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Pathways to obtaining high-quality information in Africa on cause of death

Conference theme

Innovative Civil Registration and Vital Statistics systems: Foundation for Legal Identity Management





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I. Background

High-quality statistics on cause of death are fundamental for evidence-based 1. policymaking, programme planning, and monitoring many Sustainable Development Goals. With global and regional commitments in strengthening civil registration and vital statistics systems (CVRS), CRVS stakeholders have an opportunity to prioritize having high-quality statistics on cause of death as part of their system strengthening goals. The vision of highquality statistics on cause of death of any Government should include a system that is based on international standards for data collection, mortality coding, analysis and reporting. Fundamental to a successful system that records cause of death is the achievement of complete death registration, a goal for many of the 54 member States in Africa. Progress in achieving this goal is presented in the issue paper of the fourth Conference of African Ministers Responsible for Civil Registration, "Improving mortality statistics and cause of death recording and its linkages to CRVS systems in Africa".¹ This report presents the various pathways and their technical considerations for the collection and coding of cause of death data that are of high quality, even as countries concurrently work to improve completeness of death registration. Successful implementation of these cause of death pathways that are of high quality is within a broader CRVS improvement strategy with governance and a strong legal framework as drivers for impactful and sustainable systems improvements.²

2. In a best practice system, physicians use the international medical certification of cause of death (MCCD) form that is recommended by the World Health Organization (WHO) for the medical certification of all deaths; a team of mortality coders trained in the most recent version of the International Classification of Diseases (ICD) completes the coding of the MCCD forms.³ This system is supported by a clearly written, draft legal framework on death registration and medical certification of cause of death.⁴ Additionally, this system supports the regular training of medical students and physicians in correct MCCD completion. The best practice system should be the vision and model for all countries in their efforts to achieve complete, accurate and timely information on cause of death.

3. Reaching this vision requires stakeholder engagement and support as substantial systems investments. It may require that a country apply multiple pathways, tailoring implementation to the individual country's needs, legal structure, and operational framework. To be clear, a pathway is an approach, not a tool. A tool or stand-alone training programme will not improve the quality of information on cause of death. Any approach, or pathway, selected by a country requires well-planned integration into the system for sustainable improvements.

4. The present report responds to a recommendation made in the Nouakchott Declaration from the fourth Conference of African Ministers Responsible for Civil Registration: "...to improve mortality statistics and the recording of causes of death and the linkages between the health sector and civil registration and vital statistics systems in Africa, and requests the

⁴ <u>https://unstats.un.org/unsd/demographic-social/Standards-and-</u>

¹ <u>http://apai-crvs.org/sites/default/files/public/EN%20-</u>

^{%20}Mortality%20and%20Cause%20of%20Death%20Report%20Africa%20Oct%20Updated_0.pdf.

² A number of individuals contributed to the present report, namely: Olga Joos, CDC Foundation, corresponding author; Doris Ma Fat, WHO; Kidist Bartolomeos, WHO; Sam Notzon, Center for Disease Control & Prevention; Erin Nichols, Center for Disease Control & Prevention; Daniel Cobos, Swiss Tropical and Public Health Institute; Martin Bratschi, Vital Strategies; and James Mwanza, Vital Strategies.

³ <u>https://unstats.un.org/unsd/demographic-social/Standards-and-Methods/files/Handbooks/crvs/crvs-mgt-E.pdf.</u>

Methods/files/Handbooks/crvs/CRVS_GOLF_Final_Draft-E.pdf.

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Ministries of Health to collaborate closely with ministries responsible for civil registration and vital statistics systems, with a view to promoting the reliability of health statistics".⁵ Additionally, this report expands on the strategic enablers presented in the WHO Mortality Strategy in Africa 2015-2020, developed in response to a recommendation of the third Conference of Africa Ministers Responsible for Civil Registration.⁶

II. Objective of the session

5. The cause of death data system starts with the occurrence of a death and ends with it being captured in the statistics at national level, and, ideally, subnational level, which are used for policy development and program planning. Within these system bookends are two key processes: the reporting of the cause of death and the translation of the medical terms into an alphanumeric code representing the underlying cause of death. The code defining these processes is the International Classification of Diseases (ICD), which is a common language that has been managed by WHO since 1948.⁷ ICD is the global standard for the reporting of diseases and health conditions, and is used to facilitate the analysis of trends within countries and globally. Since ICD is the language used for transforming the text version of a cause of death into a code, as described above, its application influences the pathways for the reporting of cause of death.

6. The best practice pathway for reporting cause of death is the use of the WHO recommended MCCD form by a physician for all deaths: facility, non-facility, and those referred to the medico-legal death investigation system, that is, a coroner or medical examiner system. The current recommended form, revised in 2016, includes a space for reporting causes of death in a specified format and additional questions on circumstances of death (see figure). These questions improve the quality of information reported on specific medical issues, including maternal, surgical and external deaths, for which information provided in the figure might be insufficient for the most detailed coding of cause of death. APAI-CRVS monitoring assessment found that only a third of African member States use the standard WHO MCCD form. That is disappointing, given the benefits of following the global standard. It serves, nevertheless, as a reminder of the challenges in implementing systems improvements.⁸

7. The WHO 2016 form is the *recommended* form for use in systems where a physician attends a death, in or out of a facility. WHO member States have the liberty to modify the form to meet their systems and information needs, but the section on cause of death is identical worldwide so as not to inhibit the ICD coding process for the selection of the underlying cause of death. In 2017, Morocco initiated work on adopting the WHO 2016 form. A technical working group was tasked with reviewing the WHO recommended MCCD form and suggesting modifications, additions and deletions. The revised MCCD form was piloted in Rabat in 2018 prior to it being made available at the national level in 2019. The roll-out process included the training of all public physicians in the correct completion of the form and replacement of former forms with the revised forms in public hospitals to minimize delay in uptake.

⁵ <u>http://apai-crvs.org/sites/default/files/public/Nouakchott%20Declaration%20-%20Dec2017-English.pdf</u>.
⁶ <u>http://apai-</u>

crvs.org/sites/default/files/public/IMPROVING%20MORTALITY%20STATISTICS%20IN%20AFRICA%20-%20Technical%20Strategy%202015%E2%80%932020%20-%20En_0.pdf.

⁷ <u>https://www.who.int/classifications/icd/en/</u>.

⁸ http://apai-crvs.org/sites/default/files/public/The%20Status%20of%20CRVS%20-%20EN.pdf.

8. The successful implementation and use of the WHO recommended MCCD form require a training programme that is institutionalized in medical education for students and residents, and continuing medical education for practicing physicians. A trained physician will not have difficulty completing the form, but will need to know the required detail to report and, in particular, the order to report the medical conditions that resulted in death. In view of the demand, face-to-face training sessions can be difficult to coordinate and supported. As such, self-paced e-learning courses, such as the course in English developed by WHO⁹ and the course developed in English and French by the Pan American Health Organization¹⁰, can be integrated within a training programme at scale and, ideally, be linked with the physician licensure renewal process. Ghana, Rwanda, the United Republic of Tanzania and Zambia recently adopted a MCCD e-learning course developed through the Data for Health Initiative to support MCCD training at scale. The MCCD form is one of many forms completed by physicians, so it is essential to institutionalize the training, that is, through the licensure renewal process, to train them on a regular basis on the importance of the information reported on the form, correct completion of the form, and any revisions made to meet WHO recommendations.

Administrative data (can be further specified by country)									
Sex	F	^r ema	le 🗌 Male 🗌	Unknown					
Date of birth	ΕD	MI	Y Y Y Date of death	D D M M Y Y Y					
Frame A: Medical data: Part 1 and 2									
1 Report disease or condition directly leading to death on line a			Cause of death	Time interval from onset to death					
Report chain of events in due to order (if applicable)		a b	Due to:						
State the underlying cause on the lowest used line		c d	Due to:						
2 Other significant condition contributing to death (time can be included in brackets condition)	interv								

Figure International form of medical certificate of cause of death (WHO, 2016)

⁹ <u>http://apps.who.int/classifications/apps/icd/icd10training/ICD-10%20Death%20Certificate/html/index.html</u>.

¹⁰http://www.paho.org/relacsis/index.php/es/at4-certificado-defuncion/virtual-course-on-properly-completingdeath-certificates.

Frame B: Other medical data								
Was surgery performed within the last 4 weeks?					No No	Unknown		
If yes, please specify date of surgery				·	D D N	M M Y Y Y Y		
If yes, please s	If yes, please specify							
reason for surgery (d	lisease							
or condition)				1	1			
Was an autopsy requ				No No	Unknown			
If yes were the findings used in the certification?								
Manner of death:								
Disease		Assaul	t			ould not be determined		
Accident	it 🗌 Leg		interve	ntion	Pe	Pending investigation		
Intentional self-h	narm	War			U	nknown		
If external cause or j	poisoning:		I	Date of injur	y D D N	M M Y Y Y Y		
Please describe ho								
occurred (If poisoning, please specify								
poisoning agent)								
Place of occurrence of the external cause:								
At home	Residen	itial Schoo		chool, other	institution,	Sports and		
	instituti	pu	blic adminis	strative area	athletics area			
Street and	Trade a	nd service	🗌 In	dustrial and		Farm		
highway	area		co	nstruction a	rea			
Other place (plea	ther place (please specify):					Unknown		
Fetal or infant death								
Multiple pregnancy				Yes	No	Unknown		
Stillborn?				Yes	No	Unknown		
If death within 24h, specify number of hours Pirth weight (in grame)					ame)			
survived Birth weight (in grams)								
Number of completed weeks of pregnancy				Age of	Age of mother (years)			
If death was perinatal, please state conditions								
of mother that affected the fetus and newborn								
For women, was the deceased pregnant? Yes No Unknown					Unknown			
At time of death				Wi Wi	Within 42 days before the death			
Between 43 days up to 1 year before death				Un	known			
Did the pregnancy contribute to the death?				Ye	s 🗌 No	Unknown		

9. Completion of the WHO recommended MCCD form can be in paper format, electronic, or a combination of the two. Accuracy and timeliness are the priority data quality considerations in determining the most appropriate method of data capture. For electronic capture of the MCCD form, the table in which the physician reports medical conditions should allow for entry of the condition as it is reported by a physician. It is not the role of the data entry clerk or coder to modify the medical condition reported on the MCCD form or infer any other conditions that

may have been part of the causal pathway leading ultimately to death. The role of the data entry clerk or coder is to enter or code the medical condition *exactly* as it is reported by the physician, a reason for which institutionalized physician training in MCCD is essential. Timeliness is an important consideration for paper-based systems. A system should be in place to send forms in a timely manner to the agency responsible for mortality coding so that data can be analysed for impactful response.

10. In countries with a large percentage of deaths occurring outside of facilities or in the absence of a physician, and where the use of the WHO recommended MCCD is not feasible, verbal autopsy may be used as an alternative pathway that facilitates the identification of causes of death in areas where physicians are not available to attend out-of-facility deaths. Until recently, the application of a verbal autopsy has been limited to research settings. However, lessons learned through recent initiatives, including the Bloomberg Data for Health Initiative, have elucidated key considerations for integrating verbal autopsy into the CRVS system to capture unattended deaths, often those outside of facilities or deaths that occur prior to arrival at a hospital or health facility.

11. Implementation of verbal autopsy as a pathway to obtain cause of death information requires many systems considerations spanning the domains of governance, design, operations, human resources, financing, infrastructure, logistics, information technologies and data quality assurance. table 1 presents a planning checklist with such considerations.

Table 1

Planning checklist for verbal autopsy integration within the CRVS system

Ensure that a high-level National CRVS Policy and Coordination Committee is in operation Ensure that the relevant authorities, agencies or ministries for civil registration, statistics, local government and health are engaged collectively for CRVS Ensure that a Comprehensive CRVS Assessment has been conducted in the past 4 years and has been used to develop a national CRVS vision and strategy or is being implemented Set up a National Sub-committee on Mortality and Cause of Death Establish a task force for VA implementation reporting to the National Sub-committee on Mortality and Cause of Death Ensure that detailed process mapping of CRVS processes for registration of death in health facilities and death in communities has been done as part of the comprehensive assessment, and if not, prepare such process maps With all relevant stakeholders, use these process maps of notification and registration processes of death in the community as a base to develop the plan of implementation for how VA would be integrated into a modified set of processes Prepare an investment case to justify using VA as a method to increase notification and registration of deaths and ascertain underlying cause of death Consider a legal and regulatory review of the implications of VA in CRVS as an early step in the plan Apply the enterprise architecture Digital CRVS Guidebook to assess the additional IT needs (http://www.crvs-dgb.org/en/) Map the existing CRVS and DHIS2 IT infrastructure and its gaps

Seek synergies with existing IT for population registration efforts (i.e. National Identification agencies)

Determine how mobile tablets will be supported and maintained, and how they will securely transmit/receive data (wireless, General Packet Radio Service, etc.)

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Design data flow and quality assurance mechanisms

Ensure that e-governance, interoperability, data security, confidentiality and data encryption issues are addressed

Decide how VA-coded deaths will be distinguished from medically certified deaths in aggregate databases

Decide on scale (sample system or full coverage) and phased introduction

Use a VA costing tool to develop the start-up and annualized budgets

Prepare a profile of the existing CRVS human resources and needs

Develop job descriptions, training plans and training materials for new and revised positions Plan for an increase in the workload for existing staff

Consider adding VA functions to existing position descriptions of community workers

Develop a training programme for Master Trainers, Trainer of Trainers, and training of VA supervisors, interviewers and analysts

Prepare a monitoring and evaluation plan for the new VA processes, including the use of VA costing tools to document costs and an independent quality assurance mechanism

Work with stakeholders to develop a learning platform for phased introduction and assemble necessary funding

Source: The information in the table is based on the checklist in Don de Savigny, et al., Integrating community-based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations. *Global Health Action*. 2017; 10(1).

In countries using the WHO recommended MCCD form, the best practice pathway for 12. mortality coding is through a coding team trained in the current ICD version to determine the underlying cause of death and its respective code. Results from the APAI-CRVS monitoring assessment presented at the fourth Conference of African Ministers Responsible for Civil Registration show that only 15 member States apply ICD-10 coding (see the summary of monitoring results provided in the status of CRVS systems in Africa cited at footnote 7). Mortality coding teams can be centralized or decentralized, depending on the availability of trained mortality coders and a system to support the team structure. Considerations for each type of system are presented in the Handbook on Civil Registration and Vital Statistics systems: Management, Operation and Maintenance, revision 1, cited previously (see footnote 2). Whether centralized or decentralized, a well-supported mortality coding team requires highly technical and continuous investments in supervision and training. Supervision should be conducted by an expert mortality coder who regularly reviews a sample of coded forms and provides necessary one-on-one training. Additionally, the coding team members require comprehensive training to learn the highly technical application of ICD rules and principles, and regularly scheduled retraining to maintain their skill and learn changes in coding rules and principles as ICD is revised. Investments made in adopting ICD as the mortality coding pathway are not limited to initial adoption and integration into the cause of death system, but are continuously required to ensure countries achieve best practice application of ICD coding.

13. Similar to most spoken languages which adopt new words as they become mainstream, ICD requires regular revisions to adopt new diseases and improved methods of categorizing diseases and health conditions. ICD started with 179 categories and grew to 12,000 with ICD-10, announced in 1990.¹¹ WHO has maintained ICD-10 through triennial updates, and supported a substantial revision in 2016. This revision has posed a challenge for countries with the recent adoption of the ICD-11 in 2019, as investments in capacity-building, IT, and

¹¹ ICD-11 Implementation or Transition Guide. Geneva: WHO, 2019.

reporting require substantial investments. It is beneficial to follow the most updated ICD version, as revisions are intended to improve the quality of cause of death data, but also a requirement for WHO member States, as per the 1976 WHO Nomenclature Regulations.¹²

14. As described in the *ICD-11 Implementation or Transition Guide*, referred to previously, ICD-11 was adopted by the World Health Assembly in 2019 after extensive revisions and contributions from over 270 institutions and 99 countries Revisions to this classification system are extensive and reflect detail on advances in medicine and classification required for the best quality of cause of death information. ICD-11 includes over 17,000 categories, an increase from the 12,000 in ICD-10. To support the transition period expected to last an estimated two to three years, WHO has developed various materials including an implementation guide (see table 2). WHO has also developed ICD-11 in software format, unlike previous versions, for integration into the health information system of a given country. Available for implementation in January 2022, some early adopting countries have already initiated piloting. Given the substantial investments envisioned for the implementation of 2011, countries should conduct the recommended activities in the Implementation Guide using WHO supporting materials to facilitate the transition from the former system to ICD-11.

Table 2ICD-11 Implementation or Transition Guide

Activities	WHO tooling available				
FIRST: Form a national task force for implementation, including all relevant stakeholders and ensure support at the highest levels of government					
Priority area 1: Completion of the ICD-11 language version for in	nplementation				
Finalize the translation of the Classification, tools and materials	Translation tool				
Carry out manual coding and transcription tests on computer systems to make the necessary adjustments	ICD-11 Field implementation test platform				
Priority area 2: Capacity-building					
Evaluate existing ICD coding capacity in the country	WHO-FIC platform				
Develop training programmes applicable to different profiles (as coders, staff, systems, researchers)	ICD-11 training tool				
Provide training in the use of ICD-11 and its tools. Levels: medical information coding instructors, coders, statisticians, analysts and public health experts	ICD-11 training tool				
Provide training in the use of computer tools to coders, statisticians and other key personnel	Information sheet				
Provide training in the use and implementation of Iris automated coding system for causes of death	Specialist training				
Provide training for mortality and morbidity data analysis and of the quality of the information	Specialist training				
Evaluate the impact of training activities for coders, physicians and other personnel on quality indicators	ICD-11 FIT				
Develop a coder profile and certification	WHO-FIC curriculum				

¹² <u>https://www.who.int/classifications/icd/en/.</u>

Priority area 3: Information technology infrastructure		
Carry out a technology needs assessment		
Promote access to appropriate computer tools (PC and reliable		
Internet access)		
Integrate IT personnel into the transition team for developing an		
integral transition plan		
Adjust national information systems (and subsystems) for the		
implementation of ICD-11, as revisions, updating of catalogues and		
other variables		
Explore the interoperability between the ICD-11 coding application		
and national health systems	ICD 11 antine and	
Initial testing of ICD-11 online and offline versions	ICD-11 online and container offline versions	
Implement automated coding system for causes of death	Iris - other	
Adapt the current information system to avoid unnecessary changes		
Priority area 4: Ensure comparability and quality of data		
Monitor indicators of information quality for mortality and morbidity		
recommended internationally	ANACOD 3	
Make available transition tables to map ICD-10 and ICD-11	ICD-11 toolkit	
Conduct studies on the impact analysis of mortality and morbidity		
data due to the change from ICD-10 to ICD-11: reimbursement		
schemes, case mix, mortality and morbidity statistics, legal		
frameworks		
Carry out comparability studies in selected cases in different areas to		
evaluate the quality of coding		
Conduct bridge studies, double codification, with ICD-10 and ICD-		
11, for priority subject of public health		
Monitor specific changes that will be made as part of the transition		
and implementation of ICD-11		
Priority area 5: Advocacy and dissemination		
Create and strengthen committees, councils or inter-institutional		
centres (health, statistics, social security and civil registry), health		
information, and inform stakeholders		
Integrate professional associations, colleges, universities, doctors and other sectors into national commissions to implement training and		
analysis activities		
Raise awareness of the importance of the correct use of		
classifications for different users and environments		
Develop a national transition and implementation plan for ICD-10 to		
ICD-11 aligned with the country's health information improvement	This table	
plan		

Source: Based on the ICD-11 Implementation or Transition Guide. Geneva: WHO, 2019.

15. Given the complexity of implementing and maintaining a strong coding system, and the active ICD revision process, countries should prioritize engagement in the global discussion on ICD, especially as 2022 approaches and the beginning of the implementation of ICD-11 nears. The WHO Family of International Classifications (WHO-FIC) network holds an annual meeting that brings together invited representatives from member States to discuss a range of matters, including the status of ICD, country implementation, challenges, and approved revisions. Country participation by a key coding stakeholder is strongly recommended to ensure information and updates are presented to in-country stakeholders for consideration and

discussion. Another forum for ICD support is through the WHO-FIC collaborating centres located in select countries globally to cover all regions. In Africa, the WHO-FIC Collaborating Centre is located at the South African Medical Research Council and is tasked with providing guidance on ICD-related topics to countries in its region.¹³ Countries adopting ICD to code its MCCD forms should be well connected to its regional WHO-FIC Collaborating Centre and participate in the WHO-FIC annual meeting to benefit from technical support and lesson sharing, while also contributing to the conversation with country experience in implementation of ICD mortality coding.

16. Countries supporting mortality coding using ICD-10 can consider a concurrent pathway to improve coding efficiency and quality through the implementation of Iris, a validated automated coding platform used in countries globally, including Morocco, South Africa, Tunisia and Zambia.¹⁴ Simply speaking, Iris is a platform that runs ICD-10 rules and principles to determine the underlying cause of death and its respective ICD-10 code. Iris can never replace a team of trained mortality coders and, in fact, requires a highly skilled coding team to manually code the MCCD forms rejected by Iris. Similar to implementation of the ICD coding pathway, Iris requires highly technical support for implementation within the coding process and integration within the systems architecture. As African member States utilizing Iris develop capacity in its development and implementation, regional support for Iris training and implementation will become available. Countries considering implementing Iris should only do so once they support an experienced team of well-trained mortality coders. Additionally, countries eager to implement ICD-11 will need to wait to adopt Iris as it currently runs on ICD-10 rules and principles.

17. Countries lacking a coding team to code completed MCCD forms can take another pathway to obtain cause of death information. For countries lacking technical capacity for full ICD coding, WHO developed in 2015 the Start-Up Mortality List (SMoL), a simplified ICD-10 coding system, which is in line with ICD. This method requires the use of the WHO recommended MCCD form, the development of a list of causes mapped to SMoL codes and application of simplified selection rules. To facilitate implementation in countries using the open source heath management data platform, District Health Information System 2 (DHIS2)¹⁵ in health facilities, WHO developed an SMoL application fully integrated into DHIS2 for real time reporting. In Africa, Ghana, Rwanda and the Sudan have implemented SMoL. Experiences from these countries have shown that low-resource settings are also capable of investing in capacity-building with adapted tools. Although SMoL is a useful tool for countries in the early stages of ICD implementation, in the longer term, all countries will wish to proceed to the use of the more detailed ICD listing as their skills and capacities for certification and coding improve.¹⁶

18. Before implementing any of the various pathways to obtaining high-quality information on cause of death, country stakeholders should agree on a vision, strategy and comprehensive plan for CRVS system strengthening. The pathways presented in this report will only succeed if they are implemented within a CRVS system improvement plan with broad stakeholder support. Investments required are substantial as these pathways are not tools, but methods to be integrated within the CRVS system. Many resources exist already to support implementation of these pathways, as well as expertise from country stakeholders and technical advisors. Using

¹³ <u>https://www.who.int/classifications/network/collaborating/en/.</u>

¹⁴ https://www.dimdi.de/dynamic/en/classifications/iris-institute/index.html.

¹⁵ <u>http://www.openhealthnews.com/resources/district-health-information-system-2-dhis2</u>.

¹⁶ <u>https://www.who.int/healthinfo/civil_registration/ICD_10_SMoL.pdf?ua=1.</u>

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these resources and applying lessons learned will assist countries in implementing their selected pathway and, ultimately, improve the quality of cause of death statistics for policymaking and programme planning.

III. Issues for discussion

19. In the light of the above, the following questions should be used as a basis for discussion:

(a) What methods and strategies do countries use to assess pathways and determine their implementation into the CRVS system? What are the considerations for countries in choosing the right pathway and how are they prioritized?

(b) What are valuable lessons learned from efforts to implement a pathway to obtain high-quality information on cause of death? What is the best way for countries to learn from other countries successful implementation of a pathway?

(c) What role can global agencies and non-governmental organizations play in supporting country preparation, implementation and maintenance of a pathway to obtain high-quality information on cause of death?
