in death registration, yet challenges in quality and timeliness of cause-of-death data persist. To prepare for an Electronic Death Registration System (EDRS) aligned with global best practices, we organized a virtual workshop involving countries implementing, or piloting, EDRS or electronic medical certificate of cause of death (eMCCD). Out of 14 countries approached, seven (viz. Australia, Ecuador, Kenya, Peru, Portugal, Uganda, USA) participated, sharing insights in two stages: an online survey and a 2-hour virtual workshop. Their experiences emphasized that EDRS implementation enhanced data availability, timeliness, and quality in mortality statistics. Key takeaway insights 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. International experiences indicate that with meticulous planning, South Africa can strategically and feasibly adopt eMCCD. This workshop-derived knowledge will be instrumental in advancing South Africa's CRVS system through technology-driven enhancements.

### Introduction

South Africa has a well-established Civil Registration and Vital Statistics (CRVS) system. Although completeness of death registration has improved considerably since 1994, challenges remain with both the quality and timeliness of the cause-of-death information. To draw on international best practice towards developing an Electronic Death Registration system (EDRS), we arranged a virtual participatory workshop to identify lessons learned from systems in the countries that have implemented, or are piloting electronic EDRS, with a particular focus on electronic medical certificate of cause of death (eMCCD).

### Methods & Materials

Fourteen countries that are either implementing or piloting EDRS or eMCCD, identified partly through the World Health Organization Family of International Classifications Informatics and Terminology Committee (WHO-FIC ITC), literature review and through reaching out to experts were approached. Seven countries (Australia, Ecuador, Kenya, Peru, Portugal, Uganda and USA) agreed to participate in the workshop. In preparation for the participatory workshop, we reviewed existing documentation and followed up with leads of country initiatives to describe, document and summarise international initiatives. This was done in two stages: (a) self-administered online survey questionnaire, followed by (b) a 2-hr virtual workshop to further engage with key stakeholders from countries that are currently using or piloting EDRS to share lessons for South Africa from their international experiences. The results were summarized using the nine principles for digital development<sup>1</sup> as a framework.

1. *Principles for Digital Development.* (<https://digitalprinciples.org/>)

### Digital principle

### Key points from country experience

<b>Design with the User</b>		<ul style="list-style-type: none"> <li>• Strong leadership and champions across key departments organized across different themes/functions.</li> <li>• Need buy-in from all stakeholders and end-users e.g., doctors who can become advocates once they are convinced.</li> <li>• Set up formal agreements, memoranda of understanding etc., to bring on board public and private sectors users.</li> </ul>
<b>Understand the existing ecosystem</b>		<ul style="list-style-type: none"> <li>• Have robust preliminary work before transitioning into electronic systems, including having everyone at the table and a business map the processes before digitization.</li> <li>• Map of national legislature relating to the death certification and amend legislation to ensure data can be shared.</li> <li>• Need a core team that understands all the steps needed for the process of death certification from paper to electronic format.</li> </ul>
<b>Design for scale</b>		<ul style="list-style-type: none"> <li>• There is great opportunity in having an eMCCD roll-out if it is done with all the consultations and clear milestones.</li> <li>• Easier to build a centralized system. Having a decentralized system adds a level of complexity.</li> <li>• Adopt a stepwise approach (e.g., from local to regional and national) to transition from paper to electronic system.</li> <li>• Put in place standards across systems that allow for linkage of systems to address needs of multi-stakeholders e.g., Certification framework, Integration standards etc.</li> </ul>
<b>Build for sustainability</b>		<ul style="list-style-type: none"> <li>• Sustainability will be an issue if the needs of stakeholders are not considered when planning.</li> <li>• Ensure the right infrastructures, funding, and human resources.</li> <li>• Legislation is required for doctors to complete the eMCCD form.</li> <li>• Training of all users to support change management. Provide adequate and timely technical support for users of software application.</li> </ul>
<b>Be data driven</b>		<ul style="list-style-type: none"> <li>• Timely and accurate information sharing e.g., real-time data for policy makers.</li> <li>• Rapid data flow process to where the information is needed.</li> <li>• Ensure completeness of data.</li> <li>• Automatic data coding and quality checks should be built in.</li> </ul>
<b>Use open-standards, data, source, and innovation</b>		<ul style="list-style-type: none"> <li>• Availability of data/internet access and connectivity.</li> <li>• Use of mobile application where there is no access to computers e.g., rural areas.</li> <li>• Good servers are required for the sustainability of the system.</li> </ul>
<b>Reuse and improve</b>		<ul style="list-style-type: none"> <li>• All countries mentioned the importance of ensuring we don't only transition to digital, but also to rethink how existing systems work and what processes can be improved to ensure improved alignment when the system becomes digitized.</li> </ul>
<b>Address privacy and security</b>		<ul style="list-style-type: none"> <li>• Data protection is critical and must be safely transferred while ensuring privacy. There are different ways of doing this, including transferring de-identified data etc.</li> <li>• Creation and maintenance of users (different profiles e.g., medical doctors, civil registrar, coder, police etc.) and passwords will be necessary.</li> <li>• Need to have clear data sharing protocols supported by formal agreements.</li> </ul>
<b>Be collaborative</b>		<ul style="list-style-type: none"> <li>• Clarity of role is important to allow understanding of who plays what roles, in order to avoid confusion that can result in barriers.</li> <li>• Need for champions in different areas to lead and support e.g., technology, how to complete the MCCD, etc.</li> </ul>

### Conclusions

Experiences from other countries suggest that implementing eMCCD in South Africa, with careful planning, would be strategic and feasible. Strong leadership and champions across departments are needed and it is essential to have all stakeholders on board from the beginning.

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