Online capture of the medical certificate of cause of death – Scoping study for South Africa

Participatory Workshop Report (10 November 2022):
Lessons learned from Electronic Death Registration Systems (EDRS) in countries already implementing or piloting.

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December 2023

SUGGESTED CITATION

Awotiwon O, Fruchtman CS, Groenewald P, Cobos D, Seebregts C, Nannan N, Eynstone-Hinkins J, Carvajal E, Lugmana G, Cheburet S, Vargas J, Pinto CS, Tabaro C, Sutton P, Anderson R, Morof D, Bradshaw D. *Online capture of the medical certificate of cause of death – Scoping study for South Africa: Participatory Workshop Report (10 November 2022)*. Cape Town: South African Medical Research Council, 2023. ISBN:978-1-928340-72-0

COLLABORATORING ORGANIZATIONS

South African Medical Research Council

Swiss Tropical and Public Health Institute

Jembi Health Systems

Centers for Disease Control and Prevention, South Africa

ACKNOWLEDGEMENTS

We acknowledge and thank all the workshop participants and online survey respondents for their contributions resulting in this report. Daniel Murokora is thanked for introducing us to one of the participants.

FUNDING

This study has been supported in part by the President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) under the terms of Cooperative Agreement SAMRC-CDC CoAG 1U2GGH002193-03-01. It has also been supported by the Bloomberg Philanthropies Data for Health Initiative through the CDC Foundation Civil Registration and Vital Statistics Project, and the South African Medical Research Council.

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Executive Summary

South Africa has a well-established civil registration and vital statistics (CRVS) system which evolved throughout the 20th century. The completeness of death registration has improved since 1994. However, challenges remain with the quality and timeliness of the cause-of-death information. Faced with these challenges, and to assist South Africa to draw on international best practice and identify local requirements, opportunities, and barriers towards developing an electronic death registration system (EDRS), the Burden of Disease Research Unit at the South African Medical Research Council (SAMRC) initiated the scoping study on the online capture of the medical certification of cause of death to inform the development of an EDRS. The aim of this report is to provide a summary of the participatory workshop held virtually on 10 November 2022, to draw on international best practice and lessons learned from systems in the countries that have implemented or are piloting electronic EDRS, with a focus on electronic medical certificate of cause of death (eMCCD).

We identified 14 countries (Australia, Ecuador, France, Germany, Ghana, Kenya, Namibia, Norway, Peru, Portugal, Rwanda, Sweden, Uganda, USA) that are either implementing or piloting EDRS or eMCCD. These countries were identified partly through the World Health Organization Family of International Classifications Informatics and Terminology Committee (WHO-FIC ITC) as well as through literature review and through reaching out to experts. 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 summarize international initiatives. This was done in two stages: (a) a self-administered online survey questionnaire that was circulated to each participant, 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 that would be applicable for South Africa from their international experiences.

EDRS was shown to have improved the availability and timeliness of data and improved the quality of mortality statistics. Some of the key lessons learned include having strong leadership and champions across key departments being vital to the success of EDRS, need for legislation to support and ensure compliance with using the eMCCD and sharing of data, and the need for all stakeholders to be on board right from the beginning. However, during the workshop discussions, participants highlighted some of the main challenges experienced by these countries which are worth considering. These include challenges with legislation and acceptability among some potential users, diversity in electronic systems/technologies between and across different states, and lack of clarity of roles and issues with infrastructure (e.g., computers, maintenance, internet connectivity issues in rural areas).

“EDRS was shown to have improved the availability and timeliness of data and improved the quality of mortality statistics.

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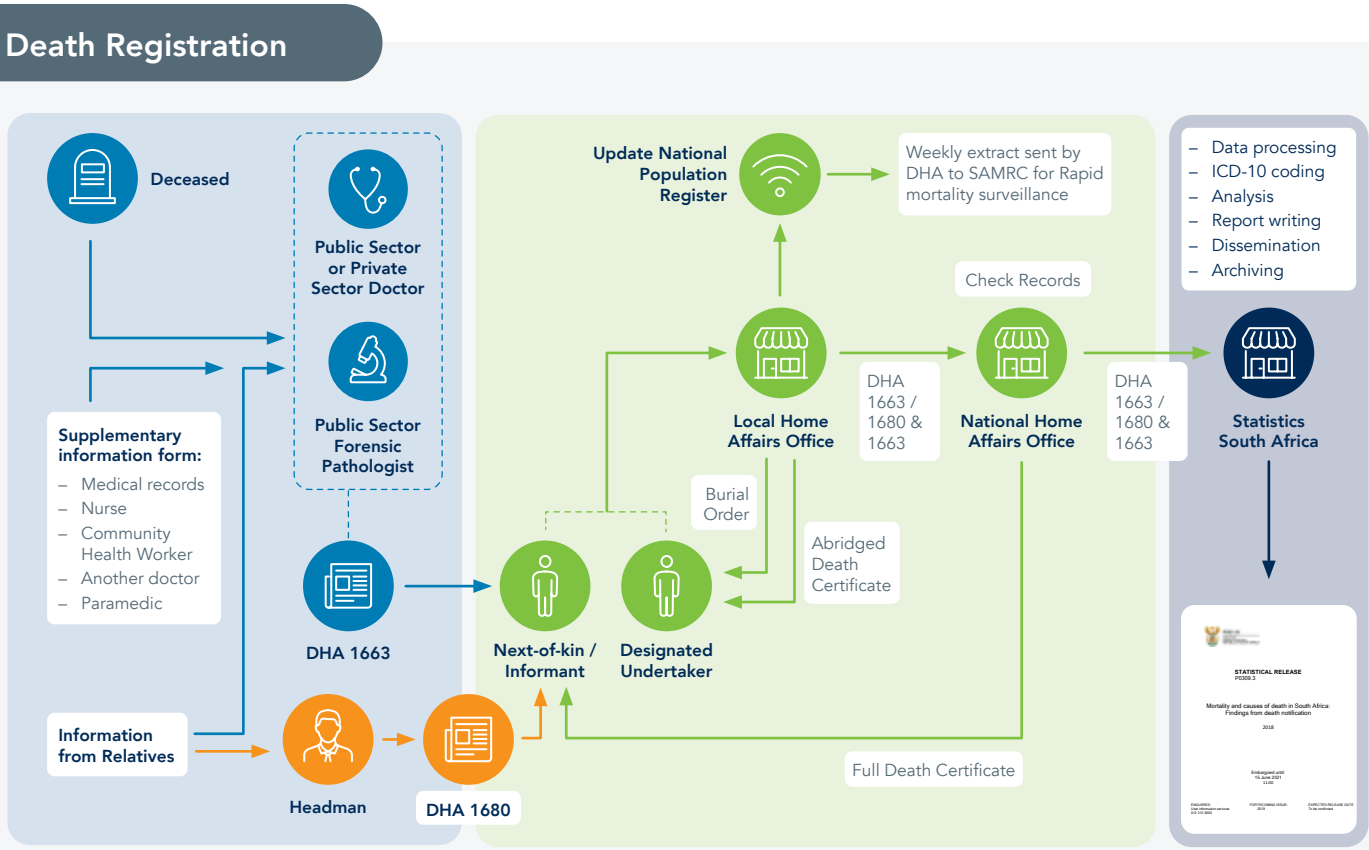
Acronyms and Abbreviations

CDC	US Centers for Disease Control and Prevention
COD	Cause of Death
CRVS	Civil registration and vital statistics
DHA	Department of Home Affairs
DHIS2	District Health Information Software
DICERCIC	National Agency for Civil Registration, Identification, and National ID Issuance
DNF	Death Notification Form
DO	Doctor of osteopathic medicine
DOH	Department of Health
EDRS	Electronic death registration system
eMCCD	Electronic medical certificate of cause of death
ICD-10	International Classification of Diseases 10th Revision
INEC	National Institute of Statistics and Censuses
MCCD	Medical certificate of cause of death
MOH	Ministry of Health
RENIEC	National Civil Registry Office
REVIT-Deaths	National Vital Data Registry System
SAMRC	South African Medical Research Council
SICO	Death Certificate Information System
SINADEF	National Death Registry Information System
Stats SA	Statistics South Africa
USA	United States of America
WHO-FIC	World Health Organization Family of International Classifications

1. Introduction

1.1 Death registration process in South Africa

South Africa has a well-established Civil Registration and Vital Statistics (CRVS) system which has evolved since the establishment of the Union of South Africa in 1910. Although the completeness of death registration has improved since 1994 from about 50% to 90% for adults, challenges remain with the quality of the cause-of-death (COD) information.[1] Currently, the CRVS system is completely paper-based. As reflected in the schematic in *Figure 1*, when a death occurs, a medical doctor in either the private or the public sector, or a forensic pathologist — in the case of a death from injuries or external causes or a sudden unexpected death — will complete the Department of Home Affairs death notification form (DNF), the DHA-1663. This form has the International Medical Certificate of Cause of Death (MCCD) for reporting the actual cause of death information, except the manner of death (i.e. natural, accidental, suicide, homicide and undetermined). In some instances where there is limited access to a medical practitioner, provision is made for the cause of death to be obtained on the DHA-1680, an affidavit completed by a traditional headman to declare that the death resulted from natural causes. In these circumstances, the headman does not collect cause of death information, but this person can briefly describe what happened and why he or she thinks the person died. The DHA uses the affidavit to complete the DNF and may include the immediate COD or specify that it was a natural cause. This excludes any injury-related causes of death, e.g. road traffic injury or other accident, as these will be referred to the forensic pathology services for investigation.



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

Figure 1. Current status of the death registration process in South Africa.

Once these forms have been completed by the doctor or the headman, they are given to either the next of kin, or to a designated funeral undertaker, who then proceeds with the registration of the death at a local Home Affairs Office where they would verify the decedent and his or her details and identification and issue a burial order and an abridged death certificate to the undertaker or the family member. This information will allow for funeral arrangements to proceed and for finalization of the deceased's estate. The National Population Register will also be updated at the local Home Affairs Office for deaths with a South African ID number. From the local Home Affairs Office, these paper forms are then transferred to the DHA national office, where the records are checked and then sent on to Statistics South Africa (Stats SA) for the data processing, which involves ICD-10 coding of the causes of death, analysis of the cause of death information, report writing and dissemination (*Figure 1*)[2]. Stats SA releases mortality and cause of death report annually (Figure 1: bottom right hand corner) but there is a lag in terms of publication of this information (the most recent published Stats SA report at the time of this workshop in November 2022 was from 2018). Furthermore, an anonymized data set with limited information on those deaths are released to the public. In a rapid assessment of the cause of death data[3], modernization of the system, which includes an electronic death registration, has been identified as an inevitable necessity.

To assist South Africa to draw on international best practice and identify local requirements, opportunities, and barriers towards developing an electronic death registration system, the Burden of Disease Research Unit at the SAMRC conducted a scoping study on the online capture of the medical certification of cause of death for South Africa in 2022. The first objective of the scoping study was to identify and review international best practice on electronic certification of cause of death. The study protocol was reviewed and approved by the SAMRC Ethics Committee (EC009-4/2022). The project was also reviewed in accordance with CDC human research protection procedures and was determined to be research; however, CDC investigators did not interact with human subjects or have access to identifiable data or specimens for research purposes. We found limited peer-reviewed literature as many countries are still in the early stages of implementing their electronic MDDC (eMCCD). Therefore, we decided to host a virtual workshop to seek more up-to-date information and learn important lessons from other countries' recent experience.

This report consolidates the information about the experiences in selected countries and draws together the lessons from the virtual workshop using the Principles of Digital Development (https://digitalprinciples.org/) as a framework. After a brief description of issues raised in the workshop, the final section of the report identifies four recommendations for South Africa in its journey towards implementing EDRS.

2. Virtual participatory workshop

2.1. Purpose of the workshop

The aim of the participatory workshop was to draw on international best practice and lessons learned from systems in the countries that have implemented or are piloting electronic EDRS, with a focus on eMCCD.

2.2 Participating countries

We identified 14 countries (Australia, Ecuador, France, Germany, Ghana, Kenya, Namibia, Norway, Peru, Portugal, Rwanda, Sweden, Uganda, USA) that are either implementing or piloting EDRS or eMCCD. These countries were identified partly through the World Health Organization Family of International Classifications Informatics and Terminology Committee (WHO-FIC ITC)[4], literature review and through reaching out to project implementors. Participants from seven countries – Australia, Ecuador, Kenya, Peru, Portugal, Uganda and the United States of America – agreed to participate in the workshop. A description of the EDRS system in each of these countries is provided in *Annex 1*, based on background information obtained from participants together with the literature review. The workshop participants are listed in *Annex 2*.

As outlined in the brief description of the eMCCD and maturity of CRVS in *Table 1*, countries are at varying stages of EDRS implementation and there is no "one-size-fits-all" system. The implementation ranges from limited electronic medical certification using a tool such as the DHIS2 (District Health Information Software) only in health facilities through customized systems to full electronic death registration systems. For example, in the USA, 50 states have custom EDRS.

Table 1: Summary of the country initiatives that participated in the workshop

Country Initiative	Brief Description of the eMCCD	CRVS Maturity
1 **Australia**	eMCCD in State of Victoria (about 80% coverage); other states adopting electronic approaches	• Population of about 26 million people[5] • Completeness of death registration (2016) 100%[6] • EDRS established in 2018 - Subnational
2 **Ecuador**	eMCCD in health facilities (REVIT-Deaths) which is integrated with CRVS (about 37.7% coverage)	• Population of approx. 17 million people[7] • Completeness of death registration (2016) 82%[7] • EDRS established in 2016 - National
3 **Kenya**	eMCCD in health facilities nationwide using DHIS2	• Population of under 56 million people[8] • Completeness of death registration (provisional 2019) 43.2%[9] • EDRS still under development[10]
4 **Peru**	eMCCD introduced in 2016 across country (about 90% coverage); integrated with CRVS	• Population of about 31 million people[11] • Completeness of death registration (2017) 78.1%[12] • EDRS established in 2016 - National
5 **Portugal**	eMCCD introduced in 2014 in all health facilities (100% coverage)	• Population of about 10.3 million people[12] • Completeness of death registration (2016) 100%[7] • EDRS established in 2014 - National
6 **Uganda**	eMCCD introduced in health facilities	• Population of about 49 million people[13] • Completeness of death registration (2016) 24.2%[14]
7 **USA**	Decentralised EDRS in 51 jurisdictions; incorporates eMCCD; varies by state	• Population of over 331 million people[5] • Completeness of death registration (2016) 100%[7] • EDRS established in first jurisdiction in 2001 with incremental implementation - National

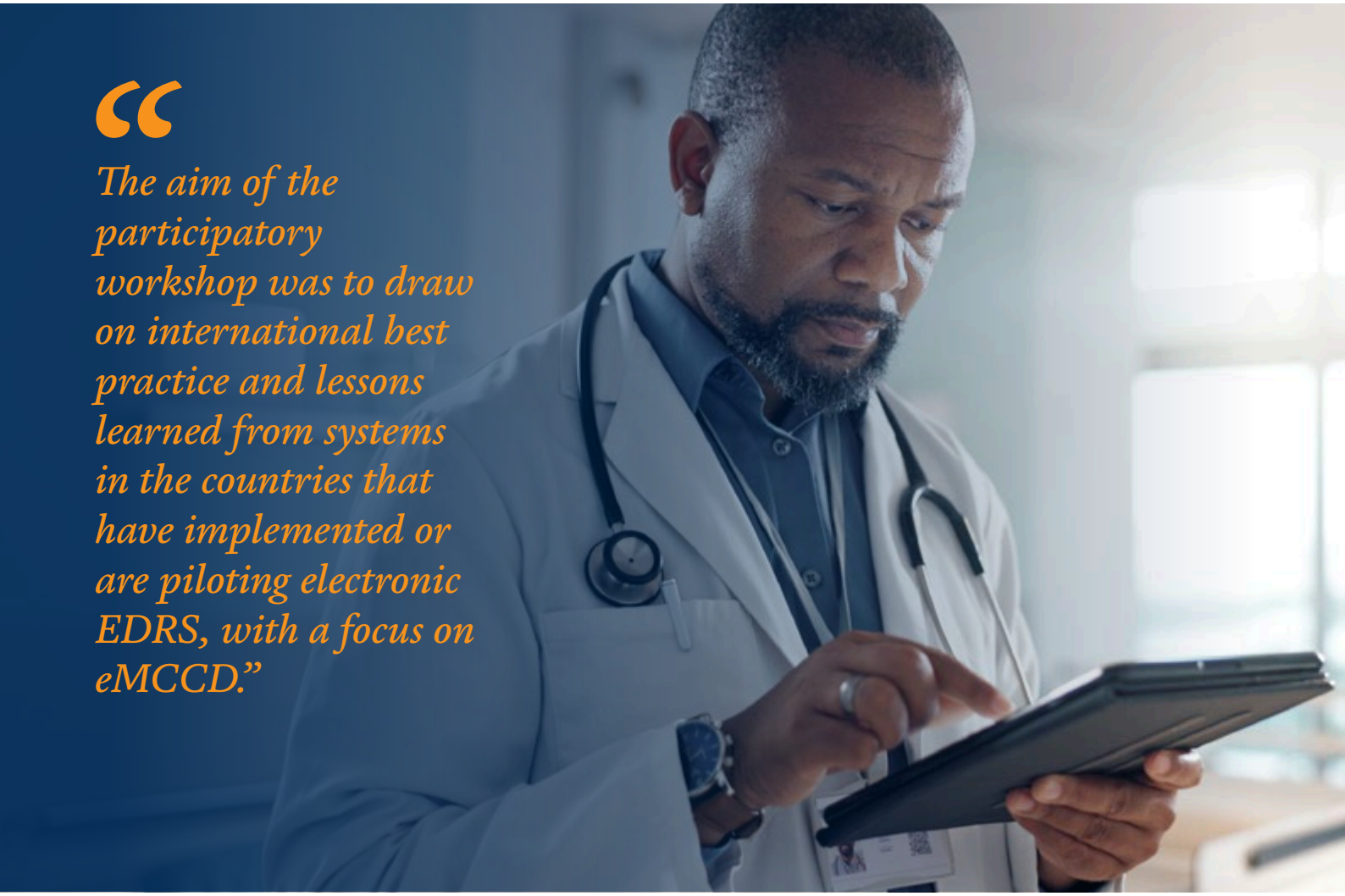
2.3. Lessons learned across countries scoped

Lessons learned and experiences from very diverse settings with different systems in place across the seven countries around EDRS implementation that South Africa can draw upon, including practical tips, were shared during a break-away group discussion. See *Annex 4. Workshop agenda and facilitators' guiding question for group discussions.*

As an ice-breaker, country participants were asked the following question: *"How would you capture in one word your EDRS experience?"*

Responses: *"Timely data for surveillance; Fair; Challenging! but very positive; Confusion from stakeholders; Evidence; Sustainability; Partnership."*

There were some similar experiences across all countries. Table 2 shows a summary of the key points shared from country experiences. We used the nine Principles of Digital Development (https://digitalprinciples.org/) as a framework (See *Annex 5* for the definitions of these principles). Common themes were *improved availability of COD data and timeliness of data.*



"The aim of the participatory workshop was to draw on international best practice and lessons learned from systems in the countries that have implemented or are piloting electronic EDRS, with a focus on eMCCD."

Table 2: Key points from country experiences mapped to Principles of Digital Development

Digital principles	Key points from country experiences
Design with the user	• Strong leadership and having champions across key departments that are organized across different themes/functions. • Need buy-in from all stakeholders and end-users e.g., doctors who can become advocates once they are convinced. • Set up formal agreements, memoranda of understanding etc., to bring on board public and private sectors users.
Understand the existing ecosystem	• Having a robust preliminary work before transitioning into electronic systems, this includes having everyone at the table, as well as mapping the processes. • Legislation and making sure that the legal environment is there to ensure that data can be shared. • Mapping national legal legislature that relates to the death certificate. • Business process is needed to establish what is needed at any data point to address any challenges that may arise before digitizing. • Need a core team that understands all the steps needed for the process of death certification from paper to electronic format.
Design for scale	• There is great opportunity in having an eMCCD roll-out if it is done with all the consultations undertaken in the first place. • Easier to build a centralized system. Having a decentralized system adds a level of complexity. • Clear milestones are important. • Adopt a stepwise approach (e.g., from local to regional and national) to transition from paper to electronic system. • 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.
Build for sustainability	• Sustainability will be an issue if the needs of stakeholders are not put into consideration when planning. • Ensure the right infrastructures, funding, and human resources. • Legislation for doctors to complete the eMCCD form. • Training of all users. • Provide adequate and timely technical support for users of software application.
Be data-driven	• Timely and accurate information sharing e.g., real-time data for policy makers. • Rapid data flow process to where the information is needed. • Ensure completeness of data. • Automatic data coding and quality check.
Use open standards, data, source, and innovation	• Availability of data/internet access and connectivity. • Use of mobile application where there is no access to computers e.g., rural areas. • Good servers are required for the sustainability of the system.
Reuse and improve	• 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.
Address privacy and security	• Data protection is also important. • Data needs to be safely transferred while ensuring privacy. There are different ways of doing this, including transferring de-identified data, the use of password protection, controls for accessing the data base etc. • Creation and maintenance of users (different profiles e.g., medical doctors, civil registrar, coder, police etc.) and passwords. • Need to have agreements on data sharing protocols • Clear data sharing protocols
Be collaborative	• Clarity of role is important to allow understanding of who plays what roles, in order to avoid confusion that can result in barriers. • Need for champions in different areas to lead and support e.g., technology, how to complete the MCCD, etc.

3. Considerations for South Africa

Recommendation 1:
A transition to a EDRS

- Transition from paper to electronic MCCD and EDRS is possible as other countries are transitioning and encouraging lessons are emerging where digital solutions have been implemented. These lessons include improved availability and timeliness of data due to faster movement of data across systems and improved quality of mortality statistics due to the addition of quality check features.

Recommendation 2:
Country leadership

- Strong leadership and champions across key departments is vital to the success of EDRS.
- Legislation to support and ensure compliance with using the eMCCD and sharing of data is also needed.

Recommendation 3:
Stakeholder engagement

- It is essential that all stakeholders are on board right from the beginning.

Recommendation 4:
Learn from challenges experienced by other countries

It is worth considering some of the main challenges experienced by other countries which include:

- Having different systems in different jurisdictions i.e., no harmonized system.
- The diversity in electronic systems/technologies between and across different states.
- Challenges with different legislations around electronic records in different states.
- Challenges with acceptability among some users e.g., reluctance by some doctors to complete eMCCD.
- Lack of clarity of roles i.e., who should be completing which part of different required forms.
- After piloting there is still the challenge of full roll out.
- Issues with infrastructure as technology is needed e.g., computers, maintenance etc. Also, internet connectivity issues in rural areas.

Transition from paper to electronic MCCD and EDRS is possible as other countries are transitioning and encouraging lessons are emerging where digital solutions have been implemented."

4. Annexures

4.1. Annex 1 – Country case studies

Case Study 1: Australia

Overview of the system

Electronic or online system either in practice or development

There are two electronic Medical Certificate of Cause of Death (eMCCD) currently in use, one in Victoria and the other in Queensland. Data is shared electronically by some jurisdictions, but in others, a paper MCCD is used. All MCCD details are transferred electronically to the Australian Bureau of Statistics regardless of how it is collected.[5,15]

MCCD collected directly by doctor

Deaths are either certified by a medical practitioner or a coroner. In Australia, approximately **86%-89% of deaths** in any given year are certified by a doctor. Deaths certified by a doctor are usually the result of natural causes, such as cancer or circulatory diseases. Coroners certify the majority of deaths which occur by unknown and external causes (e.g., accidents, assaults and suicides).[16]

86%-89%
Certified by a doctor vs coroners.

Setting

Australia is the smallest continent and the worlds' sixth-largest country with a population of about **26 million people** (2022 est). Victoria is a state in southeastern Australia (most densely populated state with a pop of over 6.6 million) and Queensland is a state situated in northeastern Australia (3rd most populous state with population of over 5.2 million).[6]

Completeness of death registration 100% (2016)[7]

26mil
Population (2022)

100%
Death registration completeness (2016)

Maturity of the system

The Victorian eMCCD was developed several years ago and is now very well established within the health system (>80% coverage). The Queensland eMCCD was only recently developed and is still in the very early stages of roll out.[5]

>80%
Health system coverage

Lessons learned

- The first eMCCD was implemented in Victoria, Australia in 2018.
- CRVS officials are the main users of the information generated by the EDRS.
- Uptake of the Victorian jurisdictional eMCCD increased over 2-3 years and now has a high level of uptake within their health system. However, paper-based certification remains an option. Other jurisdictions are in various stages of implementing eMCCDs and there is consideration of sharing technologies across jurisdictions to enable implementation where resources to develop such systems are more limited.
- The MCCD information is recorded into the system in in real-time by the medical professional who has determined cause of death.

- Some difficulties were noted in early roll-out of the eMCCD (careful planning of roll-out is important), but most certifiers found the form to be easy to use so uptake grew rapidly.
- The first eMCCD system was developed with a health system focus without mortality data in mind. This is an important distinction as the first version doesn't mirror the MCCD and this creates some challenges. Hence, it is critical to engage with all stakeholders during the planning process. However. it works very well and provides real-time data to the registry and this information is important for producing cause of death information.
- In Australia, recently they have examples of links to the justice system and coronial system and about 15% of deaths are referred to coroner. Medical certified vs coroner referred is important and will need two streams to create a complete mortality dataset in Australia. Flow of data is important and helpful between these systems.

Case Study 2: Ecuador

Overview of the system

Electronic or online system either in practice or development

All registration of vital events is done electronically. Registrars use an online platform to enter information, and they sign records using an electronic signature. The information entered is automatically added to the civil registration digital database.[8]

MCCD collected directly by doctor

Certification of death is done by health professional using online platform, or judicial authority.

Health professionals can electronically enter information of deaths at health facilities, get technical support for death classification using the ICD-10 code, and electronically sign the death certificate.

Health professionals must notify DIGERCIC (the country's National Agency for Civil Registration, Identification, and National ID Issuance) within 3 days of death.[8]

Setting

Ecuador is located in the Andean region of South America. Total population: 17,273,615 (2019 projection by the National Institute of Statistics and Censuses (INEC). The share of urban population is 64%.

Death registration rate 68% (DIGERCIC 2014, based on total estimated deaths by INEC).[8] In 2016, completeness of death registration was 82%[7]

Maturity of the system

The National Vital Data Registry System (REVIT-Deaths) was set up in July 2017. The entire implementation started with a presidential decree to all institutions. Every institution then operationalized that decree. REVIT-Deaths was developed by INEC and is now part of DICERCIC's platforms. It is also connected to the population register.

In April 2019, REVIT-Deaths was available in 25% of the country's health facilities.[8]

17,273,615
Population (2019)

64%
Urban Population

68%
Death registration completeness

25%
REVIT-Deaths availability

Lessons learned

- National Vital Data Registry System (REVIT-Deaths) is used to collect information on the cause(s) of death. Currently, REVIT-Deaths continues to incorporate both public and private health establishments into production. The total deaths processed through REVIT in 2021 was 37.7%.
- Data is recorded in real time by the medical doctor who has determined the cause of death in the web application completed through an internet network, and this has resulted in the optimization of information entry time.
- Health facility managers, public health officials, national CRVS officials and researchers are the main users of the EDRS.
- The system is endorsed inter-institutionally by the Ministry of Health, General Directorate of Civil Registry and the (INEC).
- For the sustainability of the system, good servers are required, and this must be included in the financing of the system.
- IRIS automated coding tool and manual coding are used in coding of the cause of death by INEC.
- Since the implementation of the REVIT system, there has been a need to improve the confidentiality and security of information. Information encryption security policies have been designed in which robust passwords and security are applied at the traceability level of the users who access the system (access codes). In addition, there is verification of levels of control, policy and infrastructure that guarantee that servers or data are not attacked or vulnerable to such.
- Three key successes during the implementation of the electronic solution are: (1) Automated death registration (2) Real-time data (3) Improved quality of COD information.
- Three key failures during the implementation of the electronic solution are: (1) System is currently available only for health facilities and not for registration of deaths occurring at home (paper-based in rural areas) (2) Some public and private health establishments still need to be incorporated into production (3) The server capacity is not enough, so the system crashes sometimes and cannot be used.

Case Study 3: Kenya

Overview of the system

Electronic or online system either in practice or development

eMCCD was introduced at health facilities in 2017, but civil registration is still paper-based system. Plans are underway for the issuing of digital death (and birth) certificates.[10]

MCCD collected directly by doctor

MCCD information is recorded into the system in real time by a coder who did not determine the cause of death.

Setting

Country in Eastern Africa with a population of 56,638,256 (2022), and

27.8% of the population is urban (14,975,059 people in 2020)[9]

Provisional Coverage Rates of Deaths (2019) 43.2%.[10]

Maturity of the system

DHIS2 is the system used in health facilities nationwide to collect MCCD information using the WHO 2016 MCCD form. The system is a web-based and the end user can use any device.

56.6mil
Population (2022)

28%
Urban Population (2020)

42%
Death registration completeness

Lessons learned

- Kenya has paper based MCCD and yet to adopt WHO 2016 form from the civil registration perspective. The Ministry of Health (MOH) has already adopted the eMCCD system and implementing the forms at the health facilities. However, the need from the MOH is not taken in by the civil registration. Currently having discussion with civil registration office on integrating the system. Need for champions in different areas to lead and support e.g., technology, how to fill the MCCD etc.
- It is important to have key stakeholders from the MOH, Civil Registration, and Statistics Bureau. The statistical bureau cannot drive the agenda. Need strong leadership among stakeholders who can drive this process with clear legislation in place.
- Ensure the right infrastructures and human resources.
- Information sharing is also important e.g., the MOH is waiting for statistical bureau to release statistics. Sustainability will be an issue if the needs of stakeholders are not put into consideration when planning.
- Data protection is important and requires a clear data sharing protocol.
- Clear milestones are also important.
- Benefits of EDRS include integrated system, no need for double data entry across systems, integrated data quality checks.
- The system does not use any identifiers based on existing data protection act. However, some mechanics have been put in place to prevent duplication within their system.
- Lessons learned regarding the financing of the system include (1) Investment on IT to facilitate transmission (2) Capacity building (3) stakeholder engagement.
- Infrastructure is an issue – technology available across facilities, internet connection, data bundles need to be available.
- The system was also positively received among health care workers in Kenya.

Case Study 4: Peru

Overview of the system

Electronic or online system either in practice or development

The National Death Registry Information System (SINADEF) is a web-based information application, developed by the National Civil Registry Office (RENIEC), and hosted and administered by Ministry of Health (MINSA) which is the owner of the data bank. SINADEF incorporates information not only from death certificates that can be completed through the online centralised system, but also supports consolidation of the transcription of death data from paper-based death certificates into an online format.[17]

MCCD collected directly by doctor

SINADEF allows doctors to complete death certificates in real-time immediately after verifying that a death has occurred[18].

In Peru, almost all death certificates are issued by doctors because it is a legal requirement.[18]

Where the doctor uses paper forms, an administrative staff transcribes the data to the application.

Setting

Peru has a population of over 31 million people (2017 census) with an urban population share of 79.3%. Peru is one of the fastest growing economies in South America.

Death registration rate 78.1% (RENIEC 2017, based on total estimated deaths by the National Statistics Institute).[19]

31mil
Population (2017)

79%
Urban Population

78%
Death registration completeness

Case Study 4: Peru (continued)

Overview of the system

Maturity of the system

In 2016, with the support of the Data for Health Initiative, the Government of Peru implemented the nation's new Electronic Death Notification System, known as SINADEF. There was successful operationalization of SINADEF as by early 2017, almost 90 health facilities nationwide had produced over 4,100 electronic death certificates since its introduction.[18]

From the beginning of the implementation process, each month the number of deaths with online certification surpasses the registration of the previous month, in July 2018 reaching a total of 7,303.[19]

A mobile application was developed with a technical guide for correctly completing the death certificate, with practical exercises on case presentations that supports training the doctor in the registration of causes of death. Furthermore, IRIS was implemented for automated coding of the causes of death and selection of the UCOD.[19]

>4 100
Electronic Death Certificates Produced

7 303
Deaths with Online Certification

Lessons learned

- The development of SINADEF was financed through an agreement between the National Civil Registry Office and the Ministry of Health by the Peruvian State. Peru has found the system to be a good investment, but economic studies are required to show the savings for the State and the benefit for the citizens. When the stakeholders agree, it is easier to convince the Ministry of Economy to invest in the project as there are immediate tangible economic benefits such as the targeting of beneficiaries of social programs.
- In April 2016, MINSA issued a national regulation that authorized doctors to carry out the MCCD in online electronic forms using SINADEF. In August 2016 the first MCCOD was issued.
- A training program was deployed on the correct completion of death certificates and on the use of the system in hospitals and health departments. Instructional videos were produced. Social networks were organized on Facebook and WhatsApp. Electronic MCCDs increased from 29% in 2017 to 86% in 2020. However, 15% are still paper based because there are geographical areas that do not have internet and where deaths occur at home.
- A recently published study on the perception of doctors to SINADEF found a high level of acceptability.[20]
- Some successes include (1) Increase in completeness of MCCD's from 56% in 2016 to 72% in 2019; (2) Decrease in causes of death with garbage codes from 40% in 2016 to 19% in 2019 and 10% in 2020; (3) Improved the timeliness and availability of information from a delay by 18 months in 2016 to 86% of the information available in real time in 2019.
- Interruption of coordination between stakeholders; weak security in the use of passwords by doctors, and the lack of supervision of the collection of information on paper forms were some of the challenges shared.

Case Study 5: Portugal

Overview of the system

Electronic or online system either in practice or development

Web-based software, SICO (Sistema de Informação dos Certificados de Óbito), (https://servicos.min-saude.pt/sico) is accessed by all doctors in Portugal through a high security password validated by the Portuguese Medical Association. It is also accessed by the Public Prosecution Service and Police Authorities through a high security password provided by the Ministries of Internal Affairs and Justice. Completed death certificates registered by medical doctors are forwarded to a central database maintained by the Institute of Civil Registries and made available to local civil registry offices.[21]

MCCD collected directly by doctor

In Portugal, cause-of-death certification is done by a qualified medical doctor, and it is mandatory for all deaths including fetal deaths (>22 weeks of gestational age).[23,]

Setting

Portugese Republic is a southwestern European country located along the Atlantic coast of the Iberian Peninsula. Population: over 10.3 million people (2021 est).[22]

Completeness of death registration 100% (2016)[7]

Maturity of the system

Pilot Phase started in Nov 2012 for a month. The national stepwise roll-out started in December 2012. Implementation across the country was completed in December 2013 and 100% e-death certification was achieved at the beginning of January 2014.[23,24]

Doctors can issue death certifications from a mobile app called SICO Mobile. This new app provides greater convenience and mobility to physicians.[25] Causes of death reported on death certificates and registered in SICO are available to the Ministry of Health in real time for mortality surveillance and cause-of-death coding. Once information is received and coded, it is sent through a web service to the National Institute of Statistics.[23]

10.3mil
Population (2021)

100%
Death registration completeness

100%
e-Death Certification since 2014

Lessons learned

- 100% eMCCD was established in Portugal in 2014, having started in one hospital and it took a year to fully transition from paper to electronic. This occurred following a 2012 legal framework that required certification of all deaths through an electronic registry, and the electronic transmission of death certificates for civil registration purposes. Additionally, it required setting up an integrated electronic system to synchronize and link electronic clinical and circumstantial information forms, electronic forensic autopsy reports, and electronic clinical autopsies.
- All stakeholders are needed on board. In addition, need good preliminary mapping of all processes, and legal framework of the death certificate and this requires a core team that understands all the steps needed for the process of death certification from paper to electronic format. Furthermore, it is important to design a new legal framework that will support further transformation and success of the new electronic form.
- Whenever civil registration issues a death certificate, the certificate becomes available for coding. Manual coding currently done using the SICO web-based system. ICD tables are available in the software for selection of ICD-

10 (this helps to reduce the number of errors) and are able to register multiple COD coding directly. Automatic checks are available to support coders from making certain errors. The certificates that are not yet confirmed at the civil registry level are not made available for coding. The final dataset has final medical certificate, civil registry, and coding.

- It was a challenge managing the transition periods from manual to electronic certification. Civil registry needed additional checks to prevent duplication e.g. (1 manual and 1 electronic for same person). An accurate way to double check was put in place.
- Key successes during transition were (1) Adopting a stepwise approach geographically; (2) Good training for all users e.g., regional/local training for medical doctors, public prosecution and police authorities; (3) A 24-hr phone support for users of software application or responding to any questions (including functional questions).

Case Study 6: Uganda

Overview of the system

Electronic or online system either in practice or development

Cause of death information is only collected and recorded for deaths occurring in health facilities and coded using ICD-10.[15]

MCCD collected directly by doctor

Medical officers are required by regulation to complete the cause of death form for deaths occurring in health facilities.

Setting

Uganda is a country in Eastern Africa with a population of 49,238,866 (2022), and

25.7% of the population is urban (11,775,012 people in 2020)[14]

Completeness of death registration 24.2% (2016).[15]

Maturity of the system

Web-based system using DHIS2 – integrated with National Identification and Registration Authority (NIRA) to get details. MCCD module has been integrated in the EMR.

49.2mil
Population (2021)

26%
Urban Population

24%
Death registration completeness (2016)

Lessons learned

- Having a committed leadership can help drive the process quicker.
- Benefit with monitoring health status.
- Use of locally-sourced expertise to provide input to the process.
- Some challenges include:
  1) Problems with acceptability at health facilities
  2) Clarity of roles at the health facility level
  3) Low completeness
  4) Access to broadband internet

Case Study 7: USA

Overview of the system

Electronic or online system either in practice or development

Death certificates are shared among states and the US government in electronic format. States derive an electronic file according to a standard file layout from their electronic death registration database. Data are shared either via secure network file sharing or through a specialized software program designed for sharing vital records.[5]

MCCD collected directly by doctor

Medical doctor (MD/DO) or medical examiner/coroner. In some jurisdictions, an advanced practice registered nurse (APRN), physician assistant, or a nurse also may complete the certificate if a doctor has issued an order allowing them to do so.[25]

Setting

The USA is located in North America and has 50 states with a population of over 331 million people. Each state has its own death certificate based on state laws and regulations, but these all adhere closely to the US standard.[5]

Completeness of death registration 100% (2016).[7]

Maturity of the system

The US has a decentralized vital statistics system. Electronic death registration system has been in use since 2001.[5] Many states are on their 3rd or 4th generation systems.

331mil
Population

100%
Death Registration Completion (2016)

Lessons learned

- EDRS was introduced in 2001 in one jurisdiction in the US and has been incrementally implemented for 51 jurisdictions. This was a decentralized system with state-based electronic systems, and implementation occurred on a state-by-state basis. Implementation varied within states, with some starting with medical examiners and coroners and then spread to other medical certifiers while others began in one or two counties. Easier to build a centralized system. Having a decentralized system adds a level of complexity.
- Most states, especially in the first few years of implementation, had medical certification occurring partly electronic and partly on paper.
- Financing was from state budgets, federal pandemic flu funds, social security administration funds, and maintenance is funded by state budgets.
- State systems comply with state privacy laws and regulations for access control, privacy or confidentiality features to protect the personal data stored in the web-application system. Define the uses of the data (influenced by state laws in terms of data protection).
- There is formal agreement between states to share data across states and to the federal level. In addition, there is contract in place between the federal level and the states. Standard form to share data across states with regular exchanges.
- Equitable access to data - data have to be available as soon as possible and for everyone.

- In terms of integration to other systems, same data collected across electronic systems, and this is defined by federal agencies. In the process to link up medical examiner sub-system and the general state EDRS.
- Cause of death is coded at the federal level, then sent back to the states. Electronic system is used for coding, with some manual coding required (<15%).
- In some cases, there was resistance by medical certifiers. However, doctors are used as advocates once they are convinced of its public health benefit.
- Some benefits shared are: Access decedent data within 1 month; Publication of mortality data went from 1-2 years to almost live with provisional data; Being able to provide information on current public health issues (COVID, opioids etc.) in real time; Cost saving of using electronic systems for coding; Real time data for policy making; Transformation of the entire system for all the states, including historic; The process requires the MCCD to be able to conduct the burial - EDRS improves timeliness; In the process of real-time sharing of records, coded and sent back to the jurisdiction.

“In terms of integration to other systems, same data collected across electronic systems, and this is defined by federal agencies. In the process to link up medical examiner sub-system and the general state EDRS.

4.2. Annex 2 – Workshop participant list

Country	Name	Institution
Country participants		
Australia	James Eynstone-Hinkins	Australian Bureau of Statistics
Ecuador	Erica Carvajal Gabriela Lugmana	Director of Health Statistics of the Ministry of Health Directorate of Sociodemographic Statistics
Kenya	Samuel Cheburet	Ministry of Health, Kenya
Peru	Javier Vargas	Department of Preventive Medicine, University of San Marcos
Portugal	Cátia Sousa Pinto	Public Health Specialist I Former Head of the Mortality Information System, Directorate-General of Health
Uganda	Cathy Tabaro	Ministry of Health, Uganda
USA	Paul Sutton *Robert Anderson	Division of Vital Statistics, CDC I National Center for Health Statistics
Observers		
South Africa	Gaurang Tanna	Expert
	Mercy Shoko	Statistics South Africa
	Mosidi Nhlapo	Statistics South Africa
	Wesley Solomon	National Department of Health
	Mmamokete Mogoswane	Bloomberg Data for Health
Study team	Diane Morof	CDC South Africa
	Mireille Cheyip	CDC South Africa
	Derek Treatman	Vital Waves
	Chris Seebregts	Jembi
	Sudarshan Govender	South African Medical Research Council
	Nadine Nannan	South African Medical Research Council
Facilitators		
Study team	Debbie Bradshaw	South African Medical Research Council
	Pam Groenewald	South African Medical Research Council
	Carmen sant Fruchtman	Swiss Tropical and Public Health Institute
	Daniel Cobos	Swiss Tropical and Public Health Institute
	Oluwatoyin Awotiwon	South African Medical Research Council

* Unable to attend workshop but completed pre-workshop survey questionnaire

4.3 Annex 3 – Methodology / approach

A desktop review of international practice in EDRS that included a literature review of published material as well as follow-up and documentation of current global EDRS initiatives that have been identified by the World Health Organization Family of International Classifications (WHO-FIC)[4] was done. Five electronic databases - PubMed, Scopus, ScienceDirect, Web of Science and JSTOR - were searched using the following search terms "Electronic death registration system OR EDRS OR electronic death certificate OR electronic certification of cause of death OR Online medical certificate of death OR Online MCCD OR electronic MCCOD" to obtain relevant international studies reporting on electronic death registration practices, with a focus on electronic/online medical certification of cause of death. We also searched the references of the retrieved studies for additional relevant studies. Furthermore, we searched the Bloomberg Philanthropies Data for Health Initiative repository (https://crvsgateway.info) and the Centre of Excellence for CRVS Systems (https://crvssystems.ca/home) websites for relevant grey literature.

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. (See *Annex 2. List of country participants; and Annex 3. Workshop agenda and facilitators' guiding question for group discussions).*

The MAPS Toolkit framework for assessing mHealth (https://www.who.int/publications/i/item/9789241509510) was used to inform the online survey questionnaire and we used the Principles for Digital Development (https://digitalprinciples.org/) *to develop and categorise the lessons learned from the online survey and workshop discussion (Annex 5).*

4.4 Annex 4 – Workshop agenda

Virtual Workshop: Lessons learned from electronic death registration systems in countries already implementing or piloting – **Facilitators Guide**

Workshop date

10 November 2022
(14h00 – 16h00 SA time)

Workshop duration

2 hours

Purpose

Lessons for South Africa from international experience

Zoom link to join workshop:

CLICK HERE

Meeting ID: *** **** ****
Passcode: *****

Agenda

Time	Topic	Presenter	Format
14:00 - 14:05	Welcome & Thanks	Debbie Bradshaw	Presentation
14:05 – 14:10	Introductions	All	Chat
14:10 – 14:20	Introduction to Online capture of MCCD scoping project	Pam Groenewald	Presentation
14:20 – 14:30	Q&A	All	Plenary
14:30 – 15:30	Group work 1	Pam Groenewald Carmen Sant	Jamboard discussion
14:30 – 15:30	Group work 2	Debbie Bradshaw Daniel Cobos	Jamboard discussion
15: 30 – 15:50	3 min Group Feedback General discussion	Carmen Sant Daniel Cobos	Discussion
15:50 – 16:00	Wrap – up and closing remarks	Debbie Bradshaw	

Welcome, thanks & introductions

Debbie welcomes everyone and thanks for answers and participation:

- introduces the study team – names (who we are)
- inform meeting will be recorded

Record meeting

- Country members: name, where you're from and summarize in 1 word the EDRS experience
- South African colleagues – name, institution, expectations for the EDRS.

Group discussion – Guiding questions

Section 1 – Lessons learned (25 min)

- What have been real successes in the implementation of electronic death registration system/ electronic Medical Certificate of Cause of Death in your country?
- How were initial expectations met? (from users, policymakers, other)
- What were unexpected challenges? What did you learn from them?

Section 2 – Integration lessons (20 min)

- How the electronic MCCD integrated with other systems? Which ones?
- What was useful/ not useful to overcome integration challenges?
- How were challenges linked with paper/ digital environment addressed?

Section 3 – Wrap up – final remarks (10 min)

- If you were to start again, what would you keep / change from the design?

Group feedback (30 min) – Daniel & Carmen

We close the breakout rooms after 55 minutes and come back to the plenary room.

- Carmen
  give a 3 min summary of the discussions in group 1
- Daniel
  give a 3 min summary of the discussions in group 2
- Daniel
  open the floor for questions, feedback etc. (10-15 min)

Closing remarks

- Debbie thanks everyone for participating, informs us we may follow up with other questions, etc.

4.5 Annex 5 – Principles for Digital Development

Digital Principles	Definitions
Design with the user	Successful digital initiatives are rooted in an understanding of user characteristics, needs and challenges. User-centered design — also referred to as design thinking or human-centered design — starts with getting to know the people you are designing for through conversation, observation, and co-creation. Information gathered through this engagement leads to building, testing and redesigning tools until they effectively meet user needs. By designing with the users, and not for them, you can build digital tools to better address the specific context, culture, behaviours, and expectations of the people who will directly interact with the technology. Designing together means partnering with users throughout the project lifecycle, co-creating solutions, and continuously gathering and incorporating users' feedback.
Understand the existing ecosystem	Well-designed initiatives and digital tools consider the particular structures and needs that exist in each country, region and community. Dedicating time and resources to analyze the ecosystem, or context where you work, helps to ensure that selected technology tools will be relevant and sustainable and will not duplicate existing efforts. Ecosystems are defined by the culture, gender norms, political environment, economy, technology infrastructure and other factors that can affect an individual's ability to access and use a technology or to participate in an initiative. Initiatives that do not account for ecosystem challenges are less likely to achieve their objectives or scale. This may also lead to unintended consequences. The ecosystem is fluid, multifaceted and ever-changing, requiring that digital development practitioners regularly analyze the context to check their assumptions.
Design for scale	Achieving scale is a goal that has been elusive for many digital development practitioners. The mHealth field, for example, has identified the problem of *pilotitis*, or the inability to move initiatives beyond pilot stage. Achieving scale can mean different things in different contexts, but it requires adoption beyond an initiatives pilot population and often necessitates securing funding or partners that take the initiative to new communities or regions. Different implementers may define scale as reaching a certain percentage of a population or a certain number of users. Designing for scale means thinking beyond the pilot and making choices that will enable widespread adoption later, as well as determining what will be affordable and usable by a whole country or region, rather than by a few pilot communities. You may need to evaluate the trade-offs among processes that would lead to rapid start-up and implementation of a short-term pilot versus those pilots that require more time and planning but lay the foundation for scaling by reducing future work and investment. By designing for scale from the beginning, your initiative can be expanded more easily to new users, markets, regions or countries if the initiative meets user needs and has local impact.
Build for sustainability	Building sustainable programs, platforms and digital tools is essential to maintain user and stakeholder support, as well as to maximize long-term impact. Sustainability ensures that user and stakeholder contributions are not minimized due to interruptions, such as a loss of funding. A program built for sustainability is more likely to be embedded into policies, daily practices, and user workflow. For many digital initiatives, institutionalization by a nongovernmental organization, private company or local government is the ultimate goal in achieving long-term, positive impact. For others, institutionalization is achieved by developing a business model that has sustainable revenue generation.

Be data driven	No amount of data will lead to accelerated impact if it is not used to inform decision making. When an initiative is data driven, quality information is available to the right people when they need it, and they are using those data to take action. The data produced by a digital initiative should be used for more than just outputs, such as published work or donor reporting. Examples of the types of data that can be collected to inform decision making include surveillance, research, operations, project management and data from secondary sources collected outside of the program.
Use open standards, open data, open source, and open innovation	Too often, scarce public and international development resources are spent investing in new software code, tools, data collection, content and innovations for sector-specific solutions that are locked away behind licensing fees, with data only used by and available to specific initiatives. An open approach to digital development can help to increase collaboration in the digital development community and avoid duplicating work that has already been done. Programs can maximize their resources — and ultimately their impact — through open standards, open data, open-source technologies and open innovation. By taking advantage of existing investments when you are able, you can apply finite digital development resources toward creating global goods. What being "open" means for your initiative will depend on practical and technical constraints, security and privacy concerns, and the dynamics of the people and networks in your space. For example, to what extent your initiative uses open-source software will depend on the needs identified for your context and an assessment of which of the available options best meets those needs, factoring in their total cost of ownership.
Reuse and improve	Instead of starting from scratch, programs that "reuse and improve" look for ways to adapt and enhance existing products, resources, and approaches. Reuse means assessing what resources are currently available and using them as they are to meet program goals. Improve means modifying existing tools, products, and resources to improve their overall quality, applicability and impact. Start by identifying relevant methods, standards, software platforms, technology tools and digital content that have already been tried and tested. You can learn about digital development tools that have been piloted or scaled through conferences, blogs, program evaluations and the digital development community. While an existing tool or approach may not exactly fit all your needs for reuse, consider improving and building on it, rather than creating something entirely new. The result is a tool that is now better and more reusable by all because of your improvements. Reusing and improving is not about designing shiny new objects or limiting a technology to internal use; it is about taking the work of the global development community further than any organization or program can do alone. Reusing and improving can also dramatically reduce the time needed for development and testing, and reduce your costs.

Address privacy and security	Addressing privacy and security in digital development involves careful consideration of which data are collected and how data are acquired, used, stored, and shared. Organizations must take measures to minimize collection and to protect confidential information and identities of individuals represented in data sets from unauthorized access and manipulation by third parties. Responsible practices for organizations collecting and using individual data include considering the sensitivities around the data they have collected, being transparent about how data will be collected and used, minimizing the amount of personal identifiable and sensitive information collected, creating, and implementing security policies that protect data and uphold individuals' privacy and dignity, and creating an end-of-life policy for post-project data management.
Be collaborative	Being collaborative means sharing information, insights, strategies and resources across projects, organizations, and sectors, leading to increased efficiency and impact. This Principle brings all the others together in practice. People working in digital development have a shared vision to create a better world, and collaboration is essential to making this vision a reality. No single initiative or organization can make it happen alone. We have the most impact when we work together across geographies, focus areas and organizations and in partnership with local communities and governments. By collaborating, those working in digital development and beyond can pool their resources and expertise not only to benefit each initiative but also to strengthen the global community. Collaborating does not just happen accidentally; it requires time, planning and dedicating resources to look for and develop opportunities.

Source: Principles for Digital Development. Available at: https://digitalprinciples.org/

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