

**Practical Guide on the Improvement
of Death Registration and Causes of Death
Processes within a Civil Registration and Vital
Statistics System**

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Foreword

African countries lack continuous, permanent and universal sources of mortality data, and face considerable challenges in providing reliable and essential data for tracking health trends and establishing sound identity management systems. The significance of mortality data is well underlined in Sustainable Development Goals 1, 2, 3, 13 and 16, which require routine measurement and monitoring of mortality by cause and the establishment of legal identity systems. Unfortunately, death registration levels in most African countries are low, and the recording and compilation of causes of death is very limited.

Evidence of such weakness in death registration and cause of death information systems in Africa was visible by the lack of real-time mortality data needed for tracking deaths during the Ebola virus disease outbreak experienced in Western Africa in 2014. African Ministers Responsible for Civil Registration, during their third conference, held in Yamoussoukro on 12 and 13 February 2015, took note of the situation and called upon the World Health Organization (WHO) in collaboration with pan-African organizations and other partners, to intensify their efforts in developing real-time death registration and causes of death information at systems at the country level.¹ The Economic Commission for Africa (ECA) and WHO have jointly developed a five-year strategy covering 2016 to 2020 to improve Africa mortality statistics to respond to the ministerial call for action. The overarching objective of the strategy is to make readily available continuous, harmonized, quality mortality and cause of death data and statistics for African countries, supporting the development of better planned, designed and integrated health, identity and civil registration and vital statistics systems.

One of the key challenges being faced by African countries is the lack of guidance on how to improve death registration, particularly in settings in which a majority of deaths occur outside medical institutions. Existence of a legal system providing for compulsory registration of deaths does not necessarily ensure good coverage of death registration in a country. There are very few incentives for families to register deaths; creating incentives for death registration will always remain a large challenge unlike with birth registration. Another critical consideration is the need to address the socioeconomic and cultural factors affecting the demand for registration services by the public and the demand for use of death records and documents by Government and other stakeholders.

This practical guide on improving death registration and collecting cause of death information was developed to help tackle the above-mentioned challenges. It is intended to help countries design and implement the processes best suited for them with regard to death registration starting with notification of death and ending in the compilation and dissemination of death statistics. The guide is expected to help countries systematically take steps to improve their death registration and cause of death information as a part of death registration systems covering both institutional and non-institutional deaths.

This document – *Practical Guide on the Improvement of Death Registration and Causes of Death Processes within a civil registration and vital statistics* – covers the following topics:

- An introduction to civil registration and vital statistics systems (chapter 1);

¹ See https://www.uneca.org/sites/default/files/uploaded-documents/Statistics/CRMC3/crmc3-final_resolution_third_ministerial_conference_on_crvs_en.pdf.

- Legal, organizational and infrastructural requirements for efficient death registration and cause of death systems (chapter 2);
- Innovations and novel approaches to improve death registration and cause of death registration processes (chapter 3);
- Business process re-engineering (chapter 4);
- Strategies for improving death registration and collection of cause of death information (chapter 5);
- Monitoring and evaluation (chapter 6).

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
APAI-CRVS	Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics
ANACoD	Analysing mortality levels and causes-of-death
DHIS2	District Health Information System v2
ECA	Economic Commission for Africa
HIV	Human Immuno Deficiency Virus
HMIS	Health Management Information System
ICT	Information and communications technology
ICD	International Classification of Diseases
MCCD	Medical certificate of cause of death
OECD	Organisation for Economic Cooperation and Development
UNSD	United Nations Statistics Division
WHO	World Health Organization

Executive Summary

Introduction

Alongside other vital events, death is a top priority vital event recommended for legal registration by the United Nations. The cause of death is among the core characteristics of a legally registered death. To standardize the registration of deaths and their associated characteristics, and the comparability of data derived thereof, it is prudent to adopt a standard set of definitions of relevant key concepts. Despite the existence of a legislative authority for the registration of vital events for many years in African countries, relatively little progress has been made in the development of national civil registration systems. Civil registration dates back to the colonial period in most African countries, yet the general population of these countries had not been covered by the civil registration laws. In the colonial period, registration laws only covered nationals of the colonial power, and then possibly the entire population of the country much later.

The need to continuously record deaths and their corresponding causes in Africa is fully acknowledged as data that is generated is used to guide the monitoring and management of morbidity and mortality. As manifestation of this acknowledgement, African Ministers responsible for Civil Registration called upon the World Health Organization, in collaboration with pan-African organizations and other partners, to intensify their efforts in developing real-time death registration and causes of death information systems at the country level.

Globally, death registration serves three primary purposes: (a) legal: (b) administrative: and (c) statistical. In most African countries, mortality statistics systems are deficient, often characterized by fragmented and uncoordinated collections from multiple sources. Three of the many challenges that have constrained the successful operation of civil registration and vital statistics systems in Africa in the past include: low demand because of limited awareness and barriers to registration; supply-side problems and the civil registration and vital statistic being seen as an “orphan”; and lack of integration and coordination. To address the challenges associated with health issues in the 2030 Agenda for Sustainable Development, generating the much-needed mortality data (that includes cause of death) on a continuous basis must be met through universal civil registration and vital statistics. The ongoing regional initiative on improving civil registration and vital statistics has been consolidated in a structured regional programme, referred to as the Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics. This Programme provides the policy and implementation framework for civil registration and vital statistics systems in the region.

Legal, organizational and infrastructural requirements

A legal framework consisting of appropriate laws and the establishment of mechanisms designed to enforce them nationwide are a requisite for the continuous, permanent recording of deaths and the collection of information on causes of death. While most countries in Africa have some form of a law governing the registration of births, the same does not apply for death registration. Major challenges associated with the legislative framework governing death registration, including cause of death are: outdated or incomplete laws; failure to recognize the need for the production of statistics from death records; lack of legal requirements for medical certification of cause of death; and failure to enforce the law even in cases in which legislation exists.

Irrespective of the place of occurrence, the most critical consideration is to ensure that registration service

points are as close to the public as possible, and are accessible in terms of convenience, as well as the time and costs that are incurred in completing the registration of an event of death. Experiences from a number of countries indicate that registration coverage can significantly increase when civil registration offices are established within health facilities. Ideally, all registered deaths should have a corresponding record of the cause of death. From the standpoint of public health and prevention of disease and premature death, the underlying cause of death has been defined as the basis for cause of death statistics. Unfortunately, in Africa, not all registered deaths have a corresponding record of the cause of death. Increasing the proportion of all deaths that are medically certified is the single most important challenge for civil registration and vital statistics systems in Africa.

Innovations and novel approaches

Almost all civil registration and vital statistics systems in low- and middle-income countries are failing to achieve adequate levels of coverage and quality despite attempts to apply standard methods proven to work well in high-income countries. This suggests system failure rather than technical failure. Systems analysis is the application of specific analytic approaches to achieve a better understanding of the typologies, organization, requirements, processes, and workflows in relation to outputs and objectives. The most appropriate approach to systems analysis for civil registration and vital statistics systems is the systems thinking discipline of enterprise architecture and, more specifically, business process modelling. Some business process modelling has been conducted in Africa during which time vital interlinked steps that constitute the 10 civil registration and vital statistics milestones were identified. Process mapping can be used to trace how each record is produced and used. As part of the implementation of the Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics process, a business process could be adopted to improve cause of death information for deaths occurring in health facilities.

Often, it is not possible to obtain medical certification of the cause of death. Verbal autopsy is an essential public-health tool for obtaining a reasonable estimate of the causes of mortality at a community or population level. Although the use of verbal autopsy generates useful cause-of-death information at the population level, the technique is less reliable for ascertaining cause of death on an individual basis. In addition, causes of death ascertained using verbal autopsy cannot be used for legal purposes, which usually require more rigorous medical certification and data. It should be pointed out that the verbal autopsy method is fairly complex: the interview needed for completing the appropriate questionnaire is time-consuming; the training of civil registrars in conducting a verbal autopsy has to be comprehensive; and cultural traditions might not be favourable to this approach. The Data for Health Initiative is working with the University of Melbourne to determine how best to introduce verbal autopsy into civil registration and vital statistics systems.

Once cause of death has been captured, coding according to the International Classification of Diseases is the next step. This coding is a highly specialized task, which requires a thorough understanding of the rules for determining the underlying cause of death, as it involves assigning the correct code, which should be undertaken by trained statistical clerks or coders. Coding certified deaths can be undertaken automatically through the use of automated coders, such as IRIS. However, automated coding can at best deal with 70 per cent of deaths. For countries that lack the capacity to use the standard International Classification of Diseases, the Simplified Mortality List can be used as the first step towards standardizing the reporting of cause of

death. The World Health Organization (WHO) reckons that the Simplified Mortality List is an effective way to build capacity to progress towards using the detailed list of the International Classification of Diseases.

Tools have been developed to improve the quality of mortality data. One such tool is the analysing mortality levels and causes-of-death package — an electronic tool that provides a step-by-step approach to enable users to quickly conduct a comprehensive analysis of the quality and plausibility of aggregated data on mortality levels and causes of death. The tool automatically reviews the data for errors, tabulates the information, presents the results in the form of easy-to-use tables and charts, and provides the opportunity to compare the findings with those from other countries.

Business process re-engineering

Investing in civil registration and vital statistics yields great dividends, but the cost of indifference is high. The following are some key recommendations that would help to improve the current systems at a reasonable cost and in few years: creating an enabling legal and policy environment; establishing a high-level coordination and oversight mechanism; restructuring key institutions involved in civil registration and vital statistics; re-engineering the civil registration business processes; strengthening financial support for civil registration and vital statistics; recording of cause-of-death; and enhancing the statistical quality of data and standards. A unique perspective to strengthening civil registration and vital statistics is to apply systems science and systems analysis (enterprise architecture and business process mapping) to better describe, understand, analyse and compare national civil registration and vital statistics organizations, processes, workflows and system functionality at the baseline and end line in each country.

To identify appropriate interventions to support civil registration and vital statistics systems, an “as-is” assessment must be conducted to understand the strengths and weaknesses of the existing landscape, including several components documented in the business architecture. A phased approach is recommended to re-engineer a business process mapping: preparation of the business process modelling exercise; review of the current process; evaluation and analysis of the as-is situation after which the future processes (“to-be”) get defined and elaborated; and plan for change (implementation of the new procedures). By applying business process modelling techniques to understand the organizational design and the core business processes of their current and proposed systems, pilot projects were implemented in Brazil, the Philippines and the United Republic of Tanzania between April 2015 and March 2016. Some of the lessons learned from the pilot projects on business process modelling are as follows:

- For the first time, country stakeholders were provided with end-to-end picture and analysis of their whole civil registration and vital statistics system.
- Stakeholders were collectively able to see how it is currently designed, and able to discuss the future from a common understanding.
- There was recognition of the need to formulate standard operations for the key processes.
- Potential to influence civil registration and vital statistics design, re-engineering, strategic investment plans and road maps for setting a long-term civil registration and vital statistics vision.
- Civil registration and vital statistics architectures and process diagrams are emerging as one of the most “in demand” tools from the Data for Health Initiative.

Strategies for improving death registration

The United Nations has pointed out that a major challenge for African countries is the weak coordination among the different stakeholders in civil registration and vital statistics. Interactions involving multiple institutions are necessary between the event of a death and the production of mortality and cause-specific mortality tabulations. The legal framework and the structural organization for death registration are basic administrative pillars that determine the functioning of a civil registration and vital statistics system.

Many African countries lack adequate legal or statistical recording systems for vital events. However, significant momentum has been building in this regard, owing to the emergence of regional initiatives. At their Third Conference, the African Ministers Responsible for Civil Registration, through the Yamoussokro Declaration resolved to: strengthen the capacity of the secretariat of the Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics; establish strong links with the health and other relevant sectors to improve registration service delivery at the most appropriate administrative level; establish linkages between civil registration and national identity systems in efforts to manage one legal identity; and support the development of guidelines and recommendation for maintaining and managing civil registration and vital statistics in conflict and emergency situations. They also requested the secretariat to develop guidelines to support countries in mainstreaming gender issues in civil registration and vital statistics. In many countries, the civil registration has improved significantly while, for others, the process remains unstable. In reviewing the current circumstances in African countries, it may be concluded that further improvements are needed in a number of areas. Consequently, efforts need to be intensified at all different technical and operational planes, primarily through political settings at the highest possible level.

There is no single pathway to reaching the goal of establishing an effective civil registration and vital statistics system. Because the scale and complexity of the task varies greatly among countries, strategies need to be tailored accordingly. To make progress in this area, a detailed understanding of the status and performance of current system is required. WHO has recommended a two-step self-assessment approach, which involves conducting a strategic analysis of current systems. Included also in the approach are outlines of the types of interventions and other activities that are needed based on the assessment outcome. The two steps are as follows:

- An initial rapid assessment to quickly evaluate the state of the current system and make the case for a more detailed assessment.
- A comprehensive assessment to compare current systems with the civil registration and vital statistics standards developed by the United Nations Statistics Division and WHO.

Based on the results, a typology has been developed that classifies country civil registration and vital statistics systems into four groups – dysfunctional, weak, functional but inadequate, and satisfactory - and sets out the level of actions required in each case.

Towards the development of a civil registration and vital statistics system with a focus on death registration and the collection of cause of death information, a national coordination committee should be established or strengthened. The main functions of the committee should be to coordinate the assessment and improvement process, ensure the full participation of key stakeholders, foster advocacy and high-level visibility and generate political commitment and resources. As a precaution, countries are advised to assess the functioning

of their civil registration and vital statistics systems according to a three-tier categorization: relatively intractable problems; solvable problems requiring large amounts of funding; and solvable problems, with small financial inputs. Depending on which categorization is applicable to a country's civil registration and vital statistics system, it is only prudent for a country to be pragmatic by starting with strategies that can be achieved easily and in a relatively short time.

Monitoring and evaluation

As part of the implementation of the improvement plan, countries need to monitor the progress made by periodically assessing their civil registration and vital statistics systems. As outlined by the United Nations, quality assurance encompasses the steps taken at each stage of the operations of civil registration and vital statistics systems to ensure the following: all vital events occurring within the country are registered without duplication; all related information is accurately recorded; and the compilation and processing of recorded vital events result in the proper and timely production of vital statistics. As an integral part of the civil registration system, the steps that constitute quality assurance should be followed by the registration authority on a regular basis to ensure the following: (a) all local registration areas have carried out the required registration functions; (b) every vital event occurring to members of the population in a given area is recorded in the system; and (c) all local offices transmit the records to a higher-level registration office, according to established procedures. The quality of data should be measured according to the standards prescribed by the United Nations in the *Principles and Recommendations for a Vital Statistics System*, namely completeness, correctness, availability and timeliness. Monitoring reports should include the quantitative values for the indicators, as well as some analysis of the qualitative information.

In response to the Ministerial Statement from the Third Conference of African Ministers responsible for Civil Registration, the Africa Civil Registration and Vital Statistics Core Group agreed to develop a five-year regional strategy for improving mortality statistics in Africa. The overarching objective of the five-year strategy is to make continuous, harmonized, quality mortality and cause of death data and statistics for African countries readily available to guide the development of better planned, designed and integrated mortality systems. Drawing on the WHO targets for universal civil registration of births and deaths, including causes of death, the aspirational goals for this strategy are to attain significant improvements in the reporting by 2020, such that:

- Sixty per cent of deaths in a given year are continuously notified, registered and certified with key characteristics;
- Eighty per cent of deaths in hospitals have causes of death reliably determined and officially certified in real time;
- Fifty per cent of deaths in communities have probable cause of death determined in real time, and collection systems designed in a representative way.

Chapter 1 - Introduction

1.1 Definitions of key concepts

Death is a top priority vital event recommended by the United Nations for legal registration, alongside births, marriages and divorces. According to the United Nations Statistics Division (UNSD),² death registration is the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of deaths pertaining to the population, as provided through a decree or regulation in accordance with the legal requirements in each country. Among the core characteristics of a legally registered death are the facts and circumstances leading to the death, namely the cause of death. Whereas a layperson may be able to supply information on the demographic characteristics, such as age and sex, only a trained person can provide information on the cause of death in accordance with the WHO International Classification of Diseases standards, that is, a medical certificate of cause of death. Usually, the responsibility for reporting the occurrence of a death falls on the relative closest to the deceased, who is a layperson, while the responsibility for certifying the cause of death falls upon the attending physician or, in cases in which a medical-legal officer is legally involved, upon the coroner or medical examiner who took charge of the case.²

The output of the death registration process is: (i) a legal record, an extract of which is issued to the family or persons concerned as proof of registration (“death certificate” in some countries and “permit for burial” in others); and (ii) a statistical record, which captures the demographic and socioeconomic attributes of the death and of the persons concerned; the latter is aggregated to form mortality statistics. In cases in which the death occurs in settings with appropriately trained physicians, a medical certificate of cause of death can be issued in accordance with WHO International Classification of Disease rules. In some countries, information on the cause of death is included as part of the registration of the fact of death. In other countries, cause-of-death information is collected separately and is forwarded to the civil registration agency or the vital statistics agency for tabulation. Countries where medical practitioners are not available to issue a medical certificate of cause of death, the civil registration process does not include information on cause of death and other methods are used to obtain information for statistical purposes. To standardize the registration of deaths and their associated characteristics, and the comparability of data derived thereof, it is prudent to adopt a standard set of definitions of relevant key concepts. These are offered in the appendix.

Some weaknesses in the current definitions of concepts and terms pertaining to civil registration and vital statistics have emerged. In a report³ on the Second Conference of African Ministers Responsible for Civil Registration, held in 2012, it was noted that the United Nations publication on the Principles and Recommendations of Vital Statistics System recommended a definition of “death” as an event, and of “civil registration” as a general registration framework. The definition of death and the other vital events were developed and recommended considering primarily their statistical importance and requirements. For instance, “death” is defined as: “the permanent disappearance of all evidence of life at any time after live birth has taken place”, which may not fully address the administrative and legal understanding of a death event. The definition of each of the vital events in the United Nations Principles and Recommendations are limited to the extent that it only meets the statistical and health information requirements. It is also stated in the report that

² *Principles and Recommendations for a Vital Statistics System, Revision 3* (United Nations publication, Sales No. E.13.XVII.10).

³ See E/ECA/CMRCR/2/EXP/14.

the approach followed at the international level in defining death and the other vital events falls short of addressing the legal, administrative and statistical purposes in a holistic manner.

Furthermore, the international principles, while dealing with the major concepts of civil registration and vital statistics systems, only defines “civil registration” or “civil registration system” and skips the definition of its components, that is, for example, birth registration or death registration. Similarly, while delving on registration, only the overall “civil registration method” is described and each of its components, such as method of registering death. Such an approach does not take into account the rationale for death registration and limits the understanding of the peculiar and distinct nature of issues related to death registration. As a result, therefore, there is need to develop guidelines on the management and operations of death registration, which must be different from those on the registration of births. As part of the need to provide rationale for civil registration and vital statistics systems and conceptualizing them in the African context, the following definition of “death registration” is proposed for further review and consideration. “Death registration is defined as the legal and administrative recording of an event of death of a person so as to acknowledge his/her death irrespective of his/her age, sex and citizenship/nationality, in a defined territory through a defined legal, administrative and statistical processes and procedures.” As part of the definition, the legal, administrative and statistical processes and procedures are included to underscore the rationale for a country to acknowledge a person’s death from legal, administrative and statistics perspectives. In other words, it implies that a person’s death should be acknowledged not only legally, but also administratively and statistically. Furthermore, the explanation goes beyond giving conceptual and operational guidelines, it also helps in removing misconceptions on certain aspects, such as the population to be covered in the registration, rights of persons and responsibilities of Governments, and the procedures that need to be followed. Previously, death registration, as a concept, used to be explained based on its benefits and uses, such as, inheritance, insurance, enables a spouse to remarry, burial permit and clearance of administrative files, such as updating voters registration and tax payers. This practice creates misconceptions at the operational level, in which there are practices of marginalizing population groups, such as infants and minors, stateless persons, migrants, criminal cases, war victims and low social status groups.

1.2 History of death registration

Death registration can be traced back to the mid-fifteenth century in Italy when councillors for the cities of northern Italy established boards of health to consider how best to deal with the recurring epidemics that ravaged their populations. Though the practices differed across different boards, generally, a death certificate or bill of mortality was required to be filed, containing the name and age of the deceased and the cause of death certified by a physician or a certified surgeon, before a burial certificate could be issued. Similar boards of health were set up in France, the Netherlands and Switzerland in the sixteenth century, though on a temporary basis (during the occurrence of epidemics).

In the United Kingdom of Great Britain and Northern Ireland, systematic collection of data on death and causes of death began to be conducted in 1532 after an outbreak of the bubonic plague. A weekly list of burials in London was maintained, which included the name of the deceased, the parish in which the burial took place and the cause of death. In 1534, Queen Elizabeth introduced quarantine and plague orders in the country and shortly thereafter, parish registers were established to record baptisms and burials. Starting in the

mid-eighteenth century, national civil registration systems were initially established, making it possible to record continuously births and deaths and compile birth and death statistics.

Although the legislative authority for the registration of vital events has existed for many years in African countries, relatively little progress has been made in the development of national civil registration systems. In 34 out of the 36 countries on the African continent, civil registration systems have been in existence for more than 50 years⁴ (table 1.1).

Table 1.1: Year of establishment of legislative authority for registration of vital events

Country	Year	Country	Year
Mauritius	1793	Congo	1922
Sierra Leone	1801	Burundi	1922
Nigeria	1867	Togo	1923
Madagascar	1878	South Africa	1924
Lesotho	1880	Niger	1933
Algeria	1882	Mauritania	1933
Ghana	1888	Mali	1933
Seychelles	1893	Côte d'Ivoire	1933
Swaziland	1900	Burkina Faso	1933
Somalia	1904	Benin	1933
Malawi	1904	Botswana	1939
Kenya	1904	Gabon	1940
Uganda	1905	Central Africa Republic.	1940
Senegal	1916	Morocco	1950
United Republic of	1917	Democratic Republic of the	1958
Tanzania		Congo	
Cameroon	1917	Chad	1961
Tunisia	1918	Libya	1968
Rwanda	1922	Guinea-Bissau	1976

Source: International Institute for Vital Registration and Statistics, “Organization and status of civil registration in Africa and recommendations for improvement”, Technical Paper, No. 3 (Maryland, United States of America, April 1988, p. 9). Available at https://www.cdc.gov/nchs/data/isp/031_organization_and_status_of_civil_regist_in_africa_and_recommendation_for_improvement.pdf.

Although civil registration dates back to the colonial period in most African countries, this does not mean that the general population of these countries was covered by the civil registration laws. In the colonial period, the registration laws initially encompassed only nationals of the colonial power, and then possibly the entire population of the country much later. In most countries of French-speaking Africa, registration was first limited to French subjects. In 1950, the registration law was extended in a number of these countries to include all inhabitants residing within 10 kilometres from the registration centres. In some countries, civil registration is compulsory only for the principal cities and towns and/or for the capital city.

⁴ International Institute for Vital Registration and Statistics, “Organization and status of civil registration in Africa and recommendations for improvement”, Technical Paper, No. 3 (Maryland, United States of America, April 1988). Available at https://www.cdc.gov/nchs/data/isp/031_organization_and_status_of_civil_regist_in_africa_and_recommendation_for_improvement.pdf.

In Eastern Africa – Kenya, Malawi, Somali, Uganda and the United Republic of Tanzania – birth and death registrations were made compulsory for the European population in the first two decades of the twentieth century. At about the same time, in some of those countries, registration was extended to Asians. However, it was not until after the attainment of independence in the 1960s that compulsory registration laws applicable to all population groups were passed. For example, registration of births and deaths was introduced for the first time in Kenya in 1904 and applied only to Europeans and Americans. However, in 1928 the Registration Act Cap 149 was enacted and provided for the compulsory registration of the deaths of Africans, but not for their births. After independence in 1963, compulsory registration of all births and deaths was extended in phases to other areas, beginning with Nairobi and Nyeri on 1 March 1963. On 1 September 1971, it became compulsory to register all births and deaths occurring in Kenya.

The importance of continuously recording deaths and their corresponding causes in Africa today cannot be overemphasized. There is inordinate need for data to guide the monitoring and management of morbidity and mortality. The Ebola virus disease epidemic of 2014 served as a significant reminder of the poor state of the statistical systems in Africa, and the urgent need to address this weakness. In a report released by ECA, the following was noted: “The lack of real-time data on the number of deaths by location and the causes of death has seriously affected interventions tracking the infection and promoting preventive and curative measures. Health interventions depend on continuous gathering of basic data on mortality by age, sex, location and cause of death, primarily through functional civil registration systems.”⁵ African Ministers responsible for Civil Registration, during their third conference, held in Yamoussoukro on 12 and 13 February 2015, called upon the WHO in collaboration with pan-African organizations and other partners, to intensify their efforts in developing real-time death registration and cause of death information systems at the country level. This is a manifestation of the contemporary country commitment in Africa to improving death registration.

1.3 Value of mortality data

The value of mortality globally is captured in the quotes in box 1.1:

Box 1.1: Key messages from advocates of strengthened civil registration and vital statistics systems

Establishment and development of civil registration and vital statistics systems is one of the fundamental measures that African Governments must take in addressing our challenges.

Lawrence K Masha (MP), Minister for Home Affairs, United Republic of Tanzania

Civil registration is also about improving the efficiency and fairness of the justice system. It is also about facilitating the health, education and other social services to the public. Furthermore, civil registration is about provision of vital statistics data and information, primarily to the local administration and service providers at the community level.

Berhan Hailu, Minister of Justice Federal Democratic, Ethiopia

It is important that countries recognize that civil registration is a developmental and human rights issue and our ability to monitor progress in this regard will depend on functional vital registration systems and availability of reliable and timely vital statistics.

Pali Lehohla, Chairperson, Statistical Commission for Africa, and Statistician General, South Africa

...the value of civil registration lies in its linkage between the Government and the citizens, this being one of the few direct transactions between the Government and the people. Ensuring efficient, smooth and user-friendly registration of vital events carries the added value of increasing the credibility of the authorities and their capacity to deliver services.

Paul Cheung, Director, UNSD

Sustainable civil registration systems that yield reliable information about the state of a population's health should be a key development goal.

Prasanta Mahapatra, President, Institute of Health Systems, Hyderabad, India

...the consequences of inadequate systems for civil registration – that is, counting births and deaths and recording the cause of death...Without these fundamental health data, we are working in the dark. We may also be shooting in the dark. Without these data, we have no reliable way of knowing whether interventions are working, and whether development aid is producing the desired health outcomes.

Margaret Chan, Director-General, WHO

⁵ Ecomod
www.unr

Death registration serves three primary purposes: (a) legal, (b) administrative; and (c) statistical. Each of these is discussed below.

Legal uses

It should be emphasized that the role played by civil registration in proving, establishing, implementing and realizing many of the human rights embodied in international declarations and conventions reflects one of its most important contributions to the normal functioning of societies.² Essentially, two sets of human rights can be identified in this respect: (a) human rights that require States to ensure that vital events are registered, such as the right to be registered and named, pursuant to Article 7 of the Convention on the Rights of the Child, and (b) human rights whose exercise may depend on the vital events, having been registered, for example, the right to vote, pursuant to Article 21 of the Universal Declaration of Human Rights.

Death registration is undertaken primarily to establish legal documents and record provided for by the law. Death certificates provide legal evidence of the fact and circumstances of death. In many countries, death certificates are used to provide documentary evidence on which to base claims of identity (particularly by establishing family relationships), and hence facilitate the realization of ensuing rights, such as enabling the legal transmission of property, inheritance, remarriage, and social insurance and other benefits. Death certificates are in many cases required as prerequisites for burial.

Administrative uses

The United Nations maintains that a functioning system for the registration of vital events has certain administrative advantages not found in any other system.² Keeping individual records for each vital event allows for them to be used for identifying a subset of the population requiring intervention or services on an individual basis, such as households in need of public-health services following a death from a contagious disease. Universal registration allows for the monitoring of causes of death and the maintenance of, among other things, population registers, personal identification registers, electoral rolls and pension funds registers. In addition, a full registration system makes it possible to meet the need for data and information on small civil or geographical divisions. Civil registration is the most cost-effective way to obtain data for smaller population areas on a continuous basis.

Death records serve numerous administrative purposes; primary among these is the crucial role they play in updating other administrative databases, such as national population registers, national identification databases, voters' registers, taxation registers and government service files. In so doing, death records help to avoid identity fraud and ensure that services are correctly targeted. The rise in cases of ghost voters and ghost employees is well evidenced in many countries today, contributing to civil strife and the loss of billions of government resources. These cases arise from failure to purge records and documents of the dead from existing databases. Death records also play a critical role in guiding policy in public safety and accident prevention.

Statistical uses

Death and cause of death records provide the basis for the compilation of mortality statistics, which are primary inputs for the following: health policy and planning; monitoring and evaluation of health

programmes; and identifying and prioritizing health research and the generation of evidence. Accurate and timely data on mortality by age, sex and cause of death justify public health spending on interventions aimed at tackling major causes of premature mortality, such as immunization to prevent measles, access to skilled care to prevent maternal mortality, tobacco control measures to prevent deaths from cancer and cardiovascular diseases, and behaviour-change interventions to prevent HIV/AIDS.

Citizens in developing countries pay a heavy price when public health decision-making is impeded by the absence of reliable and comprehensive data. Vital statistics systems, which are based on civil registration, furnish the most reliable data source to track progress towards the achievement of national and international development goals and targets, such as the Sustainable Development Goals. Civil registration stands out as the principal source of data as it is conducted continuously and universally and generates records that are relatively free from certain types of response errors and are not subject to sampling errors. As a result, mortality statistics can be made available in real time and at subnational levels as required, to permit public health surveillance of emerging mortality levels, trends and differentials. The United Nations reiterates that vital statistics derived from civil registration will constitute the only nationally representative source of information on mortality by cause of death, provided that civil registration is universal, continuous and permanent. Such information is invaluable for the assessment and monitoring of the health status of a population and for the planning of adequate health interventions.² Table 1.2 below reveals the comparative advantages of civil registration based mortality data as compared to other sources.

Table 1.2: Comparative advantages of registration based mortality data as compared to other sources

Statistics & key indicators	Level of estimate	CRVS	Household surveys	SRS/SAVVY	HDSS	Health facility records	Population censuses
Deaths by age & sex	National	Yes	Yes	Yes	No	Yes [¶]	Yes [¶]
	Subnational	Yes	Limited	Limited [#]	Partially	Partially*	Yes [¶]
	Socioeconomic differentials	Limited [°]	Yes	Limited [#]	Partially	No	Yes [¶]
	Trends	Yes	Partially [□]	Yes	Yes++	Partially*	Partially [¶]
Infant and child mortality rates	National	Yes	Yes [□]	Yes	No	Partially*	Yes [¶]
	Subnational	Yes	Limited [#]	Limited [#]	Partially	Partially*	Yes [¶]
	Socioeconomic differentials	Limited [°]	Yes	Limited	Partially	No	Yes [¶]
	Trends	Yes	Yes	Yes	Partially	Partially*	Partially [¶]
Maternal mortality ratio	National	Yes	Yes [□]	Yes	No	Partially*	Yes**
	Subnational	Yes	Limited [□]	Limited [#]	Partially	Partially*	Yes**
	Socioeconomic differentials	Limited [°]	Limited [□]	Limited	Partially	No	Yes**
	Trends	Yes	Limited [□]	Yes	Partially	Partially*	No
Causes of death	National	Yes [§]	Limited ^{&}	Yes	No	Partially ^{§*}	Limited ^{&}
	Subnational	Yes [§]	Limited ^{&}	Limited [#]	Partially	Partially ^{§*}	Limited ^{&}
	Socioeconomic differentials	Limited ⁺	Weak	Limited [#]	Partially	No	Limited ^{&}
	Trends	Yes	No	Yes	Partially	Partially ^{§*}	Limited

* Not nationally representative unless all deaths occur in health facilities

¶ For a recent period by indirect estimates

For higher level administrative areas (regions, provinces) only

• Use of direct or indirect methods

** With assessment and possible adjustment: methods do not always work

§ Through use of the international Classification of Diseases (ICD)

• Wide confidence intervals for detailed analyses

++ For the surveillance area only

& Through follow on survey and verbal autopsy (VA)

° Possible if registration records can be linked to socioeconomic data in a population register

Source: World Health Organization, Economic Commission for Africa and African Symposium on Sustainable Development, “Improving mortality statistics in Africa: technical strategy, 2015–2020” (Addis Ababa, ECA, 2015) Available at <http://repository.uneca.org/handle/10855/23023>.

All data-collection methods have their strengths and weaknesses, as outlined in table 1.1. Some data sources, such as censuses and household surveys have proven to be effective for generating all-cause mortality indicators. Other sources, such as health and demographic surveillance systems and facility-based information systems, can produce detailed information but the data are not representative of the general population. Moreover, most data sources have limitations with regard to cause of death statistics and data for subnational administrative areas. As attention turns to the challenges associated with health issues in the 2030 Agenda for Sustainable Development, attaining mortality data that are available on a continuous basis, for national and subnational areas, and which includes cause of death, can only be met through universal civil registration and vital statistics.

Horton⁶ notes that neglect of civil registration systems (including death registration) has been called “the single most critical failure of development over the past 30 years.” The importance of a well-functioning civil registration and vital statistics systems is explicitly recognized, as data from such a system is required for monitoring many of the Sustainable Development Goal indicators, as direct and indirect data sources. To monitor progress in meeting many of the health targets of the Sustainable Development Goals, data on all-cause and cause-specific mortality are required. Efforts to meet the Goals require a significant increase in mortality data as compared with what was required to achieve the Millennium Development Goals. Integrated and better designed systems on mortality in the context of civil registration and vital statistics should be used to monitor progress towards achieving the Sustainable Development Goals, including universal health coverage in a more efficient fashion than further fragmentation of collection.⁷ For example, civil registration and vital statistics data are required for estimating and monitoring progress in achieving the following nine targets listed in table 1.3.

Table 1.3: Targets of the Sustainable Development Goals that require civil registration and vital statistics data

SDG	Title	Targets
3	Ensure healthy lives and promote well-being for all at all ages	3.1 By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births
		3.2 By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births
		3.3 By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases
		3.4 By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being
		3.5 Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol
		3.6 By 2020, halve the number of global deaths and injuries from road traffic accidents
		3.9 By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and

⁶ Economic Commission for Africa, “Strengthening cause-of-death information in countries through Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics Systems”. Workshop on the Principles and Recommendations for a Vital Statistics System, Addis Ababa, 2-5 December 2014.

⁷ World Health Organization, Economic Commission for Africa and African Symposium on Sustainable Development, “Improving mortality statistics in Africa: technical strategy, 2015–2020” (Addis Ababa, ECA, 2015) Available at <http://repository.uneca.org/handle/10855/23023>.

		air, water and soil pollution and contamination
11	Make cities inclusive, safe, resilient and sustainable	11.5 By 2030, significantly reduce the number of deaths and the number of people affected and substantially decrease the direct economic losses relative to global gross domestic product caused by disasters, including water-related disasters, with a focus on protecting the poor and people in vulnerable situations
16	Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels	16.1 Significantly reduce all forms of violence and related death rates everywhere

Source: See E/CN.3/2016/2/Rev.1.

Also, many indicators under Goal 4 (quality education) and Goal 5 (gender equality) require continuous updates of vital statistics and population figures in order to calculate participation rates and measure different forms of gender gaps. More importantly, a substantial number of indicators on sustainable development requires either the information on the total population or specific population groups as a denominator. Without accurate, regular and complete vital statistics produced from civil registration, it is not possible to develop timely and reliable population estimates, especially at the subnational level.

To achieve the Sustainable Development Goals, health information and statistical systems must be able to bring together mortality data from multiple sources, including mortality data from health facilities, mortality surveillance, deaths occurring in the community; and administrative data.¹¹ One of the most important data sources for linkage to civil registration and vital statistics systems are health facility information systems that record births, deaths and causes of death. Birth and death notifications can play an important role in registering these events, and deaths in health facilities recorded using medical certifications are a critical aspect to understanding causes of death.

Surveillance systems are important for the collection of mortality data as part of a civil registration and vital statistics system. In many African countries, health and demographic surveillance sites have been established. Some of the activities of these sites entail tracking all vital events in a specified area through active case finding (visits to households) in order to track births and deaths and other demographic information, such as migration. The sites can be valuable sources of fertility and mortality data, especially localized data on community deaths. Cause of death information can be generated through the application of verbal autopsy techniques, in households in which a death is identified.¹¹

African countries, and regional and global development partners, recognize that mortality statistics improvement in the continent is critical to future health development. The recent Ebola outbreak demonstrates the need for real-time mortality data to be in place in all countries. At their third Conference, , the African Ministers Responsible for Civil Registration, including many African Ministers of Health, adopted the Yamoussoukro Declaration in which they recognized the critical need for real-time mortality data in African countries,⁶ especially in the aftermath of the Ebola outbreak.

The importance of civil registration and vital statistics will continue to grow as a critical enabler of improved country governance and planning and as a means for improving development outcomes.⁸ Accurate vital statistics and the ability to monitor and respond to causes of death and disability underpin many global health targets, including new commitments to universal health coverage and tackling the global epidemic of non-communicable diseases. For instance, as maternal and child mortality rates decrease over time and become

⁸ World Bank and WHO, *Global Civil Registration and Vital Statistics Scaling up Investment Plan 2015–2024*, (Washington, D.C., World Bank, 2014).

rare events, the only way to accurately track progress will be through complete civil registration and vital statistics systems, which will provide data on the complete registration of deaths among pregnant women and children.

1.4 Situation of death registration and cause of death information in Africa

Civil registration records are the best source of vital statistics because they generate data on a continuous basis and for the whole country, at national and local levels. However, such systems are often weak or incomplete in developing countries. In most African countries, mortality statistics systems are deficient, often characterized by fragmented and uncoordinated collections from multiple sources.¹¹ As a result, African countries lack continuous, permanent and universal sources of mortality data, and therefore face considerable challenges in developing health interventions and building health systems, measuring and monitoring mortality, and in reporting on national and global development mortality goals and targets, such as those set under the Sustainable Development Goals.

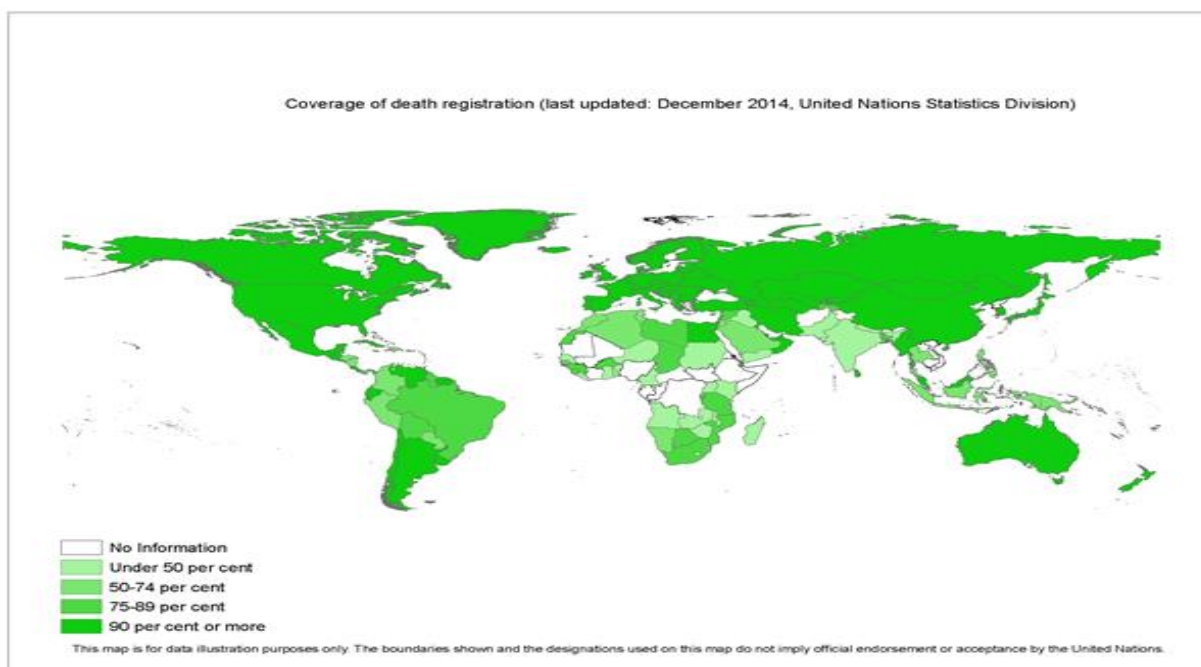
As noted earlier, evidence of this weakness was visible by the lack of available real-time mortality data during the Ebola outbreak experienced in Western Africa. During their third conference, the African Ministers responsible for Civil Registration took note of the situation and called upon the WHO and its pan African partners to take urgent steps to support African States in establishing real-time death registration and cause of death information systems.

Many developing countries are now facing a rapid health transition, but they lack reliable, timely and relevant information to guide the identification of health priorities for their populations. The strengths of a civil registration system for producing mortality data cannot be fully realized unless registration coverage levels are at least 90 per cent.² Currently, however, only a handful of low-income countries attain such levels and many countries, especially those in sub-Saharan Africa, do not report death registration coverage. Nonetheless, it is possible to produce useable mortality data even when registration is less than complete, particularly if registration levels exceed 60 per cent. In the words of Prabat Jha, “...One of the best ways to help the living is by counting the dead”. Helping the living however, cannot stop at counting the dead. We must proceed to collect basic characteristics, such as age and gender, those of who have died and what the person died of.”⁹

Figure 1.1, which as developed by UNSD, provides an indication of the state of death registration coverage worldwide as at December 2014. The data collected reveal that only 57 per cent of countries, territories and areas have at least 90 per cent death registration coverage. Africa is the worst performing among all regions. Eleven countries in Africa have not been able to report on the state of death registration to UNSD, while a majority report under 50 per cent registration coverage.

⁹ World Health Organization, “Improving mortality statistics through civil registration and vital statistics systems: guidance for country strategies and partner support”, Outcome of a technical meeting, Geneva, 4-5 November 2014. Available at http://www.who.int/healthinfo/civil_registration/CRVS_MortalityStats_Guidance_Nov2014.pdf.

Figure 1.1: Death registration coverage in Africa relative to other regions of the world, 2014

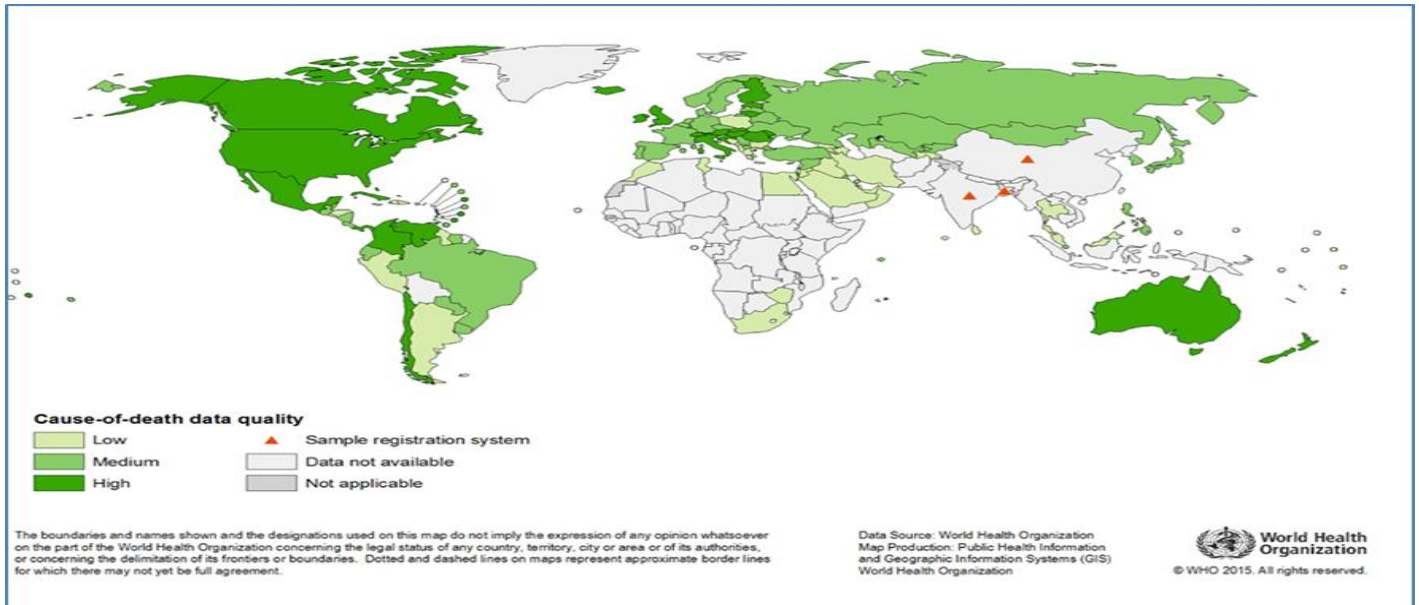


The situation is even more problematic when it comes to the quality of cause-of-death statistics in Africa. Cause of death information is compiled in three ways: through the collection and coding of routine medical certification records from health facilities; through lay reporting (as is the case in Kenya where assistant chiefs identify the cause of death, though not according to the WHO International Classification of Diseases standards); and through collecting information about community deaths through verbal autopsy. According to WHO,¹⁰ only five countries in Africa produce cause-of-death data on a national basis (Cabo Verde, Egypt, Mauritius, Seychelles, and South Africa). Morocco, Tunisia and Zimbabwe produce cause-of-death data, but the data are limited to certain areas of the country.

Figure 1.2 presents WHO estimates of the quality of cause of death statistics in 2014 across various regions of the world, which is based on a combination of registration completeness and quality of cause of death ascertainment as represented by the version of the International Classification of Disease used.

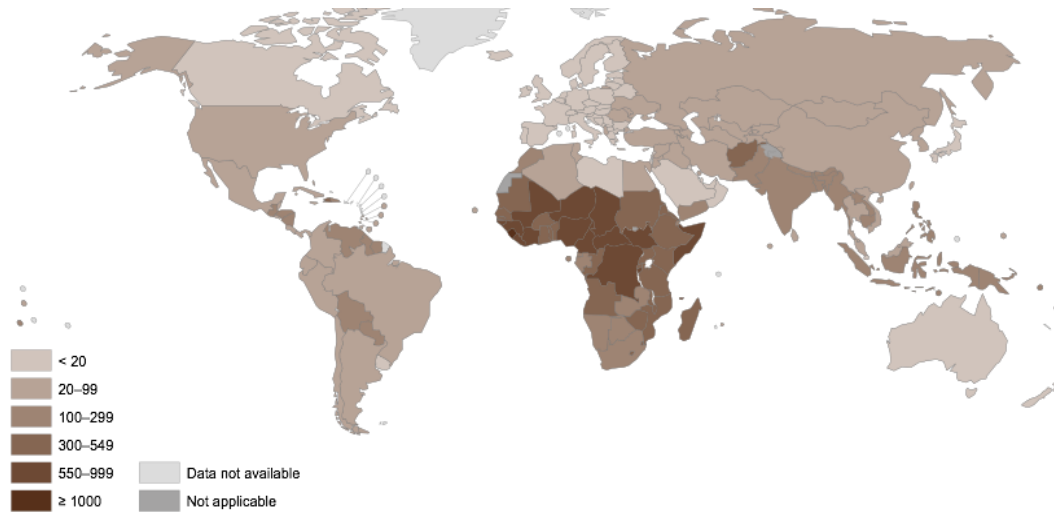
¹⁰ World Health Organization, WHO Mortality database. Available at http://www.who.int/healthinfo/mortality_data/en/. (accessed 25 September 2017).

Figure 1.2: Quality of cause-of-death statistics, 2014



An attempt to correlate figures 1.1 and 1.2 with figure 1.3 derived from the 2014 WHO world health statistics report may lead to a plausible conclusion that countries with weak systems of death registration, namely low death registration coverage, are also the countries with the highest estimated maternal mortality levels. Generally, strong death registrations systems in countries are required, especially in African countries, where the levels of mortality are alarmingly high.

Figure 1.3: Variations in national maternal mortality ratio (maternal deaths per 100,000 live births), 2013



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Many challenges have constrained the successful operation of civil registration and vital statistics systems in Africa in the past. Three broad areas have been identified as contributors to these challenges.¹⁵

Demand-side: lack of awareness and barriers to registration

Many people are not aware of the importance of death registration for them and their families and the implications it has for access to core government services. This extends to groups in the community, such as burial authorities, who can play an important role in reporting deaths. Current registration systems are frequently difficult to access and to understand, so demand for better registration service is often low. Registration forms are often difficult to fill out. They need to be simplified and better designed, taking examples from successful civil registration and vital statistics initiatives, such as the one implemented in Brazil. There are often financial barriers to registration; obtaining identity documents, for example, often entails official fees, fines for late registration, opportunity costs, transportation expenses and bribes. For many poor families, it is simply too costly in terms of time and money.

In addition, individuals may not bother to register vital events because they do not perceive any personal interest in doing so. For example, birth registration in a country can, for instance, be only 50 per cent in terms of coverage while immunization coverage is 90 per cent – mothers see an incentive for immunizing their children and are willing to bring them to immunization centres, but fail to report births to the local registration office because they do not see an immediate incentive for registration.

Supply-side problems and the civil registration and vital statistic “orphan”

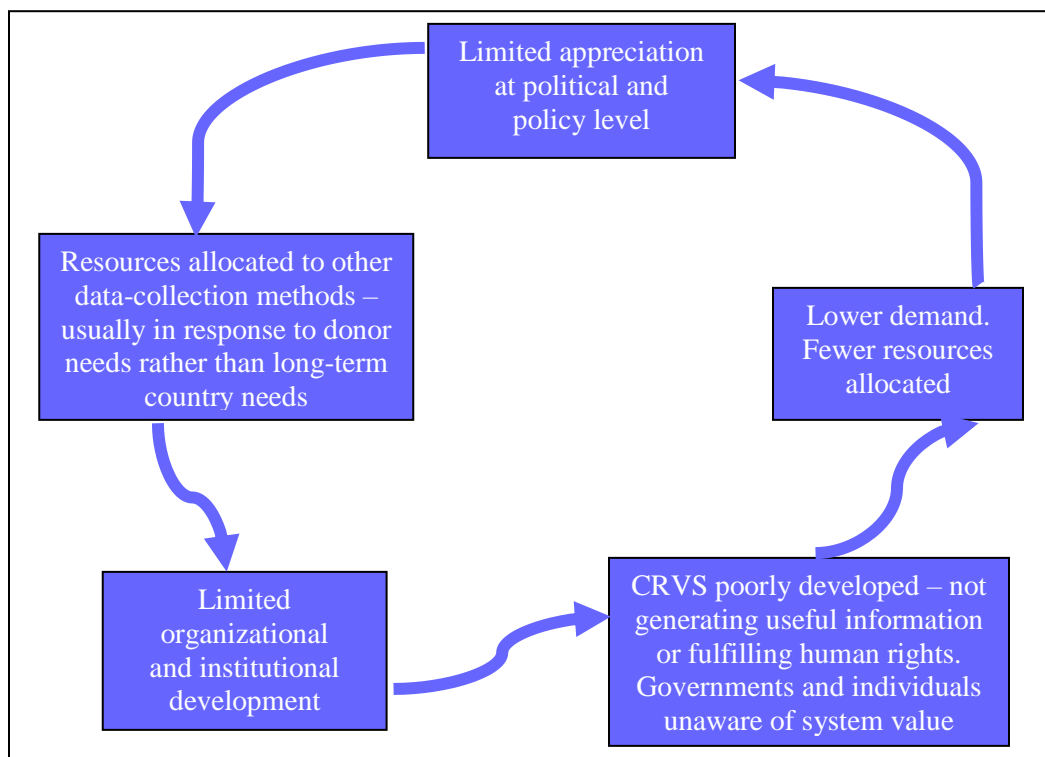
There are different, often conflicting, legal frameworks governing each of the agencies in charge of civil registration and vital statistics services, such as the health system, civil registry and national statistics agency. Many countries have burdensome procedures and non-standardized systems, leading to confusion regarding what individuals need to do or present. Supportive documentation may be requested even if it is not legally mandated.

Those involved in operating the civil registration and vital statistics systems often lack the necessary skills. Physicians, who are required by law to complete medical certificates on cause of death, are often not aware of the importance of this responsibility and have inadequate training to carry out this function. Civil registration is too often just a passive collection of events and not an active search of new or more accurate collection data. Use of mobile phones for registration is stimulating a lot of interest, but this is an experimental stage with no nationwide experience yet to report.

Paper documents will remain important for legal purposes, and most of African countries do not have in place information and communications technology (ICT) laws that allow electronic records to be used as evidence. Lack of a political priority has resulted in inadequate policies and poorly managed, underfunded civil registration and vital statistics systems, deficient in full-time professional staff. Some such systems, such as for birth registration and statistical capacity, have been the target of some international support, but there has been little support for strengthening the civil registration system as a whole – it is seen as the donor “orphan.” Collection of essential data, for example, monitoring progress in achieving the Millennium Development Goals had focused more on interim measures and surveys, with inadequate investment in sustainable civil registration and vital statistics systems.

Because of the low prioritization accorded to civil registration and vital statistics in many African countries, advocacy is essential in efforts to break the “vicious cycle” of underinvestment in civil registration and vital statistics systems shown in figure 1.4.¹¹ If the civil registration and vital statistics systems are weak and dysfunction, it is not possible to generate vital statistics or provide legal documentation on vital events. As a result, there is little support for allocating resources to improve the system. As long as policymakers fail to see the potential benefits of civil registration and vital statistics systems, they will allocate resources to alternative data collection methods, not realizing that these have a number of limitations as compared to well-functioning civil registration and vital statistics systems. This, in turn, results in the weak institutional and organizational development of civil registration and vital statistics systems, thus perpetuating the circle of neglect.

Figure 1.4: Vicious cycle of underdevelopment of civil registration and vital statistics systems



Source: World Health Organization, Strengthening Civil Registration and Vital Statistics for Births, Deaths and Causes of Death RESOURCE KIT (Luxembourg, WHO, 2013, p.166). Available at http://apps.who.int/iris/bitstream/10665/78917/1/9789241504591_eng.pdf.

Lack of integration and coordination

The civil registry deals with individual, personalized, transaction-level data, while vital statistics systems usually focus on aggregated, anonymized data in relational databases, data warehouses or repositories. Getting the civil registry and vital statistics systems to interact efficiently is difficult, and administrators derive no benefit from linking to other parts of Government; it is just one of many functions that they have to perform, which makes such linkages tenuous at best.

¹¹ World Health Organization, Strengthening Civil Registration and Vital Statistics for Births, Deaths and Causes of Death RESOURCE KIT (Luxembourg, WHO, 2013, p.166). Available at http://apps.who.int/iris/bitstream/10665/78917/1/9789241504591_eng.pdf.

Integrating the different components is also a technical challenge related to standards, protocols, and data exchange, often requiring institutional agreements across many government departments. The first challenge of coordination is assigning clear responsibilities within the civil registration and vital statistics systems and ensuring that there is no duplication or gaps during the registration lifecycle. Some basic activities, such as those involving the national statistics agency during the process of designing a new certificate form, can greatly enhance the effectiveness of the civil registration and vital statistics system. Modern technology has only progressed piecemeal in many countries. Meanwhile there has been a proliferation of databases that capture different information about citizen records, which are incompatible with one another, and often contain inaccuracies and inconsistencies in identifying citizens and their attributes. In such situations, laws covering privacy and the need for confidentiality are difficult to enforce. Civil registration and vital statistics databases are often neither connected nor interoperable with any of the other management information systems in other agencies with which they need to interact, such as those dealing with health, education and social protection.

Given that within Governments, civil registration systems are the responsibility of a number of ministries or departments, health, interior, justice and statistical offices, coordination and communication among multiple agencies is key to functioning well, but difficult to achieve.

Although some of these challenges are being addressed by ongoing current initiatives, there are still several hurdles that need to be overcome. Specific examples include:

Governance

1. Weak country ownership and leadership in national civil registration and vital statistics systems. Many policymakers are still unaware of the value and importance of, hence lack appreciation for, civil registration records and the role they play in the development of systems;
2. National statistics offices are overwhelmed with provisional demographic methods and techniques. After the introduction of indirect methods in the 1960s, data collection and analysis on mortality statistics in most national statistics offices moved to censuses and surveys. This trend has created ignorance and led to the marginalization of initiatives and projects in the civil registration and vital statistics field;
3. Lack of a long-term vision and commitment. Civil registration and vital statistics systems, once properly installed, would last for generations with little cost. Although putting the system on the right track might initially require a considerable effort, this would be paid back as soon as the system starts to function properly. Creating such a vision and committing to it is the current challenge in Africa;

Law

4. Outdated laws and registration procedures. Many African countries still have in place laws inherited from colonial times that are no longer relevant. Registration procedures in the majority of countries are based on these outdated laws and regulations;
5. Common challenges in collecting cause of death for deaths in health facilities: in most African countries, neither does the law make it mandatory for medical institutions to record cause of death, nor does it recognize the use of the WHO conventional standard in assigning cause of death; cause of death is not completed using the International Form of the Medical Certificate of Cause of Death; certification of cause

of death by doctors is usually not ICD-10 compliant; and there is no clear business process for flow and compilation of derived data;

Management

6. Lack of properly articulated national standards, operational manuals and guidelines. The majority of African countries do not have operational and management guidelines that provide systematic procedures and directives to the registrars and practitioners of civil registration;
7. Lack of monitoring and evaluation standards and procedures. Most African countries, including those with well-developed civil registration and vital statistics systems, lack systematically developed standards to measure the coverage and completeness of the registration system or the content and quality of the statistics produced;
8. Lack of comprehensive national action plans. In most African countries, civil registration and vital statistics is treated as a traditionally run business with no formal planning and no strategy development requirements;
9. Challenges in collecting data on cause of death: only a very limited number of deaths in Africa occur in medical institutions where there is a physician able to issue a medical certificate, including cause of death, yet verbal autopsy is not an established practice for the derivation of cause of death for deaths occurring outside health facilities;
10. Common challenges in collecting cause of death for deaths outside health facilities: most of such deaths are not registered; a systematic process is not in place for recording and compiling cause of death for death outside health facilities; and the use of verbal autopsy for the collection of cause of death information has been limited to a few experimental areas or through special surveys in selected countries;

Capacity

11. Limited expertise. There is limited opportunity for formal education in civil registration and vital statistics in Africa. Most of the civil servants who operate and manage civil registration and vital statistics systems on the continent have no formal training except through their exposure to civil registration laws and regulations. In addition, there is limited international classification of diseases certification and statistical coding expertise;

Integration and coordination

12. Inadequate efforts to mainstream civil registration and vital statistics into national statistical systems. A majority of African countries have started preparing and implementing national strategies for the development of statistics, but, in most instances, civil registration and vital statistics have not been included in a comprehensive way or as an integral part of national statistical systems;
13. Lack of interoperability and data exchange between health information systems which collect vast information about vital events and the information systems of the civil registries.

1.5 Regional efforts to strengthen civil registration and vital statistics

The Second Conference of African Ministers responsible for Civil Registration⁴ observed that in the past 50 years, efforts and initiatives of installing and developing civil registration and vital statistics systems based on conventional methods and procedures in the developing world, particularly in Africa, did not succeed, largely because of lack of appreciation of the basics and fundamental principles of civil registration and vital statistics functions and services. In 2009, a new approach was developed in Africa, which critically reviewed

past practices and interventions and proposed a paradigm shift in the methodological approaches, management and operation of the systems in the region. The three premier regional organizations, the ECA, the African Union Commission and the African Development Bank took the lead coordinating role at the regional level and treated civil registration and vital statistics as an integral part of the regional development agenda. To address the various political and policy implications of civil registration and vital statistics and the complexities of managing the multi-sectoral and multidisciplinary operational requirements, at the national and regional levels, a high-level regional forum was established in 2010. It was also decided to set up a regional programme supported by a time-bound roll-out plan, in the form of a medium-term plan, which is now being implemented. Few policy measures have been taken that would contribute to efforts to implement a much-needed civil registration and vital statistics regional initiative directed towards developing a coordinated and harmonized management and operation systems guided by standard methodologies and operational procedures developed following the United Nations standards, principles and recommendations.²

The ongoing regional initiative on improving civil registration and vital statistics has been consolidated in a structured regional programme, referred to as the Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics (APAI-CRVS). This programme provides the policy and implementation framework of CRVS systems in the region. The APAI-CRVS implementation framework furnishes a new policy direction for developing technical and management principles and frameworks, which will result in the setting of systematized and harmonized operational procedures for civil registration and vital statistics. Considering the different levels of development of civil registration and vital statistics systems in the continent, under APAI-CRVS, a phased implementation approach, which is expected to be applied across all work streams of civil registration and vital statistics as a part of the process to reform it.

In the context of the Ministers' call for action, a regional reference mortality group was formed in August 2015 to consider how best to position mortality statistics development within APAI-CRVS. The group has agreed to undertake immediate actions to move the agenda forward. For 2015, the actions taken were the following:

- Developed a five-year strategy for improving mortality statistics for civil registration and vital statistics in Africa;
- Sponsored regional expertise through a workshop and consultation on mortality statistics design, which was held in Cairo in September 2015, and funded by the ECA and WHO;
- Presented the strategy for discussion and endorsement at the eleventh African Symposium on Statistical Development, which was held in Libreville on 23 November 2015, and included health representatives as participants;
- Hosted a donor coordination meeting in Africa in late 2015 to support the improvement of mortality statistics and civil registration and vital statistics systems in Africa.

Collaborative efforts between the public and private sectors are contributing towards strengthening civil registration and vital statistics systems. The end products of functional civil registration and vital statistics systems are useful to the private and public sectors. The private sector has a major role to play in providing new solutions to the information needed for such systems. One obvious example is the expansion of mobile phone services to most parts of sub-Saharan Africa, with special initiatives aimed specifically at sharing good practices and building interoperability. Groups, such as GSMA, for example, have developed special

initiatives for Africa to ensure that the benefits help both the industry and local health services.¹² Another example of this is found in South Africa, where smart card technology from the private sector is being used for identification systems.¹³

¹² Mobile World Live, “GSMA mHealth Tracker.” www.mobileworldlive.com/mhealth-tracker.

¹³ Brand South Africa, “South Africa to pilot Smart ID Cards,” 8 May, 2012. Available at www.southafrica.info/services/government/smart-id-081512.htm#.U1lZ1sXD-3o.

Chapter 2 - Legal, organizational and infrastructural requirements for efficient death registration and cause of death systems

2.1 Legal requirements for death registration and cause of death systems

The necessity for law

Continuous, permanent recording of deaths and the collection of information on causes of death can best be ensured through a proper legal framework of appropriate laws and the establishment of mechanisms designed to enforce them nationwide. Making registration of vital events subject to the law and establishing procedural rules and regulations are essential for the efficient management, operation and maintenance of the death registration and cause of death information collection systems and processes. Improving death registration processes would entail the establishment and/or review of the existing legislative framework and, particularly, ensuring that it aligns with international standards and requirements.

The law is required for several functions. Among them are to make it obligatory to register events of death and to set corresponding penalties for failure to register; to define the administrative structure, designation of informants, and time period within which registration should be conducted; to define the legal procedures and standards to be followed while collecting information on death and cause of death; to define the roles and responsibilities of different agencies in the registration of deaths; and to safeguard the privacy of personal information collected and protect it against misuse. Determining who shall be entitled to copies of vital records and who shall have access to information from the register about individuals other than themselves should be clearly set out in the law or in supporting regulations. These provisions should include appropriate mechanisms for the transfer of files of vital records among government agencies for authorized purposes, and procedures for access to, or release of files for approved research, consistent with overall confidentiality protection, particularly to the vital statistics system for the production of continuous vital statistics, and more generally, to ensure that the practice is institutionalized, namely that it is conducted on a permanent, universal and continuous basis and is aligned with existing international practices and standards. The *United Nations Handbook, Civil Registration and Vital Statistics Systems: Preparation of a Legal Framework*, No. 71 (1989), includes a “model civil registration law”, which is intended to assist with the development and reform of legislation for civil registration and vital statistics. The WHO assessment framework, entitled “Improving the Quality and Use of Birth, Death and Cause-of-Death Information: Guidance for a Standards-Based Review of Country Practices”, may also be referred to for guidance on the legal and regulatory framework necessary to support the introduction and operation of a robust civil registration and vital statistics system.

Challenges affecting death registration laws

While most countries in Africa have some form of a law governing the registration of births, the same does not apply for death registration. Quite similarly, in the laws in a majority of the countries, there is no mention of the need to collect information on cause of death. Such loopholes contribute substantially to the low levels of coverage in death registration and, even more importantly, to the lack of information on cause of death across the continent.

Major challenges associated with the legislative framework governing death registration and collection of information on cause of death include:

- **Outdated laws:** The laws in most African countries were inherited from the colonial era and have never been revised to align with the prevailing national contexts. The provisions in such laws are often

irrelevant and inapplicable. An example is the legal requirement to follow manual or paper-based processes for registration, vis a vis the rapid technological advancements today;

- **Incomplete laws:** The laws in most countries do not align with the recommended international standards and practices. For example, in many countries, death registration is not set as a compulsory practice. Some laws exempt particular populations groups from registration, such as refugees, temporary migrants and internally displaced persons, as well as some geographic areas of the country. Some laws discriminate against registration of children born out of wedlock;
- **Failure to recognize the need for production of statistics from death and cause of death records:** As described in the first chapter, among the primary functions of registration is the production of the corresponding vital statistics. However, often, this function is not properly defined in law, resulting in confusion concerning who is responsible for generating the vital statistics from the registration records. It is pertinent that the law should explicitly underline the need for production of vital statistics and that it designates the responsibility for statistical production to the relevant authority;
- **Lack of legal requirements for medical certification of cause of death:** Countries without regulations on who should medically certify causes of death face major problems in generating quality data and statistics on cause of death. It is important that the law clarifies that only a medically trained person can certify cause of death. The law should also provide guidance on the expected standards when verbal autopsy is applied to generate cause of death data.

Failure to enforce the law even in cases in which legislation exists: many African countries find themselves in a dilemma on how best to enforce civil registration laws given that a majority of the population is not compliant with the existing legislation. As to which approach between the “stick” (punish those who fail to comply as per the law) and the “carrot” (enlighten and motivate the populace to register their vital events) they should employ constitutes this dilemma. Linking registration to incentives as well as penalties is likely to achieve even better outcomes as the existence of a law in itself will not guarantee full compliance, and penalties may be difficult to administer.²¹ Incentives to encourage registration are used in many countries, including linking it to eligibility for services, such as schooling, social and health care, and insurance schemes. In some settings, financial incentives are used, such as the provision of a child allowance or contribution to funeral expenses. There are also penalties for late registration and for failure to register.

Generic elements of a model law for registration of deaths and collection of information on cause of death

A civil registration system must be adaptable to changing circumstances and developments in society. To confer the legal framework with greater flexibility and allow for necessary modifications to be introduced over time, a two-pronged approach is recommended when preparing legislation:²¹ laws – which can be changed only by legislative amendments – should contain only those major elements of the civil registration process that are fairly immutable; and rules and regulations – which can be changed by administrative processes – should cover the operational and technical aspects that are expected to change over time. Such rules and regulations, unlike the laws, can normally be changed without the authorization of Parliament. For example, the legal instrument could state that “certified copies can be prepared for any registered event for a fee” while the precise amount of the fee is specified in a regulation that can, if needed, be modified by the head of the civil registration and vital statistics system. Monetary amounts should never be included in the act itself as they rapidly become out of date. By giving strong regulatory powers to the civil registration directorate, rules and regulations can be updated and revised outside of the parliamentary process. This is usually done by

issuing circulars showing amendments by the head of the civil registration and vital statistics system, and circulating these to the local offices to ensure that registration procedures remain uniform throughout the country.

Box 2.1 provides basic elements that should be covered by the legislative framework governing death registration and the collection of information on cause of death (please note that these are not in any way exhaustive but form the basic minimum for a well-functioning registration system).

Box 2.1: Summarized contents of a legal framework for registration of deaths

General provisions

- Defines the vital events to be covered –live births, deaths, stillbirths, and fetal deaths, and gives clear definitions for each.
- Defines the sphere of action of the law – i.e. all national territory (including consular services for citizens temporarily abroad).
- States the compulsory nature of registration and penalties for non-compliance, the timeframe for registration, who must register the event and the documentary evidence needed for registration.
- Describes statistical obligations and required collaborations with other government offices.
- Identifies strong measures needed to respect and protect individual privacy and confidentiality.

System infrastructure

- Outlines the structure and administrative organization of the civil registration service and its main functions, including the appointment process and authority of registrars.

Entries in the registers

- Describes how and when to enter events into the registers, on what forms and the number of copies, and what official certificates signed by the registrar to deliver.

Registration of death

- Details how to register deaths, what to include, what information to abstract from the medical certificate, what to do if no medical certificate is available, and what to do in the case of coronial cases, stillbirths and fetal deaths. Describes need for verification of all evidence and of the names to be entered on the death certificate.
- Provides instructions on what to do with the information – including storage, transferring of a copy to the central archive, or forwarding for the production of statistical reports.
- Describes how to issue burial permits.

Amendment of registration records

- Details which type of errors registrars can correct and which can only be amended following a court ruling.

Proof of registration

- Describes how to prepare certified copies of the registration papers and who can request these, pursuant to the law, upon payment of the charge set by the registrar-general.

Statistical reports

- Indicates how statistical reports using individualized data are to be prepared, what checks to carry out on the data, and when to forward the reports to the central office and compiling agency.

Funding arrangements

- States that initial registration with first its certified copy, medical certificate of cause of death and the funeral permit are to be issued free of charge, and that the provision of subsequent certified copies will be subject to a fee.

Transitory and derogatory provisions

- Specifies the date at which the law will enter into effect and the transitory arrangements.
- Lists the laws that are repealed by the new act.

Source: World Health Organization, Strengthening Civil Registration and Vital Statistics for Births, Deaths and Causes of Death RESOURCE KIT (Luxembourg, WHO, 2013, p.34). Available at http://apps.who.int/iris/bitstream/10665/78917/1/9789241504591_eng.pdf.

2.2 Organizational arrangements

The ultimate goal is to ensure that all deaths occurring within the boundaries of a country are legally registered within the time period prescribed by the law. A second critical goal is that the required legal and statistical

variables are recorded accurately, on time, and in the required format. To achieve these two objectives, an appropriate administrative and organizational framework, complemented by the required human and material resources, is required. In the section below, issues pertaining to the organization of death registration services in the country and the resource requirements for the accurate recording of the facts and characteristics of death are discussed. Integration and coordination in the civil registration system are important considerations as they are key factors in developing a smooth and efficient operation.²

(a) Uniform legislation and regulation nationwide

Regardless of whether a centralized or decentralized registration system model is applied within a country, it is essential that uniform registration laws and regulations used for establishing the basic policies and procedures that must apply in every part of the country are in place. Without such uniform standards and requirements, completeness of registration may not be achieved in some areas and the interpretation of vital statistics and their comparability, nationally as well as internationally, will be imperfect. Provision for uniform registration throughout the country is desirable even when the extent of compliance with the registration law is likely to vary among different regions or sectors of the population. To limit compulsory registration to one segment of the population, however large that segment might be, is not recommended, except in countries where unsatisfactory conditions prevail. Where compliance with registration requirements is still at an early stage of development, adjustments should be made by the responsible agency for vital statistics, at the statistical collection or tabulation levels, so as to safeguard the quality of the resulting statistics.

(b) Inter-agency coordination committee

The clear delineation of duties should be supplemented by arrangements for the coordination of needs and services among the official agencies concerned with the registration of events for legal purposes, those responsible for compiling information on vital events for statistical purposes, and those that use those data for administrative or analytic purposes in connection with economic and social matters, or for planning, operating and evaluating public-health programmes, maintaining, for example, population registers or personal identification files.

The coordinating mechanism established to achieve the objectives associated with civil registration and vital statistics should have a direct relationship with the agency responsible for the general coordination of the national system of statistics and the agency responsible for planning economic and social development. It is neither efficient nor effective to attempt to carry out these inter-agency coordination functions through a series of bilateral meetings, committees or communications with other agencies, one at a time. Instead, an inter-agency coordinating committee should be established, comprising representatives from each involved agency.

(c) Other coordination, liaison and communication within the civil registration system and with users

In addition to external coordination, coordination within the civil registration system is essential so as to ensure that uniform processes and practices are followed at every level. Regardless of whether the system is centralized or decentralized, good communication among the various offices involved in civil registration and in the production of vital statistics is required in order to establish and maintain high standards of quality. The communication links must function in both directions: from the local offices to the central authority and from the central authority to the field offices. In addition, communications must be good between those working in the registration domain and those working on vital statistics production and analysis.

A number of communication techniques are effective with regard to both civil registration and vital statistics systems, including, among them, the use of periodic workshops, conferences and national conventions and newsletters, and the employment of travelling field consultants. Contemporary Internet-based networks and social media outlets can serve as ideal platform for establishing real-time and effective communication among various offices and institutions. Representatives of other entities outside the system should be included in the communications network when coordination with other agencies and disciplines is appropriate. For example, representatives of the above-mentioned inter-agency coordinating committee should be included within appropriate areas of the communications networks.

Death registration service points

Generally, deaths occur either in health facilities or at home or the community level. Irrespective of the place of occurrence, the most critical consideration is to ensure that registration service points are as closest to the public as possible, and are accessible in terms of convenience, as well as the time and costs that are incurred in completing the registration of an event of death.

a) Deaths occurring within health facilities

A practical and vital strategy to employ to register deaths that occur in health facilities is to enlist all health facilities in the registration process. This will entail the following: (i) using health facilities as registration service points (hence the need to address the attendant legal and practical implications); and (ii) using service providers within these health facilities as informants of vital events. In most countries, the responsibility of notifying the occurrence of a death is entrusted with individuals and families. While it is relatively easy to undertake such notification responsibilities for births, events of death more often go unreported, unless there is sufficient incentive for such reporting, such as the linkage of death registration with permission to transport the deceased to the burial place, as is the case in India, Kenya and South Africa. India and Kenya have successfully enlisted health institutions to serve as registration service points and informants for both births and deaths. In these countries, health institutions are required to submit returns of births and deaths registered to the local civil registration office on a regular basis.

On the other hand, experience from a number of countries indicates that registration coverage can significantly increase when civil registration offices are established within health facilities. Such registration offices are increasingly being set up in health facilities in Botswana, Namibia and Zimbabwe, among other countries. In some countries in Latin America, such as Argentina, Bolivia and Uruguay, this approach is also being deployed. As the proportion of deaths that occur in health facilities is increasing in most settings, this strategy can yield significant and rapid improvements in death registration coverage.

b) Deaths occurring at a community level or at home

In most African countries, a majority of deaths occur outside health facilities. Moreover, most of these countries do not have restricted places of burial; often, the dead are buried in the backyard of their homes. This sociocultural practice has substantially contributed to the current low levels of death registration, especially for cases of death of young children who die at home. Generally, in most of these settings, there is very low appreciation for the value of death registration among the general public. Such value is largely

attached to access to the deceased's estates for inheritance – a situation that only affects a very small proportion of the population in most African countries.

Improving death registration coverage in such settings necessitates not only the engagement of the local administrative structure, but even more importantly introducing registration incentives to increase demand and raise public awareness in matters related to registration. The authorities responsible for public administration at the community level can play a vital role in acting as informants for every death occurring within their jurisdiction. This can be achieved through establishing working relations between the civil registration offices and those of public administration at the local level. Community health workers have also been found to be critical as local resource persons in the registration process in many countries. While undertaking their responsibilities of administering health services, community health workers can act as informants of vital events, collect and relay information on deaths. This approach has effectively been applied in such countries as Burkina Faso and Mali.

The performance of the death registration system is largely measured by the quantity and quality of information that is recorded during registration, and the ability to translate such information into a credible statistical output. The structure and content of death registration forms are significant determinants of the quantity and quality of the output of the entire process. Countries in Africa use different types of death registration forms. Irrespective of the type of registration form used, it is important to ensure, first, that the forms are designed to collect fundamental legal and statistical variables, and second, that the forms are designed in a manner that allows easy collection and processing of the statistical variables. The United Nations Principles and Recommendations for a Vital Statistics System set out the topics or variables that are to be investigated for vital statistics purposes through the civil registration system for each vital event. The list of recommended topics is structured around two collection priorities: higher priority or core topics; and less urgent or additional topics. A further distinction is made between direct and derived topics; the former are collected through questions made to the informant and the latter are computed or inferred.²

Table 2.1 provides the minimum fundamental legal and statistical variables that should be collected during registration of deaths, as recommended by UNSD.² It is noteworthy that WHO recognizes that not all the specified variables may be collected in emerging registration systems.¹⁴ However, it is important that countries review their forms to ensure that they align with this international recommendation.

Table 2.1: Fundamental legal and statistical variables to be included in death registration forms

Characteristics of the death	Characteristics of the decedent
1. Date of occurrence	1. Date of birth
2. Date of registration	2. Sex
3. Place of occurrence	3. Marital status
4. Place of registration	4. Place of usual residence
5. Cause of death	5. Place of usual residence of the mother (for deaths under one year of age)
6. Certifier	

¹⁴ WHO. *Application of ICD-10 for Low-resource Settings Initial Cause of Death Collection: The Startup Mortality List (ICD-10-SMoL)*, V2.0 (Geneva, WHO, page 15) Available at www.who.int/healthinfo/civil_registration/ICD_10_SMoL.pdf?ua=1.

For foetal deaths add the following	
Characteristics of the mother	Characteristics of the father
1. Date of birth	1. Date of birth
2. Date of last previous live birth	2. Place of usual residence
3. Previous live births	
4. Previous stillbirths	
5. Previous abortions	
6. Date of marriage	
7. Place of usual residence	

Source: *Principles and Recommendations for a Vital Statistics System, Revision 3* (United Nations publication, Sales No. E.13.XVII.10).

International form for medical certification of cause of death

Ideally, all registered deaths should have a corresponding record of the cause of death. From the standpoint of public health and prevention of disease and premature death, the underlying cause of death has been defined as the basis for cause of death statistics. The underlying cause of death is either: “(a) the disease or injury which initiated the train of morbid events leading directly to death; or (b) the circumstances of the accident or violence which produced the fatal injury”.¹⁵ It is this underlying cause of death that is amenable to preventative public health interventions. Thus, it is extremely important that the underlying cause is determined and accurately recorded. To achieve the above public-health objective, it is imperative that the medical certification form recommended by the World Health Assembly be used² according to the standards set out in the International Classification of Diseases. The application of these standards enables the production of high-quality statistics on causes of death in the population disaggregated by age, sex and location. The International Classification of Diseases is updated and revised every decade or so to reflect the latest knowledge available on the etiology of major diseases and health conditions. The version being used presently in countries is the tenth revision (1998). WHO is developing the eleventh revision. The WHO form for the medical certificate of cause of death (MCCD) was last updated in 2015. The use of this form places the responsibility for recording the train of events leading to death on the medical practitioner whose legal responsibility is to sign the medical certificate of cause of death. The form is designed to facilitate the selection of the underlying cause of death, especially when two or more conditions are recorded. It is assumed that the certifying medical practitioner is in a better position than any other individual to decide which of the morbid conditions led directly to death and to state the antecedent conditions, if any, that gave rise to this cause.

Unfortunately, in Africa, not all registered deaths have a corresponding record of the cause of death. Even when available, such a record of cause of death, in most cases, is inaccurate and inconsistent with the required international standards of reporting. Among the factors contributing to this unfortunate situation are weaknesses in the registration legislative frameworks in use. The law, in many cases, fails to not only specify the need for cause of death reporting, but also designate the responsibilities and requisite standards for such reporting. Adding to this challenge is that most deaths in Africa occur outside health facilities, and hence out of the supervision of a medical professional (who should ideally certify the cause of death). However, even in

¹⁵ World Health Organization, WHO Mortality database. Available at http://www.who.int/healthinfo/mortality_data/en/. (accessed 25 September 2017).

cases in which the occurrence of a death is within a health facility, there are significant challenges in deriving a credible cause of death record for each event of death.

The first challenge is to offer physicians responsible for issuing medical certificates of cause of death the training and skills required to correctly complete the international form of the death certificate. Unfortunately, such training is rarely built into medical curricula and in-service training is often neglected. Various educational materials for certifying physicians have been developed but their use remains limited. However, experience indicates that once physicians have understood the importance of correct cause-of-death certification, they can readily acquire the needed competencies to do so.¹⁸

The second challenge is to ensure that the cause of death on the certificate is correctly assigned an appropriate statistical code contained in the International Classification of Diseases – this is not easy. Because of the increasing complexity associated with the International Classification of Diseases, only expert statistical coders and classification experts can use it properly. In response to this, software programmes for coding and the selection of underlying cause of death have been developed. These programmes use computerized mortality-coding tools to ensure the consistent application of the International Classification of Diseases rules and produce comparable cause-of-death data. However, automated coding is not feasible in at least 30 per cent of deaths, including all deaths resulting from external causes, because of the complexity of the coding process. Automated coding is applied only to the simple causes of death. Complex cases and all deaths resulting from external factors have to be coded by expert statistical clerks and expert coders (nosologists). Various in-person and online training tools are available to build capacities among certifying physicians and coders. However, these approaches have yet to be scaled up to a level sufficient to secure improvements in cause of death reporting at the global level. The following sections contain descriptions of the requirements for cause of death reporting for deaths occurring in health facilities and those occurring outside health facilities.

a. Recording causes of death for events occurring within health facilities

Causes of death are medically certified using the WHO International Form of Medical Certificate of Cause of Death on which the underlying cause of death is correctly coded according to the rules and principles of the tenth revision of the International Classification of Diseases (ICD-10). For a cause of death to be medically certified, a physician must complete a death certificate and pass judgment on the causes that led to the death. Only a medically trained person can reliably diagnose the precise cause of death. The medical knowledge and skills of those responsible for certification critically affect the quality of cause-of-death data. A copy of the medical certificate of cause of death form is shown below.

Medical certificate of cause of death form

Administrative Data (can be further specified by country)												
Sex		<input type="checkbox"/> Female			<input type="checkbox"/> Male			<input type="checkbox"/> Unknown				
Date of birth		D	D	M	M	Y	Y	Y	Y	Date of death		
		D	D	M	M	Y	Y	Y	Y			
Frame A: Medical data: Part 1 and 2												
1		Cause of death						Time interval from onset to death				
Report disease or condition directly leading to death on line a												
Report chain of events in due to order (if applicable)		Due to:										
State the underlying cause on the lowest used line		Due to:										
		Due to:										
2		Other significant conditions contributing to death (time intervals can be included in brackets after the condition)										
Frame B: Other medical data												
Was surgery performed within the last 4 weeks? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown												
If yes please specify date of surgery												
If yes please specify reason for surgery (disease or condition)												
Was an autopsy requested? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown												
If yes were the findings used in the certification? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown												
Manner of death:												
<input type="checkbox"/> Disease				<input type="checkbox"/> Assault				<input type="checkbox"/> Could not be determined				
<input type="checkbox"/> Accident				<input type="checkbox"/> Legal intervention				<input type="checkbox"/> Pending investigation				
<input type="checkbox"/> Intentional self harm				<input type="checkbox"/> War				<input type="checkbox"/> Unknown				
If external cause or poisoning:								Date of injury		D D M M Y Y Y Y		
Please describe how external cause occurred (If poisoning please specify poisoning agent)												
Place of occurrence of the external cause:												
<input type="checkbox"/> At home		<input type="checkbox"/> Residential institution		<input type="checkbox"/> School, other institution, public administrative area				<input type="checkbox"/> Sports and athletics area				
<input type="checkbox"/> Street and highway		<input type="checkbox"/> Trade and service area		<input type="checkbox"/> Industrial and construction area				<input type="checkbox"/> Farm				
<input type="checkbox"/> Other place (please specify):								<input type="checkbox"/> Unknown				
Fetal or infant Death												
Multiple pregnancy								<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown				
Stillborn?								<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown				
If death within 24h specify number of hours survived								Birth weight (in grams)				
Number of completed weeks of pregnancy								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?								<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown				
<input type="checkbox"/> At time of death								<input type="checkbox"/> Within 42 days before the death				
<input type="checkbox"/> Between 43 days up to 1 year before death								<input type="checkbox"/> Unknown				
Did the pregnancy contribute to the death?								<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown				

Source: WHO. Application of ICD-10 for Low-resource Settings Initial Cause of Death Collection: The Startup Mortality List (ICD-10-SMoL), V2.0 (Geneva, WHO, page 15) Available at www.who.int/healthinfo/civil_registration/ICD_10_SMoL.pdf?ua=1.

The medical certificate displayed above is designed to facilitate the selection of the underlying cause of death when two or more causes are recorded. Part 1 of the form covers diseases related to the train of events leading directly to death and part 2 covers unrelated but contributory conditions. The condition recorded on the lowest line used in part 1 of the certificate is usually the underlying cause of death. Details in completing the International Form of Medical Certificate of Cause of Death are contained in box 2.1.

Box 2.1 Summary guidelines on completing cause of death certification

Part 1 – including diseases or conditions directly leading to death, and antecedent causes.

Part 2 – other significant conditions.

A **column** to record the approximate interval between onset and death.

Important concepts in death certification

It is very important that all death certifiers understand the following concepts.

- **Underlying cause of death and sequence of events leading to death** – mortality statistics are based upon the underlying cause of death, which is the disease or injury that initiated the sequence of events that led directly to death. It is extremely important that the underlying cause of each death is correctly determined and accurately recorded.
- **Contributory cause(s) of death** – causes that may have contributed to the death but do not form part of the sequence are listed on the death certificate as contributing causes.
- **Approximate interval between onset and death** – the column on the right-hand side of **parts 1** and **2** is for recording the approximate time interval between the onset of the condition and the date of death. The time interval should be entered for all conditions reported on the death certificate, especially for the conditions reported in **part 1**. These intervals are usually established by a doctor on the basis of available

Source: World Health Organization, Strengthening Civil Registration and Vital Statistics for Births, Deaths and Causes of Death RESOURCE KIT (Luxembourg, WHO, 2013, p.78). Available at http://apps.who.int/iris/bitstream/10665/78917/1/9789241504591_eng.pdf.

Once the form has been filled out and signed by the medical practitioner, it is the responsibility of the civil registrar to ensure that the form (either in paper or electronic format, depending on the prevailing system) is combined with other information needed for statistical purposes and submitted to the statistical authorities for processing and the production of vital statistics. It is of critical importance to emphasize that the cause of death as specified by the medical practitioner may be disclosed to the closest relatives only and that the civil registrar must ensure the complete confidentiality of this information.

b. Recording causes of death for events occurring outside health facilities

The notion of assessing cause of death through the use of retrospective interviews originated in London in the seventeenth century, when “death searchers” would visit the houses of people who had died to make enquiries about the death – especially in cases that were thought to be the result of a communicable disease. Verbal autopsies are, however, the most practical option for assessing cause-of-death patterns for deaths that occur outside health facilities and for deaths in health facilities with only limited diagnostic capability. It is also recommended that verbal autopsies should be used in countries where doctors are not available to certify the cause of death. However, verbal autopsies cannot be used for legal purposes, which usually require more rigorous medical certification.

Lay certification of cause of death

In many African countries where a high proportion of people die outside health facilities, the cause of death is not certified by a medical doctor but instead by a coroner, police officer, village chief, registrar or other layperson without medical training.²¹ Cause-of-death data certified by non-medically trained individuals do not generate reliable and accurate mortality statistics. Many such deaths are attributed to ill-defined and nonspecific causes, such as “old age”, “fever”, “witchcraft”, or “stopped breathing”. Such diagnoses are of no

value whatsoever to disease control and prevention programmes. Increasing the proportion of all deaths that are medically certified is the single most important challenge for civil registration and vital statistics systems in Africa.

2.3 Infrastructural arrangements

Use of technology

Information technology can be a useful tool for expanding capacities across the spectrum of activities from data collection, through compilation, and eventually to dissemination. Customized tools have been developed to assist data entry and compilation, data presentation and the production of periodic reports. Well-functioning ICT infrastructure, including a reliable power source, Internet, and cell phone coverage, provides the enabling environment for developing modern civil registration and vital statistics systems, which, in turn, provides the platform for interoperable civil registration and vital statistics information systems and databases. While ICT is not a silver bullet, it can provide a means to collect, store and retrieve data in a rapid, cost-efficient and user-friendly way. Recent advances have been made in such areas enterprise architecture design and mobile technologies, and many synergies can be found with ongoing efforts.¹⁵

The level of sophistication of information technology and analysis contribute substantially to the levels of timeliness and quality. New technologies offer potentially significant benefits to the civil registration and vital statistics systems: they may increase efficiency in operations and timeliness, improve the quality of the records collected and the safety of the documents in storage, extend services and improve services provided to the public, among other things.²

In many African countries, the civil service workforce in charge of recording vital events and preparing vital statistics are usually neither equipped nor trained to carry out such tasks.¹⁵ Most civil registration and vital statistics systems have remained largely paper based and manual. However, the arrival of new technology in resource-constrained environments creates an enabling environment for developing more efficient and effective information systems. This technology was not present when civil registration and vital statistics systems were developed in Organisation for Economic Cooperation and Development (OECD) countries, so many African countries can leapfrog to more efficient systems. Contemporary requirements placed on the civil registration system in terms of providing services to the population and the technological environment call for complete and comprehensive computerization of all registration operations and production of vital statistics.² The computerization of civil registration is even more imperative, taking into consideration that other government functions are increasingly relying on computer technology, reflecting the development of so-called e-government. With the introduction and the massive use of the Internet, populations expect similar functionality in the delivery of services by Government as well.

Good practice is now being established on who should own the new technology, how the new technology should be deployed to ensure accurate and comprehensive records, and how these records should be used and updated to the benefit of citizens. This requires careful design and not the implementation of ad hoc projects. Building a well-functioning technology platform for civil registration and vital statistics remains a challenge, given its multi-sectoral nature.

There are currently too many lost opportunities; for example, data on births and deaths are being captured in the routine Health Management Information System (HMIS) of a country, but are not captured in the civil registration and vital statistics records. Mobile phones and increased access to the Internet have enabled new groups to notify civil registration authorities. This includes community-based vaccination programme workers, community health workers and village elders. In cases in which country context is similar, some models can be transferred across countries; however, barriers and solutions usually vary considerably across countries. Local assessments are always the starting point to sustainable solutions. The full value of data from civil registries is achieved when they are properly integrated within government systems – for example, with the statistical institutions, population registers, national identification systems and voter registration systems. There are now opportunities to do this through the latest civil registration and vital statistics systems that draw on the wide availability of ICT and innovations linking health records with civil registries. New internationally applicable civil registration and vital statistics standards are required in order to use unique identifiers and the various tools and devices for collecting and transmitting data, and to achieve interoperability.

As civil registration is designed to be permanent, continuous, compulsory and universal, it is recommended that policies focused on the development of a computerized civil registration system be designed jointly with the agencies concerned, including the agency entrusted with the production of vital statistics. Any changes in the recording, processing, storing and transmission of events or information will have an impact on the other main users of registration data, such as the ministry of health, the population registration agency, the identification service and the electoral services. The main users should, therefore be consulted and kept informed from the outset of any changes and developments associated with establishing a computer-based system. In the planning of a computerized civil registration system, several major decisions need to be taken. A checklist of activities for a plan for eventual computerization can be established even when the implementation of it is to be limited to a portion of the system. This type of planning makes the inclusion of new actions and events a transparent process. Government officials responsible for civil registration and vital statistics should routinely monitor the emerging technologies to assess their applicability to the current system, while considering both the benefits and costs of innovation.¹⁶ There are both benefits and costs associated with innovations. Systematic monitoring of emerging technologies provides the civil registration and vital statistics systems with an opportunity to increase awareness of new technologies and to assess them in terms of cost-effectiveness. Therefore, to effectively manage them, a component for reviewing currently available information technology, automation and communications systems must be built in the systems. This will enable them to keep pace with the rapid changes occurring in this field and to benefit from them.

During the last decade, new technology has been used substantially to facilitate the collection and computerization of health information data. The District Health Information System (DHIS2) was implemented on a national scale in several countries, including in Bangladesh, Ghana, Kenya and the United Republic of Tanzania. The DHIS2 platform can be used for individual mortality data capture, coding, and analysis and may contribute to obtaining real-time data on causes of death. The centralized server structure of DHIS2 facilitates central analysis and reporting, as well as local data tabulation.

¹⁶ National Center for Health Statistics, International Statistics Program. 2015. CDC Global Program for Civil Registration and Vital Statistics Improvement. Hyattsville, Md.

By integrating a mortality module, such as the WHO Start-Up Mortality List into DHIS2, the users in health facilities are able to access a standard data entry module for entering information from the medical certificates of the cause of death. Selection of the underlying cause of death as carried out by the trained coders or health information system officers is automatically stored in the central server. Integrated data dashboards and reports can be generated at any time to monitor reporting and results by the facility.

Chapter 3 - Innovations and novel approaches to improve death registration and cause of death registration processes

3.1 Dealing with the complexity of civil registration and vital statistics systems

Civil registration and vital statistics systems are extraordinarily complex and have evolved over decades somewhat differently in each country. Even though all civil registration and vital statistics systems have the same output objectives, each country's system has followed different paths with differing approaches to governance and policies- since different systems are accountable to different ministries, such as justice, security, local government or health. The organization, implementation, processes, scale, partners and capacities of the system vary from country to country. All civil registration and vital statistics systems are part of a country's larger political, economic, social, health, and information systems, but are placed within them are subsystems concerned with, for example, legal identity, civil registries, vital statistics and information technologies. Almost all civil registration and vital statistics systems in low and middle-income countries are failing to achieve adequate levels of coverage and quality despite attempts to apply standard methods proven to work well in high-income countries.¹⁷ This suggests system failure rather than technical failure. To date, most attempts to improve civil registration and vital statistics systems have been reductionist and aimed at the technical faults. Consequently, civil registration and vital statistics systems have been slow in achieving results. On the other hand, strengthening them could lead to the achievement of high-leverage tipping points that could rapidly improve the overall performance of the systems.

Systems analysis is the application of specific analytic approaches to achieve a better understanding of the typologies, organization, requirements, processes, and workflows in relation to outputs and purpose. The most appropriate approach to systems analysis for civil registration and vital statistics systems is the systems thinking discipline of enterprise architecture and, more specifically, business process modelling. The term "enterprise" here refers to the civil registration and vital statistics organizations concerned, regardless of ownership, geographical distribution or operating model. It includes the civil registration and vital statistics organizations' complete sociotechnical systems, including people, information, processes and technologies. Enterprise architecture is a conceptual blueprint that defines the structure and operation of an enterprise. As part of enterprise architecture, business process modelling is applied to gain a better understanding of the activities, participants and information flows of the core business processes that enable an organization (or system) achieve its goals or do its work.

3.2 The 10 civil registration and vital statistics process milestones

Some business process modelling has been conducted in Africa during which time 10 vital interlinked steps that constitute the 10 civil registration and vital statistics milestones (six comprising civil registration and four comprising vital statistics) were identified as outlined below.

¹⁷ The University of Melbourne. Enterprise Architecture (EA): Process Mapping for Strengthening CRVS Design. 1st Year Draft Report, April 2015 – March 2016



Source: Don de Savigny and Daniel Cobos Muñoz. *Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design*, page 33

Each stage entails the following:

1. Notification of a death
 - *Form indicating that a death has occurred*
 - *Interaction between the declarant and the civil registration system*
 - *Medical certificate of cause of death completed (as applicable, namely if an authorized medical professional has sufficient knowledge to fill the medical certificate of cause of death)*
2. Validation of a death
 - *Ensure completeness of records as per requirements*
 - *Captures the standard documents needed as proof*
3. Registration of a death
 - *Details of the death are entered into the official civil register by the registrar*
4. Certification of a death
 - *Death is certified by the registrar*
 - *Issuance by the civil registrar of a legal document*
5. Share information on death
 - *Integration with other stakeholders (ministry of health, agency in charge of IDs, electoral commission, national statistics office, among others)*
 - *Confidentiality issues*
6. Storage and archiving of a death record
 - *Electronic versus paper*
 - *Final location of archives*
7. Compilation of vital statistics

- *Compile standard summary statistics from civil registration data*
- *Parallel systems*
- 8. Quality control of vital statistics
 - *Quality check of summary statistics*
 - *Cross checking of vital statistics produced from civil registration with other data sources (such as sample registration surveys)*
- 9. Generation of vital statistics
 - *Production of vital statistics report*
- 10. Dissemination of vital statistics
 - *Distribution of vital statistic to users using push versus pull approach*

Process mapping can be used to trace how each record is produced and used.

Notification

Notification of deaths is the key to strengthening mortality statistics. Establishing a fully functional and continuous system for death registration, which includes notification processes, has two benefits: because deaths are registered when they occur, the data generated are **real time**, which is important for public health surveillance; and data collected can be more **representative**, as the system is established to notify all deaths in a population (in and outside of health facilities). To increase notification and registration coverage, multiple sources of information should be considered to detect the occurrence of death. Some examples are burial permit, a hospital notification, surveillance records, and other relevant records of death. For deaths that occur outside health facilities, notification can be given through the use of community structures, such as village health workers as currently practiced in Ethiopia and Rwanda.

Death notification and registration should be seen as a continuum of the same process and inherently linked in a way that every correctly filled notification form leads to the registration of that death. In such a situation, death registration is guaranteed for every death notification. For example, in Kenya, Namibia and South Africa, notification (through issuance of a burial permit) is done after the death has been registered (a death register is completed first, then a burial permit is completed and issued). Where the two are delinked, (for example, if health facilities issue notifications that need to be transmitted to the civil registration office by the family in-person), there is a considerable risk of the registration being missed.

Health institutions play a critical and dual role in the vital statistics system. First, health institutions act as informants of the occurrence of deaths; and second, the certification of causes of death can be performed only by physicians attached to health institutions. In addition to these functions, which are carried out within the framework of the vital statistics system, information collected by health institutions is crucial in generating health statistics, which, in turn, provide irreplaceable information regarding the overall health of the population, and the functioning and the needs of the public-health system.² In contemporary societies, more and more deaths are occurring in health institutions, which places health institutions in a unique position with respect to compiling relevant information regarding the death and informing the civil registration system of its occurrence.

Registration

In an ideal scenario, each death occurring in a health facility should have both a **legal record** (such as a death notification) and a **medical record**. From a statistical perspective, such medical records help generate health

facility, regional and national vital statistics on mortality and cause of death data. In practice, health facilities may have multiple sources of data on deaths:

- **Health facility records** may include inpatient medical records, medical certificates for cause of death, outpatient records, and formal mortuary records. In some cases, mortuary processes can be used to determine cause of death for deaths that are not otherwise medically certified.
- **Legal documents** issued for deaths may include hospital notifications of death, burial or cremation permits.
- **Death audit records**, for example for maternal or perinatal deaths, which serve as a record of a death, and can be linked to medical certification, and also to civil registration and vital statistics systems.

In cases in which multiple sources exist, it is advisable to **map all** the possible sources of death notifications in the business process mapping, especially when there are legal requirements (burial permits, hospital notifications, maternal and perinatal death records, surveillance records, police records (homicide deaths, traffic accidents, and suicides)). Each possible source of mortality data should be documented for its content, the legal requirements for collection, the process for collecting and using the record, the interaction or duplication between records within the system, the use of the records in the health information system, and the completeness of recording, such as whether all deaths are captured. Such multiple notification sources can be collected, validated and reconciled to support the registration of the death.

The reconciliation can also be used to generate a report for these administrative data, which will enhance the understanding of the strengths and limitations of each data source. Through business policy monitoring, it would be possible to identify design flaws (parallel channels of reporting or multiple information systems) and also to support the reconciliation of different data sources as a measure of the performance of the civil registration and vital statistics system.

Medical certification of cause of death

The quality of medical records should be sufficient that the following can be collected under the routine system: individual patient data, including sex, age, date of admission, date of discharge, death, pregnancy, accident, treatment, and diagnosis (including reason for admission plus morbid condition); and individual cause of death collected on the medical certificate of the cause of death, the standard data collection form for cause of death in routine health facility settings. In cases in which a death occurred as a result of an accident or violence, it is common to have a judicial procedure to determine the precise cause of death. In both cases, the cause of death is subsequently coded to the statistical categories defined by the International Classification of Diseases.

A number of challenges arise in the collection of cause of death information in health facilities. Some of the notable ones include:

- **Law** – the current law may not make it mandatory for health facilities to record causes of death; the law does not make it compulsory for the use of the WHO standards as the conventional standard that the country should follow in assigning causes of death; and

- **Standards** - the causes of death are not completed using the medical certificate of cause of death; or the causes of death are recorded in the WHO standard form but their descriptions are not clear, making it difficult to assign appropriate codes according to the International Classification of Diseases.

The following are some of the actions required to tackle many of the common challenges with medical certification.

- **Training** - ensure that certifying physicians have the requisite knowledge and skills and that they are aware of and appreciate the importance of correct cause-of-death certification. This involves both pre-service and in-service training for physicians in medical certification of the cause of death and in the business process for data collection. In addition, doctors, administration and nursing staff should receive training on legal regulation of death registration, data flows and responsibilities;
- **Medical school curricula** – lobby for the introduction of medical certification according to WHO in medical schools’ curricula;
- **Judicial procedures** – establish mechanisms to ensure that cause of death is correctly assigned in cases that require judicial investigations; and
- **Quality assurance** processes should be adopted for quality assurance of certification – for example, ensuring that the medical certificate of cause of death is fully completed and the sequence of the causes is ICD-10 compliant. Feedback should be provided to physician certifiers as an incentive for good quality certification.

Under the APAI-CRVS process, a business process could be adopted to improve cause of death information for deaths occurring in health facilities. This entails constituting a core team to implement the strategies and plan of action for the improvement of information relating to causes of death. This team should design a business process that includes the identification of institutions and their responsibilities in the value chain, form flow, and monitoring and evaluation mechanisms. It should determine the necessary steps to implement this, which need to include the development of a proposal of implementation with timelines. The provision of a medical certificate of cause of death should be part of the business process. It is important to ensure that the law provides for compulsory recording of causes of death in all health facilities. The law should also specify that the medical certificate of cause of death should be used by all health facilities. Finally, the law should designate responsibility to one institution – for example, the national statistics office, for coding, compilation and dissemination of death statistics on an annual basis.

Verbal autopsy

In several circumstances, such as when deaths occur at home or in areas where health facilities are scarce, it is not possible to obtain medical certification of the cause of death. For that purpose, WHO developed international standards on the use of verbal autopsy, which is an interview carried out with family members and/or caregivers of the deceased using a structured questionnaire to elicit signs and symptoms, and other pertinent information, which can later be used to assign a probable underlying cause of death. Verbal autopsy is an essential public-health tool for obtaining a reasonable estimate of the cause of mortality at a community or population level, although it may not be an accurate method for attributing causes of death at the individual level.⁴³

For this purpose, verbal autopsies involve the use, by a trained interviewer of a questionnaire designed to enable him or her to collect information about signs, symptoms and demographic characteristics for a recently deceased person from an individual familiar with the deceased. In 2007, WHO published *Verbal Autopsy Standards, Ascertaining and Attributing Cause of Death*. In this publication, three questionnaires were introduced: for a death of a child aged under four weeks, for a death of a child aged four weeks to 14 years, and for a death of a person aged 15 years or above. In July 2012, WHO released a shorter version of the three questionnaires.⁴⁰ The simplified instrument is approximately 40 per cent shorter than the 2007 verbal autopsy instrument and should result in interviews averaging 20 minutes in length. The 2012 WHO verbal autopsy instrument can be used with mobile devices for data collection. In addition, it has been programmed for use with InterVA-4, an automated verbal autopsy analysis software. The aim of the 2012 WHO verbal autopsy instrument is to expand use of verbal autopsy as part of routine death registration in developing countries.

The responses are usually reviewed by a physician to determine the probable cause of death; this is referred to as physician-reviewed verbal autopsy. However, a physician review is time-consuming and demanding and not good use of the physician's time.¹⁸ In recent years, automated methods have been applied to determine the cause of death from the received responses without the need for a physician. One approach – InterVA – is now used widely, especially in health and demographic sites, such as those in the INDEPTH Network. More recent research has generated new automated techniques that are claimed to perform better than physicians¹⁸ – though WHO advises that these techniques be field-tested in a range of settings before they can be recommended for universal application. Automated methods have the advantage of speed (algorithms can process many verbal autopsies at the same time) and reduce the burden on physicians who are generally required to prioritize their clinical responsibilities over other activities. Although the use of verbal autopsies generates useful cause-of-death information at the population level, namely cause-specific mortality fractions, the technique is less reliable for ascertaining cause of death on an individual basis. In addition, causes of death ascertained using verbal autopsy cannot be used for legal purposes, which usually require more rigorous medical certification and data obtained. Therefore, verbal autopsy should not be merged with data obtained from medical certification in civil registration. In this respect, WHO cautions: “The purpose of verbal autopsy is to describe the causes of death at the community or population level where no better alternative sources exist. Therefore, it is a limited substitute for proper medical certification. The quality of information and of the diagnoses varies depending on the skills of the interviewer and the memory of the respondents.”¹⁸

Principles of verbal autopsy:

- Requires recognition of symptoms for various diseases (not always possible for adult diseases);
- Based on recall of symptoms or illness prior to death by informants;
- Based on reporting of symptoms to the interviewer;
- So far, found to be useful and accurate for infant and maternal deaths and deaths due to injuries;
- Recent experiences suggest utility of gathering information from medical documents if available within household.

Although the verbal autopsy generates a smaller number of causes of death, the information produced is still useful for public health planning purposes. The advantages of using a computer system are: the :

¹⁸ World Health Organization, *Verbal Autopsy Standards: Ascertaining and Attributing Cause of Death* (Geneva, WHO, 2007).

determination of cause of death is more consistent; it is more rapid than using a panel of physicians; and it is less costly.⁴⁰ However, collecting verbal autopsy information has its own challenges:

- The law does not specify that cause of death information can be collected through verbal autopsy processes;
- International standards are not always used in the verbal autopsy process, potentially meaning that data may not be comparable to other cause of death data (for example, hospital cause of death data);
- In many countries, there is no systematic process in place for recording and compiling cause of death information for deaths occurring outside health facilities;
- The verbal autopsy process is not effective in assigning causes of death for each individual death. It is good at the population level when errors are compensated;
- Although some attempts have been made in a few countries to collect causes of death data through verbal autopsy methods, these are largely limited to a few experimental areas. No real attempts have been made to use verbal autopsy for recording causes of death data for general populations. The Bloomberg Data for Health initiative involves ongoing efforts to implement verbal autopsies at a larger scale within civil registration and vital statistics systems in several countries in Africa.

Should the verbal autopsy method be part of civil registration in cases in which there is no possibility to obtain a medical certification of the cause of death? In this regard, it should be pointed out that the verbal autopsy method is fairly complex: the interview needed for completing the appropriate questionnaire is time-consuming; the training of civil registrars in conducting a verbal autopsy has to be comprehensive; and cultural traditions might not favour such an engagement with a government official. All of these factors, as well as the need to conduct thorough holistic testing in sample areas, must be taken into account when attempting to answer the above question.

The Data for Health Initiative is working with the University of Melbourne to determine how best to introduce verbal autopsy into civil registration and vital statistics systems.¹⁹ So far, it has been noted that medical certification and verbal autopsy should be linked to the notification and registration of deaths through a country's civil registration and vital statistics system. It should be recognized that to introduce verbal autopsy, careful analysis of, and response to, the structure and capacity of peripheral health and statistical services in each country are required. However, it has been determined that integrating verbal autopsy within civil registration and vital statistics systems is not simply a technical undertaking, as there are many profound system-wide effects that should be carefully considered when planning the implementation of it.

International Classification of Diseases coding

Once cause of death has been recorded through medical certification or verbal autopsy, coding according to the International Classification of Diseases can be undertaken. This coding is a highly specialized task that requires a thorough understanding of the rules for determining the underlying cause of death, and assigning the correct code. It is important that this task is undertaken by trained statistical clerks or coders. Countries can use centralized coding units to code cause of death data. For example, coding may be done at the ministry of health or by the national statistics office. In some countries, decentralized coding units are used. However, in decentralized systems, it may be difficult to maintain the quality of coding, especially if each coder has only a

¹⁹ University of Melbourne, "Technical guidance to D4H staff for the introduction of verbal autopsy into civil registration and vital statistics systems: Technical Report 2", November 2016 (Melbourne, Australia: Civil Registration and Vital Statistics Initiative, Data for Health).

relatively small number of deaths to code. In centralized and decentralized systems, it is important to ensure quality of coding, especially, the consistency of the coding rules. It is also important to note that coding technology can allow for quick and standardized coding of many deaths, if the death certification system is of sufficient quality. Coding certified deaths can be undertaken automatically through the use of automated coders, such as IRIS, an interactive coding system dedicated to the coding of cause of deaths, and the Mortality Medical Data System. For example, South Africa uses automated coding technology. Once classified correctly, the data can be aggregated and used to enhance understanding of deaths in health facilities, deaths that occur outside of facilities, and mortality patterns at different levels. However, as noted earlier, automated coding can at best deal with 70 per cent of deaths; complex cases (with multiple comorbidities) and all external causes, have to be coded by trained nosologists.

Currently, challenges associated with the International Classification of Diseases coding are as follows:

- In most countries, the law does not specify that cause of death information should be coded using the international form of the medical certificate for cause of death;
- The standards and rules of the International Classification of Diseases are rarely applied appropriately and consistently to all deaths, meaning that the data cannot be aggregated;
- Medical certification or verbal autopsy information is not received for coding, or is of poor quality, meaning that appropriate causes of death codes cannot be applied;
- Coding is a highly specialized function. For the many issues that can specifically affect coding and the quality of it, please refer to the WHO Resource Kit (www.uq.edu.au/hishub/resource-kit).

The following are the key steps required to improve the process of International Classification of coding:

- **Document processes** - document business processes for centralized and/or decentralized coding of the medical certificate of the cause of death using the standard provided in the International Classification of Diseases;
- **Training** - ensure that coding staff are trained in the requirements of International Classification of Diseases coding using the manual or automated system and residual handling;
- **Quality assurance** - establish a quality assurance process for electronic or manual coding, for example, by including congruency between age-disease, unexpected leading cause, ill-defined diagnoses, missing diagnoses, non-lethal conditions, longitudinal disruption and causes in “wrong” departments.

The available tools and resources for International Classification of Diseases coding are summarized in box 3.1.

Box 3.1: World Health Organization tools and resources for International Classification of Diseases coding

The following tools and resources for the International Classification of Diseases coding are available online:

- **Browse and use the ICD-10 online:** www.who.int/classifications/icd/icdonlineversions/en/
- **ICD-10 Instruction Manual**
http://apps.who.int/classifications/icd10/browse/Content/statichtml/ICD10Volume2_en_2016.pdf
- **International Classification of Diseases online training:**
<http://apps.who.int/classifications/apps/icd/icd10training/>

Compilation of cause of death statistics

This step does not necessarily have to be undertaken in health facilities – it can be done centrally in a health department, or even through a national statistics office. It involves the following:

- **Establishing a routine compilation process** that includes data sharing among facilities and agencies, when required;
- **Developing an analytical framework**, including national reporting, table requirements and timelines;
- **Establishing a quality assessment process:** quality checks at various levels, including use of automated quality checking tools.

Use of mortality data

Facility-based information on mortality and causes of death should be used for public health and prevention purposes within facilities and beyond.

- **Produce and disseminate annual or biennial reports on facility mortality**, with tables and charts on key indicators, including distribution of causes of death by age and sex and cause fatality rates for major causes of death.
- **Use facility mortality data** to identify avoidable deaths and deficiencies in quality of care.
- **Use data on mortality and causes of death** to trigger facility audits of adverse events (such as maternal and perinatal mortality) in order to identify avoidable factors within the facility and at the community level.
- **Compile mortality statistics** from the health facilities to create a national picture of facility mortality and develop system-wide responses to reduce preventable mortality.

The following innovations aimed at improving the quantity and quality of mortality statistics collected should be considered.

Use of the simplified mortality list

For countries that lack the capacity to use the standard International Classification of Diseases, the Simplified Mortality List can be used as the first step towards standardizing the reporting of cause of death, and to provide initial data to inform public health priorities and track progress towards achieving national and international targets and goals. The Simplified Mortality List was developed in 2015 by WHO. Its design is fully in line with the structure of the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). It contains 107 causes and 17 subcategories and is recommended as a first step towards standardizing the reporting of causes of death (in limited resources countries) before using the complete International Classification of Diseases. The tool consists of a simplified set of rules for underlying cause, but it is expandable to the full list of International Classification of Diseases, when possible. It has been adapted to existing training materials for doctors and certifiers and a small training manual for clerical staff to input information has been developed for using it. The data capture platform for the tool is an integrated data entry interface into DHIS2 such that there is real-time information all in one place. WHO²⁰ reckons that the Simplified Mortality List is an effective way to build capacity to progress towards using the detailed list of the International Classification of Diseases, when ready. The Simplified Mortality is designed to be fully interoperable with the District Health Information System, which is used in many African countries as the key database for health statistics.

²⁰ World Health Organization. “Capturing cause-of-death information in health facilities: the start-up mortality list – a simplified approach”. Presentation at the multi-country workshop on improving cause-of-death statistics in health facilities, Dar as Salaam 25-26 July 2016.

Automation of International Classification of Diseases coding

There are freely available automated coding tools to help ensure standardization of coding and deal with greater volumes of coding. A number of advantages have been identified through the use of automated International Classification of Diseases coding.

1. **Fewer transition challenges and expenses.** Without ICD-10 automation tools, physicians and coders need extensive training on the new code set and providers may need to hire additional coders. Coding errors are likely, especially during the transition. When coding tools are part of the clinical documentation process, less provider training is required because physicians are offered appropriate codes based on the patient's history and current documentation. Coding accuracy is enhanced, meaning fewer claim corrections and faster claim processing and payment.
2. **Physicians save time.** ICD-10 automation tools, particularly those that can sift through a patient's complete history and identify items relevant to a current visit, can save physicians considerable time. More than ever before, providers have access to vast amounts of clinical data from health information exchanges, hospitals, labs, and other providers. Technology has advanced to a stage that data can be sorted regardless of the original source and terminology logical links between clinical information can be created. This means that when a physician reviews a patient record and creates a chart note, the system not only advises the provider of relevant history, but it also considers the historical data when proposing ICD-10 codes.
3. **The coding process is more efficient.** When the system automatically prompts providers with appropriate codes during the documentation process, physicians can remain in the chart entry area while identifying the accurate codes. Coders do not need to review the documentation to assign codes, nor do they need to hunt for codes themselves.
4. **Codes are more accurate.** The use of automated ICD-10 technology can result in more precise coding when a patient's current visit and relevant clinical history are considered. Codes are identified and entered correctly at the point of care, resulting in more accurate and timely reimbursement. When codes are accurate the first time, providers and staff do not waste time and resources making corrections.
5. **Workflow is smoother.** ICD-10 coding technology allows providers to identify correct codes while documenting a patient visit at the point of care. Physicians sign off on charts immediately, rather than interrupting the care process to hunt for codes or waiting until the end of a long day to complete coding and close charts. Providers save time and are assured that documentation and coding are final as soon as the visit is over.

Although a well-functioning automated system can automate coding for the majority of records, manual coding may still be required in some cases.

Resources to improve mortality statistics

This interactive and self-training online tool is designed to improve understanding and enhance the use of ICD-10. Specific tracks for different users include an introduction to cause of death certification for physicians, a fast track for people such as managers, and an in-depth training path for coders.

Tools have been developed to improve the quality of mortality data. One such tool is the Analysing mortality levels and causes-of-death (ANACoD) package. This is an electronic tool that provides a step-by-step

approach (a 10-step process) to enable users to quickly conduct a comprehensive analysis of the quality and plausibility of aggregated data on mortality levels and causes of death. The tool automatically reviews the data for errors, tabulates the information, presents the results in the form of easy to use tables and charts, and provides the opportunity to compare the findings with those from other countries. Box 3.2 shows the available resources to improve mortality statistics.

Box 3.2: World Health Organization and Economic Commission for Africa resources to improve mortality statistics

- Improving Mortality Statistics through Civil Registration and Vital Statistics Systems: Strategies for country and partner support
www.who.int/healthinfo/civil_registration/CRVS_MortalityStats_Guidance_Nov2014.pdf?ua=1
- African Technical Strategy
- Analysing mortality levels and causes-of-death
<http://www.who.int/healthinfo/anacod/en/>
-

3.3 The role and use of District Health Information System Software v2

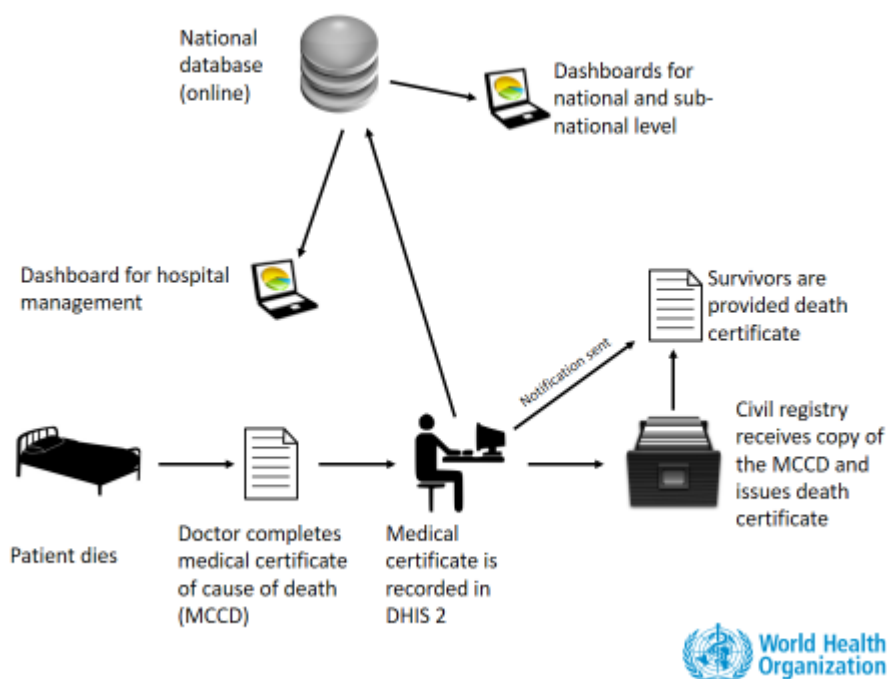
The District Health Information System Software v2 (DHIS2) was designed and developed under the Health Information Systems Project, a global research and development initiative that originated from the Department of Informatics, University of Oslo, Norway. The overall objective of DHIS2 is to be able to generate, analyse and disseminate health information to facilitate effective policy formulation, management, planning, budgeting, implementation, monitoring and evaluation of health services and programme interventions in the health sector. It is a web-based application that is accessible on the Internet. The programme is a free and open source database and application for collecting, processing, and analyzing health information, and is being used in many countries in Africa, including, among them, Botswana, Ethiopia, Kenya, Nigeria, the United Republic of Tanzania and Zambia. DHIS2 is able to support collection and analysis of routine health services data, as well as non-routine data, such as population estimates, facility workload and survey data.

To facilitate the use of the Start-Up Mortality List, WHO, in collaboration with the University of Oslo, have developed a module in the DHIS2 that comprises:

1. The **Start-Up Mortality List** – a simplified standard list of causes of death (107 causes and 17 optional subcategories);
2. WHO international form of the medical certificate of the cause of death – 2016 version;
3. A specific training manual for certifiers and coders;
4. A user-friendly interface into DHIS2 to input and store the data in one place;
5. a dictionary of medical diagnostic terms; and
6. routine validation checks and statistical reports.

The web-based DHIS2 is intended to capture health facility service delivery data and allow analysis at that level, promoting data use at all levels for decision-making. It is configured to allow the generation of reports, which can be in a standard format or customized to meet the user requirements; and to also carry out data quality analysis and provide a dashboard for monitoring and evaluation of health programme indicators. The essential reports have already been built into the system and are immediately available for review at all levels,

by the health facility, district, province and national health departments. Data quality is handled through mechanisms incorporated into the data collection process and functions within the DHIS2 software. Another advantage of the DHIS2 platform is its very modular web interface, which allows for easy incorporation of various modules, enabling easier replication of the complex paper reporting formats that are unique to each country where it is being implemented. DHIS2 offers one great dashboards, which easily enable all available data to be placed in a single view. Users can search and drag charts, maps and pivot tables into dashboards, as well as create any number of dashboards and easily switch between them.



The following is a summary of the current cause of death features in DHIS2:

- Integrates the International Standard Medical Certificate of Cause of Death;
- Uses the concept of the standard start-up list of causes that is built in the existing International Classification of Diseases shortlist and includes causes of relevance to the global burden of disease;
- Allows the application of simplified International Classification of Diseases rules to select the underlying cause of death;
- Applies validation checks to avoid data entry errors and blanks;
- Enables data visualization through dashboards.

Chapter 4 - Business process re-engineering

4.1 Introduction

Re-engineering is defined as “the *fundamental* rethinking and *radical* redesign of business *processes* to achieve *dramatic* improvements in critical, contemporary measures of performance, such as cost, quality, service and speed”.²¹ This definition contains four key words. The first key word is *fundamental*. In re-engineering, people must ask the most fundamental questions about their organizations and how they operate: “Why do we do what we do? And why do we do it the way we do?” Secondly, *radical* design means getting to the root of things, not making superficial changes or fiddling with what is already in place, but throwing away the old. The third key word is *dramatic*. Re-engineering isn’t about making marginal or incremental improvements, but rather about achieving performance improvements. Finally *processes*, most organizations are not process-oriented; they are focused on tasks, jobs, people and structure and not on processes. A process can be defined as a collection of activities that takes one or more kinds of input and creates an output that is of value to the customer.⁵²

Business process re-engineering began as a technique used by the private sector to help organizations fundamentally rethink how they do their work in order to dramatically improve customer service, cut operational costs and become world-class competitors. A key stimulus for re-engineering has been the continuing development and deployment of sophisticated information systems and networks. Re-engineering is the fundamental reconsideration and radical redesign of organizational processes in order to achieve a drastic improvement in the current performance in terms of cost, services and speed.²² The claim in support of business process re-engineering is simple: most of the work being done does not add any value for customers, and this work should be removed, not accelerated through automation. Instead, companies should reconsider their processes in order to maximize customer value, while minimizing the consumption of resources required for delivering their product or service.

The rise of business process re-engineering challenges many of the assumptions that underpin the way organizations have been run for the last two centuries.²³ First, it rejects the idea of reductionism – the fragmentation and breaking down of organizations into the simplest tasks. Second, it encourages organizations to capitalize on substantial developments made in technology. Third, business process re-engineering enables organizations to take advantage of the more highly developed education and capabilities of the staff they employ.

Task-oriented jobs in today’s world of constant change are obsolete. Instead, companies must organize work around processes. Business process re-engineering entails the restructuring of processes prior to structuring institutions and hierarchies, and structuring these processes in different ways than before. This is predicated on the assumption that information technology potentially can make it possible to come up with innovative ways to carry out work. At least in theory, business process re-engineering provides the missing link between the

²¹ Michael Hammer and James Champy, *Reengineering the Corporation: A Manifesto for Business Revolution* (New York, Harper Business, 1993).

⁵⁴ Assefa, Berihu. Business process re-engineering in Ethiopia. Short note prepared on business process re-engineering (BPR) in Ethiopia, May 2009. Available at www.grips.ac.jp/forum/af-growth/support_ethiopia/document/May09_berihu_bpr.pdf.

²³ Myriam Parys and Nick Thijs, “Business Process Reengineering; or how to enable bottom-up participation in a top down reform programme”, Paper presented to the annual meeting of the European Group of Public Administration Study group on Public Personnel Policies: “Staff participation and involvement in European public services”, Oeiras, Portugal 3-6 September 2003.

layer of strategy and that of the information system design. Moreover, through it, recommendations are given based on a holistic perspective, which encourages the bringing of objectives, human resources, organization, information technology and culture into a coherent perspective.

When it comes to the public sector, one must wonder about the political and economic feasibility of an effort to redesign the business process of any agency or service from scratch.²⁴ Therefore re-engineering is often perceived as a call for creativity and imagination in the search for new ways to accomplish the objectives of the business process as opposed to process modification or process-incremental improvement.

The conclusions of one study indicates that there certainly are possibilities for the implementation of business process re-engineering within the public sector.⁵⁶ However, this does not mean that a perfect match is at hand. The added value of business process re-engineering for public organizations is mainly derived from its potential as an incentive to get (complex) change processes within organizations started. Government organizations are often tied to different kinds of regulatory connections, such as connections with other organizations and boundary conditions specified in a legal framework. For most public organizations, radical changes in the way Government delivers its services and products can be problematic. This is because any change in one part of the organization is likely to trigger change(s) or disruption(s) in other areas. As each area of a public agency is monitored by and serves multiple stakeholders, a successful change cannot take place without the consent of all the affected stakeholders. Forging such a consensus may be beyond the ability of many public administrators. To change radically the structure, culture and way of working of such organizations is very difficult. However, business process re-engineering has the potential to set the level of ambition of an intended change and, therefore, can motivate and mobilize people for such an ambitious change. It serves as a sort of a “change agent” and should, therefore, be considered more as a catalyst than as a blueprint for organizational change.

4.2 Required governance structure

As explained in section 3.1 above, business process mapping has been applied for decades to improve the manageability, effectiveness, efficiency and agility of “business” processes in enterprises by:

- Providing an end-to-end description of the core processes of the enterprise;
- Aligning operations with the strategy;
- Exposing design flaws and inefficiencies in the processes;
- Standardizing processes and increasing consistency in the implementation of them;
- Supporting change management in process re-engineering;
- Helping stakeholders to communicate and advocate for process change.

Investing in civil registration and vital statistics yields great dividends, but the cost of indifference is high. The following are some key recommendations that would help to improve the current systems at a reasonable cost and in few years:²⁵

²⁴ Arie Halachmi and Tony Bovaird, “Process reengineering in the public sector: learning some private sector lessons”, *Technovation*, vol.17, No. 5 (May 1997), pp. 227-235.

²⁵ Rwanda, *Rwanda Civil Registration and Vital Statistics Systems. Comprehensive Assessment Final Report Volume I* (Kigali, November 2016).

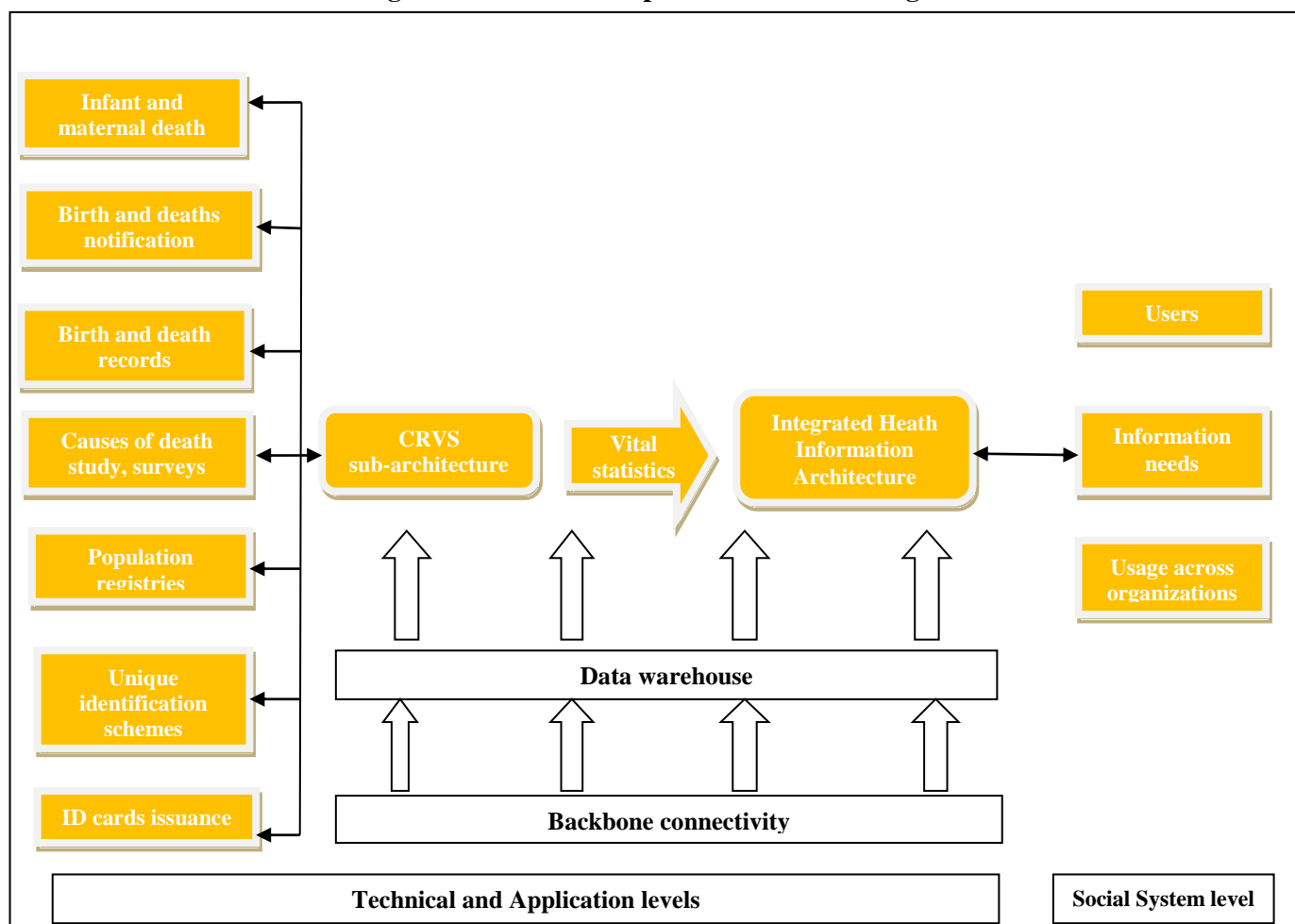
- a. **Enabling legal and policy environment:** In order to create a comprehensive civil registration and vital statistics system, the legislative environment relating to death, late and delayed registration, registration of neonatal deaths, among others issues, needs to be aligned with international standards. It is highly recommended to establish, with a strengthened legal framework, solid linkages between civil registration and other various national systems, and interoperability of civil registration and vital statistics databases and other management information systems, such as the national population registry, civil registration and vital statistics web-based application system and the Health Management Information System.
- b. **High-level coordination and oversight mechanism:** Putting in place an appropriate institutional coordination mechanism that brings on board key stakeholders involved in civil registrations processes, the production and use of vital statistics and establishing a high-level oversight and guidance committee is paramount. Technical working groups may be constituted to focus on particular aspects of development – for example, improving death notification, registration and reporting of causes of death procedures.
- c. **Restructuring key institutions involved in civil registration and vital statistics:** Reorganize organizational structures, functions and roles and responsibilities of key stakeholders involved in civil registration and vital statistics.
- d. **Re-engineer the civil registration business processes:** Eliminate duplication of efforts in the current paper-based registration, which would reduce waiting time for the public; and harness the efficiency from computerization of the civil registration and vital statistics and identification management systems through integrated solutions, interoperability and defining clear standards.
- e. **Financing of civil registration and vital statistics:** Prioritize the civil registration and vital statistics programme by making it as part of the line ministries.
- f. **Recording of cause-of-death:** Ensure that the causes of each death in health facilities is determined and recorded in accordance with WHO guidelines; and the application of verbal autopsy for community deaths. Collecting reliable data on major diseases will help to identify the major causes of death for appropriate corrective and preventative measures.
- g. **Capitalize on hanging fruits:** Activating the law on burials where different administrative levels organize cemeteries in an incremental phase approach would bring a profound increase in death registration in a short time, thus enabling the country to meet the monitoring requirements of many targets of the Sustainable Development Goals.
- h. **Enhancing the statistical quality of data and standards:** Improving the quality of registration information by analysing statistics from civil registration regardless of the level of completeness as a means to determine the state of the system and improve it.

A unique perspective to strengthening civil registration and vital statistics is to apply systems science and systems analysis (enterprise architecture and business process mapping) to better describe, understand, analyse and compare national civil registration and vital statistics organizations, processes, workflows and system functionality at the baseline and end line in each country. This will result in a systematic review applying systems thinking as a necessary prerequisite for better understanding how other civil registration and vital statistics interventions or innovations can be most effectively applied. Enterprise architecture is often used to improve the manageability, effectiveness, efficiency and agility of the “business” processes in a complex enterprise. Civil registration and vital statistics systems need to generate continuous flows of essential information. Enterprise architecture is the organizing logic that can be applied for understanding how civil

registration and vital statistic processes and civil registration and vital statistics information technologies work together to deliver system performance and products.²⁶

Enterprise architecture is a methodology for systematically analysing user needs, such as citizens, civil registrars, health planners and policymakers, mapping business processes (information and work flows), gathering and documenting technical requirements to meet the needs, specifications, and planning of ICT-enhanced solutions.¹⁵ Designing and deploying these solutions requires data and ICT standards, and ultimately operating and maintaining these (interoperable) solutions, as shown in figure 4.1.

Figure 4.1: CRVS enterprise architecture design



Source: World Bank and WHO, *Global Civil Registration and Vital Statistics Scaling up Investment Plan 2015–2024*, (Washington, D.C., World Bank, 2014, p. .17).

At its centre, are “backbone” connectivity and a central data warehouse and repository. A data warehousing approach involves integrative thinking. For example, if a database for issuing birth certificates is also used by ministries of home affairs for issuing passports, there are additional incentives for keeping the databases up to date.

²⁶ Bloomberg for health initiative, “CRVS systems architecture & analysis. Available at https://innovationxchange.dfat.gov.au/sites/dfat/files/D4H%20Innovations_0.pdf.

Actors in one part of the civil registration and vital statistics system may not know how other parts of the system work and may also struggle to describe precisely what occurs in their own part of the system. The civil registration and vital statistics system's architecture and analysis approach is an important contribution to collective thinking and could have important ramifications for reforming it through the use and influence on civil registration and vital statistics design, strategic investment plans and road maps for long-term CRVS vision.

To measure progress, it is crucial that national vital statistics offices and analysts are able to interrogate the quality of vital registration information on mortality rates and causes of death in real time as it becomes available in order to take timely corrective action. Furthermore, assuring and knowing the quality of mortality data should increase the confidence of civil registration and vital statistics personnel to interpret and use such data available for further analysis, dissemination and use. This is not currently the case in most low- and middle-income countries where civil registration and vital statistics data are widely underutilized because of ill-informed, but justified concerns about their quality.

4.3 Description and analysis of the “as-is process”

To identify appropriate interventions to support civil registration and vital statistics systems, an “as-is” assessment must be conducted to understand the strengths and weaknesses of the existing civil registration and vital statistics landscape, including several components documented in the business architecture, such as civil registration and vital statistics business processes. Basing subsequent decisions on these findings will ensure that the interventions directly address identified weaknesses. *Note: If a comprehensive assessment has been conducted, this should be used as an input to complete the steps below.*

1. Identify all key stakeholders to be consulted and involved throughout the as-is assessment.
2. Assess the civil registration and vital statistics business processes:
 - Identify the bottlenecks, inefficiencies, delays and informal practices, consulting stakeholders involved in the current civil registration and vital statistics process;
 - Assess the capacity of actors to conduct current process steps, consulting stakeholders involved in the current civil registration and vital statistics process;
 - Identify registration barriers, namely reasons why citizens do not actively register vital events, consulting a representative sample of citizens and those involved in administering the current civil registration and vital statistics process;
 - Annotate the business process flow diagrams with identified bottlenecks and registration barriers.
3. Assess the civil registration and vital statistics system architecture:
 - Document the existing civil registration and vital statistics system architecture (including interfaces with other systems);
 - Document the existing logical and physical data model;
 - Assess the current systems based on the following criteria, consulting stakeholders who maintain and use the system: accuracy of data; timeliness and relevance of data; system reliability; system performance; system security; recoverability; accessibility to users; usability; and legality.
 - Annotate the system architecture diagram with any identified weaknesses, including the absence of key system components.

4.4 How to design an improved process

A five-phase approach is recommended to re-engineer a business process mapping:²⁷

²⁷ Prof. Don de Savigny and Dr. Daniel Cobos Muñoz. Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design, Kigali, 21-23 June, 2016

Phase 1: Preparation of the business process mapping exercise

During this phase, the organization's mission and vision and strategic and operational goals are specified. The business process re-engineering method is driven by a business vision, which implies specific business objectives, such as cost reduction, time reduction and output quality improvement. Specifically, the following should be performed:

- Create a business process mapping core team (the head of the team should be part of the current system, and must have deep knowledge about the processes and workflows of the system);
- Get the necessary support (the team must be appointed and empowered by relevant authorities, depending on the scale of the activity);
- Identify the process or processes to be improved (core processes – these fulfil the system's mission and goals; support processes – these support the operational functions of the system; and management processes – these support the planning, decision-making or monitoring the performance of the business process within a system)

Phase 2: Current process

Phase 2 contains the elaboration of a clear vision in line with the strategic and operational objectives for each *change opportunity*. The business processes to be redesigned should be identified in this phase: most firms use the “high impact” approach, which focuses on the most important processes or those that conflict most with the business vision. A lesser number of firms use the “exhaustive approach” in which an attempt is made to identify all the processes within an organization and then prioritize them in order of redesign urgency.

It is expected that that during this phase, the following will occur:

- Understanding of the context (develop a stakeholders' map – see figure 4.2);

Figure 4.2: Potential stakeholders in a country



Source: Don de Savigny and Daniel Cobos Muñoz. *Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design*, page 26

- Compilation of the architecture reference library (documentation of previously conducted business process mapping activities through a review of strategic documents; standard operating procedures and workflow diagrams; operational guidelines, manuals and protocols; job descriptions of positions

involved in the system; memoranda of understanding between different stakeholders; performance monitoring reports; and international standards with regard to the processes under analysis); Development of the as-is business process map (use standard notation, and balance between detail and manageability)

Phase 3: Analysis

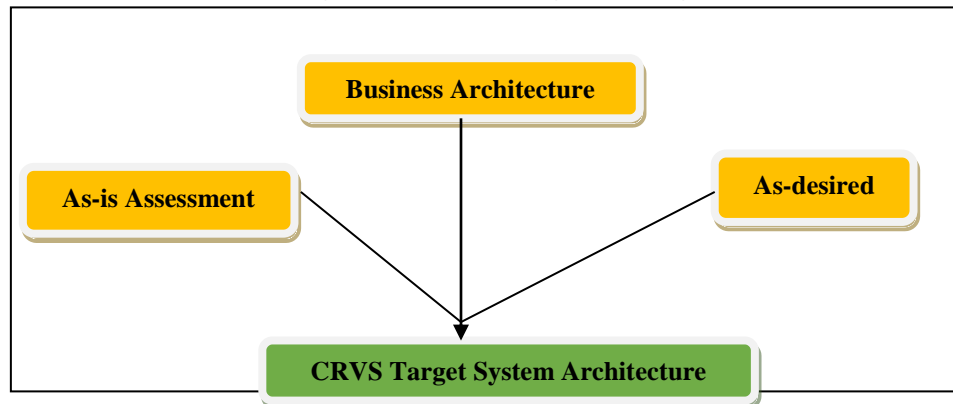
Phase 3 entails an evaluation and analysis of the as-is situation after which the future processes (“to-be”) get defined and elaborated. The selected quick win projects are implemented. In so doing, it is critical to understand and measure the existing processes so as to avoid repeating old mistakes and provide a baseline for future improvements. The specifics in this phase include:

- The following questions should be answered: Is the process fit for the purpose? Does it satisfy the business requirements?; Are there points where the process is delayed or stopped abruptly?; and Are time and resources used efficiently in the process?
- Assess the performance by identifying design flaws in the process, (for example some civil registration and vital statistics systems rely on the family to register vital events, validation process for vital events or quality assurance activities are not described, death registration is disconnected from cause of death data, fragmented storage system, or information is transmitted using parallel channels);
- Identify the root causes of the underperformance (outputs and outcomes of the process, namely the per cent of deaths registered; intermediate results, namely the number of deaths notified versus those registered; number of interactions to deliver an output; cost, time and resources to deliver an output; and user satisfaction.

Phase 4: Improved process

The gap analysis between the “as-is” process and the “to-be” process is performed during phase 4, as illustrated in figure 4.3.

Figure 4.3: Modelling for change



Source: Don de Savigny and Daniel Cobos Muñoz. Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design, page 24

Based on the analysis, develop the “as-desired business process mapping” of the new process and assess the implications of the future design in terms of: legal and regulatory implications; coherence with the current vision and strategy associated with civil registration and vital statistics; human resources and infrastructure, equipment, among others; and the generation of standard operating procedures. The new process should be aligned with the key stakeholders and clear mechanisms are needed for getting feedback.

Phase 5: Plan for change

During the fifth phase, the focus should be on the implementation of the new procedures. Design and build a prototype of the new process: the actual design should not be viewed as the end of the business process re-engineering process, instead it should be viewed as a prototype, with successive iterations. The metaphor of prototype aligns the business process re-engineering approach with a quick delivery of results, and the involvement and satisfaction of customers. The key activities are as follows:

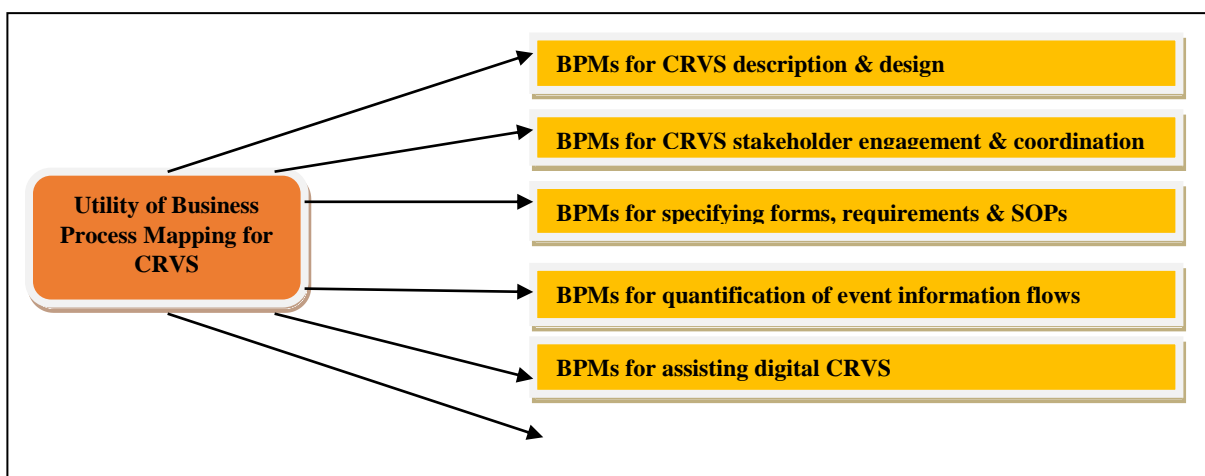
- Identify the gap between the current and the future design of the process;
- Develop a business case for the new design;
- Establish an enterprise architecture governance structure;
- Share, discuss and negotiate the new design with all relevant stakeholders;
- Create an implementation plan or road map.

A number of potential uses of enterprise architecture process mapping have been identified⁶¹ as outlined below.

- **System redesign:** A detailed description of the current and the future system is extremely useful to support change management.
- **Planning:** Analysis of the business process mapping is helpful in identifying flaws in the system and areas in which specific interventions could be relevant. This process also shows if the operations in civil registration and vital statistics processes are aligned with the overall strategy and goals of the system.
- **Regional variations:** In highly decentralized countries where lower levels of the system can adapt or modify the civil registration and vital statistics processes, business process mapping could provide them with a blueprint of the standard process with laws and regulations that support this design.
- **Standard operating procedures, requirements and forms:** Business process mapping exposes processes that are not described with sufficient detail and thus, are not implemented consistently, such as validation activities.
- **Align stakeholders:** Presenting and analysing business process maps is an opportunity for stakeholders to work together as a group.
- **Identify bottlenecks and inefficiencies:** The analysis of the business process maps would expose design flaws and inefficiencies that limit its performance.
- **Engineer new interventions:** Any new intervention or activity that would be added to the existing system must be assessed using business process mapping.

These potential uses are summarized in figure 4.4:

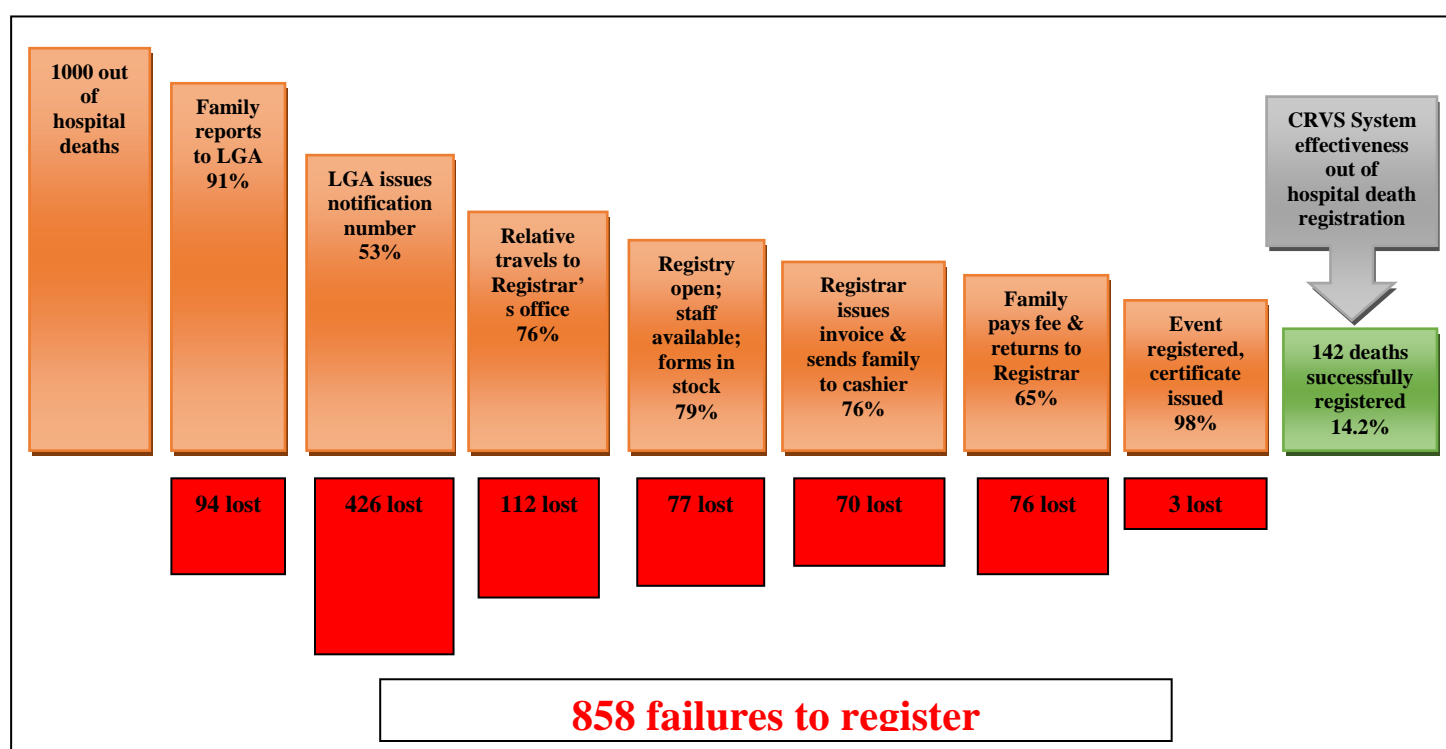
Figure 4.4: Utility of enterprise architecture and business process mapping for civil registration and vital statistics



Source: Don de Savigny and Daniel Cobos Muñoz. *Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design*, page 29

A practical example of enterprise architecture and business process mapping analysis is illustrated in figure 4.5

Figure 4.5: An example of system effectiveness in registering 1,000 deaths



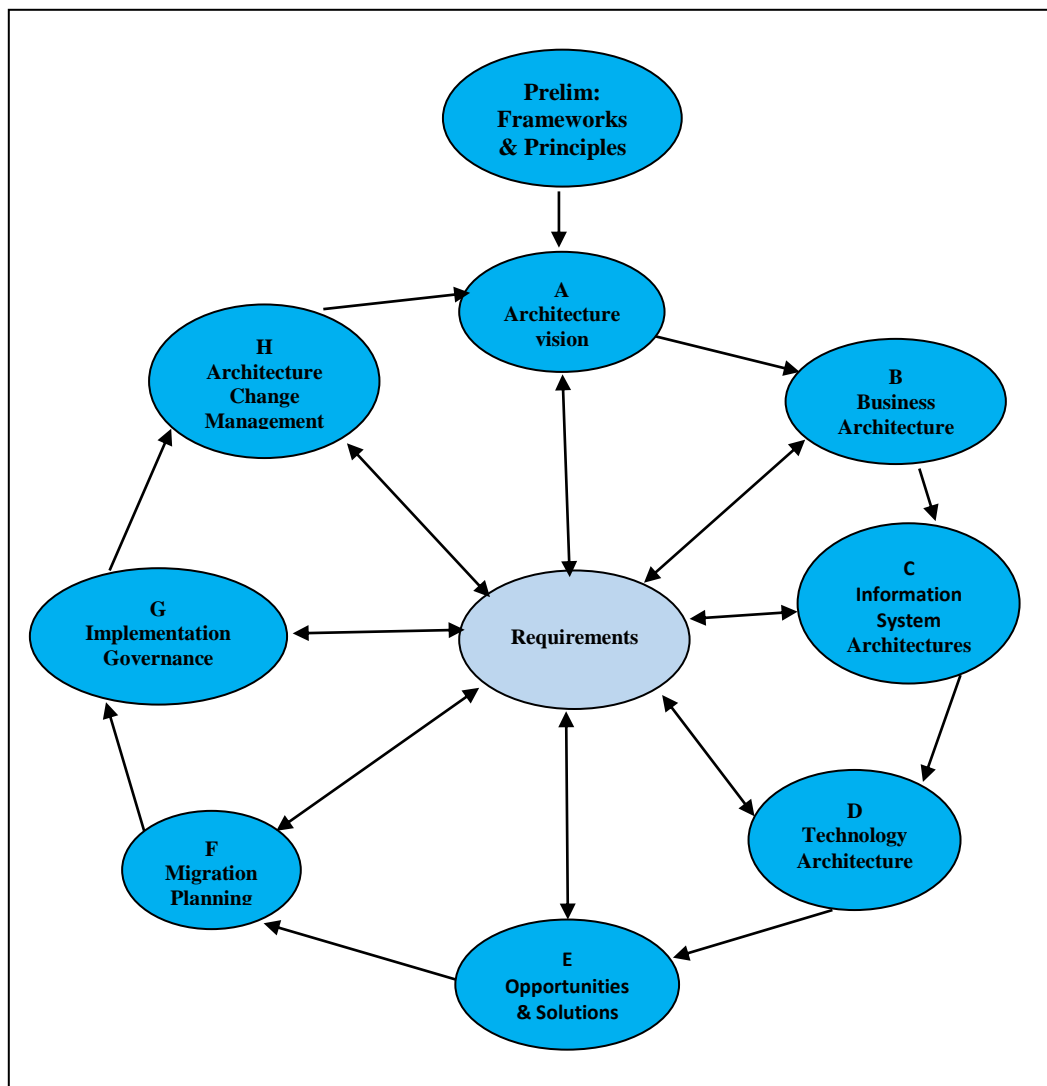
Source: Don de Savigny and Daniel Cobos Muñoz. *Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design*, page 103

4.5 How to plan for change: definition and implementation of interventions for change

There are several frameworks to guide the implementation of an enterprise architecture approach in a system. One of the most used in the private sector is The Open Group Architecture Framework.²⁸ This framework is usually described as a cycle (figure 4.6).

²⁸ University of Melbourne. *Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design*, Draft 1st Year Report, April 2015 – March 2016

Figure 4.6: The Open Group Architecture Framework



Source: University of Melbourne. Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design, page 3

It is used to analyse processes in relation to three “architecture domains”. First, the business architecture defines the strategy and describes the key business processes of the system. Second, the information system architecture describes the data and information flows in the process, as well as the data management activities. Finally, the technology architecture describes the information technology infrastructure and core applications used in each process. In a sense, the three architectures described above are three different representations of the same reality, of the same system.

Business process modelling is commonly used to describe the business architecture. Such modelling provides a snapshot of the current processes to be analysed and potentially re-engineered. Table 4.1 shows the different levels of analysis in business process modelling.

Table 4.1: Levels of analysis in business process modelling

Level of analysis	Type of map	View
Organization	Relationship map	Organization: the parts of the civil registration and vital statistics system and their connections
Processes	Process map	Workflows: the path of work, including that which cuts across parts of the system; the architecture that connects people, information and activities
Activity	Flow chart map	Activities: the specific work performed for an output (both value and non-value creating)

Source: University of Melbourne. Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design, page 4

The relationship map or stakeholder analysis graphically depicts the parts of the national civil registration vital statistics ecosystem with all its subsystems. It gives a detailed organogram of the system’s structural building blocks at the institutional level (government agencies, funding partners, suppliers, offices and users) at various levels of the system from the national level to the community level if present. It shows the part-to-whole relationships, connections or linkages among these parts of the civil registration and vital statistics organization.

The process map graphically depicts the workflow of the civil registration and vital statistics system at a macro level. It derives from the relationship map, which provides the horizontal bands or swim lanes for each part of the system so that the handoffs of information or work between the functionally (organizationally) distinct parts of the system become clear, such as triggering an event of a death in a health facility or the community > notification steps > registration steps > certification steps > data management steps > coding steps > vital statistics steps > data use steps). It illuminates the interfaces in the system. This is the most instructive of the three types of process mapping in terms of describing the system and its design impediments. The flow chart map graphically depicts the sequence of more detailed work activities used to produce a particular output within a process. This gives the most granular view of the work. It also distinguishes a value creating activity from a non-value creating activity, such as wastage, delays, storage, batching, movement and rework and illuminates where losses in time, data and data quality occur.

The general approach followed during the implementation of the different activities has three main features:

- **Participatory:** both the development of the maps and analysis should be the result of country discussions with all relevant stakeholders.
- **Action oriented:** drawing the maps is not an end, but a means. The business process modelling should be presented as tools to understand and improve the core civil registration and vital statistics processes of the system in the country. Countries use the maps based on their different needs.
- **Systems thinking:** business process modelling should capture all activities undertaken by relevant stakeholders in the process and with sufficient amount of detail. The objective is to produce maps that capture the end-to-end process in a system. For practical reasons, the maps may not be as detailed as they could be, but they should include all relevant activities and stakeholders.

A number of system design flaws have been identified using business process maps, some of which are present in several countries.⁶³ These maps limit the performance of the system or produce inefficiencies. Some of the most relevant flaws are as follows:

1. A number of civil registration and vital statistics systems rely on the **family to register vital events**. In countries where there is no strong incentive to register vital events, this type of system design challenges the objective of universal death registration. In countries, such as the United Republic of Tanzania, the family must have up to three interactions with different stakeholders of the system before registering a death. As a consequence, there are several decision points in the process during which the family can decide not to continue and thus, this death will not be captured.
2. All civil registration and vital statistics processes analysed through business process mapping contain a step in which the vital event is validated and another one in which the quality vital statistics is assessed. However, the **validation process for vital events or quality assurance activities are not described**. Experiences in different countries suggest that these activities are not implemented in a systematic way and there is a need for developing standard operating procedures to describe this critical step.
3. **Death registration is disconnected from cause of death data**. This is the case in most developing countries, including, among them, Brazil, Rwanda and the United Republic of Tanzania. The sub-system within a country's ministry of health identifies the cause of death, and is often kept only in the health sector – yet this information should be transmitted to the civil registration subsystem to store it with all data related to the vital event.
4. Brazil and the Philippines are more advanced with regard to digitalizing the civil registration and vital statistics as compared to Rwanda and the United Republic of Tanzania. However, in both cases, systems are designed with local databases that must be updated (regularly in the case of Brazil). This **fragmented storage system** leads to inconsistencies between the different databases if officials fail to update them. This is particularly important in the case of the Philippines where there is no systematic way to provide feedback about the national and provincial level databases to the municipalities.
5. **Information is transmitted using parallel channels**. Although this design responds to the reporting functions of the various stakeholders, gains in efficiency are erased when taking into account the system as a whole.

4.6 Lessons from pilot projects on business process mapping

Through the Bloomberg Data for Health Initiative, pilot projects were carried on how to use business process mapping to show countries an end-to-end visualization and analysis of how their civil registration and vital statistics systems work for birth and deaths in community and health facilities.⁶³ By applying business process

mapping techniques to understand the organizational design and the core business processes of their current and proposed systems, pilot projects were implemented in Brazil, the Philippines and the United Republic of Tanzania between April 2015 and March 2016. The following are the most relevant lessons learned from these projects:

- Country stakeholders provided for first time with **end-to-end picture and analysis of their whole civil registration and vital statistics system**. An analysis of the pilot project showed that even for people who have never seen a business process map, a brief introduction of the enterprise architecture approach and a description of the different symbols used in the maps were enough to be able to read and analyse them. One of the most powerful features of business process maps, according to several project participants, was that they were able to show an end-to-end visualization of complex processes, such as the civil registration and vital statistics processes. This macro picture of the system helped them to see where the bottlenecks were, areas with room for efficiency gains and other design flaws.
- Stakeholders were **collectively able to see how it is currently designed**, and able to **discuss the future from a common understanding**. The business process mapping was also very successful in bringing together the stakeholders to discuss their civil registration and vital statistics systems. It was also clear that countries saw in the maps a tool that could be used for different purposes. The tool proved to be very flexible, as it was used for planning in the United Republic of Tanzania, to establish standards in the Philippines; to align stakeholders' views with each other in Brazil; and to engineer a new intervention, such as verbal autopsy in Rwanda.
- **Recognition of the need to formulate standard operations for the key processes**. The enterprise architecture workshops gave the stakeholders the opportunity to share ideas and discuss solutions to improve the performance of the system.
- Potential to **influence civil registration and vital statistics design, re-engineering, strategic investment plans and road maps** for setting a long-term civil regulation and vital statistics vision. Some participants pointed out that the workshop was the first time that all institutions involved in their civil registration and vital statistics system were in the same room working together.
- Civil registration and vital statistics architectures and process diagrams are **emerging as one of the most “in demand” tools** from the Data for Health Initiative.

Specific outputs from the pilot projects in Rwanda and the United Republic of Tanzania are summarized in box 4.1.

Box 4.1: Outputs from the pilot projects in Rwanda and the United Republic of Tanzania

United Republic of Tanzania: Example of system redesign - Outputs

- First time all stakeholders could see civil registration and vital statistics processes end to end
- Analysis of the current and future processes showed fundamental flaws in the design, namely. dead ends for data and parallel channels
- Raised the need to apply detailed business process mapping to inform the digitalization process
- Identified areas in which civil registration and vital statistics processes do not follow current regulations and laws
- Used to conceptualize a mobile verbal autopsy approach

Rwanda: Example of engineering for new interventions - Outputs

- Business process mapping exposed existing unexploited systems that could capture deaths occurring in the community not used in the current processes
- Business process mapping was used to conceptualize and engineer mobile verbal autopsy into the existing system
- Business process modelling was used to secure high-level inter-ministerial support

Source: University of Melbourne. Enterprise Architecture (EA) Process Mapping for Strengthening CRVS Design, Draft 1st Year Report, April 2015 – March 2016 pages 8 and 16

Chapter 5 - Strategies for improving death registration and the collection of cause of death information

5.1 Service delivery

The United Nations has pointed out that a major challenge countries in Africa face is the weak coordination or cooperation among the different stakeholders in civil registration and vital statistics.²⁹ The existence and functions of a coordination mechanism among different agencies is often not clearly stated in the civil registration law or regulation. Descriptions on how information on the registered vital events should be transferred to either upper-level administrative offices or to a different agency are mostly missing from the legislation. A number of countries have created a coordination agency or committee, namely Egypt, Ghana, Kenya, Lesotho, Mozambique, Rwanda, the United Republic of Tanzania and Zimbabwe. In other countries, for example in Gambia and Swaziland, the system is fragmented with limited coordination; sectors concerned do not or rarely coordinate activities.

Interactions involving multiple institutions are necessary between the event of a death and the production of mortality and cause-specific mortality tabulations at the national level. Generally, more than one government department is involved and the compliance of the general public, the civil registration authorities, the health system and the statistical office are crucial for the system to function adequately. The legal framework and the structural organization for death registration are basic administrative pillars that determine the functioning of the system. Understanding these aspects at the county level are an important first step in making improvements. A few salient characteristics of these aspects are described below.

Legal framework

A sound and comprehensive legal framework is fundamental to the establishment of a well-functioning death registration system. A national registration act, and an associated set of rules and regulations, should provide, for example:

- A sufficient definition of duties and responsibilities of the citizens as well as the government;
- A complete set of forms and instructions on use of the forms;
- A clear administrative hierarchy for the collection and submission of data;
- Nomination of responsible individuals at each level in the hierarchy, with adequate delineation of roles and responsibilities;
- Responsibilities of central agencies for collation, analysis, and publication of vital statistics;
- Provisions for public access to individual records, as stipulated in the law.

Organizational issues

Civil registration is usually entrusted with ministry of home affairs in most African countries. Responsibilities for registration are devolved through an administrative hierarchy to primary units, which are typically municipal or city councils in urban areas, and village councils or headmen in rural areas. Health facilities, health practitioners, coroners and pathologists are expected to be compliant and collaborate with others to record proper cause of death attribution at the time of death registration. Overlapping responsibilities and poor

²⁹ United Nations Statistics Division, "Status of civil registration and vital statistics: African English speaking countries", CRVS Technical Report Series, Vol. 3 June, 2016. Available at <https://unstats.un.org/unsd/demographic/CrVS/Technical-report-CrVS-in-English-speaking-African-countries3.pdf>.

collaboration between different sectors have been cited as major impediments to the development of the system in Kenya and Zambia.³⁰ When advising structural changes to the system, it is useful to bring together data producers and data users to effectively plan reforms.

System design

To effectively compare data across populations and over time, standard data definitions, design forms, procedures for cause of death certification, coding systems and formats for summary tabulations are essential. While all these issues are subtly related, the latter two are more technical and are dealt with separately in the next section. Standard data definitions are especially important for issues related to mortality. Regarding adult deaths, proper definitions and guidelines are required for determining whether a specific death requires an official investigation as to the cause of death, as a medico-legal case. WHO prescribes an international form of medical certificate cause of death to be used uniformly by all member States although this form is not widely used in most African countries. The use of standard methods for compiling cause-specific mortality statistics for international comparison is an area of technical expertise that cuts across the disciplines of demography, epidemiology and statistics. Capacity needs to be built in these disciplines by academics with practical experience in such data collection and management, with the intention that they will transfer technical expertise and teaching skills to local personnel to sustain capacity development for enhancing registration systems. Specific technical aspects include coding of causes of death, various elements of capacity-building and quality control measures.

Capacity-building requirements

Extending training on registration and vital statistics to staff contributes significantly to the strengthening of the civil registration and vital statistics systems. Training programmes provide the knowledge and skills necessary for the required functions to be carried out efficiently. Through a better understanding by staff of what is expected, errors are reduced and morale is improved. Periodic training and retraining also provide opportunities for the staff to provide feedback on problems and possible alternative procedures and solutions. It is also important that statistical personnel be well informed about the operation and the strengths and weaknesses of the civil registration system. Similarly, civil registration staff need to understand the uses and importance of statistical items, and the requirements in this regard for completeness and accuracy. The training plan should distinguish between internal training, which is oriented for civil registrars, vital statisticians and other technical and administrative personnel, and external training, which is oriented for policymakers, local officials, medical and health personnel and others that are affected by the quality and uses of civil registration and vital statistics.²

Internal training should focus on techniques, methods and skills and address issues of professional roles and functions. External training should be designed to inform participants about the needs and functions of civil registration and vital statistics systems, and should seek to develop improved understanding and cooperation. External training is a crucial improvement mechanism and should not be neglected: an environment characterized by cooperation and support is essential to its success. In the case, for example, of medical and

³⁰ Paul Kowal, P.V. Chalapati Rao and Colin Mathers. Report on a WHO Workshop: Minimum Data Set Version 1.0 on Ageing and Adult Mortality Data in sub-Saharan Africa Pretoria, South Africa 12 - 14 February 2003. Available from http://www.who.int/healthinfo/survey/ageing_mds_report_en_pretoria.pdf.

health personnel who provide data to the system, the quality of the information is dependent on their understanding of the importance of accurate data and the uses to which they will be applied. For these reasons, both internal and external training programmes should be an integral part of the civil registration and vital statistics systems. The responsibility for these programmes, which should be carried out on a regular rather than an ad hoc basis, must be shared between both systems.

A newly designed or restructured registration system cannot function without trained administrative and technical personnel. The importance of physician training for cause of death certification cannot be overemphasized. Simple training programmes using locally available resources (for example, hospital case records and completed cause-of-death certificates providing correct and incorrect examples) can be drawn up and conducted periodically. Training on cause-of-death certification and on the uses of such information should be included in medical training curricula and in continuing professional training.

Capacity-building is also required for administrative personnel. In Kenya, lack of training and feedback has been mentioned as a cause of apathy and lack of motivation among the staff.⁶⁷ Coupled with this, is the lack of capacity to analyse data at the local level, with the resultant non-utilization of data at local levels, leading to further neglect to the system. Training on International Classification of Diseases coding is central to the production of useful statistics on causes of death. Support in this type of coding and data analysis is needed at the country level, with support from WHO on a regional basis. At national level, training is required for personnel involved in data transfer, processing, analysis, tabulations, data validation and dissemination. Computerization, with proper training, can greatly improve the speed and accuracy of data processing and analysis. However, the capacity to assess the quality of data and to interpret them is also essential to ensure that the data can be used optimally to inform policy.

Quality control aspects

Coverage of civil registration systems and the quality of cause of death information are two important aspects that need to be monitored. There are several other aspects in which reported cause of death statistics need to be evaluated for assessing their usability for health policy and monitoring. These assessments should be built into regular quality control mechanism in the death registration system.

Political will

Strong political support is essential for establishing collaboration between different agencies and personnel involved in the registration system. Improvements in death registration data require a concerted demand for valid and reliable mortality data from policymakers, bureaucrats, social scientists, and health professionals. Short capacity-building programmes on the importance and uses of data from vital registration systems should be organized for policymakers and other key stakeholders. Such programmes can generate political and administrative support required to formulate and implement reforms in national registration systems, and subsequently monitor performance, and improve accuracy.

In recent years, efforts related to engaging ministers at the regional level have been introduced as a tool for improving civil registration and for bringing this issue to the forefront of political and government agendas. Such a process in Africa, which is in progress, is resulting in a major commitment by all Governments to improve their civil registration and vital statistics.²

Public education, information and communication For civil registration and vital statistics systems to function properly, the parties involved in the overall operation of the system must have a good understanding of the system and cooperate with each other.² These groups are as follows: the general public; representatives of institutions, professions and agencies; senior government officials; and personnel working directly within the civil registration or vital statistics systems.

a. Government officials

Senior government officials, under whose jurisdiction civil registration and vital statistics fall, should be made aware, preferably by special in-person briefings, of the importance of civil registration and vital statistics systems to the general public and to Government and the several government programmes that rely on these systems. They should be informed of the dependency of vital statistics on the registration system and should be aware of the need for an acceptable level of data quality to ensure statistical reliability. Senior government officials should be involved at an early stage in any major initiatives aimed at improving the systems. Their support must be enlisted for activities having budgetary implications. These officials should also be kept informed, on a timely basis, of the results of evaluations of the systems to ensure a good level of understanding of the strengths, weaknesses and probable future requirements. Communications with high-level government officials should be designed specifically for these individuals and be as concise as possible.

b. The general public

The general public is the “target population”, comprising individuals whose vital events have been or will be registered; these individuals may from time to time provide information regarding a vital event. They use the registration system to obtain legal documents or to otherwise document the vital events occurring to themselves or other family members. Therefore, the public should be made aware, on a long-term, continuous basis, not only of the requirements for registration of vital events, but also of the value and benefits that accrue to them through utilization of the registration system. Without the public being motivated to register events promptly and accurately, civil registration and vital statistics systems will not function properly. Every effort should be made to inform the members of the public of the following: the reasons why they should register on a timely basis and accurately; their obligations in this regard; and the benefits of compliance for individuals and society. The general public needs to know where, when and how to register vital events, and to appreciate why they must do so. Communications carrying these messages, aimed at educating the general public, may be brief and transmitted by radio, television, posters, pamphlets or other media. The messages should include not only an enumeration of the important uses of civil registration and the benefits to individuals, but also a short description of how, when and where this simple process is to be carried out.

Active public participation is essential in the process of civil registration. This can be increased through public awareness of the basic purposes of civil registration, and the responsibilities of citizen and government regarding it. Linking individual records of civil status to basic citizen’s rights can help increase awareness, such as school enrolment, property transfer mechanisms and survivor dependency benefits. Public cooperation can be actively solicited through linking vital records to respect for human rights. At the same time, the State has an obligation to provide the necessary organizational structure, sound legal framework, and adequately trained staff.

Innovative approaches are available for enhancing public awareness. In Zimbabwe, mobile registration campaigns are conducted occasionally, which includes waiving certain fee liabilities for delayed death registration. In South Africa, an unofficial notifier system involving midwives, nurses, graveyard attendants, school teachers and religious officials has been developed with the objective to increase awareness and enable the general populace to become part of the registration process, has been developed. In many countries, mass media campaigns use newspapers, radio and television to promote public awareness of citizens' rights and responsibilities towards registration of vital events.

c. Members of institutions, professions and agencies

This group includes those who may participate directly or indirectly in the civil registration and vital statistics process, but whose principal duties are outside the systems. Among them are physicians, health workers, midwives, clinic and hospital personnel, educational officials, such as directors of medical schools and schools of public health, and local government authorities dealing with civil registration. When appropriate, job descriptions for persons in this group should specifically include their responsibilities under the civil registration and vital statistics systems. An educational campaign designed for members of this group should emphasize their part in the overall success of the system and reinforce awareness of their specific responsibilities and duties, including a step-by-step description of the required procedures. In addition, educational materials should focus on the value of educating the public in order to help members of this group perform their role as educators of that segment of the public representing their clientele.

5.2 Improvements and new developments

Many African countries lack adequate legal or statistical recording systems for vital events. However, significant momentum pertaining to civil registration and vital statistics has been building up recently, owing to the emergence of regional initiatives.⁶⁶ The First Conference of African Ministers Responsible for Civil Registration, Member States, which was held in Addis Ababa in August 2010, endorsed a standing regional platform to advance civil registration and vital statistics policies in Africa. Two years later, the Second Conference of African Ministers Responsible for Civil Registration launched the Africa Programme on Accelerated Improvement of Civil Registration and Vital Statistics (APAI-CRVS), a regional programme developed under the leadership of ECA to provide management and programmatic guidance to the regional agenda to reform and improve civil registration and vital statistics systems. At their Third Conference, the African Ministers Responsible for Civil Registration, through the Yamoussoukro Declaration, resolved to: strengthen the capacity of the secretariat of APAI-CRVS; establish strong links with the health and other relevant sectors to improve registration service delivery at the most appropriate administrative level; establish linkages between civil registration and national identity systems in efforts to manage one legal identity; and support the development of guidelines and recommendations for maintaining and managing civil registration and vital statistics in conflict and emergency situations. They also requested the secretariat to develop guidelines to support countries in mainstreaming gender issues in civil registration and vital statistics.¹

Since its inception, APAI-CRVS has identified the following bottlenecks in civil registration and vital statistics systems that need to be dealt with:

- Project-based ad hoc efforts (pilots, models) that are operating independent of national plans and programmes;

- Uncoordinated efforts and support by donors – with a focus on fragmented components of civil registration and vital statistics systems;
- Initiatives that do not address systemic issues, namely those that relate to legal, organizational, management and capacity development matters;
- Uncoordinated and fragmented regional efforts;
- Lack of commitment at the political and policy levels;
- Insufficient efforts to create demand and improve service delivery;
- Multidisciplinary and multi-sectoral approaches in the management of the civil registration and vital statistics system;
- Civil registration based on colonial laws and not in sync with local cultural and religious practices.

Many countries have already conducted an initial assessment of their civil registration and vital statistics systems, using the tool developed by APAI-CRVS, and developed an improvement plan. Among other findings, the comprehensive assessments have highlighted the fact that in many African countries, no mechanism exists to count the number of vital events registered and hence compute the registration level, and the mechanism to compile the information gathered from civil registration into tabulations is weak or fragmented. When registration data are used in the compilation of vital statistics, little effort has been directed to conducting qualitative assessments. Thus, decisive actions need to be taken to factually improve the flow of information from the moment a vital event occurs, is notified, is registered – together with all the recommended core topics – until the relevant data are used for vital statistics tabulations.

Since the inception of the Conferences of African Ministers Responsible for Civil Registration in 2010, the United Nations has concurred that visible progress has been achieved at the national and regional levels and the momentum generated then is getting strong.⁶⁶ Yet the state of the art of civil registration and vital statistics is far from homogenous. In many countries, the civil registration has improved significantly while, for others, the process remains unstable. In reviewing the current circumstances in the countries of the African region, it may be concluded that further improvements are needed in a number of areas. This finding is supported by the Yamoussoukro Declaration, as noted above. Consequently, efforts need to be intensified at all different technical and operational planes, primarily through political settings at the highest possible level.

Strategies for improving death registration

There is no single pathway to reaching the goal of establishing an effective civil registration and vital statistics system. Because the scale and complexity of the task varies greatly between countries, strategies need to be tailored accordingly. To make progress in this area, a detailed understanding of the status and performance of the current civil registration and vital statistics system are required. Such an understanding will allow for the identification of the main issues that need to be addressed, especially in the short to medium term. WHO recommend that a two-step self-assessment approach be undertaken, which involves conducting a strategic analysis of current systems, and outlines the types of interventions and other activities that are needed based on the assessment outcome.²¹ The two steps are as follows:

- An initial rapid assessment to quickly evaluate the state of the current system and make the case for a more detailed assessment. Through this, a series of numerical scores reflecting the strengths and weaknesses of the current systems is generated, and one overall score for classifying systems into one of four categories;

requisite actions associated with each of the four categories are suggested. This is primarily aimed at raising awareness and preparing the way for a more-comprehensive review;

- A comprehensive assessment to compare current systems with the civil registration and vital statistics standards developed by UNSD and WHO. This assessment is intended to produce the evidence needed to prioritize improvement activities and develop an improvement plan.

The rapid and comprehensive assessments were developed through close collaboration between country and technical partners, and are designed to be self-assessments completed by a suitably broad group of local stakeholders – with technical support if needed. Broad participation is a crucial factor in the eventual improvement of civil registration and vital statistics systems, as this will require effective collaboration between government departments in both the health and non-health sectors, and cooperation with non-governmental organizations and other civil society groups. The rapid assessment can be completed by the major stakeholders in less than a day. The comprehensive assessment requires more time and involves more participants, but yields a much more-detailed diagnosis of the problems and provides clearer guidance on the priority actions required.

Rapid assessments have been conducted in more than 30 countries – mainly in the Asia-Pacific region. Based on the results, a typology has been developed that classifies country civil registration and vital statistics systems into four groups – dysfunctional; weak; functional but inadequate; and satisfactory. Table 5.1 contains an outline of the main challenges that countries face in each of the four typology groupings and sets out the level of actions required in each case.

Table 5.1: Typology of national civil registration and vital statistics systems according to overall rapid-assessment scores

Score (%)	Typology	Description	Actions required
<35	Dysfunctional	There is very limited registration of births and deaths and medical certification of cause of death. The systems do not produce vital statistics	Systems require improvements in all areas
35–64	Weak	There is incomplete or variable registration of births and deaths (with higher coverage in urban areas for example), limited medical certification of cause of death (mainly confined to secondary and tertiary hospitals), and vital statistics are not generally compiled and analysed	Many aspects of the systems do not function well and multiple areas require attention
65–84	Functional but inadequate	There is complete registration of births and deaths and medical certification of cause of death in hospitals, but limited medical certification for non-hospital deaths. There are concerns about the compilation, quality, and dissemination of vital statistics	Systems work but some elements function poorly and require attention. The comprehensive assessment should be completed to identify weaknesses in the systems
85–100	Satisfactory	There is complete registration of births and deaths with medical certification of cause of death. Vital statistics are produced and used, but there are some concerns regarding data quality	Minor adjustments may be required for otherwise well-functioning systems

Source: World Health Organization, Strengthening Civil Registration and Vital Statistics for Births,

Assessing current status

The first step in strengthening CRVS systems is to conduct an assessment of the current situation. In the case of both the initial rapid and comprehensive assessment tools, all aspects of civil registration and vital statistics systems that focus on births, deaths and causes of death are addressed. However, neither is intended to cover other aspects of civil registration and vital statistics systems, such as marriage and divorce. Other assessment tools that focus on specific aspects of systems, such as completeness or quality of cause-of-death data, are available.

Application of the rapid assessment tool will help decision-makers to position their current systems, and to identify feasible and realistic options for moving forward. The tool is particularly relevant for senior decision-makers. It is also appropriate for settings where systems are dysfunctional or weak and resources are limited, as it helps to generate the evidence needed to advocate strengthened civil registration and vital statistics systems. The rapid assessment tool consists of 25 questions on the functioning of civil registration and vital statistics systems grouped into the following 11 component areas:

1. Legal framework for civil registration and vital statistics;
2. Registration infrastructure and resources;
3. Organization and functioning of the vital statistics system;
4. Completeness of birth and death registration;
5. Data storage and transmission;
6. International Classification of Diseases-compliant practices and certification within and outside hospitals;
7. Practices affecting the quality of cause-of-death data;
8. International Classification of Diseases coding practices;
9. Coder qualification and training, and quality of coding;
10. Data quality and plausibility checks;
11. Data access, dissemination and use.

This simple-to-complete assessment should be conducted by a group of knowledgeable individuals with responsibilities for various aspects of civil registration and vital statistics systems. Question responses should be agreed-upon and selected following thorough group discussions. For each of the 25 questions, respondents must select from one of four possible scenarios, choosing the one that they consider most closely reflects the country situation. A numerical value (0–3) is assigned to each scenario to indicate how well this aspect of the system functions. The total score is computed by adding together the numerical scores for each of the 25 questions. This overall score is then expressed as a percentage of the maximum possible score (n=75) to provide a reasonable measure of the broad functionality and quality of national civil registration and vital statistics systems. In addition, percentage scores can also be calculated individually for each of the 11 component areas listed above. Taken together, these results should enable decision-makers working in civil registration, vital statistics and health information systems to identify realistic broad areas requiring improvement in the near to medium term, and to identify the detailed operational activities and phasing that will be most relevant to their needs.

The rapid-assessment instrument can thus be helpful in highlighting the main strengths and weaknesses of current civil registration and vital statistics systems, but it is not sufficient for identifying detailed development priorities and feasible improvement strategies. The rapid assessment should, therefore, be seen as a precursor to the more-comprehensive assessment made against international standards. This involves a wider array of country stakeholders and comprises a detailed analysis of all the civil registration and vital statistics system components. Such an assessment helps to identify the precise elements that need to be developed, strengthened or adjusted.

Identifying strategic options

By evaluating results of the rapid and comprehensive assessments, countries will be able to better identify what steps are needed to improve their civil registration and vital statistics systems. Country experiences in Africa and the Asia-Pacific region have shown that the four-group typology of countries shown in table 5.1 is relevant and helpful in identifying key actions and implementing “pathways” suitable to individual country circumstances and capacities. For each of the four country groupings, the key priority actions are outlined below, with corresponding pathways for strengthening civil registration and vital statistics systems. Based on the outcome of rapid assessment and subsequent positioning within the typology, countries should be able to identify which of these four proposed pathways best is suited to their situation.

Countries with dysfunctional systems

In these settings, key actions include but are not limited to:

- Advocating improved civil registration and vital statistics systems among high-level policymakers.
- Reviewing legal and regulatory framework contents and compliance.
- Reviewing resources (human, infrastructural and financial) for civil registration.
- Establishing a coordination mechanism linking key stakeholders, such as the offices of the registrar-general and national statistics, ministry of health and civil registration authorities.
- Developing training manuals on civil registration and vital statistics.
- Reviewing and revising death forms.
- Providing training for physicians in correctly certifying cause of death for deaths that occur in health facilities.
- Introducing computerized systems for civil registration, and for data transfer, storage and analysis.
- Compiling, reviewing and analysing available health facility data, and producing summary statistics, particularly in urban areas where people are more likely to use formal health facilities.
- Starting in urban areas that have civil registration in place, improve the system and compile and analyse available data.
- Applying verbal autopsy techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in health facilities.
- Making maximum use of data from existing health and demographic surveillance sites to generate evidence on levels of mortality by age and sex.
- Considering the conducting of applied research into the potential use of technologies, such as mobile telephones or other hand-held devices, to record vital events at the community level, and to compile and transmit the information to higher levels for statistical analysis. Such studies should focus on

settings in which community workers have been assigned responsibility for counting vital events or monitoring pregnancy outcomes.

- Considering the use of mobile phones to standardize reporting procedures and improve information completeness and timeliness in settings where local-level procedures already exist for identifying and counting deaths, for example within clans, villages or groups linked by religious affiliation.
- Mobilizing communities by conducting information, education and communication campaigns on the importance of civil registration.
- Introducing computerization to facilitate the compilation, transfer and dissemination of available data.
- Facilitating access to available data by decision-makers and researchers.

Countries with weak systems

In these settings, key actions include but are not limited to:

- Advocating improved civil registration and vital statistics systems among high-level policymakers.
- Reviewing legal and regulatory framework contents and compliance.
- Reviewing resources (human, infrastructural and financial) for civil registration.
- Establishing a coordination mechanism (or strengthening an existing mechanism), linking key stakeholders such as the offices of the registrar-general and national statistics, ministry of health and civil registration authorities.
- Developing training manuals on civil registration and vital statistics.
- Reviewing and revising death forms.
- Conducting a comprehensive assessment of current systems.
- Developing a prioritized improvement plan.
- Developing curricula to support the ongoing training of physicians in cause-of-death certification.
- Developing a cadre of coders to correctly assign underlying causes of death.
- Introducing computerized systems for civil registration, and for data transfer, storage and analysis.
- Compiling, reviewing and analysing available health facility data, and producing summary statistics, particularly in urban areas where people are more likely to use formal health facilities.
- Using data on deaths in health facilities to produce summary statistics, particularly in urban areas where people have greater access to formal health facilities, and generating age-, sex- and cause-specific mortality patterns using the WHO ANACoD tool.
- Starting in urban areas, which typically have registration offices and populations more likely to respond to registration incentives, improving the systems in place and ensuring that the vital statistics produced are used. Key actions include: compiling and analysing existing urban data on deaths to produce summaries of mortality patterns in urban areas; enrolling public-service health workers to supply official information on deaths; developing publicity campaigns and incentive schemes for registration; and opening additional registration offices and extending mobile registration to more remote areas.
- Applying verbal autopsy techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in health facilities.
- Making maximum use of data from existing health and demographic surveillance sites to generate evidence on levels of mortality by age and sex.
- Introducing sample registration.

- Considering the conducting of applied research into the potential use of technologies, such as mobile telephones or other hand-held devices, to record vital events at the community level, and to compile and transmit the information to higher levels for statistical analysis. Such studies should focus on settings in which community workers have been assigned responsibility for counting vital events or monitoring pregnancy outcomes.
- Considering the use of mobile phones to standardize reporting procedures and improve information completeness and timeliness in settings where local-level procedures already exist for identifying and counting deaths, for example within clans, villages or groups linked by religious affiliation.
- Mobilizing communities by conducting information, education and communication campaigns on the importance of civil registration.
- Deploying mobile registration units in remote areas and making registration forms available in local languages.
- Introducing electronic medical records in major health facilities to facilitate data transmission and analysis.
- Introducing computerization to facilitate the compilation, transfer and dissemination of available data.
- Facilitating access to available data by decision-makers and researchers.

Countries with functional but inadequate systems

In these settings, key actions include but are not limited to:

- Advocating for improved civil registration and vital statistics systems among high-level policymakers in health and non-health sectors.
- Reviewing legal and regulatory framework contents and compliance.
- Reviewing resources (human, infrastructural and financial) for civil registration.
- Strengthening coordination mechanisms linking key stakeholders such as the offices of the registrar-general and national statistics, ministry of health and civil registration authorities.
- Updating training manuals on civil registration and vital statistics.
- Revising death forms if required.
- Conducting a comprehensive assessment of current systems.
- Developing a prioritized improvement plan.
- Conducting reviews of quality of death certification and coding.
- Improving physician certification practices.
- Improving coding practices.
- Using the WHO ANACoD tool mortality levels and causes-of-death tool to analyse available data and interpret the results for action.
- Introducing new software to facilitate and speed up the compilation, transfer and analysis of existing data, even if based upon incomplete reporting from urban areas only.
- Making the resulting vital statistics available to health and other officials, and to researchers, the media and the public, at the local and national level. This feedback loop will encourage local officials to improve registration coverage, and enhance public support for civil registration and vital statistics systems.
- Applying verbal autopsy techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in health facilities.

- Introducing sample registration systems (incorporating existing health and demographic surveillance sites as appropriate) to generate nationally representative vital statistics. Initiating sample systems can help to build capacities prior to an eventual extension to comprehensive civil registration.
- Conducting community outreach to underserved populations, and targeting civil registration advocacy and communication efforts to remote and underserved areas and population groups.
- Increasing coverage in remote or marginalized populations by reaching out to underserved population groups and providing incentives for registration.
- Deploying mobile registration units in remote areas, involving local communities themselves in running registration offices and ensuring that registration forms are available in local languages.
- Introducing electronic medical records in major health facilities to facilitate data transmission and analysis.
- Introducing computerization to facilitate the compilation, transfer and dissemination of available data.
- Introducing automated coding software to standardize and speed up the analysis of mortality data.
- Improving the timeliness and dissemination of data.
- Facilitating access to available data by decision-makers and researchers.

Countries with satisfactory systems

In these settings key actions include but are not limited to:

- Assessing the functioning of existing coordination mechanisms, and strengthening them, as needed.
- Introducing regular quality control and feedback mechanisms into current cause-of-death certification and coding approaches.
- Improving the skills and capacities of physicians in relation to WHO standards for certifying causes of death.
- Strengthening the skills of health information management specialists responsible for mortality coding according to International Classification of Disease rules.
- Introducing automated coding software to standardize and speed up the analysis of mortality data, and ensure the timely availability of mortality data for public health decision-making.
- Rolling out electronic patient-record systems in health facilities, incorporating appropriate software for facilitating data transmission and analysis.
- Improving the timeliness and dissemination of data.
- Facilitating access to vital statistics and other available data by decision-makers, researchers and other users.

5.3 Potential for civil registration and vital statistics development with a focus on death registration and the collection of cause of death information

A national coordination committee for the improvement of civil registration and vital statistics systems should be established or strengthened. The committee should include representatives of the major agencies involved in civil registration and vital statistics, including, for example, the office of the prime minister or president; the ministry in charge of the registration of vital events (justice, interior); the national statistics office; the ministry of health; and other relevant line ministries. The national coordination committee should be chaired by a high-level official. The main functions of the committee are to coordinate the assessment and improvement process, ensure the full participation of key stakeholders, foster advocacy and high-level visibility, and generate

political commitment and resources. In support of its functions, the committee should bring together, as needed, technical experts, academic institutions, development agencies, non-governmental organizations, funding bodies and foundations involved in different aspects of death registration and collection of cause of death information. The close involvement of local administrators and district managers is also recommended as they will be responsible for implementing changes to the system and will have valuable insights into what is feasible in the field and how obstacles can be overcome.

As a precaution, countries are advised to assess the functioning of their civil registration and vital statistics systems according to a three-tier categorization outlined below.

- *Relatively intractable problems*: such as widely dispersed populations, lack of adequate infrastructure to provide services, illiteracy and low public compliance.
- *Solvable problems requiring large amounts of funding*: staff development, office space, record storage and retrieval facilities, essential forms and supplies require significant capital and running investments. The amounts required may be substantial enough to deter the attempt to set up a comprehensive vital registration system.
- *Solvable problems, with small financial inputs*: such as adequate legislation, procedural problems that can be solved by planned intersectoral collaboration, targeted training requirements for specific weak elements in the system..

Depending on which categorization is applicable to a country's civil registration and vital statistics system, it is only prudent for a country to be pragmatic by starting with strategies that can be achieved easily and in a relatively short time. It is also critical to impress upon all key stakeholders that significant improvement in the civil registration and vital statistics system takes time – hence the need for patience and time.

Chapter 6 - Monitoring and evaluation

6.1 Routine monitoring of the performance of the system

As part of the implementation of the improvement plan, countries need to monitor the progress made by periodically assessing their civil registration and vital statistics systems. Because of the importance of civil registration information and register-based vital statistics on an individual record basis and in an aggregated form, the maintenance of high standards of quality should be a major and continuing concern to those responsible for the administration of the systems. Therefore, adequately funded evaluation activities of civil registration and vital statistics systems must be regarded as essential components of the management, operation and maintenance functions of such systems. Such critical evaluations are necessary for the strengthening and improvement of systems that are not operating efficiently and for maintaining high standards of quality in those systems that are functioning satisfactorily.

As outlined by the United Nations, quality assurance encompasses the steps taken at each stage of the operations of civil registration and vital statistics systems to ensure the following: all vital events occurring within the country are registered without duplication; all related information is accurately recorded; and the compilation and processing of recorded vital events result in the proper and timely production of vital statistics. Quality assurance is considered an integral part of functioning civil registration and vital statistics systems and should be conducted on a regular basis. Persons responsible for quality assurance are usually those who are working within different domains of both systems.²

Quality assessment entails specific studies that aim to answer specific questions of quality as it applies to the civil registration and vital statistics systems. These questions may relate to the coverage of the registration of a vital event at the country level or in a smaller area; the accuracy of one of the variables recorded or published in vital statistics; or the overall status of civil registration and vital statistics systems. Quality assessment can be conducted regularly or on an ad hoc basis.

As an integral part of the civil registration system, the steps that constitute quality assurance should be followed by the registration authority on a regular basis to ensure the following: (a) all local registration areas have carried out the required registration functions; (b) every vital event occurring to members of the population in a given area is recorded in the system; and (c) all local offices transmit the records to a higher-level registration office, according to established procedures. When local offices do not report registered events, serious problems arise. Therefore, it is important for the registration authority to evaluate the performance of each local office with regard to sending records to regional offices. Even when all registration offices have carried out their work so that geographical coverage is complete, there are other quantitative and qualitative issues of registration that need to be evaluated on a regular basis.

The quality of data should be measured according to the standards prescribed by the United Nations in the *Principles and Recommendations for a Vital Statistics System*, namely completeness, correctness, availability and timeliness, as described below:

(a) Complete registration is achieved when every vital event that has occurred to the members of the population of a particular country (or area), within a specified time period, has been registered in the system,

or in other words has a vital event registration record. This means that the system has attained 100 per cent coverage. Any deviation from complete coverage is measured by “coverage error”. Vital statistics from registration data are complete when, in addition to the registration of each event, there is a vital statistical report, which is forwarded to the agency responsible for the compilation and production of vital statistics;

(b) Correctness or accuracy of registration is achieved when data items for each vital event on the vital record are accurately and completely filled in, (there are no response errors or missing items). The measurement of any deviation from correctness is called “content error”. In register-based vital statistics, accuracy means that data items in the statistical report are accurately and completely filled in and no errors have been introduced during the transcription of data from the vital records to the statistical report (if this is the case) or during the processing stages (coding, editing, imputation and tabulation);

(c) Availability means that data that are collected, filed, processed and stored in each system (civil registration and vital statistics) are accessible to users in a user-friendly format, upon request;

(d) Timeliness in registration means that every event that has occurred in the country (or area) is reported for registration within the legally stipulated time allowance. In register-based vital statistics, it means that for every timely registered event, a statistical report form has been forwarded to the agency responsible for vital statistics within the fixed time schedule established by the vital statistics programme. It also implies that the production, publication and dissemination of the vital statistics have been carried out promptly enough to ensure that users’ needs are served.

Consequently, the evaluation of quality of data should address the level of completeness of the civil registration and vital statistics, correctness or accuracy of each item of data and the availability and timeliness of registration and statistics. Note that the four criteria do not carry the same weight for assessment purposes. Completeness and accuracy, for example, should not be jeopardized in order to achieve timeliness.

Any improvement process or implementation plan needs to be monitored to ensure that goals will be reached; it is, therefore, important to define a short list of indicators for monitoring progress. WHO lists some potential indicators (see table 6.1), but each country needs to identify the core indicators that are most likely to reflect progress in their specific areas of concern. The selection of indicators should be based on explicit criteria, such as relevance, measurability, understandability, responsiveness to change and data availability. A database of core indicators – including baseline measures and related metadata – should be established and made publicly available, and progress should be reported at regular intervals.

Table 6.1: Suggested indicators for monitoring progress in national civil registration and vital statistics systems

Monitoring and evaluation aspect	Areas covered
Inputs	Budgets of the civil registration and vital statistics systems
	Human resource component of these budgets
	Number of staff performing registration duties
Processes	Access to civil registration
	Availability of civil registration (number of registration points)
	Number and percentage of hospitals with registrars in situ
	Completeness of death registration, nationally and by region

	Medically certified deaths as a percentage of total deaths annually
	Number and percentage of civil registration points that report late (such as after scheduled date)
	Percentage of all registration offices linked by computers to central level
Outputs	Time lag between data collection and publications (years)
	Number of tables provided to the <i>United Nations Demographic Yearbook</i> (the United Nations requests countries to provide 15 tables on mortality for this publication)
	Ill-defined causes of death as a percentage of all deaths annually
	Cancer deaths assigned to ill-defined site as a percentage of all cancer deaths annually
	Cardiovascular deaths assigned to ill-defined causes as a percentage of all cardiovascular deaths annually
	Injury deaths assigned to undetermined causes as a percentage of all injury deaths
	Infections and parasitic disease deaths assigned to septicaemia as a percentage of all infectious and parasitic deaths

Source: World Health Organization, *Improving the Quality and use of Birth, Death and Cause-of-death Information: Guidance for a Standards-based Review of Country Practices* (Geneva, WHO, 2010). Available at www.who.int/healthinfo/tool_cod_2010.pdf.

A frequently used indicator of the quality of cause-of-death data is the percentage of all deaths for which the cause is classified as ill-defined (chapter XVIII of ICD-10). Ill-defined causes are of no public health value. Also, in areas where they are common, they will make the cause-of-death distribution unreliable, because true causes of death are hidden and hence underestimated. Generally, the percentage of deaths for which the cause is ill-defined should be less than 10 per cent at ages 65 years and over, and less than 5 per cent at ages below 65 years.³¹ If the percentage of ill-defined causes has declined significantly, caution must be exercised when interpreting trends in specific causes (such as cancers or heart disease), because changes in death rates from these causes may be largely or entirely the result of a redistribution effect from ill-defined to more-specific causes. The need to reduce ill-defined causes of death should not force the certifying doctor to give a defined cause in all instances: there will inevitably be occasions when a cause of death cannot be indicated with precision. Such, “unknown” causes (code R99) should be measured and tabulated separately, and should not constitute more than 3 per cent of all deaths.

Monitoring reports should include the quantitative values for the indicators, as well as some analysis of the qualitative information. Documentation of progress will help to generate continuing support for the improvement plan, as well as additional funding from national or external sources. Monitoring need not be onerous if it is planned for from the beginning; only a subset of the suggested indicators in in table 6.1 needs to be selected. Some of the indicators may already exist and be in use for the annual reviews of the health sector.

6.2 Work plan for death registration and recording of cause of death information

Strengthening the civil registration and vital statistics system has increasingly become a priority for many countries and the global development community. The formal registration of vital events underpins the realization of civil, social and political rights by providing evidence of individual identity and family relationships. Civil registration and vital statistics is associated with numerous administrative and statistical benefits for public and private entities and is considered the foundation of modern administrative systems. The

³¹ World Health Organization, *Improving the Quality and use of Birth, Death and Cause-of-death Information: Guidance for a Standards-based Review of Country Practices* (Geneva, WHO, 2010). Available at www.who.int/healthinfo/tool_cod_2010.pdf.

establishment and maintenance of comprehensive civil registration requires political will and long-term efforts to build up the necessary administrative infrastructure and create community awareness and participation in the act of registration. However, demand is growing for reliable vital statistics – including mortality and cause of death statistics – and in a global civil registration and vital statistics investment plan, explicit targets for mortality statistics are proposed, including that by 2030, 80 per cent of deaths in children under 5 are reported, disaggregated by age and sex; 100 per cent of causes of death in health facilities are reliably determined and officially certified; 80 per cent of countries have community assessments of probable cause of death determined by verbal autopsies using international standards.³² Currently, the availability and quality of mortality statistics in most countries fall well below these targets.

In some countries, the civil registration and vital statistics system is sufficiently developed to achieve improvements in data availability and quality in the short term. By contrast, in countries where the civil registration and vital statistics system is rudimentary or weak, progress is likely to be too slow to meet expectations, in particular with regard to completeness of death reporting and reliable cause of death ascertainment. The production of accurate and representative cause of death statistics requires complete reporting of all deaths by location, age and sex, along with well-functioning medical certification of deaths according to International Classification of Diseases, and improved community-based mortality reporting through the use of verbal autopsy techniques.

To establish a sound evidence base for public health decision-making, a strategic approach needs to be developed to improve mortality and causes of death statistics that is aligned with and supportive of efforts to strengthen the civil registration and vital statistics in countries. What is required is not a research initiative, but an approach that is part and parcel of a country's plan to strengthen its civil registration and vital statistics system. Such a systemic approach would avoid the creation of separate, competing systems and enhance the likelihood that investments in mortality statistics systems would be viewed as being integral to the development of civil registration and vital statistics systems. Many countries are conducting national assessments of their civil registration and vital statistics systems and developing national strategies and investment plans. These plans do not always adequately address the generation of improved vital statistics, especially on mortality and causes of death. Clear guidance and support are needed to ensure that the vital statistics component is included as an integral part of civil registration and vital statistics investment planning. This is also important in the context of the establishment of a global funding facility for reproductive, maternal, newborn, child, and adolescent health with a special window for strengthening civil registration and vital statistics.

Training and capacity development are urgently needed. For example, although cause of death certification is a key responsibility of physicians, they rarely receive the training required to do this function effectively, either during medical education or subsequently when in service. The result is that their performance is often mediocre with damaging effects on the quality of cause of death statistics produced. There is need to develop a cadre of statistical clerks and nosologists in order to ensure correct coding of causes of death to statistical categories as recommended by the International Classification of Diseases. The potential of automated

³² WHO, "Improving mortality statistics through civil registration and vital statistics systems". Outcome of a technical meeting, Geneva, 4-5 September 2014.. WHO Press, World Health Organization (Geneva, WHO, 2014).

systems for coding health facility deaths should be fully exploited, although this does not obviate the need for skilled statistical clerks and nosologists. Capacity development is also urgently needed in the critical analysis of the quality of mortality data and to interpret inconsistent data from different data sources. The growing reach of innovation, especially use of information technology and mobile devices to record and report deaths and causes of death, imposes its own demands on human resources. Information technology systems need to be maintained and updated along with the kinds of computer skills that are often in short supply in the public sector. Some data sources, notably household surveys and DHSS, are externally funded by multilateral agencies, funds and foundations. Others, especially those associated with routine administrative systems, such as civil registration and vital statistics and health facility information systems, rely heavily on in-country financing. The latter may be more sustainable in the long term but it suffers from severe underinvestment in many countries.

It is not sufficient that the *certification* of cause of death is correctly done according to International Classification of Diseases rules, the *coding* of the cause of death must also be correct and compliant with the International Classification of Diseases rules and standards. Correctly selecting the underlying cause of death and coding it according to International Classification of Diseases rules and procedures is not a trivial matter; it requires training and skills development.

Countries are strongly advised by WHO⁷⁷ to use the alphanumeric codes of the International Classification of Diseases classification for coding and classifying deaths, and to use the latest version, which is currently the second edition of ICD-10. If this version is not being used, it is important to discuss the specific steps required to upgrade to ICD-10. The basic International Classification of Diseases classification is a list of three-character categories, each of which can be further divided into up to 10 four-character subcategories. When coding skills and resources are limited, it is useful, and sometimes necessary, to code to a less detailed summary list of categories. Although summary lists reduce the precision of coding (because each category represents a group of diseases rather than a single disease or injury entity), using these larger aggregates tends to diminish the public health impact of diagnostic and coding errors, and improve comparability. Volume 1 of ICD-10 contains recommended tabulation lists intended for use in circumstances in which the three-character list is too detailed.

The business process should propose the inclusion of the WHO verbal autopsy standard forms. Verbal autopsy processes may be difficult to implement for deaths occurring outside of health facilities. Countries may consider the introduction of verbal autopsy techniques in sentinel surveillance sites. The newly developed PDA/mobile based verbal autopsy tool by WHO could be tried out in scientifically selected representative sample clusters. The pilots should be used to test the whole process from end to end (collection to compilation). Countries may designate nationally representative sample sites in which verbal autopsy would be conducted on an ongoing basis in order to generate nationally representative data on causes of death. Based on the results of the pilot and tool testing exercise, a core team should be formed to redesign the business process which should include identification of institutions and their respective responsibilities in the value chain, form flow, and monitoring and evaluation. Then appropriate steps to implement this, which should include development of a proposal with implementation timelines, need to be set.

Data tabulation

The United Nations recommends that vital statistics be compiled according to date of occurrence.⁷⁷ However, in many countries, death statistics are compiled according to date of registration because this is simpler than reallocating events to the year of occurrence. Vital statistics tabulated by date of registration can be misleading, particularly if a large number of delayed deaths are registered as a result of periodic registration campaigns. Place of occurrence is usually the geographical location (locality/town) where the death took place. For policy and services planning, it is also important to know the place of usual residence of the deceased. All mortality data should be tabulated separately by age, sex and underlying cause of death. The probability of dying varies substantially at different ages for men and women but can also vary substantially within a country between different regions. Each country should decide what geographic disaggregation of death statistics is appropriate for its policy and planning needs.

Data access and dissemination

The main data users should be involved in determining the most appropriate cross tabulations and regional breakdowns of the vital statistics data that are relevant to their needs. It is important to solicit feedback from users about the relevance, utility and quality of vital statistics. There is little point in producing data that are not used, or are regarded as unnecessary. Timeliness of data is one of the quality criteria that users rate most highly. This is particularly important for local-level and small-area data. Data release dates are important for producers and users. Keeping to release dates allows users to plan their work around availability of vital statistics.

To be useful, data have to be accessible to as many legitimate users as possible, preferably in both print and electronic form. Every effort should also be made to ensure that data are available to users at minimal cost. The more the data are used, the more feedback will be received about their quality. Official vital statistics should be published annually by a trustworthy government source. The correct use and understanding of the data depends on supplying information about the data (“metadata”) along with the data themselves. These metadata ensure that the data are interpreted appropriately by the end users.

Proposed five-year strategy

As noted earlier, in the Ministerial Statement from the Third Conference of African Ministers responsible for Civil Registration, the Yamoussoukro Declaration, the Ministers called upon Who, in collaboration with pan-African organizations and other partners, to intensify their efforts in developing real-time death registration and cause of death information systems at the country level.¹ In response to this, the Africa Civil Registration and Vital Statistics Core Group, at a meeting in Zimbabwe in June 2015, agreed to develop a five-year regional strategy for improving mortality statistics in Africa. The overarching objective of the five-year strategy is to make readily available continuous, harmonized, quality mortality and cause of death data and statistics for African countries, guiding the development of better planned, designed and integrated mortality systems.¹¹

Vision: The vision is to record all deaths in Africa, to provide essential information to shape resilient health systems for healthy African lives.

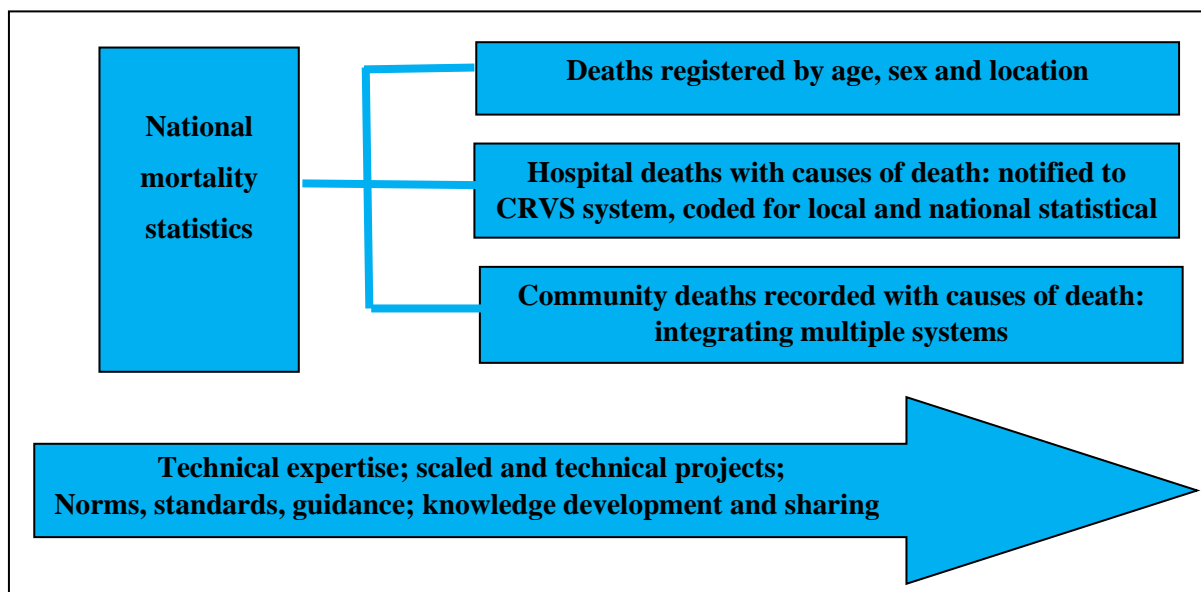
Aim: The aim is for at least 20 African countries to record continuous data on all deaths by age, sex, location and cause of death, and improve mortality statistics through better planned, designed and integrated mortality statistics systems.

Goals: Drawing on the WHO targets for universal civil registration of births and deaths, including causes of death, the aspirational goals for this strategy are to have significant improvements in their reporting by 2020, such that:

- Sixty per cent of deaths in a given year are continuously notified, registered and certified with key characteristics;
- Eighty per cent of deaths in hospitals have causes of death reliably determined and officially certified in real time; and
- Fifty per cent of deaths in communities have probable cause of death determined in real time, and collection systems designed in a representative way.

Ensuring improved national mortality statistics will entail achieving the three important components as indicated in figure 6.1.

Figure 6.1: Three elements to better design



Source: World Health Organization, Economic Commission for Africa and African Symposium on Sustainable Development, “Improving mortality statistics in Africa: technical strategy, 2015–2020” (Addis Ababa, ECA, 2015) Available at <http://repository.uneca.org/handle/10855/23023>.

To achieve these goals, health information and statistical systems must be able to bring together mortality data from multiple sources, including mortality data from health facilities, mortality surveillance, deaths occurring in the community; and administrative data. Recognizing that each country’s approach depends on its particular needs, the strategy includes “building blocks”, which can be used to develop improved systems. The key building blocks to support the strategy are outlined below.¹¹

- **African countries take action for better designed mortality statistics systems**, including: developing a baseline report on mortality collection at the national level; reviewing the civil registration and vital statistics comprehensive assessment; creating a mortality statistics technical working group; and developing a national, costed plan for improvement of mortality statistics, linked to the improvement plan for civil registration and vital statistics.
- **Partners focus on:** developing expertise and capacity in country, and at the regional level; developing better norms, standards and guidance; and investing in scaled and integrated technical projects.
- **Partners and countries create knowledge development and sharing.**

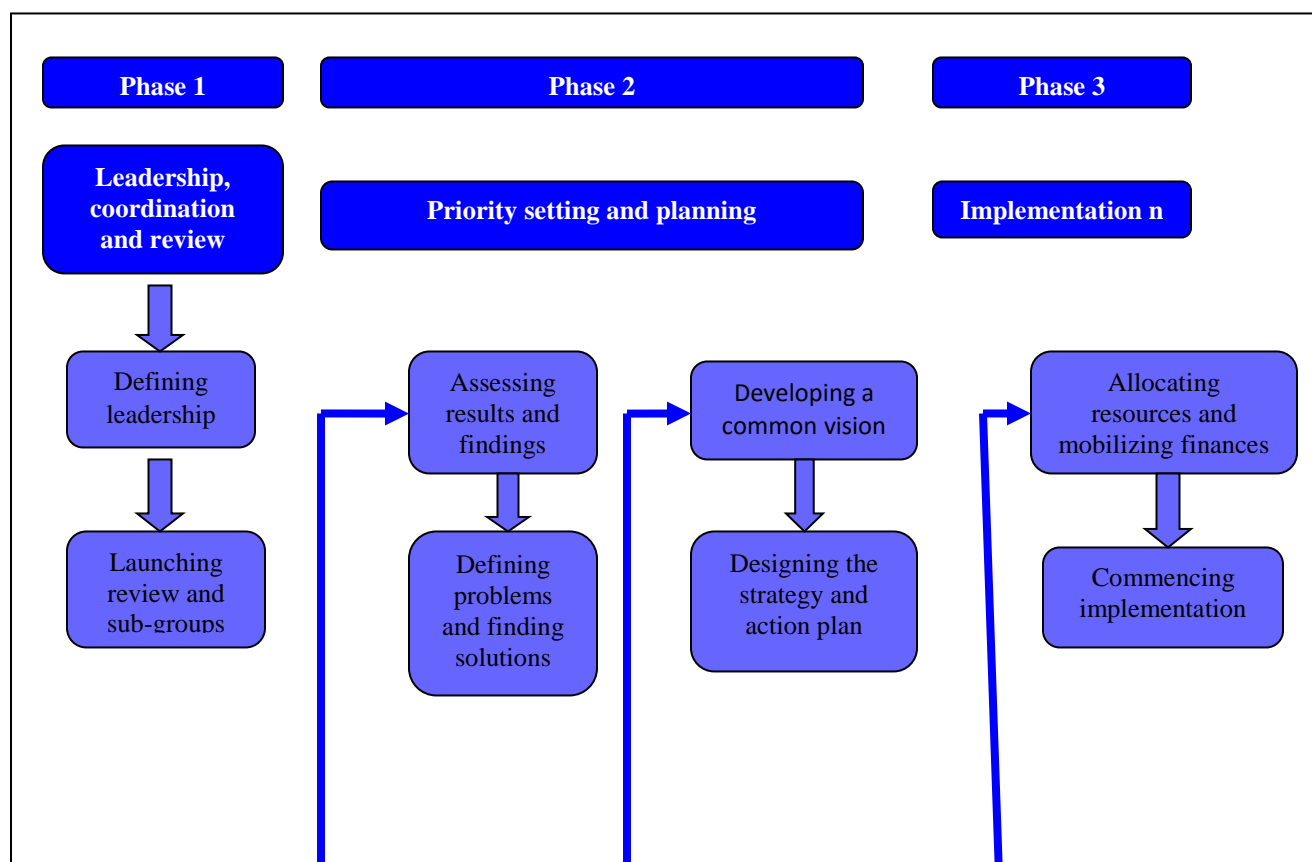
Strategic planning for strengthening the vital statistics system

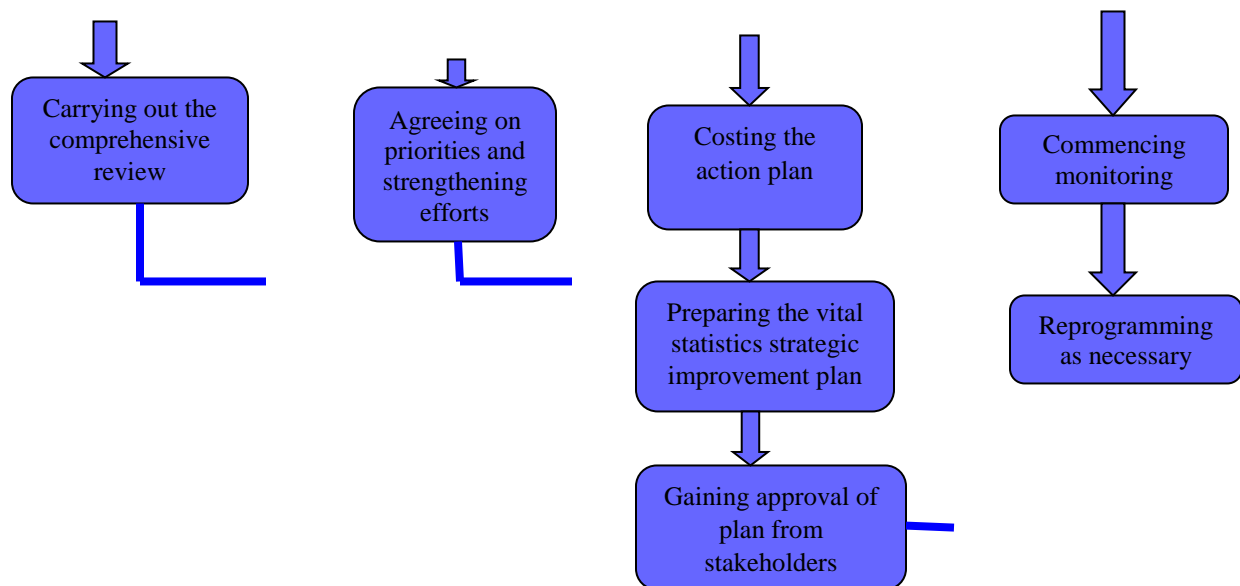
The steps required for preparing a strategic plan for strengthening the civil registration and vital statistics systems are described in figure 6.2. It is important to ensure that the strategic plan is:

- Part of the overall efforts that countries are undertaking to improve their health information system;
- Aligned with and building on current efforts to strengthen the national statistical information system.

Figure 6.2 contains an outline of the process and the main elements of the road map for carrying out the review of a country’s civil registration and vital statistics systems, which is divided into the three standard phases commonly used for planning.

Figure 6.2: Process for preparing a plan to strengthen the vital statistics system





Source: World Health Organization, *Improving the Quality and use of Birth, Death and Cause-of-death Information: Guidance for a Standards-based Review of Country Practices* (Geneva, WHO, 2010, p. 65). Available at www.who.int/healthinfo/tool_cod_2010.pdf.

Appendix

Appendix: Definitions of key concepts – Death and cause of death registration*

Automated Classification of Medical Entities – programme which automates the underlying cause-of-death coding rules. The inputs to the programme are the multiple International Classification of Diseases cause-of-death codes assigned to each entity (for example, disease condition, accident or injury) listed on cause-of-death certifications, preserving the location and order as reported by the certifier. The programme then applies WHO rules to the codes and selects an underlying cause of death. It has become the de facto international standard for the automated selection of underlying cause of death.

Burial permit – an official document, usually issued only for a legally registered death, authorizing the removal of the dead body (corpse) to a cemetery or other final site.

Causes of death – all diseases, morbid conditions or injuries that resulted in or contributed to death, and the circumstances of the accident or violence that produced any such injuries. Symptoms or modes of dying (such as heart failure or asthenia) are not considered to be causes of death for vital statistics purposes (see **underlying cause of death**).

Certification – the issuance by the civil registrar of a legal document certifying a birth, death or marriage.

Certifier (of cause of death) – a person authorized by law to issue a medical certificate of cause of death in a prescribed format, stating the underlying and contributory causes of death and other facts related to the event for submission to the local registrar or other appropriate authority. The certifier is usually the physician who attended to the deceased in their final illness or, in the case of individuals, who were not attended by a physician during their final illness or who may have died due to violence or injury, the medical-legal officer (for example, coroner or medical examiner).

Civil registration - “The continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events (live births, deaths, fetal deaths, marriages and divorces) and other civil status events pertaining to the population as provided by decree, law or regulation, in accordance with the legal requirements in each country. Civil registration establishes and provides legal documentation of such events. These records are also the best source of vital statistics”.

Civil registrar - Official tasked with registering vital events in a defined area, such as a country, district, municipality or parish, and for reporting the information for legal and statistical purposes.

Civil registration system – the institutional, legal and technical settings established by Government to conduct civil registration in a technical, sound, coordinated and standardized manner throughout the country, taking into account cultural and social circumstances particular to the country (see **civil registration** and **vital statistics system**).

Completeness of civil registration –a measure of the extent to which the births and deaths that occur in a country in a given year are registered by the civil registration system. Several demographic techniques have been developed to assess and adjust the information on births and deaths derived from civil registration. Some methods compare data from independent sources (direct **capture-recapture** approaches), whereas others are indirect analytical methods based on assumptions about the population age distribution. There are various indirect demographic techniques for estimating the completeness of death registration; for example, the Bennett–Horiuchi Method, the Chanrasekaran–Deming Technique and the Brass–Growth Balance Method.

These methods are often used by a national statistics office or academic institution to estimate registration completeness.

Coroner – an officer of a county, district, municipality, parish or other administrative division authorized by law to hold an inquest into deaths that may have involved violence, injury or suspicious circumstances to determine if the death was due to non-natural causes, such as accident, suicide or homicide.

Crude death rate – a vital statistics summary rate based on the number of deaths occurring in a population during a given period of time. Typically expressed as the number of deaths occurring among the population of a given geographical area during a given calendar year per 1,000 midyear total population of the given geographical area during the same year.

Data dashboard – a means of providing at-a-glance views of key performance indicators. Data dashboards are typically limited to showing summaries, key trends, comparisons and exceptions.

Data dictionary – a centralized repository of information on data, such as meaning, relationships to other data, origin, usage and format. Also known as a **metadata** repository.

Date of occurrence – the day, month and year of occurrence of a vital event; and hours and minutes in the case of births and infants dying in the first week of life.

Date of registration – the day, month and year when an entry of registration of a vital event is made in the civil register.

Death – the permanent disappearance of all evidence of life at any time after live birth has taken place (postnatal cessation of vital functions without capability of resuscitation). This definition excludes **foetal death**.

Delayed registration – the registration of a vital event after the period prescribed in existing laws, rules or regulations (including any specified grace period). A late registration is the registration of a vital event after the prescribed period but within a specified grace period. As the grace period is usually considered to be one year following the vital event, delayed registration is usually considered to be the registration of a vital event one year or more after its occurrence.

Foetal death - “Death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy; the death is indicated by the fact that after such separation the foetus does not breathe or show any evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles”.

ICD-10 - International classification of diseases and related health problems, tenth revision, known as the International Classification of Diseases, sometimes shortened to ICD-10, is a classification maintained by the WHO for coding diseases, signs, symptoms and other factors causing morbidity and mortality. It is used worldwide for classifying morbidity and mortality statistics, and is designed to promote international comparability in the collection, processing, classification and presentation of statistics.

Ill-defined cause of death – a collection of vague diagnoses that should not be used as the underlying cause of death, and consisting of “symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified” (ICD-10, chapter XIII). For further information, see Section 4.1.10 in ICD-10, volume 2.

Infant mortality - Deaths of children occurring before their first birthday, usually measured as infant deaths per 1,000 live births.

Informant – an individual responsible by law for reporting the occurrence of a vital event to the local registrar and for providing all the information and characteristics related to the event. On the basis of such a report, the event may be legally registered by the local registrar.

Legal framework for civil registration and vital statistics – the system of regulations and guidelines that govern the civil registration system and the vital statistics derived. This includes regulations on the medical certification process and burials and on the dissemination and publication of vital statistics, with these different aspects potentially coming under different jurisdictions and acts.

Maternal death - Death of a woman while pregnant or within 42 days of termination of pregnancy (irrespective of the duration and the site of the pregnancy) from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.

Maternal mortality ratio – a vital statistics rate based on the number of deaths due to maternal causes relative to the number of live births occurring during a given period of time, usually a calendar year. Typically expressed as the number of deaths of women resulting from (a) direct obstetric complications of pregnancy, labour and the puerperium; (b) from interventions, omissions or incorrect treatments or their results; or (c) from indirect obstetric causes resulting from a previously existing disease or disease arising during pregnancy and which was not due to direct obstetric causes but which was aggravated by the physiological effects of the pregnancy, occurring in a given geographical area during a given calendar year per 100,000 (or 10,000) live births occurring in the given geographical area during the same year.

Medical certification of cause of death— Process by which a doctor confirms the fact of death, states the causes leading to it and issues a death certificate that specifies the underlying cause of death, according to the rules and procedures of the ICD.

Metadata – “descriptive metadata” is information about data, such as data sources, purpose of the data, standards, definitions, statistical methods and possible sources of bias. “Structural metadata” relates to the design and specification of data structures and databases.

Mode of death - The way a person died; for example, “respiratory failure”. To write this on a death certificate is not sufficient because it does not indicate what disease or condition caused the death.

Notification – the issuance by an appropriate authority (such as a health care worker) of a form confirming a vital event (birth or death). Often this notification form is used by the family to report the event to the civil registration office. It can also be required to obtain a **burial permit** in the case of a death. This form does not have the legal status of a birth or death certificate.

Quality of data – in civil registration or vital statistics systems, the quality of data is measured in terms of the degree of data completeness, correctness (accuracy), timeliness and availability.

Registration – the formal act of reporting a birth or death, and obtaining a birth or death certificate issued by the civil registration authority. At this stage, details of the event are written into the official civil register by the registrar. Registration is the essential step prior to obtaining a certificate.

Timeliness in register-based vital statistics – for every vital event registered within the interval specified by legislation, a statistical report form must be forwarded to the agency responsible for the compilation of vital statistics within the established time schedule of the vital statistics system. In addition, the production, publication and dissemination of the vital statistics must be prompt enough to serve the needs of users.

Timeliness in registration – this element of a vital event report is determined by the time difference between the date of the event and the date of its registration when compared to the interval specified by legislation.

Underlying cause of death - Either (a) the disease or injury that initiated the train of morbid events leading directly to death; or (b) the circumstances of the accident or violence that produced the fatal injury. The underlying cause of death is used as the basis for the tabulation of mortality statistics.

Usual place of residence – although no standard definition exists, most countries agree that a person can only have one “usual” (or “primary”) residence, which is typically defined as the place where they spend most time and where they are registered for voting in elections.

Verbal autopsy – a structured interview administered to caregivers or family members of households following a death. It is used to determine the probable cause(s) of death in settings where most deaths occur outside of health facilities and where direct medical certification is rare.

Vital event - “The occurrence of a live birth, death, foetal death, marriage, divorce, adoption, legitimation, recognition of parenthood, annulment of marriage, or legal separation”.

Vital registration - All sanctioned modes of registering individuals and reporting on vital events.

Vital statistics – summary measures of the frequency of occurrence and relevant characteristics of specified and defined **vital events** derived from civil registration, enumeration and other sources of vital events data. In settings where civil registration functions poorly or not at all, the United Nations acknowledges that a variety of data sources and systems are used to derive vital statistics.

Vital statistics system - “The total process of (a) collecting information by civil registration or enumeration on the frequency or occurrence of specified and defined vital events, as well as relevant characteristics of the events themselves and the person or persons concerned, and (b) compiling, processing, analyzing, evaluating, presenting, and disseminating these data in statistical form”.

* These definitions have been adopted by the World Health Assembly (resolutions WHA20.19 and WHA43.24) under Article 23 of the Constitution of the World Health Organization