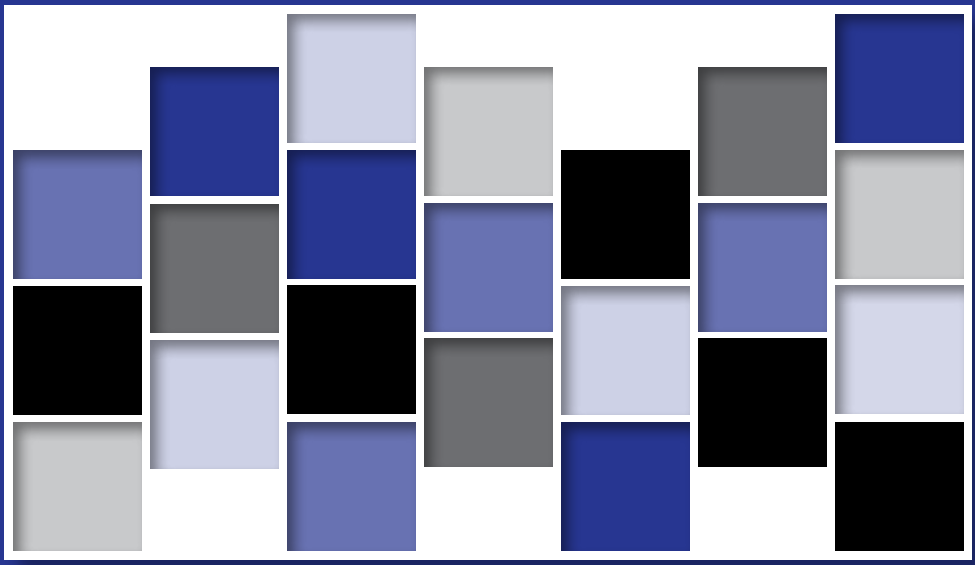
Strengthening civil registration and vital statistics for births, deaths and causes of death

RESOURCE KIT



HMN

World Health Organization

The University Of Queensland
AUSTRALIA

Health Information Systems Knowledge Hub
School of Population Health
University of Queensland

Australian AID

Strengthening civil registration and vital statistics for births, deaths and causes of death

RESOURCE KIT

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MODULE 6: Data quality checks, access and use

MODULE 7: Interim methods for generating vital statistics when civil registration is inadequate

MODULE 8: Building support for strengthening civil registration and vital statistics

Annexes

Abbreviations

ACBA	Australian Coding Benchmark Audit
ACME	Automated Classification of Medical Entities
AfDB	African Development Bank
AIDS	acquired immunodeficiency syndrome
AU	African Union
AusAID	Australian Agency for International Development
CDC	Centers for Disease Control and Prevention
CD-ROM	Compact disk – read only memory
CIEC	Commission Internationale de l'État Civil (International Commission on Civil Status)
CPR	Central Population Register
CRVS	civil registration and vital statistics
DCMI	Dublin Core Metadata Initiative
DDI	Data Documentation Initiative
DSA	demographic surveillance area
DOA	dead on arrival
DQAF	Data Quality Assessment Framework
DSP	Disease Surveillance Point (China)
ECA	Economic Commission for Africa
ERN	entity reference number
ESCAP	Economic and Social Commission for Asia and the Pacific
GDDS	General Data Dissemination System
GPS	global positioning satellite
HDSS	Health and demographic surveillance system
HIS Hub	Health Information Systems Knowledge Hub, School of Population Health, University of Queensland
HIV	human immunodeficiency virus
HMN	Health Metrics Network
ICCS	International Commission on Civil Status
ICD	International Statistical Classification of Diseases and Related Health Problems
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision
ICT	information and communications technology
IFHIMA	International Federation of Health Information Management Associations
IHME	Institute for Health Metrics and Evaluation
IMF	International Monetary Fund
INDEPTH	International Network for the Demographic Evaluation of Populations and Their Health in Developing Countries

LAC	Latin America and the Caribbean Region
MDG	Millennium Development Goal
MIMDES	Ministry of Women and Social Development, Peru
MMDS	Mortality Medical Data System
MoVE-IT	Monitoring of Vital Events, including through the use of Information Technology
NCHS	National Centre for Health Statistics, United States
NGO	nongovernmental organization
NIHS	National Institute of Health Sciences, Sri Lanka
OSCE	Organization for Security and Co-operation in Europe
OECD	Organisation for Economic Co-operation and Development
PAHO	Pan American Health Organization
PARIS21	Partnership in Statistics for Development in the 21st Century
PHMRC	Population Health Metrics Research Consortium
PIN	personal identification number
PRIA	Society for Participatory Research in Asia
RDM	reference data model
SAVVY	Sample vital registration with verbal autopsy
SRS	Sample Registration System (India)
UNFPA	United Nations Population Fund
UNHCR	Office of the United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNSD	United Nations Statistics Division
USAID	United States Agency for International Development
VA	verbal autopsy
WHO	World Health Organization
WHO-FIC	World Health Organization Family of International Classifications

Foreword

This Resource Kit appears at just the right moment. The 2015 deadline for the Millennium Development Goals (MDGs) is fast approaching, and health and development practitioners are engaged in a wide-ranging critical analysis of the progress made, the challenges remaining and emerging needs. The world is, however, a very different place now compared with the year 2000 which carried all the hopes and expectations of a new millennium. Today we are grappling with financial, economic and food crises, accelerating environmental change, ongoing wars and civil conflict and a myriad of challenges to human health and sustainable development. In these circumstances, accountability is at a premium – health actions must be carefully monitored, results delivered and efficiency enhanced. And accountability implies the ability to count. This is what this document is all about – the ability to count births and deaths, and to correctly determine the causes of those deaths.

Currently, millions of people in Africa and Asia are born and die without leaving any trace in legal records or official statistics – because these systems have stagnated over the past 30 years. Civil registration and vital statistics (CRVS) systems are not only a source of legal documentation and empowerment for individuals, but also generate crucial evidence for economic, social and health decision-making. The global commitment to the MDGs has highlighted the urgent need for reliable, continuous and comparable vital statistics and has created a momentum to improve birth and death data. As attention shifts to understanding and addressing the challenges posed by the post-2015 agenda – including disease control, human rights, equity, sustainable development and access to basic services – it is becoming ever more apparent that weak CRVS systems impair the ability of countries to monitor and strengthen targeted development policies, particularly for health. This Resource Kit specifically provides key guidance that countries with weak CRVS systems can use to develop and successfully implement improvement strategies.

The registration of vital events thus provides the foundation for policy and programme development and implementation, and a platform for the delivery of government services to the population. It also contributes to efforts to promote equity and justice by enhancing access to public services by the poorest and most vulnerable population groups. It bolsters the capacity of national and local administrators to deliver services by helping to identify what interventions are needed and by whom. Investments in civil registration pay for themselves many times over by improving the targeting of services and increasing the efficiency of resource allocation. Generating trustworthy statistics on mortality levels and trends, and on causes of death, enables not only the identification of those groups at most risk, but is the key to evaluating the responses mounted to emerging health threats.

In 2011, at the request of the Secretary-General of the United Nations, the Commission on Information and Accountability for Women's and Children's Health was convened by the World Health Organization. The Commission recommended that countries prioritize increased efforts to strengthen their CRVS systems. In all regions, including Africa, the Americas, Asia, the Eastern-Mediterranean and the Pacific, regional and country activities are now under way, with the full support of the United Nations, the World Health Organization, the Health Metrics Network and development partners.

All stakeholders working to strengthen national statistics on births, deaths and causes of death will find this Resource Kit to be of great and immediate value. It presents materials, drawn from many sources, in a user-friendly format that is accessible to both experts and those with a general interest in evidence-based decision-making. The kit is part of a set of tools prepared by the World Health Organization, the Health Metrics Network and the University of Queensland which uses a standards-based and country-driven approach to assessing CRVS systems and developing improvement plans. Some of these tools are intended to support countries in developing a strategic plan that is based on evidence. This Resource Kit is of particular value at the implementation stage and will enable its users to identify, locate and make use of the core standards, tools and materials needed to build stronger and more-efficient systems.

Thanks to the technical inputs of many individuals representing a broad range of expertise in the areas of civil registration, vital statistics, health information systems and public health, this Resource Kit represents a truly unique compilation of knowledge, experiences and resources. We have no doubt that it will serve as a valuable tool for all those working in this critically important area of human development.

It is a fundamental principle of human rights that every life counts and that every individual matters. If we are to give life to such principles it is time to start counting everyone. Whether you are engaged in CRVS on a day-to-day basis or only occasionally, a technical expert or an interested layperson, a producer or user of vital statistics, we urge you to make use of this document, draw upon the resources it contains and become part of the growing global momentum for action in this vital endeavour.

Richard Horton
The Lancet

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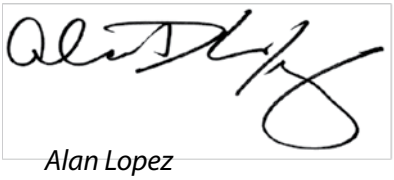
World Health Organization
HMN Executive Secretary, a.i.



Alan Lopez
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Executive summary

This Resource Kit is designed to support countries in planning and implementing improvements to their civil registration and vital statistics (CRVS) systems. It has been compiled using critically assessed materials drawn from many sources, and is presented in a user-friendly way that is accessible to both experts and users with a general interest in evidence-based decision-making. The Resource Kit will enable all users to identify, locate and make use of core standards, tools, materials and country experiences. It has benefitted from the many technical inputs of a broad range of individuals with expertise in the areas of civil registration, vital statistics, health information systems and public health.

Why civil registration and vital statistics systems matter

Decision-makers depend on sound and timely statistics for policy development, and for programme monitoring and evaluation. Reliable vital statistics on the numbers and distribution of births and deaths – and including causes of death – are needed to inform social and economic planning across both public and private sectors. These sectors include health, education, labour and employment, urban planning, finance and economic development, industry and trade, social insurance, environment and population.

The health sector has a particularly strong need for functional CRVS systems. Tracking the progress of strategies to reduce the levels of child, maternal and disease-specific mortality and to address inequalities in all these areas requires reliable, continuous and timely data on age- and cause-specific mortality. Similarly, monitoring the spread and distribution of noncommunicable diseases – a growing epidemic in Asia and the Pacific, and other developing regions – can only be achieved with reliable vital registration systems that count all deaths and reliably certify their causes.

The most effective and efficient source of reliable vital statistics is a civil registration system that covers the whole population, and that generates statistics on a continuing basis. However, many countries cannot draw upon a reliable and continuous flow of accurate vital statistics because their CRVS systems are weak or dysfunctional.

Interest in strengthening CRVS has recently accelerated, with a number of global and regional initiatives being led by development institutions in partnership with nongovernmental organizations, academia and the donor community. Countries are increasingly taking action to strengthen their CRVS systems, with support from the World Health Organization (WHO) and other United Nations agencies, the Pan American Health Organization (PAHO), the Health Metrics Network (HMN), the Secretariat of the Pacific Community, and the Health Information Systems Knowledge Hub at the University of Queensland (HIS Hub).

Purpose of the Resource Kit

Developed as a supporting contribution to these national, regional and global initiatives, the Resource Kit is a distillation of what is known about effective approaches and actions that can be taken to address the most common challenges of CRVS systems. Through the provision of essential information in areas such as the agreed international standards for CRVS systems, the common challenges faced in low- and middle-income countries, and the lessons learnt from experience in overcoming them, the Resource Kit is intended to help build capacity for strengthening civil registration systems, leading to the improved coverage, quality and consistency of vital statistics.

The scope of the Resource Kit is defined mainly by the needs of the health sector for regular and reliable statistics on births and deaths by age, sex and cause of death. Although the Resource Kit does not explicitly address issues in the registration and compilation of data on marriages, divorces, adoptions or migration, these topics are partially covered in several of the references and resources cited.

Potential users of the Resource Kit

The Resource Kit has been developed for all those who use – or work to produce – regular and reliable information and statistics on births and deaths by age, sex, and cause of death. These will include, as a minimum, agencies responsible for the registration of births and deaths (such as civil registrar's office or ministry of the interior), the national statistics office, and the ministry of health. However, the range of stakeholders with an interest in CRVS is much broader. Other government ministries, including justice, education, employment, social insurance and security, contribute to and draw upon functioning CRVS systems.

How the Resource Kit was developed

The Resource Kit draws from a wide array of materials developed by numerous technical partners and institutions, and is the product of an ongoing collaboration between experts in civil registration, vital statistics and public health. Contributions were received from experts in all aspects of CRVS and from representatives of the following institutions: the United Nations Economic Commission for Africa; the United Nations Economic and Social Commission for Asia and the Pacific; WHO headquarters and its six regional offices; the Australian Bureau of Statistics; the Bill and Melinda Gates Foundation; the Ifakara Health Institute, United Republic of Tanzania; the Institute for Health Metrics and Evaluation at the University of Washington, United States; the School of Public Health, Queensland University of Technology, Australia; the Australian Centre for International and Tropical Health, University of Queensland, Australia; the HIS Hub at the School of Population Health, University of Queensland, Australia; the Swiss Tropical and Public Health Institute, Switzerland; and the USAID-supported MEASURE Evaluation project.

Structure and contents of the Resource Kit

The Resource Kit is structured to support a process of national convening, mobilization, strategic analysis, prioritization and planning in support of efforts to strengthen CRVS. It consists of eight modules, each of which addresses a specific set of challenges and the resources required to address them. Each module starts with introductory and background sections, describes common problems encountered, identifies key actions required, provides links to essential tools and resources, and concludes with a summary roadmap for implementation.

Taken together, these modules represent a synthesis of the experiences and knowledge gathered from countries, international research, global and regional workshops, and from technical experts. Although each module is geared to improving the functionality of a specific aspect of CRVS systems – and can therefore be selectively applied – obtaining the maximum benefits is likely to result from the systematic application of the entire series.

- The **Introduction** describes the purpose and importance of CRVS systems and sets out the many functions of civil registration in terms of legal proof of identity and age which enable the exercise of individual legal and human rights, and in terms of the establishment of family relationships. It goes on to explain why civil registration is the most effective and efficient source of the vital statistics on births and deaths that are used by multiple sectors, including the business sector. Finally, the introduction highlights the growing momentum to strengthen country CRVS systems after many years of neglect by national authorities and by development partners.
- **MODULE 1: Strategic options and road map for improvement** – introduces a set of interrelated steps and two complementary assessment tools for countries with CRVS systems at different stages of development. The "rapid assessment" tool allows users to quickly ascertain the maturity and functioning of their system, and the location and nature of major problems or bottlenecks. The use of a "comprehensive assessment" tool then allows for an in-depth review of the whole system, generates the evidence needed for an improvement plan, and identifies priority actions for specific circumstances.
- **MODULE 2: Legal basis for civil registration and vital statistics** – presents guidance, resources and tools that address legislative issues in civil registration systems. After explaining why a legal framework for CRVS is important, the module describes what should be covered in law and indicates who should be involved in reviewing and improving the legal framework. A number of key actions and approaches to the more common problems encountered are then outlined.
- **MODULE 3: Registration practices, coverage and completeness** – introduces practical advice on the steps to be taken if the legal framework is to be successfully operationalized. The module describes practical implementation issues, and offers guidance and resources for those engaged in the day-to-day running of CRVS systems. Explanations are given of who should be collecting information on births and deaths and at what level of the system; how vital statistics data should be compiled, stored, managed, disseminated and shared; the minimum information that should be collected on each birth and each death; how to ensure that data flow smoothly between different parts of the CRVS system; and how to monitor the completeness of vital events registration.

- **MODULE 4: Death certification and cause of death** – focuses on the processes of medical certification of the cause of death. The module explains the importance of having deaths certified by a medically qualified doctor and how to ensure that this is done correctly. It explains what good death-certification practices are – and why they are important – and describes how to address common problems and bring about improvements in this area.
- **MODULE 5: Coding mortality data** – explains how certification and coding are sequential processes, with the quality of coding heavily dependent on the quality of death certification. Both need to be done well to enable the production of reliable and useful data on causes of death in populations. The module examines common problems with the coding of mortality data, and suggests key actions and approaches for addressing them, including how to improve the qualifications and training of coders.
- **MODULE 6: Data quality checks, access and use** – introduces methods and tools for assessing and improving the quality of vital statistics, including on causes of death. It then suggests how data can be made more accessible to potential users, and introduces ways of ensuring that the data produced are effectively used for policy and programme development.
- **MODULE 7: Interim methods for generating vital statistics when civil registration is inadequate** – is of particular relevance to countries where a high proportion of deaths occur outside hospitals and are not medically certified, and to countries with weak or dysfunctional civil registration systems where decision-makers are anxious to know something about the levels, trends and patterns of fertility and mortality. The module describes methods that can be used to generate evidence on levels of mortality by age and sex on an interim basis, and introduces and explains techniques to cost-effectively generate information on the causes of deaths that occur outside hospitals.
- **MODULE 8: Building support for strengthening civil registration and vital statistics** – introduces resources that can be used to strengthen CRVS advocacy and to help mobilize the support needed to revise legislation and to secure human and financial resources for improving the existing system. This module outlines advocacy approaches and case studies, explains how to identify supportive stakeholders, and presents tools and resources to support the development of a tailored advocacy strategy.

The Resource Kit also includes a comprehensive list of cited **References**, a **Glossary** and a series of **Annexes**.

Developing and implementing a national plan for strengthening CRVS systems requires that all country stakeholders have a shared understanding of the weaknesses of current systems and are able to reach joint agreement on priority actions and on feasible strategies for improvement that can be implemented in the short to medium term. There is no single pathway or template, and the scope and contents of a plan will depend upon the starting circumstances and capacities. In all settings, it is likely that information and communication technologies will have a growing role to play in strengthening the different aspects of CRVS and ensuring sustainability. In all cases, the actions proposed and undertaken must be tailored to the nature, scale and complexity of the challenges faced.

Introduction

Overview

For many people, awareness of civil registration and vital statistics (CRVS) systems is limited to their own personal experience of registering a birth or death, applying for a copy of a birth certificate, getting married or divorced, or making arrangements for the funeral of a relative. For others, their day-to-day work may involve the completion of forms for recording births, marriages or deaths – perhaps in a registry office or health facility. In some cases, individuals may be responsible for compiling birth and death data, and generating vital statistics, while others routinely use statistics on births and deaths in their role as health-service planners, programme managers, policy-makers or demographers analysing fertility and mortality statistics.

Many people are thus actively involved in CRVS systems as individuals, health-care practitioners and planners or data users – sometimes as all of these. Nevertheless, there is often little awareness that the simple acts of registering a birth, filling out a death certificate or entering a code into a database lie at the heart of larger and crucially important systems that are vital, for example, in providing proof of identity to individuals, or in generating information about whole populations. Such information is the basis of sound governance and the key for responsible planning – not only in health but in other social and economic sectors.

The primary purpose of civil registration is therefore to meet legal requirements by:

- providing documentary evidence on which to base claims of identity, legal status and ensuing rights;
- providing proof of age, and allowing access to rights based on age such as school entry, voting and pension rights;
- establishing family relationships;
- enabling the legal transmission of property, inheritance, social insurance and other benefits.

CRVS systems can then generate administrative data, which serve as the basis for databases across multiple sectors and can be compiled to produce vital statistics. Vital statistics are therefore a by-product of the registration system – not its main goal. CRVS systems thus have three main components:

- registration of events – focusing on the registering of births and deaths;
- certification – issuing original birth and death certificates, and providing copies to individuals when needed;
- vital statistics – compiling, analysing and disseminating statistics resulting from registration and certification.

If any one of these components is missing or ineffective then CRVS systems will not function well.

Advantages of CRVS systems in generating key data

Fully functional CRVS systems have important characteristics that make them more effective than other approaches for generating fertility and mortality data. These characteristics can be summarized as the "seven Cs".

1. CRVS systems produce data on a **continuous** basis. Births and deaths are registered and monitored as they occur, and ongoing statistics can be produced – unlike surveys, which are conducted at intervals. Well-functioning CRVS systems can therefore provide reports of fertility and mortality levels and patterns every year at any time.
2. CRVS systems produce data that are **consistent** and **comparable** – both over time and from place to place. This is because such systems are based on standard definitions of vital events that are applied uniformly. For example, good CRVS systems use the internationally agreed definitions of live birth, fetal death and causes of death described in the International Statistical Classification of Diseases and Related Health Problems (ICD) now in its 10th Revision (1).
3. Vital statistics from CRVS systems are **complete** because registration covers the whole population. Special efforts are made to ensure that all groups are covered, even those living in remote areas. This is very important for identifying inequities between different geographical areas and population groups.
4. Vital statistics from CRVS systems are more likely to be **correct** than those from other sources because vital events are recorded as close as possible in time and place to where they happen. The facts are carefully checked because of their importance in producing legal documentation.
5. CRVS systems are **cost-effective** for producing statistics because the data required are produced as a by-product of the established administrative and legal registration system. In some settings, resources for this purpose are generated by charging individuals for certified copies of vital event documentation.
6. CRVS systems can produce statistics on **cause of death** for all deaths. Deaths that occur in health facilities or under the supervision of a health worker can be medically certified and coded in accordance with the ICD. Where many deaths occur outside health facilities, verbal autopsy (VA) methods can be used to determine the probable cause of death.

A global movement for civil registration and vital statistics

Given the huge importance of well-functioning CRVS systems to both the public and policy-makers, it is remarkable that this issue has received so little attention from the global health and development community. In part, this is because CRVS systems are taken for granted in highly developed countries where all births and deaths are routinely registered and certified. In these countries, vital statistics are readily available for governments to monitor and to use for social and economic planning in key sectors such as health, education, employment and housing. However, governments in low- and middle-income countries have the same need for data for planning their development and ensuring the effective use of limited resources. As a result, there is now a momentum building within these countries and within the global development community towards the strengthening of CRVS systems.

In 2007, a series of papers was published in The Lancet which drew attention to the "scandal of invisibility" (2) in which the poorest and most vulnerable people in society went unregistered, uncounted and uncared for. In 2008, the Australian Agency for International Development (AusAID) established the Health Information Systems Knowledge Hub (HIS Hub). Since then, the hub has developed a number of tools and resources to support countries working to improve their vital statistics systems. More recently, the Health Metrics Network (HMN) – a partnership of health and statistical constituencies hosted by the World Health Organization (WHO) – has established the Monitoring of Vital Events, including through the use of Information Technology (MoVE-IT) initiative to promote the strengthened monitoring of vital events (3). In 2011, the Commission on Information and Accountability for women's and children's health recommended that countries prioritize their efforts to strengthen CRVS systems (4).

Alongside these developments in the health sector, several multisectoral regional initiatives are under way in Africa, Asia and the Pacific, and the Americas which aim to generate high-level political commitment for the strengthening of CRVS systems.

- In Africa, the United Nations Economic Commission for Africa (ECA) and the African Development Bank (AfDB) sponsored a series of ministerial meetings and expert working groups in 2010 and 2011. An ECA regional plan for 2011–2015 was developed to support reform and improve CRVS systems in Africa (5). This plan guides countries and regional and international organizations in managing interventions and monitoring the progress made in strengthening CRVS systems in Africa.
- In Asia and the Pacific, the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) passed a resolution in 2011 calling on countries and development partners to support activities for strengthening CRVS systems (6). In the Pacific, the Secretariat of the Pacific Community has included the issue of vital statistics among its statistical priorities, and has developed and begun to implement a Pacific Plan for Improving Vital Statistics in partnership with the HIS Hub, United Nations Children's Fund (UNICEF), United Nations Population Fund (UNFPA), WHO and other stakeholders in the region (7).
- In the Americas, the Pan American Health Organization (PAHO) has been implementing a Regional Plan of Action for Strengthening Vital and Health Statistics since 2008 as part of broader efforts for health information systems strengthening (8).

The demand to demonstrate results in health is growing

In most countries, the office of the registrar-general, ministry of the interior or ministry of justice is the agency responsible for civil registration and vital statistics reporting. However, the role of the health sector in strengthening CRVS systems is growing – in part due to increasing pressures to demonstrate that health interventions are achieving measurable results. It is not enough to show that health workers have been trained, medicines distributed, antenatal and delivery care provided, and education campaigns carried out. It is also crucial to demonstrate that these programmes are saving lives, reaching vulnerable population groups and reducing inequities. In addition, results need to be tracked not only at national level but also at a regional and/or district levels, where many of the decisions on resource allocation and the prioritizing of activities are made.

Decision-makers in the health sector – including managers and practitioners such as physicians and others – require an up-to-date understanding of levels and causes of mortality. This information is essential for monitoring trends, evaluating the impact and effectiveness of health programmes, and forecasting the burden of disease. Planners and managers need to be able to reliably report on key indicators and targets set out in national health-sector and poverty-reduction plans, including reporting on progress towards the Millennium Development Goals (MDGs). They also need to be able to understand emerging health challenges, such as the prevention and management of noncommunicable diseases.

The data produced by facility-based information systems can help to meet these information needs, but such systems are insufficient as they only generate data on the users of health-care services, not on those who need but do not use them. For example, data on mortality and causes of death are mainly drawn from hospital records, but in settings where many deaths occur outside hospitals these data are not representative of the whole population.

In many countries, household surveys are used to generate data on important indicators such as birth rates, maternal, infant and child mortality, use of health services, and individual and household behaviours. However, surveys are not always appropriate for measuring cause-specific mortality in adults – for example, maternal mortality (9). To better understand evolving patterns of mortality, some countries have set up demographic surveillance systems in sample districts to track all births and deaths. Using a technique known as verbal autopsy (VA) deaths are actively monitored and causes of death are ascertained through interviews with family members. Examples of this approach include the Disease Surveillance Point (DSP) system in China, the Sample Registration System (SRS) in India and the use of sample vital registration with verbal autopsy (SAVVY) in the United Republic of Tanzania. However, these alternative approaches cannot match the advantages of comprehensive civil registration systems, either in ensuring the provision of legal documentation to individuals or in generating vital statistics.

Using this resource kit to develop a country improvement plan

The development of national plans for strengthening CRVS systems requires that all country stakeholders have a shared understanding of the weaknesses of current systems and are able to reach joint agreement on priority actions and on feasible strategies for improvement that can be implemented in the short to medium term. The guidance, tools and links provided in this "resource kit" have been developed to support such a process by making it easier for those involved in CRVS systems to find and make use of important technical materials and other resources. Whether working in a national ministry of health, a registrar-general's office, ministry of the interior, or related government agency, or in a development or donor agency, this resource kit is aimed at helping individuals and organizations to build sustainable capacity for strengthening existing systems, and thus improve the coverage, quality and consistency of vital statistics.

The resource kit focuses primarily on the needs of the health sector for regular and reliable statistics on births and deaths by age, sex and cause of death. Although it does not directly

address issues such as the registration and compilation of data on marriages, divorces, adoptions or migration, a number of the resources referred to in several of its individual "modules" do. Taken together, these modules represent a synthesis of the experiences and knowledge gathered from countries, international research, global and regional workshops, and from technical experts. This includes the incorporation of lessons learnt from research into ways of improving vital statistics systems undertaken or supported by the HIS Hub during the period 2009–2011.

- **MODULE 1** introduces a set of interrelated assessment tools to help users to critically and systematically evaluate current CRVS systems and identify priority actions. The use of a rapid-assessment tool allows for the location and nature of major problems to be quickly ascertained. A more-comprehensive assessment tool can then provide guidance for an in-depth review of the whole system, and can generate the evidence needed to develop an improvement plan.
- **MODULE 2** and **3** outline the resources and tools for addressing legislative issues and operational practices in civil registration systems, respectively.
- **MODULES 4** and **5** focus on the challenges of generating high-quality statistics on causes of death from civil registration.
- **MODULE 6** outlines resources, tools and methods to help users to critically assess the quality of vital statistics from civil registration, and to strengthen the dissemination and use of vital statistics for policy-making and programming.
- **MODULE 7** focuses on the interim strategies needed to generate vital statistics in settings where the majority of deaths take place outside hospitals, and where the current CRVS systems are very weak. Principal resources include guidance materials for longitudinal health and demographic surveillance developed by the International Network for the Demographic Evaluation of Populations and Their Health in Developing Countries (INDEPTH) along with accounts of the experiences of countries in implementing sample registration, for example in India and the United Republic of Tanzania. This module also includes resources to support countries in conducting verbal autopsies as a way of generating data on patterns of cause of death in settings where most deaths occur without a physician present.
- **MODULE 8** introduces resources that can be used to develop an advocacy strategy to support the strengthening of CRVS systems, and to mobilize the support needed to revise CRVS legislation or to secure resources for improving systems. Tools such as policy briefs, business cases, and advocacy and communication campaigns can be used to bring about change.

Taken together, this series of modules consolidates current best practices and recommended guidance, and provides a number of key resources to help address many of the common problems associated with CRVS systems in low- and middle-income countries. Although each module is geared to improving the functionality of a specific aspect of CRVS systems – and can therefore be selectively applied – the systematic application of the entire series is likely to provide the maximum benefits.

MODULE 1:
Strategic options and roadmap for improvement

1.1 Introduction

There is no single pathway to reaching the goal of establishing effective CRVS systems. Because the scale and complexity of the task varies greatly between countries, strategies need to be tailored accordingly. Making progress will require a detailed understanding of the status and performance of current CRVS systems. Such an understanding will allow for the identification of the main issues that will need to be addressed, especially in the short to medium term.

This module describes a two-step self-assessment approach that will allow for the strategic analysis of current systems, and outlines the types of interventions and other activities that will be needed based on the assessment outcome. The two steps are:

- An initial rapid assessment (10) to generate a series of numerical scores reflecting the strengths and weaknesses of the current systems, and one overall score for classifying systems into one of four categories. This is primarily aimed at raising awareness and preparing the way for a more-comprehensive review.
- A comprehensive assessment (11) to compare current systems with the CRVS standards developed by the United Nations Statistics Division (UNSD) and WHO. This assessment is aimed at producing the evidence needed to prioritize improvement activities, and to develop an improvement plan.

1.2 Background

Both 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 CRVS systems, as this will require effective collaboration between government departments in both the health and non-health sectors, and cooperation with nongovernmental organizations (NGOs) 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.

The rapid assessment has now 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 CRVS systems into four groups – dysfunctional; weak; functional but inadequate; and satisfactory. **Table 1** outlines 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 1: Typology of national CRVS 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.

Assessing current status

The first step in strengthening CRVS systems is to carry out an assessment of the current situation. In the case of both the initial rapid (10) and comprehensive (11) assessment tools, all aspects of CRVS 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 are also available that focus on specific aspects of systems, such as completeness (12) or quality of cause-of-death data (13).

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, and in settings where systems are dysfunctional or weak and resources are limited, as it helps to generate the evidence needed to advocate for strengthened CRVS systems. The rapid assessment tool consists of 25 questions on the functioning of CRVS systems grouped into the following 11 component areas:

- legal framework for CRVS
- registration infrastructure and resources
- organization and functioning of the vital statistics system
- completeness of birth and death registration
- data storage and transmission
- ICD-compliant practices and certification within and outside hospitals
- practices affecting the quality of cause-of-death data

- ICD coding practices
- coder qualification and training, and quality of coding
- data quality and plausibility checks
- 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 CRVS systems. Question responses should be agreed-upon and selected following thorough group discussion. 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. Adding together the numerical scores for each of the 25 questions will reveal the total score. 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 CRVS 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. To support this process, the technical guidance and other resource materials provided in this resource kit are designed to assist in the formulating of improvement plans and the implementing of priority activities.

Country experiences of rapid assessment

The rapid assessment tool has now been used in over 40 countries in the African and Asia-Pacific regions. For example, in Kenya, the visualized assessment outcome shown in **Figure 1** indicates that progress has been made in establishing the legal framework for CRVS systems (score closest to 100%) but that very little progress has been made in most of the other components.

An evaluation was also conducted of the results of rapid assessment of CRVS systems in 26 countries in the Asia-Pacific region (15). The countries covered a broad income and development spectrum, with overall assessment scores ranging from 11–97% (average 73%; median 77%). Countries with the lowest scores (<65%) identified major issues in relation to the completeness of vital statistics, malfunctioning systems, poor cause-of-death certification and coding, and absence of overall data quality. Countries in the middle group (average scores 65–847%) identified some weaknesses in completeness, cause-of-death certification, training of ICD coders, transmission of data, intra-governmental collaboration, and data dissemination. Countries scoring >85% – generally those in the highest income group – identified different weaknesses, mainly in relation to the quality of mortality coding, coder training and inter-agency cooperation. **Figure 2** summarizes the average scores for each of the 11 component areas listed above.

Figure 1: Results of rapid assessment of CRVS systems in Kenya, 2011 (14)

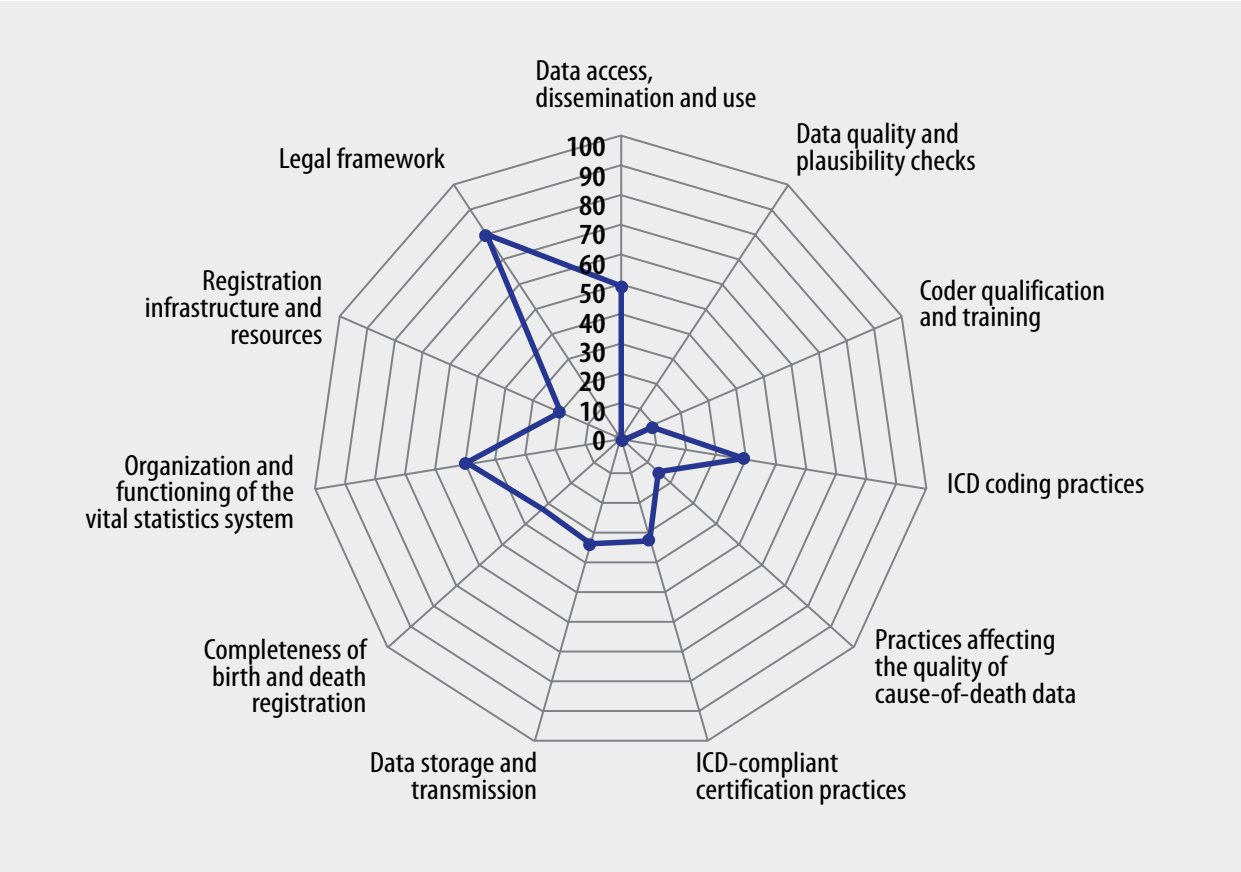
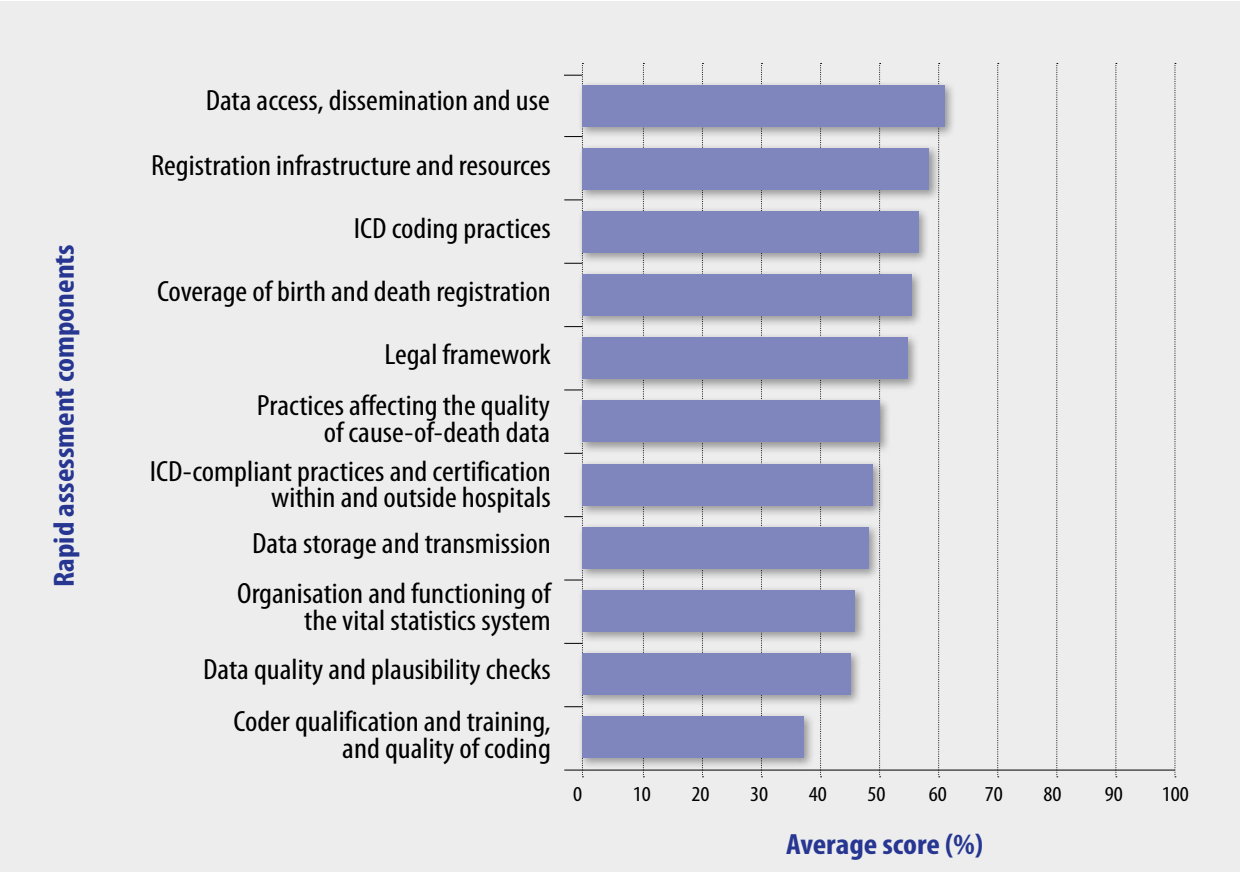


Figure 2: Results of rapid assessment of CRVS systems in 26 Asia-Pacific region countries, 2010



The rapid-assessment instrument can thus be helpful in highlighting the main strengths and weaknesses of current CRVS systems but 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 CRVS system components. Such an assessment helps to identify the precise elements that need to be developed, strengthened or adjusted.

1.3 Key actions

Identifying strategic options

By evaluating the results of rapid and comprehensive assessments, countries will be able to better identify what steps are needed to improve CRVS systems. Country experiences in Africa and the Asia-Pacific region have shown that the four-group typology of countries shown in **Table 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 CRVS systems proposed in **Table 2** (at the end of this section). 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 matches their situation.

Countries with dysfunctional systems

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

- Advocating for improved CRVS systems among high-level policy-makers in health and non-health sectors (see Module 8).
- Reviewing legal and regulatory framework contents and compliance (see Module 2).
- Reviewing resources (human, infrastructural and financial) for civil registration (see Module 3).
- 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 (see Modules 2 and 3).
- Developing training manuals for civil registration.
- Reviewing and revising birth and death forms (see Module 3).
- Providing training for physicians in correctly certifying cause of death for deaths that occur in hospitals (see Modules 4 and 5).
- Introducing computerized systems for civil registration, and for data transfer, storage and analysis.
- Compiling, reviewing and analysing available hospital data, and producing summary statistics, particularly in urban areas where people are more likely to use formal health facilities – see the WHO ANACoD tool (16).
- Starting in urban areas that have civil registration in place, improve the system and compile and analyse available data.

- Applying VA techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in medical facilities (17) (see Module 7).
- Making maximum use of data from existing health and demographic surveillance sites to generate evidence on levels of mortality by age and sex (see Module 7).
- 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 births and 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 for improved CRVS systems among high-level policy-makers in health and non-health sectors (see Module 8).
- Reviewing legal and regulatory framework contents and compliance (see Module 2).
- Reviewing resources (human, infrastructural and financial) for civil registration (see Module 3).
- 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 (see Modules 2 and 3).
- Developing training manuals for civil registration.
- Reviewing and revising birth and death forms (see Module 3).
- 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 (see Module 4).
- Developing a cadre of coders to correctly assign underlying causes of death (see Modules 4 and 5).
- Introducing computerized systems for civil registration, and for data transfer, storage and analysis.
- Compiling, reviewing and analysing available hospital data, and producing summary statistics, particularly in urban areas where people are more likely to use formal health facilities – see the WHO ANACoD tool (16).

- Using data on deaths in hospitals 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 (16).
- 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 births and deaths to produce summaries of fertility and mortality patterns in urban areas;
  - enrolling public-service health workers to supply official information on births and deaths;
  - developing publicity campaigns and incentive schemes for registration, such as the requirement for a birth certificate in order to receive government services;
  - opening additional registration offices and extending mobile registration to more-remote areas.
- Applying VA techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in medical facilities (17) (see Module 7).
- Making maximum use of data from existing health and demographic surveillance sites to generate evidence on levels of mortality by age and sex (see Module 7).
- Introducing sample registration (see Module 7).
- 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 births and 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 hospitals 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 CRVS systems among high-level policy-makers in health and non-health sectors (see Module 8).
- Reviewing legal and regulatory framework contents and compliance (see Module 2).

- Reviewing resources (human, infrastructural and financial) for civil registration (see Module 3).
- Strengthening coordination mechanisms linking key stakeholders such as the offices of the registrar-general and national statistics, ministry of health and civil registration authorities (see Modules 2 and 3).
- Updating training manuals for civil registration.
- Revising birth and death forms if required (see Module 3).
- Conducting a comprehensive assessment of current systems.
- Developing a prioritized improvement plan.
- Conducting reviews of quality of death certification and coding (see Modules 4 and 5).
- Improving physician certification practices (see Modules 4 and 5).
- Improving coding practices (see Modules 4 and 5).
- Using the WHO ANACoD tool (16) 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 local and national level. This feedback loop will encourage local officials to improve registration coverage, and enhance public support for CRVS systems.
- Applying VA techniques to generate data on cause-specific mortality patterns in settings where deaths do not occur in medical facilities (17) (see Module 7).
- Introducing sample registration systems (incorporating existing health and demographic surveillance sites as appropriate) to generate nationally representative vital statistics. The initiating of sample systems can help to build up human capacities prior to an eventual extension to comprehensive civil registration.
- Conducting community outreach to under-served populations, and targeting civil registration advocacy and communication efforts to remote and under-served areas and population groups.
- Increasing coverage in remote or marginalized populations by reaching out to under-served 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 hospitals 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 as needed.
- Introducing regular quality control and feedback mechanisms into current cause-of-death certification and coding approaches (see Modules 4 and 5).
- 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 ICD rules (see Modules 4 and 5).
- 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 (see Modules 4 and 5).
- Rolling out electronic patient-record systems in hospitals, 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.

Implementing mechanisms and processes

A national coordination committee for the improvement of CRVS systems should be established or strengthened. The committee should include representatives of the major agencies involved in CRVS, 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, NGOs, funding bodies and foundations involved in different aspects of CRVS. 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.

Table 2: Suggested pathways for strengthening CRVS systems according to country grouping

Key actions	Countries with dysfunctional systems	Countries with weak systems	Countries with functional but inadequate systems	Countries with satisfactory systems
Advocate for improved CRVS				
Review legal and regulatory framework contents and compliance				
Review resources (human, infrastructural and financial) for civil registration				
Establish coordination mechanism linking key stakeholders				
Review functioning of existing coordination mechanisms and enhance as required				
Develop or update training manuals for civil registration implementation				
Conduct comprehensive assessment of all aspects of current systems				
Develop a prioritized improvement plan				
Review and revise birth and death forms				
Conduct reviews of quality of death certification and coding				
Develop curricula and provide ongoing training for physicians to correctly certify causes of death				
Improve physician certification practices				
Strengthen skills and capacities for mortality coding				
Improve coding practices				
Introduce computerization for registration, and for data transfer, storage and analysis				
Compile, review and analyse available hospital data and produce summary statistics				
Starting in urban areas, improve the systems in place and compile and analyse the data				
Compile and analyse available mortality data and interpret the results for action				
Use verbal autopsy to generate data on cause-specific mortality in settings where deaths do not occur in medical facilities				
Make use of data from health and demographic surveillance sites to generate data on levels of mortality by age and sex				

Key actions	Countries with dysfunctional systems	Countries with weak systems	Countries with functional but inadequate systems	Countries with satisfactory systems
Introduce sample registration to generate nationally representative vital statistics				
Conduct research into the potential of mobile phones for recording vital events at community level				
Where there are already local-level procedures for identifying and counting births and deaths, use mobile phones to standardize reporting and improve data completeness and timeliness				
Mobilize communities by conducting information, education and communication campaigns				
Increase coverage in remote or marginalized populations by reaching out to under-served population groups and providing incentives for registration				
Deploy mobile registration units in remote areas and make registration forms available in local languages				
Introduce computerization to facilitate the compilation, transfer and analysis of existing data				
Introduce electronic patient records in major hospitals, incorporating appropriate software for facilitating data transmission and analysis				
Introduce automated coding software to standardize and speed up the analysis of mortality data				
Improve the timeliness and dissemination of data				
Facilitate access to vital statistics by decision-makers and other users such as researchers				

1.4 Tools and resources

• Rapid assessment of national civil registration and vital statistics systems (10)

This rapid assessment tool is the first step in developing an understanding of the current structure and functioning of national CRVS systems. It can be used for both a baseline analysis and for subsequent occasional monitoring of progress as country interventions are implemented. The outcome of the assessment can be used to make the case to senior decision-makers for a more-comprehensive analysis to be conducted.

Prior to its finalization and release, the tool was extensively peer-reviewed by technical experts and field-tested in three countries. It is available as text at: **http://whqlibdoc.who.int/hq/2010/WHO_IER_HSI_STM_2010.1_eng.pdf**

A spreadsheet version to facilitate the compilation and automated calculation of data can also be found at: **http://www.who.int/healthinfo/CRVS_electronic_final.xls**

The rapid-assessment tool should be seen as a companion to the more-comprehensive tool described below.

• Improving the quality and use of birth, death and cause-of-death information: guidance for a standards-based review of country practices (11)

This comprehensive assessment tool provides guidance on the detailed assessment of different aspects of country CRVS systems, including the legal and regulatory framework; registration, certification and coding practices; and the compilation, tabulation and use of the resulting data. The tool comprises a roadmap outlining the main steps in conducting the review – starting with the formation of a review committee of key stakeholders – and an assessment framework which serves as a template for the review process.

The focus of the tool is on births, deaths and causes of death because these are the fundamental events that countries need to know about in order to guide public health programmes, monitor population dynamics and measure key health indicators. The approach described is largely directed to those countries where civil registration is established but is inadequate in terms of its coverage, quality or both. Countries where civil registration is not established may still find the approach useful, even though parts of the assessment framework will not be relevant. If the extent of completeness or coverage of vital statistics data is known, then even incomplete information can yield valuable insights into mortality patterns and the main causes of death. This tool can be found at: **http://whqlibdoc.who.int/publications/2010/9789241547970_eng.pdf** or can be obtained in its spreadsheet version from WHO at **healthstat@who.int**.

• Mortality statistics: a tool to enhance understanding and improve quality (18)

This document is intended to help build analytical capacity for assessing the quality of mortality statistics in order to enhance their value in informing health policies and programmes. It is associated with an electronic spreadsheet (ANACoD) produced by WHO (16) for facilitating the analysis of available mortality and cause-of-death data. This tool is described in more detail in Module 6 of this publication.

1.5 Summary

The course of action required to develop effective CRVS systems will depend upon the existing country situation, and upon the availability of national expertise, capacities and resources. In all cases, an understanding of the current status and performance of CRVS systems will be needed if progress is to be made. Such an understanding will enable priority actions to be identified and addressed. The strengthening of CRVS systems can be achieved by following the basic roadmap shown in **Box 1**.

BOX 1. Basic roadmap for strengthening CRVS systems

Step 1: Conduct the rapid assessment to establish an overall CRVS systems score in the context of the typology shown in **Table 1**.

Step 2: Consider the next steps to take in accordance with the required actions set out in **Table 1** and decide which approach is the most relevant and feasible. In some cases, the next step may be to conduct the more-detailed comprehensive assessment to help determine which specific interventions will be the most feasible in the national context. Alternatively, where systems are found to be dysfunctional, it may be preferable to first address the major weaknesses.

Step 3: Develop a strategic improvement plan comprising the steps and activities needed to address each of the priority actions shown in the relevant pathway of **Table 2**. The modules of this resource kit can be used to identify approaches and technical resources to support activities.

Step 4: Define roles and responsibilities within agreed-upon implementing mechanisms and processes, and mobilize the resources required for action.

MODULE 2:
Legal basis for civil registration and vital statistics

2.1 Introduction

To be part of the modern world, with its advantages and obligations an identity is required. (19)

This module looks at some of the common problems found with current CRVS legislation, and provides guidance on what constitutes a solid legal basis for CRVS systems. The module outlines the key actions that can be taken to improve the legal framework of registration systems, and describes some selected key tools and resources for assisting in the creation or updating of such frameworks.

The key questions addressed include:

- Why is a legal framework or civil act needed for CRVS systems?
- Can a legal framework really help to improve system functioning?
- What should be included in civil registration laws?
- Do good legal models exist that can be used as examples?
- How can it be determined whether current legislation is appropriate or needs to be updated?

2.2 Background

Civil registration needs to be anchored in a legal framework

Although the essential purpose of civil registration is to provide legal proof of identity, origin, marriage or death, the information collected on these vital events also has important administrative and statistical uses – and these uses are growing in importance everywhere. Public administration, health service provision and commercial and business services all require valid forms of personal identification. In addition, agencies at all levels of government need reliable population and health-status statistics to plan and implement services efficiently.

Making registration activities subject to the law, and establishing procedural rules and regulations, is essential for the efficient management, operation and maintenance of CRVS systems. Legislation helps to ensure the completeness of registration and to improve the accuracy of information held in the civil record. Obligatory registration, deadlines and penalties for non-compliance cannot be enforced without relevant laws in place. Laws are also needed to safeguard the personal information of individuals by ensuring that it remains confidential and secure, and protecting against its misuse. Finally, anchoring civil registration in a law helps to ensure the continuity, consistency, correctness and comprehensiveness of CRVS systems.

A legal framework for civil registration also plays an important role in delivering the basic human rights set out in United Nations declarations, covenants and resolutions (20). These include the right of all individuals to be registered, the right to be given an identity from birth to death, the right of a child to know the names of their parents, the right to non-discrimination by reason of birth, and the right of a child to a nationality.

The most notable declarations, covenants and resolutions are:

- The Universal Declaration of Human Rights, adopted by the United Nations General Assembly in 1948.
- The Declaration of the Rights of the Child, proclaimed in 1959.
- Article 24 of the International Covenant on Civil and Political Rights, adopted in 1966.
- Article 12(2) of the International Covenant on Economic, Social and Cultural Rights, adopted in 1966.
- The resolution entitled: "Birth registration and the right of everyone to recognition everywhere as a person before the law" adopted by the United Nations Human Rights Council, in 2012.

The latter resolution seeks action for universal registration at birth, underlining the fundamental connection between human rights and the civil registration of individuals to ensure their legal identity. By introducing civil registration and supporting it with proper legislation, countries are automatically enacting these aspects of international human rights legislation.

The utility of a comprehensive Civil Act or legal framework that maps out systems, establishes their organization and defines responsibilities for each of the events to be registered is often poorly understood both by central and local governments. However, in the absence of a proper legal framework that obliges individuals to register births and deaths, local authorities may not fully collaborate in ensuring that all vital events are registered. As a result, CRVS systems would be unable to deliver useable vital statistics, and governments would have to obtain the information from surveys. The additional expenditures involved are likely to make governments less inclined to allocate further resources to improve the civil registration system, leading to a vicious cycle of under investment and neglect which has been observed in many countries.

Common problems encountered

Outdated and incomplete legislation

In most countries, vital events registration is not recent and the laws which govern registration practices have been in place for many years. It is therefore not uncommon to have paper-based civil registration systems that have functioned the same way for decades, with events entered by hand into books, often under a head-of-household system. Such systems only function well in societies with little migration and stable family systems. Many countries that have experienced rapid development and intensive migration towards urban areas have found that their established registration systems have increasingly become dysfunctional and no longer able to deliver the services needed by citizens. Because of the redistribution of populations within countries, and in some cases sizeable emigration abroad, many people no longer live where they were born

and registered, and where the original record was created. Retrieving information from paper-based records of families and households is both cumbersome and slow, creating a bottleneck in system functioning. Where the laws underpinning the system have not been revised and modern technology not introduced to facilitate registration and allow records to be easily transferred, the completeness and quality of registration data are likely to decline.

Experience has shown that in systems with poor records retrieval there is usually significant double registration occurring, as well as records being maintained of people who are no longer alive. For example, the Albanian Population Census for 2001 found that the civil registration registers held records for 960 000 more people than were counted by the census. One third of these records were duplicates, while the remainder were either of people who were living abroad or had died. The large number of deaths that had clearly never been registered resulted in records that had continued to age in the register long after individuals had died (19). To prevent registration systems becoming obsolete, countries should make sure that the legal basis that underpins national systems is up-to-date, so that systems remain responsive to the needs of citizens, and are able to provide reliable and useful information.

In some countries where there are no comprehensive civil or statistics acts, a series of disparate laws and regulations are in place which oblige people to register vital events. Responsibility for these laws and regulations often falls to different ministries or government departments, with frequent problems in their implementation caused by inconsistent or even contradictory approaches. Women and girls are more likely to encounter situations where they cannot easily register or where registering a birth is problematic, for example because they are unmarried, cannot name the father (for example, in the case of rape) or are unaware of their own place of origin. Laws can also be particularly discriminatory towards children born outside marriage, who may receive a fictitious family name. In some countries the birth certificates issued to such children are a different colour and format, resulting in a stigma that can stay with the individual throughout their lives.

Civil registration law may also be incomplete by leaving out certain population groups altogether – for example, refugees and other displaced persons are often not covered by existing laws and cannot register their vital events. As a result, children born to refugees may become stateless as without a legal identity they cannot prove their origins. Both UNHCR and UNICEF have reported that unregistered children are at increased risk of sexual exploitation, early and forced marriages, slavery and trafficking, illicit adoptions and other human rights abuses (21). The registration process should not discriminate against any child, and the right to be registered should be completely separate from the establishment of paternity, marital status of parents, nationality or origin status.

Advocacy by civil society groups in many countries has played an important role in raising awareness of some of these and other issues. This has led to reform and to new or updated laws on civil registration in a large number of countries, including Albania, Angola, Argentina, Bangladesh, Bulgaria, Chad, the Democratic Republic of the Congo, the Dominican Republic, Indonesia, Madagascar, Morocco, Niger, Peru, Thailand and Timor-Leste (22).

Inadequate protection of confidentiality

Data confidentiality is typically an important aspect of CRVS systems irrespective of whether they are paper-based or not. Existing confidentiality laws, however, are likely to need revision and strengthening whenever different information technologies are introduced into the system. As countries modernize their CRVS systems and introduce computers at various system levels, concerns have rightly been raised about confidentiality and the potential misuse of data, particularly when unique personal identification numbers (PINs) have been introduced – often coupled with biometric information. Confidentiality and data-security measures become ever more pressing when countries develop full national population registers that are updated from civil registration records and contain information on place of residence.

Where there is a perception that data confidentiality measures are inadequate and personal data are not kept strictly private, then trust in the civil registration system will be lost and people may be reluctant to register. Civil registration law should protect the confidentiality of all personal information in registration records and safeguard it from unlawful access. Any breach by staff or any data misuse that involves civil records should be punishable.

The introduction of computers into all aspects of administration, including civil registration, makes it imperative to ensure that there are laws, policies and mechanisms governing the release of individual data and its use. Only the close family of a deceased person should have access to information on the death record or to private information on the birth certificate. The strict application of such laws is also necessary to avoid identity fraud of various types. At the same time, it is important that confidentiality restrictions do not impede different government departments in legitimately sharing individual records for statistical or administrative purposes. Where appropriate, such sharing might involve a formal agreement outlining the security procedures to be followed and specifically listing all the restrictions on data use.

Confidentiality is particularly important in the accurate certification of causes of death as social insurance schemes often exclude or pay less for certain causes. Medical doctors may also hesitate to report certain causes of death if they fear that the information could be used against them or their institutions. The need to address this is increasingly important due to the growing interest in conducting hospital "audits" and making confidential enquiries into adverse health outcomes and preventable deaths such as those due to maternal mortality (23) or related to hazardous industrial exposures. In order to preserve confidentiality, some countries include two sections on the same death form – the "death certificate/notification" requires a medical signature and has legal value, while the "statistical report" that provides the foundation of the vital statistics system does not (24). In Argentina, as in many other countries, the statistical report does not include identifying information such as names or ID numbers. After the combined death certificate/notification is received at the office of the civil register the two elements are separated and follow independent processes.

Lack of recognition of the statistical function of civil registration systems

The United Nations advocates that civil registration has two basic functions – a legal function that provides identity and registers vital events, and a statistical function in generating national vital statistics data. These two functions should be viewed as being of equal importance (20). However, it is commonly the case that the latter function is not properly defined in law, resulting in confusion concerning who is responsible for generating the vital statistics from the registration records. Making the statistical function of civil registration very clear in law, and setting out the cooperative processes required between civil registration bodies and other public administrations for compiling and disseminating the data is highly advisable. This aspect of the civil registration system should therefore be fully recognized in either the Civil Act or Statistical laws, and resources made available to ensure that required activities are sustainable and well implemented. Vital statistics are a highly valuable resource for governments in implementing or evaluating ongoing social and economic development programmes. The dynamic nature of data from civil registration arises from the fact that they are collected at the time of the event rather than being derived afterwards as is the case with other data sources.

Obtaining statistical data as a by-product of administrative processes is relatively inexpensive and avoids duplicate collections by different government agencies. Registrars therefore provide a very valuable service by recording, for statistical purposes, several additional characteristics of the vital events they register. This additional information, which often includes birth parity, weight of the neonate, and the occupational, educational and marital status of the parents, adds value to vital statistics data but has no intrinsic relevance to the registration process itself.

To enable the civil registration office to focus on registration and associated legal issues, most countries have allocated the task of compiling vital statistics to another government agency specializing in data processing, such as a national statistics office. Given that national statistics offices also often collect information about vital events through sources such as censuses or surveys, steps should be taken to ensure that definitions and concepts are aligned between these different data sources.

The need to enforce registration

The need for civil registration systems to register all vital events and ensure both the quality and completeness of information means that birth and death registration must be made legally compulsory, and linked to some form of penalty for those who do not comply (20), (25). 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. As outlined in Module 3, there is a range of incentives that can be used to encourage people to register. However, the existence of a law will make it more likely that local authorities will be persuaded to collaborate in enforcing and promoting registration in the populations they administer.

Legislation can also help by establishing the authority and duties of the office of the registrar-general, which should include the conducting of information campaigns to encourage registration. An information campaign on the requirement to register, and on the incentives and benefits linked to registration, should be implemented at the same time as compulsory registration is enacted. Special campaigns and incentives targeting local registration authorities may also be needed as these can be the key to improving coverage.

Through a combination of the law, policy changes and well-targeted promotional efforts countries can greatly improve their registration coverage. For example, the level of birth registration in Bangladesh went from <10% in 2004 to 40% by 2008, and the country is now moving quickly towards full birth registration (22).

A legal framework can also support the registration process by broadening the responsibility for registration. For example, regulations in many countries oblige health services and funeral authorities to begin the registration process. By linking death registration with permission to transport the deceased to the burial place or with a funeral permit, there is a strong incentive to register the death quickly, while avoiding the burden of paperwork falling on the family. Similarly, obliging doctors and midwives to forward copies of birth and medical death certificates to the local civil registration office or health department proactively encourages registration. In summary, a legal framework of appropriate laws can significantly help countries reach acceptable levels of birth and death registration.

Lack of legal requirement for medical death certification

In countries where lay people are allowed to certify death, the quality of cause-of-death attribution is inevitably poor, and the distribution of causes of death becomes dominated by ill-defined causes. If cause of death is not medically certified, the public health value of collecting the information is lost and compiled cause-of-death statistics will not be reliable. The law must therefore specifically state that only a medically trained person can certify the cause of death. The medical certification of all deaths may not be possible in those countries where a high proportion of deaths occur at home with no or very limited contact with medical authorities. While this situation cannot be changed simply by altering the legal framework, it is a first step in a series of remedial actions described in subsequent modules of this resource kit. In the interim, the adverse impact of non-medically certified deaths on the utility of vital statistics can be reduced by using verbal autopsy (VA) methods to ascertain cause of death at the population level (see Module 7).

Lack of clear definitions in legislation

The legal framework should clearly define the important concepts underlying CRVS systems, including infant and child mortality. The importance of clear definitions of the terms used lies in the need to understand the precise scope of the data collected, and how the indicators widely used to measure health status and provide proxy health-system indicators have been calculated. Without standard definitions, it is impossible to use data to reliably calculate basic indicators such as neonatal, perinatal and infant mortality rates, which are needed to assess population health trends. In addition, it is not possible to generate statistics that are internationally comparable or consistent over time.

In many countries, deaths which occur within a short time of birth are inadequately dealt with in the civil registration system (26). For example, early neonatal deaths (deaths occurring within the first week of life) are sometimes classified as stillbirths to avoid having to register both a birth and a death within a few days of each other. However, this seriously distorts the resulting statistics and prevents public health authorities from identifying and addressing important issues in perinatal health. In addition, although fetal deaths (beyond a certain period of gestation) and stillbirths are not usually entered into the birth register, a declaration is made to the registrar (26). Even though these events are not included

when measuring infant mortality, they are useful for estimating perinatal mortality. It is important therefore that civil registration laws include clear definitions of terms such as "fetal death", "stillbirth" and "live birth" and that these accord with international standards (see Glossary).

Lack of legal obligation for hospital and health-facility reporting

In many countries there is no legislation that obliges hospital and health facilities – especially in the private sector – to report vital events to authorities. As a result, many such events may not be included in official counts. This is a major concern in countries where the private sector is growing and providing a sizeable share of health services. In addition, although public hospitals and health facilities usually report deaths and births to the ministry of health, these are not always subsequently reported to the civil registration authorities. Wherever there is a lack of close collaboration between government and other agencies, inconsistencies in the vital registration process can arise.

In the development of a legal framework for civil registration steps must therefore be taken to ensure that regulations exist which make it obligatory for all hospitals and health facilities to report vital events, and for this information to be shared with the civil registration service. Experience from a number of countries indicates that registration coverage can be significantly increased when civil registration offices are established within health facilities. In Latin America, for example, registry offices have been set up in maternity hospitals in Argentina, Bolivia and Uruguay. Other countries in the region, including Brazil and Colombia, are now introducing similar approaches (24). As the proportion of births and deaths that occur in health facilities is increasing in most settings, this strategy can yield significant and rapid improvements in registration coverage.

Lack of clarity in relation to the population covered by legislation

A recurrent problem in many countries is a lack of clarity concerning the scope and population coverage of civil registration laws. For example, it can be unclear if the law refers to all national citizens, or to citizens living in the country, or to all residents in the country. The situation is further complicated by the issue of inclusion or otherwise of transient populations such as refugees. The United Nations recommends that all people residing in a country, including refugees, be given the right to register vital events, irrespective of whether they are citizens or not (21), (25). This is also considered to be the best solution at local level, where it is particularly important that all individuals living in an area appear in the system in order to guide the planning and allocation of resources.

Where there is doubt about the population covered, the calculation of reliable rates becomes impossible due to the lack of a clear denominator. Nevertheless, in many countries, national legislation still does not clearly specify which groups are covered by CRVS systems, and whether or not certain categories of people, such as foreigners, refugees and displaced persons, temporary migrants, nomadic populations and citizens temporarily living abroad are excluded.

2.3 Key actions

Any initiative to introduce a Civil Act or modify existing legislation will require careful preparation, and is unlikely to succeed without broad support from government, parliamentarians and civil society in general.[1] To raise the broad-based support needed an advocacy strategy should be developed early in the drafting process. Community information and mobilization along with strong stakeholder involvement will be essential in bringing about legislative and policy change. In some countries, local NGOs play an important role in working with communities and providing inputs to the legislative process (see Annex A).

Where there is little understanding in government of what vital statistics from civil registration can be used for then developing a business case should also be considered. This will not only make an "economic case" for change but will also promote better understanding of the importance of developments such as the introduction of PINs in registers. The value of such developments is often not clear to all stakeholders but can easily be highlighted as part of the business case. If, for example, all children are assigned a PIN at birth then matching the population register with a list of registered pupils in schools easily allows authorities to verify the proportion of school-age children in education. Without the use of PINs this would be a major and potentially expensive undertaking given problems such as misspelt or identical names and ages.

The following sections provide general advice on strategies that can be useful when developing a sound legal framework. If a legal framework for civil registration legislation already exists, then the model presented in **Box 2** at the end of this section can be used to help ascertain whether there are any gaps in the current approach or elements that do not meet good practice or the standards defined by the United Nations. Where CRVS legislation has not been revised for many years, it is highly likely to be outdated and require adjustment. In this case, conducting the full comprehensive assessment of CRVS legislation using the WHO/HIS Hub assessment tool is recommended (see Module 1). The tools and resources introduced in this module can then be used to address any specific weaknesses that are found.

Obtaining input and advice on the design or revision of a legal framework for CRVS systems

Whether planning to prepare a new legal framework or to revise an existing framework, the first step before involving legal experts should be to establish an advisory committee comprising current or potential stakeholders. The agencies and departments invited to take part might typically include:

- civil registration service or other public agency currently responsible for CRVS;
- health department;
- national statistics office;
- police;
- departments concerned with personal identification, voter registration and military recruitment;

[1] For more information on building support for strengthening CRVS systems please see Module 8.

- judiciary;
- department of the interior or home affairs;
- department of education;
- social security department;
- department of employment;
- tax authorities and other finance departments;
- private sector organizations such as insurance companies and banks;
- representatives of civil society.

Involving representatives of civil society will bring important user perspectives into the discussions, for example in relation to the ease, acceptability, inclusiveness and "user-friendliness" of the registration process. Civil registration is usually performed by a public administration and as such it has an obligation to serve people and facilitate business transactions between citizens and the State. The legal framework should support a national civil registration system that is compulsory, continuous, permanent and universal. Given the number of stakeholders involved in most national CRVS systems, the specific designation of responsibilities for tasks, duties, and cooperation arrangements should be discussed early in the process, and clearly set out in law to avoid unnecessary duplication (20).

One important aspect of any proposed legislative change is an estimate of the budgetary implications. Costing should take into account both the initial establishment of the system and its annual running costs. Cost estimates should be discussed in advance and agreed with the ministry of finance. The source of funding for CRVS systems should be stated in law and not left to be decided upon by the executive arm of successive governments. Experience shows that a significant proportion of the running costs of civil registration is covered by income from the provision of certified copies of birth and death certificates, and by fees for forwarding registrations to different places (20). The expected income from these sources should therefore be estimated even if it is unlikely to cover all of the running costs. Civil registration is a public good and an essential duty of government and should, therefore, be financed as part of the government services provided to citizens.

Information needs for vital statistics

A vital event record should serve both legal and statistical purposes. For this reason, when creating or revising the registration system, it is timely to assess which characteristics are most important in meeting information needs at national and local levels – and should therefore be included in registration documents. In a new system, overloading the civil registration process with collection requests should be avoided by keeping to the basic characteristics needed to generate vital statistics. Once agreement on which data items to include on the form has been reached, arrangements should be made for the information to be collected through the civil registration process. A recommended list of high-priority characteristics to include in birth and death registration forms has been developed by the United Nations, based on their value in supporting national policy and programme development (25). Countries can use this list as a basis for identifying their own priority data needs. For example, in the case of births it is useful to collect characteristics on the health status of the infant, as well as information on the age of the mother and birth parity,

as these can be useful in developing child and maternal health policies, and planning the provision of local health services. It is also important that the law allows the information to remain on an individual level throughout the reporting and compiling chain. This will ensure that different users can aggregate the information into the vital statistics and information they need to better perform their functions without having to collect these data themselves.

While the legislative instrument should specifically provide for the collection of this information, it does not need to incorporate all the individual data items. These can be spelt out in regulations, and may change over time as information needs and collection capacities grow. It is also advisable to provide for the collection of fetal death data, even though collecting this information might not yet be viable in places where most births take place outside health facilities. As the proportion of births occurring in health facilities increases, it will become possible to more accurately record stillbirth and fetal death rates, which are important for monitoring pregnancy outcomes and maternal health.

Selecting a structure and organizational model for civil registration systems

Where a country has no current CRVS systems, a range of possible alternative structures and organizational arrangements should be considered before the legal framework is designed. The United Nations recommends the use of centralized models for both the civil registration and vital statistics components of CRVS systems (27), (20) with the two functions assigned to different independent public agencies. The precise structure and organizational model used will clearly be strongly influenced by existing national administrative structures, as well as any current legislation on vital statistics. However, regardless of the organizational model selected, there will need to be a central unit that can ensure the application of uniform standards throughout the system and take responsibility for the production of national vital statistics.

In countries with federated states, such as Argentina, Australia, Canada, India, Mexico and the United States of America, the civil registration system is decentralized, with each state or province responsible for registration activities within their borders. Vital statistics, however, are produced by the federal government for the entire country. By contrast, in other countries, for example, Costa Rica, Sri Lanka, and Thailand, the civil registration system is centralized with a single nationwide administrative organization responsible for collecting data and information through its local agencies. Data compiling and publishing activities are usually the responsibility of the national statistics office or ministry of public health. In the Philippines a hybrid system is used in which civil registration is decentralized to the regional governments but the production of national vital statistics is carried out by the National Statistics Office. The Director-General of the National Statistics Office also carries out the functions of the Civil Registrar-General.

The structure and organization of the system selected will determine the planning of administrative arrangements at each level, and the roles of the registration, health, and statistical authorities. The structure is the skeleton of the institution, while the organization is the way in which its physical elements and resources are arranged. These two key elements must be set up in such a way as to guarantee that CRVS systems have nationwide coverage with sufficient numbers of registrars and offices to allow people to register

without the need for excessive travel and high costs. Although a strong central directorate should direct, guide and supervise performance and activities throughout the system, the actual registration of events must take place in registration offices located close to where people live and where the vital events occur. This means that the entire country must be subdivided into registration areas that preferably correspond to existing local, political or administrative areas. Enacting or strengthening legislation and setting out the structure and organization of the civil registration system in law will greatly help to ensure its continuity and permanence.

Keeping legal frameworks for CRVS systems up to date

A civil registration system has to be able to respond 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, in which the law sets out the general principles while regulations are used to govern the operational and technical aspects (20). Regulations, unlike acts, 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 registrar-general. 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 and to the function of registrar-general or director-general, regulations can be updated and revised outside of the parliamentary process. This is usually done by issuing circulars showing amendments by the registrar-general, and circulating these to all local offices to ensure that registration procedures remain uniform throughout the country.

Use of information and communication technologies and the legal framework

The use of computers, scanners and mobile phones has become an integral part of improving and modernizing CRVS systems. All of these technologies facilitate and help to speed up data management and the transferring and archiving of records. Computerization is normally introduced progressively from the central office to the regional and local offices. Because of technological advances, some developing countries have made very rapid progress in moving from a manual paper-based system to an e-system. For example, in Albania, the computerization of the paper-based system started in 2003 and by 2008 the new e-system was able to issue registration certificates directly from a central database. Mobile phones are also being used in a number of countries to report births and deaths occurring in outlying regions.

As the capacities and use of computer technologies have increased, countries have successfully established population registers – i.e. single centralized computer databases in which all population and civil registration data have been integrated, and from which files required for various administrative purposes can be extracted. As a unique identifier for each person is required for this to work, special legislation detailing how the information can be used, and who can access it, has typically needed to be passed if this is not already reflected in national statistical laws.

As discussed in section 2.2 above, computerized systems require stronger legal measures than paper-based systems to ensure security and confidentiality as data theft and destruction are potentially easier to carry out and more difficult to detect. In addition to restricting access to passwords to accredited staff to reduce the risk of misuse, most such systems also incorporate a comprehensive login programme to allow identification of individual operators during any necessary investigations. Some basic guidance on the computerization of CRVS systems can be found in various United Nations handbooks (28), (29).

Outlining a model law of CRVS

A draft "model civil registration law" has been proposed by the United Nations (20) consisting of 178 articles organized into 14 chapters, and based upon United Nations principles and recommendations. It is assumed that the civil registration system is attached to a ministry and is managed by a registrar-general or director-general with substantial authority and sufficiently broad powers. It is further envisaged that the system consists of a directorate of civil registration, a central archive and local offices covering the entire national territory. The approach also assumes that within the system four registers are maintained covering births, deaths, marriages and divorces. Five highly recommended organizational and operational features are reflected in the draft model law:

- local registrars must have the status of public attestors to give legal value to the documents they sign;
- the four registers should be kept in duplicate so that one can remain in the local office and one in the central archive;
- the registration of vital events must be compulsory;
- registration is free but there are charges for the provision of certified copies;
- the information provided is strictly confidential.

The draft model law also advocates the use of two separate forms for each event, rather than a single form. This is based on the recognition that a registration record has to fulfil a legal function and must be retained, while a statistical report can be destroyed once processing is complete. With the advent of modern electronic technologies two separate forms may no longer be necessary.

The national administrative system assumed in the draft model law consists of two centralized agencies with separate functions. Under this system, a civil registration agency has responsibility for collecting information at the time of vital event registration, while an independent statistical agency is tasked with the compiling and disseminating of statistics. In some countries, the national health system is also involved due to its specific interest and expertise in this area. The function of the central archive is seen as the storage and custody of duplicates of all registrations made in the country, as well as activities related to the registration of nationals who are resident or travelling abroad.

Although the draft model law is specifically designed for a civil registration system with a centralized administrative structure, the precise structure of a national system is not important provided that a civil registration office is responsible for the data-gathering function. The basic functions and procedures carried out by most CRVS systems do not differ significantly and are all covered by the draft model law. In addition, the intention is

not for the model to be adopted in its entirety, but for the articles that are most relevant to be selected and adapted to suit the national legal system and local contexts. The system described is not dependent upon any specific technology but a basis is provided for the incorporation of advanced technology when needed.

While the cause of death is irrelevant to the legal functioning of civil registration, it is a vital element of the statistical report, hence the draft model law contains detailed provisions regarding the obligation of physicians to certify death and provide a medical certificate. Finally, it is important to note that combining all registration rules into a single legal act is in itself an improvement of the registration system, as the process often results in the replacement of existing disparate and haphazard laws and regulations which often cause confusion.

As the text of the draft model law is extensive, **Box 2** presents only a summary of its contents in the specific area of birth and death registration. Each heading represents one of the relevant chapters in the draft model law.

BOX 2. Summarized contents of a legal framework for registration of births and deaths (20)

General provisions

- Defines the vital events to be covered – i.e. 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 birth

- Details how birth events should be registered and what characteristics to include.
- 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 need for verification of all evidence and of the names to be entered for the child and parents on the birth certificate.

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.

BOX 2. Continued

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.

2.4 Tools and resources

The limited amount of relevant literature on the legal aspects of CRVS systems can be divided into two broad categories:

- resources that provide standards, norms and other guidance materials – for example, the United Nations handbooks;
- examples of legal frameworks for civil registration in specific countries, and related manuals.

United Nations handbooks, standards and other guidance

• Handbook on Civil Registration and Vital Statistics Systems: Preparation of a Legal Framework (20)

This handbook is a key resource for countries that have no relevant legislation and want to prepare a comprehensive framework or civil act. The handbook provides a generic model of a draft legal framework (see section 2.2. and **Box 2** above) designed to assist countries in drafting a robust and standards-based national framework. The handbook also describes the different administrative aspects of a civil registration system, as well as their function and major responsibilities, and discusses the main concepts used in civil registration. The relationship between civil registration and human rights is also explained. The handbook can be found at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_71E.pdf**

• Handbook on Civil Registration and Vital Statistics Systems: Management, Operation and Maintenance (27)

Establishing a legal basis for CRVS systems requires a clear understanding of the organizational structure of these systems and the functions they are expected to perform. This handbook details the administrative structures of different types of CRVS systems and discusses their management and operational functions and activities. Validation measures to assess the quality and completeness of the systems are also discussed. The handbook can be found at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_72E.pdf**

• Model State Vital Statistics Act and Regulations – 1992 Revision (30)

The United States vital registration and statistics system is based upon cooperation between the Federal and State Governments, with the latter having legal responsibility for registration. The National Center for Health Statistics (NCHS) has been given the coordinating role and works with states to build a uniform system that produces records that satisfy their legal requirements, and that meet the statistical and research needs at local, State and national levels. This cooperation includes the development and promotion of standard certificates, forms, training and quality-control programmes, and model legislation.

Although prepared specifically for American states, the above resource nevertheless provides useful guidance for anyone considering developing comprehensive registration legislation and regulations. The publication is divided into two sections – the Model State Vital Statistics Act (35 Sections) and the Model State Vital Statistics Regulations (17 Regulations) – and provides detailed guidance to State Registrars. In addition, it specifically allows for the modernization of systems and the incorporation of technological advances. The model law is written in plain English, is easy to understand and use, and can be found at: **http://www.cdc.gov/nchs/data/misc/mvsact92b.pdf**

• Guide Pratique International de l'état Civil (31)

The Commission Internationale de l'État Civil (CIEC)[2] is an intergovernmental body comprising 16 member states. Its purpose is to compile and maintain up-to-date documentation on legislation relating to civil status, family and nationality in its member states. It also carries out studies and makes recommendations aimed at harmonizing the relevant laws that are in force. CIEC guides and studies usefully describe the ways in which specific issues are addressed in different countries.

For example, the above guide compares civil status law in force in different countries, mainly in Europe, and can be found at: **http://www.ciec1.org/GuidePratique/index.htm**.

• Civil status and perinatal death in CIEC member states (26)

This study looks at the legislation regarding fetal deaths and stillborn babies in a number of countries. These perinatal deaths give rise to specific civil status issues, particularly in respect to stillborn babies and children born alive but dead on registration. The study shows a growing tendency in member states to record these cases not for purposes of "legal personality" but for public health ends, and can be found at: **http://www.ciec1.org/Etudes/DecesPerinatal/CIECDecesTraductionAngl.pdf**

Examples of legal frameworks for civil registration in specific countries

• Selected Documents on the Modernisation of the Civil Registration System in Albania (32)

This English translation of the updating of the civil registration system and the passing in 2002 of associated laws in Albania describes the practical application of a legal framework during a period when an entire system was being modernized. The resulting Albanian

[2] English abbreviation: ICCS (International Commission on Civil Status).

"Law on the Civil Status" is simpler than the UNSD generic model and contains 74 articles divided into the following eight chapters:

1. General dispositions
2. The civil status
3. Nature and documentation of the components of the civil status
4. Registration of birth acts
5. Registration of marriage acts
6. Register of the acts of death
7. Civil status service
8. Final provisions.

At birth, a unique ID number is assigned to the birth act by the civil registration office and certified copies of registration papers can be issued electronically without delay. The legal framework also includes the Albanian law on the identity number of citizens which establishes the purpose, content and use of the identity number in relation to civil registration data. The civil registration system is now fully computerized and all data are stored in a national population database.

Although the legal framework is largely aligned with United Nations principles, it does contain several weaknesses and is therefore not considered to be ideal. For example, a fee is payable even for first registrations, there is no definition of "live birth", and the reporting of stillbirths, fetal deaths and causes of death is not covered. The legal framework does however provide a potentially useful real-life example and can be found at: **http://www.ssb.no/english/subjects/02/90/doc_200402_en/doc_200402_en.pdf**

• How to modernise a Civil Registration System: The case of Albania (19)

The agency that provided technical guidance to Albania during the modernization of its civil registration system and the passing of its Law on the Civil Status was Statistics Norway. The agency produced a paper on this cooperative undertaking that usefully sets out all the practical details and challenges involved during the four phases of the project:

- pilot phase civil registration
- scaling up to national civil registration
- scanning the old archive registers
- transferring data from the civil registration system to the national statistics office.

The paper accurately conveys the sizeable challenges encountered at each stage arising from the use of an outdated poor-quality system, with no prior experience of computerization, a lack of trained staff and difficulties in securing interagency cooperation. Among the lessons learnt was the importance of a clear and supportive legal system covering both civil registration and the production of vital statistics. The paper can be found at: **http://www.ssb.no/english/subjects/00/90/doc_201232_en/doc_201232_en.pdf**

• Civil Registration Act of the Republic of the Northern Marianas Commonwealth

This Act from the Northern Marianas in the Pacific is known as the "Vital Statistics Act of 2006" and is based on the **Model State Vital Statistics Act and Regulations** from the United States described above. It contains 31 sections covering aspects such as definitions; the duties of the registrar; vital statistics office functions; birth and death registration; delayed registration; adoption; fetal death; vital reports; authorization for final disposition; disclosure of information; and provision of certified copies. Despite its simplicity, the Act covers all of the essential aspects, and can be found at:
http://www.cnmilaw.org/pdf/public_laws/15/pl15-50.pdf

• Manual of Instructions on Civil Registry Forms: Accomplishment and Coding (33)

Although this manual was prepared mainly for the use of civil registrars and staff in the Philippines, it does provide a significant level of general advice, and offers a good example for other countries to follow. It details the organizational structure of the national system, and the duties and responsibilities of registrars at different levels. It also explains how certifiers should complete medical certificates of death, including fetal death. A copy of this manual is available on request from the Philippines National Statistics Office.[3]

2.5 Summary

National authorities in countries that have not yet adopted a civil act, and in which CRVS systems are being undermined by a weak and fragmented legal basis, should consider integrating all existing laws and regulations into a single coherent legal framework to regulate registration services and ensure that vital statistics are compiled and disseminated. The draft model law for civil registration proposed by United Nations provides a sound basis for making improvements in countries with incomplete or inadequate legislation. The proposed model is particularly useful because it deals with the subject in a way that is not dependent upon a single type of legal system. Each country can apply its own legal procedures for enacting the law and can deal with the details of its implementation through regulations.

Where a national legal framework for civil registration exists but requires strengthening, then any of the actions shown in **Box 3** that have not already been taken should be considered. These actions were derived from group discussions during workshops and training courses on improving country CRVS systems. Together they constitute a useful list of actions for addressing weaknesses in the legislative base, which can be tailored to improve specific aspects of CRVS systems in individual countries.

The roadmap proposed in **Box 4** outlines the major steps that should be taken when preparing a civil act for adoption by parliament. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

[3] For further information, please contact: L.Hufana@census.gov.ph

BOX 3. Key actions for improving the legal framework for birth and death registration

1. Make it obligatory to register births and deaths within a given time.
2. Include definitions of all events requiring registration (such as live birth, death, stillbirth and fetal death) and define the population covered by the CRVS systems.
3. Indicate how death and cause of death should be certified, and make it obligatory for deaths to be certified by a doctor.
4. Ensure that the law incorporates measures for ensuring the confidentiality of data and reporting.
5. Make burials and cremations dependent on the issuing of a funeral permit.
6. Stipulate the important characteristics of vital events that need to be collected during the registration process for statistical purposes.
7. Institute procedures to ensure that all vital events are reported, and that information is routinely sent to a designated office or department for statistical compilation and dissemination.
8. Make provision for a central registration authority to direct and standardize vital-event registration throughout the country.
9. Establish a coordinating mechanism between relevant agencies – for example, a committee that meets regularly to discuss issues of concern.
10. Use the standard WHO or other United Nations definitions and recommended procedures for recording and registering births, stillbirths, deaths, fetal deaths, and causes of death.
11. Ensure that first registration and the first certified copy of a vital event is free of charge – fees can be charged for additional certified copies or for late registrations.

BOX 4. Basic roadmap for preparing a civil act for CRVS systems

Step 1: Form an ad hoc committee with high-level representation from all government agencies directly concerned with CRVS, as well as civil society representatives. The function of the committee is to:

- Prepare a workplan and time schedule for the preparation of a civil act.
- Decide upon the structure and organization of the CRVS systems.
- Appoint an interdisciplinary drafting team.
- Carry out a costing of the new law.
- Keep the ministers of each department in the committee informed and ensure their support.

Step 2: Have the members of the drafting team gather all laws and regulations currently available for registering births and deaths, including any that refer to the compilation and dissemination of vital statistics, disposal of dead bodies, certification of births and deaths, and reporting of these from health establishments. Once this material is gathered:

- Have the material reviewed by technically competent staff. These may come from the statistics office; justice department (individual and family law, identification services); ministry of health (public health); and ministry of the interior (voter registration, military recruitment, planning department and tax authorities). As part of review, the existing laws should be checked against the UNSD model, revisions suggested and missing items marked for inclusion.
- Prepare a first draft of all of the contents of the civil act.
- Undertake a survey among the main users of vital statistics to determine which additional characteristics would be most useful and viable to collect.

Step 3: Present the first draft to a broader group of stakeholders, including civil society and NGO representatives. Obtain their views and support. Discuss the need for advocacy and information campaigns, and recruit civil society groups and NGOs for the advocacy campaigns.

Step 4: Assemble a legal team to prepare the articles and regulations based upon the agreed contents.

Step 5: Conduct an advocacy campaign directed towards parliament or congress to gain their support, and implement an information campaign directed towards the general public.

Step 6: Present the preliminary bill and associated costs to the relevant ministers for discussion.

Step 7: Review the bill and submit it to parliament for adoption and enactment.

MODULE 3:
Registration practices, coverage and completeness

3.1 Introduction

In Module 2 the approaches, tools and other resources needed to develop an appropriate legal framework for CRVS systems were discussed. Although such a framework is a necessary basis for well-functioning CRVS systems, simply having legislation in place is not enough. There are also a number of practical steps that need to be taken for systems to progress from legislation to implementation. Each of these steps must be properly addressed if systems are to function smoothly, both in terms of the provision of registration and certification services to the population and in the generation of reliable vital statistics.

In this module, practical implementation issues are addressed and guidance and resources provided for those engaged in the day-to-day activities of CRVS systems. The key issues addressed include:

- Who should collect information and at what level of the system? Are the tools needed for data collection and transmission available and appropriate?
- Who is responsible for compiling data, and storing, managing and disseminating information, and how are these activities implemented?
- Are individuals and communities aware of the importance of birth and death registration? Do community education campaigns need to be run?
- What is the minimum amount of information that should be collected on each birth and each death? Do notification and registration forms need to be revised accordingly?
- What systems need to be in place to ensure that vital-events registration is available to all members of society? What systems are needed to collect information on births, deaths and cause-of-death, and to generate vital statistics for use by all relevant sectors?
- Are the statistics derived from information-collection activities reliable? How can their quality be assessed?
- How can the smooth flow of data between different parts of the system be ensured?

When addressing such issues, it is important to bear in mind what approaches are already in place, and to consider how these could be improved upon and strengthened. It is also vital to develop a good understanding of how the registration system functions in terms of generating basic information, transferring data and making available the databases needed for compiling data into useful statistics. It is advisable to focus initially on information that is easier to collect and then to build in complexity as capacities and resources grow.

3.2 Background

Even in countries with good CRVS systems, some vital events may not be registered or recorded for a variety of reasons. For example, in settings where there is no legal framework or where the law is inadequate and poorly implemented, loopholes and ambiguities may result in numerous vital events not being counted, even when registered by families. Understanding the detailed operational aspects of systems is also vital to understanding why some vital events are not registered or recorded, and why vital statistics are incomplete. Such operational awareness helps to identify ways in which systems could be better managed to meet legal and statistical requirements, and to effectively respond to public health needs.

Common problems encountered

In most settings, it is challenging to collect comprehensive information on every vital event and to ensure complete data collection and transfer. Based on country experiences, some common practical problems encountered during the implementation of CRVS systems are described below.

Barriers to registration

Successful civil registration systems depend upon individuals and families registering vital events. If the registration process is cumbersome, difficult or unpleasant then people will be less likely to register and the resulting vital statistics will be inadequate. Efforts should therefore be made to facilitate the efficiency and effectiveness of the registration process, and to ensure that the public are made aware of the vital importance of CRVS systems and of their civic duty to register vital events.

As discussed in Module 2, 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. However, whatever incentives or penalties are in place, registration will be incomplete if families are unaware of the obligation to register or if they face barriers that are difficult to overcome. For example, in rural or remote areas such as isolated islands, there may be too few registration points and families can face long and costly journeys to register. This situation will be made worse if families are also required to attend more than once to complete the registration process.

Registration must be welcoming, easy and fast. Families and individuals registering vital events should not face long queues, bureaucratic delays, or direct or unexpected costs. It is also important to remember that although registering a birth is generally a happy event for a family, registering a death typically happens during a time of mourning and grief. Creating a respectful environment in registration offices will help to avoid adding to the difficulties experienced by families during such times.

Failure to capture all information on births and deaths

The registration process usually focuses on the information needed for legal and administrative purposes – such as name, place of usual residence, nationality, birthplace of parents or decedent, age and sex, as well as the identity of the person declaring the event. However, from a public health perspective, information on the circumstances of a birth or death – including cause of death – is crucial. For example, the medical details of births are extremely valuable in identifying children or mothers at risk. Useful public health information includes birth weight, prematurity, birth deformity, birth order (for multiple births), method of delivery and any complications. Cause-of-death information – vital for determining the burden of disease across population groups – is often collected on a separate form, and sent to the ministry of health as the main user of the data. To support the public health aspect of birth and death registration, the United Nations has defined a set of minimal key data elements (25).

In settings where many births and deaths take place in health facilities, the health sector may play a proactive role in the notification and registering of vital events. For example, in many countries the Ministry of Health is responsible for registering all births and deaths, even those that occur outside health facilities. The Ministry of Health is often also responsible for compiling vital statistics, with the Ministry of the Interior charged with issuing certificates and archiving all registration records.

Where numerous agencies collect information on births or deaths, it is imperative to ensure that all information is fed into the civil registration process. For example, in settings where the health sector is an active participant in birth and death registration, measures must be taken to ensure that all vital events are recorded, included those occurring in private health facilities. Some private health facilities are not required to report vital events which may then be missed in the absence of strong incentives to forward information. Penalties can include the withholding of hospital accreditation for non-compliance.

Attention should also be given to the way in which births and deaths outside hospitals are included in notification and registration systems. In some countries, health workers at community level are responsible for notifying births and deaths occurring outside health facilities. Community leaders and health workers can thus be valuable allies in efforts to improve registration. They are close to their communities and generally aware of all vital events, especially where communities are relatively small and geographically close. Consideration should be given to establishing mechanisms for involving community leaders and community health workers as key links in the chain from occurrence of a vital event to its formal registration in the system.

One frequently encountered problem is the non-registration of both the birth and death of a neonate that dies shortly after birth. This can happen to spare family anguish and to avoid having to register two events. However, as a result, these deaths will not be reflected in vital statistics, leading to underestimates of neonatal mortality and possible neglect of the issue. Because such information is crucially important in guiding policies to reduce perinatal, neonatal, and infant mortality, and improve maternal and child health services, ways should be found of working with communities to ensure that all such vital events are registered. Although not generally a requirement of the civil registration system, it is thus important from a public health perspective that fetal deaths are recorded, along with information on the mother and the pregnancy.

In some countries, other vital events are also routinely missed by the registration system. This can happen, for example, where the registration of abandoned children or children of underage or unmarried mothers is discouraged. Efforts should be made to identify these issues, and to ensure that such children are not discriminated against, and that all vital events are registered and included in national statistics.

Inconsistencies between registration records and compiled statistics

Even if all vital events are registered and recorded, information can still be lost prior to the compilation of vital statistics. In many countries, the number of registered vital events is greater than that shown in vital statistics reports, indicating information leakage somewhere in the system. Because registration and the production of vital statistics are often the responsibilities of different government agencies, there is a potential for inconsistencies to arise. Any failure to ensure that all registered vital events are reflected in vital statistics is a major concern in terms of the overall quality of CRVS systems.

Different types of errors and inconsistencies can occur between the registration of a vital event and the generation of vital statistics. For example, errors can arise from both under- or over-reporting. Over-reporting can occur when a vital event is noted as a delayed registration without checks being carried out to ensure that it has not already been previously registered in another district. In other cases, "re-registration" occurs because the initial registration papers cannot be traced – possibly because registration occurred in another area and there is no centralized storage of records, or because of archiving problems. Avoiding duplication of registration requires a well-managed computerized central register and effective archiving, checking and retrieval procedures.

The under-reporting of registered events is far more common than their over-reporting. This will be reflected in data showing that the annual number of registrations is higher than the figure presented in vital statistics reports. Under-reporting can result from:

- no reporting or transfer of the information from civil registration agencies to the vital statistics system;
- delayed registrations being treated differently from timely registrations, and not being transferred to the vital statistics system;
- failure to transmit information that arrived after a scheduled transmission period;
- failure to transmit information on coronial cases once they have been resolved and returned to the civil registration system.

The best way of reducing under-reporting at community level is to introduce incentives for people to register. Under-reporting can also be reduced by introducing an audit system clearly outlining responsibilities for logging all registration events sent to the vital statistics system, and for recording what is received.

Challenges related to registration of deaths due to accidents

In most countries, special procedures are in place for registering and certifying accidental or non-natural deaths such as homicides or suicides. Doctors or police workers called to attend these deaths usually report them to a coroner or judicial authority, and an investigation is carried out to determine the precise cause of death. In practice, such deaths are frequently under-reported, even though they typically represent around 10% of the total number of deaths and a much higher percentage in some countries.

Inconsistent data forms

Data should be collected using the same standard forms at all levels of the civil registration system. Standard forms allow microdata to be aggregated to the national level, and for comparisons to be made over time and across administrative areas. A designated national authority should set the standards for data collection and the compilation of key indicators. In countries with separate data-collection systems at state or provincial levels, coordination is needed to ensure the use of consistent data-collection forms.

Lack of clear roles and responsibilities

Organizational or administrative ambiguities or bottlenecks may complicate and delay the compilation of statistics or affect the quality of the data. Civil registration and vital statistics are highly complex and interrelated systems in which minor organizational changes can accumulate gradually over time and cause problems. For example, if one agency introduces a new electronic system of data collection or compilation this may affect another agency that is still operating a paper-based system. In addition, even within a single agency, the allocation of responsibilities between departments may be unclear or overlap.

These types of problems are less likely to occur where there is joint management and a central unit to coordinate systems, set standards and assign responsibilities for specific functions at different organizational levels. CRVS systems cannot function effectively and efficiently unless there is a clear delineation of roles and responsibilities among responsible agencies. These responsibilities should be clearly defined in the legal framework governing CRVS systems.

In practice, administrative systems tend to evolve and take on additional activities in response to emerging needs and demands. For example, if the civil registration system is not producing good-quality vital statistics, the health system may decide to generate birth and death statistics based on data collected in health facilities. This approach has been used effectively, for example in Brazil and Egypt. However, it can also result in inefficiencies and discrepancies in vital statistics that create confusion and discredit the whole system, especially when not all vital events occur in health facilities or are recorded by civil registration agencies.

Confusion over the meaning of notification, registration and certification

Problems can arise where there is confusion over the meaning of terms such as vital event "notification", "registration" and "certification", and "medical certification of cause of death".

- *Notification* is the issuance by an appropriate authority – such as a health worker – of a form confirming that a vital event (birth or death) has occurred. Often the notification form is used by the family to report an event to the civil registration office. In the case of a death, a notification form can also be required when obtaining a burial permit. Notification forms do not have the legal status of a birth or death certificate.
- *Registration* is the act of formally registering an event at a civil registration office. At this point, details of the event are entered into the official civil register by the registrar. Registration is an essential step in obtaining a birth or death certificate.
- *Certification* is the issuance by the civil registrar of a legal document certifying a birth or death.

- *Medical certification of cause of death* is the completion of a death certificate by a medically trained person listing the cause of death in accordance with ICD certification standards.

In the case of births, a birth notification form is usually issued by the health worker who assisted at the delivery. The notification form should then be taken by the family to register the event and obtain the relevant birth certificate. However, families may not always understand the difference between the notification form completed by the doctor and the legal birth certificate issued by the civil registration office, and may therefore fail to register the event.

For deaths, notification and certification of cause of death are the responsibility of the attending doctor, or family doctor if the death occurred at home. In some places, deaths that are medically certified in hospital can fail to be registered if burial or cremation is allowed to take place without a permit from the civil registration authorities. One way of avoiding any misunderstandings between notification and registration is to give the responsibility for registration to the hospital, health facility or funeral director.

Delays in production of statistics

After a birth or death has been registered, the information must be processed and forwarded to the agency responsible for compiling data (microdata) from the individual records and for analysing the statistics (aggregated data). This is usually the responsibility of the national statistics office. Microdata collected at local-level registration offices have to be transmitted to higher-level district, provincial, state and national offices, and compiled. This is an essential step in converting the information recorded on a birth or death registration form into statistics that can be summarized and analysed for statistical and public health purposes.

If statistics are to be useful to decision-makers, they have to be both timely and complete. A delay of several years between the registration of births and deaths and publication of the corresponding statistics will mean that the information will be of only limited use in guiding programme planning and implementation. Any delays in transmitting microdata from local registration offices to higher levels will have a significant negative impact on the availability and quality of aggregated vital statistics and, by extension, on the ability of policy-makers to make evidence-based decisions. The computerization of records can greatly facilitate and accelerate data transmission, and help to identify basic recording errors. However, in many settings, computerization is only available at the higher levels of the system with local registration offices still relying upon paper-based systems.

3.3 Key actions

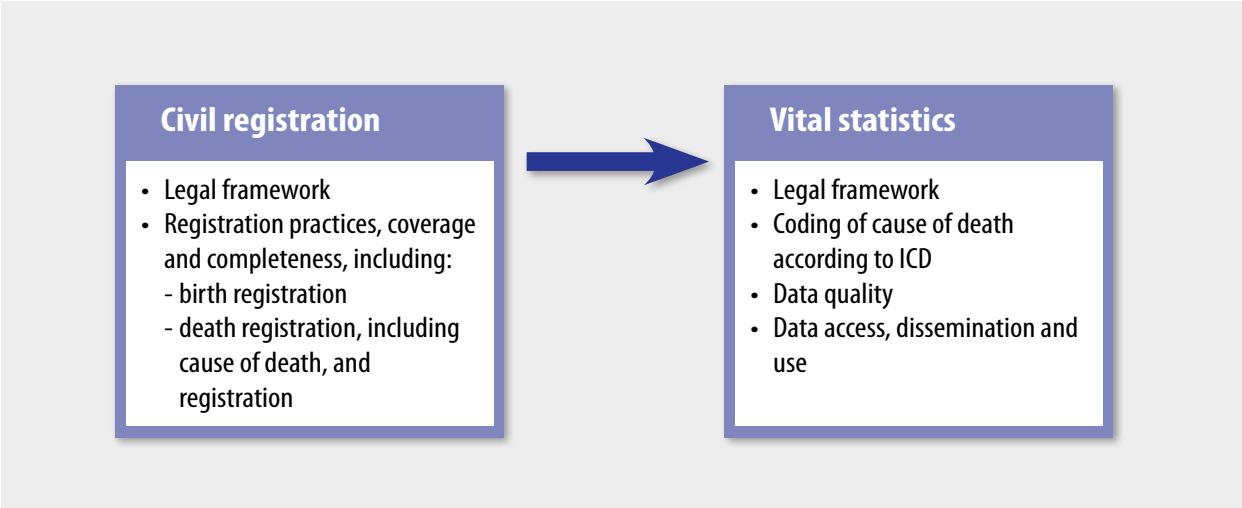
Analyse data collection and flow

The first step in addressing CRVS systems problems is to visualize the process of birth and death registration using a flowchart. As a starting point, the steps that people need to take to register a birth or death should be considered. This should also show the role that the health services may play in birth and death notification. In many countries, family members are required to have a copy of the notification form provided by a health

worker before going to the registry office to register the event. The health services may also directly inform the registration authorities of births and deaths occurring within their facilities. All of these various path ways should be included in the flowchart. Consideration should also be given to the way in which deaths are medically certified, and the resulting cause-of-death information transmitted to registration and health authorities.

When mapping data collection and data flow, it is important to remember the two distinct but related functions of CRVS systems – namely the registration of vital events to permit the issuing of the relevant legal documentation, and the subsequent incorporation of vital-event data into the vital statistics system. **Figure 3** illustrates these two functions and their components.

Figure 3: The two functions of CRVS systems and their components



In most countries, different programme units are responsible for carrying out the different functions of CRVS systems, and different administrative structures are possible (27). In some settings, there is a single centralized national agency responsible for both civil registration and vital statistics (**Figure 4a**). The advantage of this structure is that national standards can be applied coherently throughout the system, from local-level registration facilities to national-level statistical analysis and dissemination. In other settings, CRVS systems are assigned to separate administrative agencies (**Figure 4b**). Responsibility for registration may lie with any one of several ministries (for example, justice, the interior, home affairs or health) or with any combination of these. A different agency, such as the ministry of planning, finance or the national statistics office is then responsible for the vital statistics system. Countries with federal political systems, large territories or populations sometimes adopt decentralized CRVS systems (27). These can be organized in such a way that the national office exercises legal oversight of the registration and vital statistics functions carried out at regional and/or local levels (**Figure 4c**). Alternatively, the national office may have only an advisory and cooperative role in respect to regional and local administrations (**Figure 4d**). Various permutations and combinations of these organizational schemas exist in different settings, and a full and detailed understanding of how individual systems are structured is required in order to identify where problems may have arisen and how they can be dealt with.

Regardless of the administrative structure, the day-to-day work of civil registration is carried out at local level by civil registration offices. There may however be intermediary structures between the local and national levels such as those at state or provincial level.

Figure 4a: Centralized system: single agency

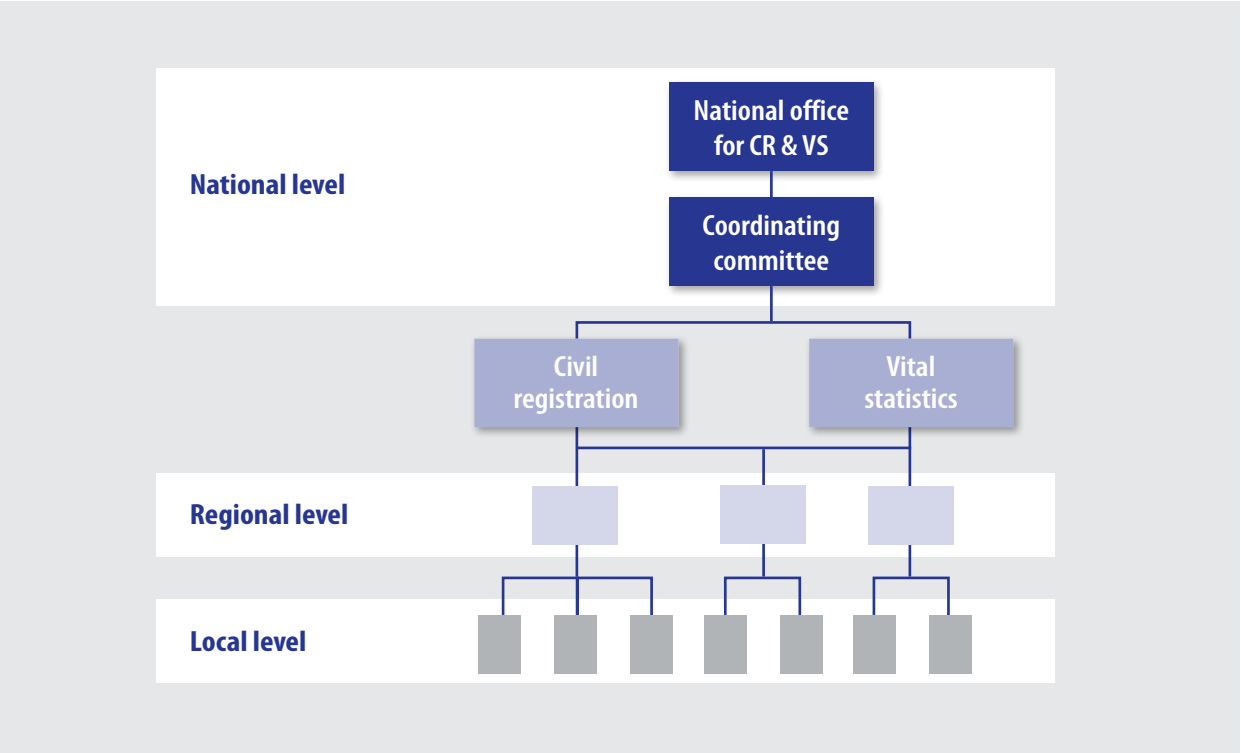


Figure 4b: Centralized system: dual agencies

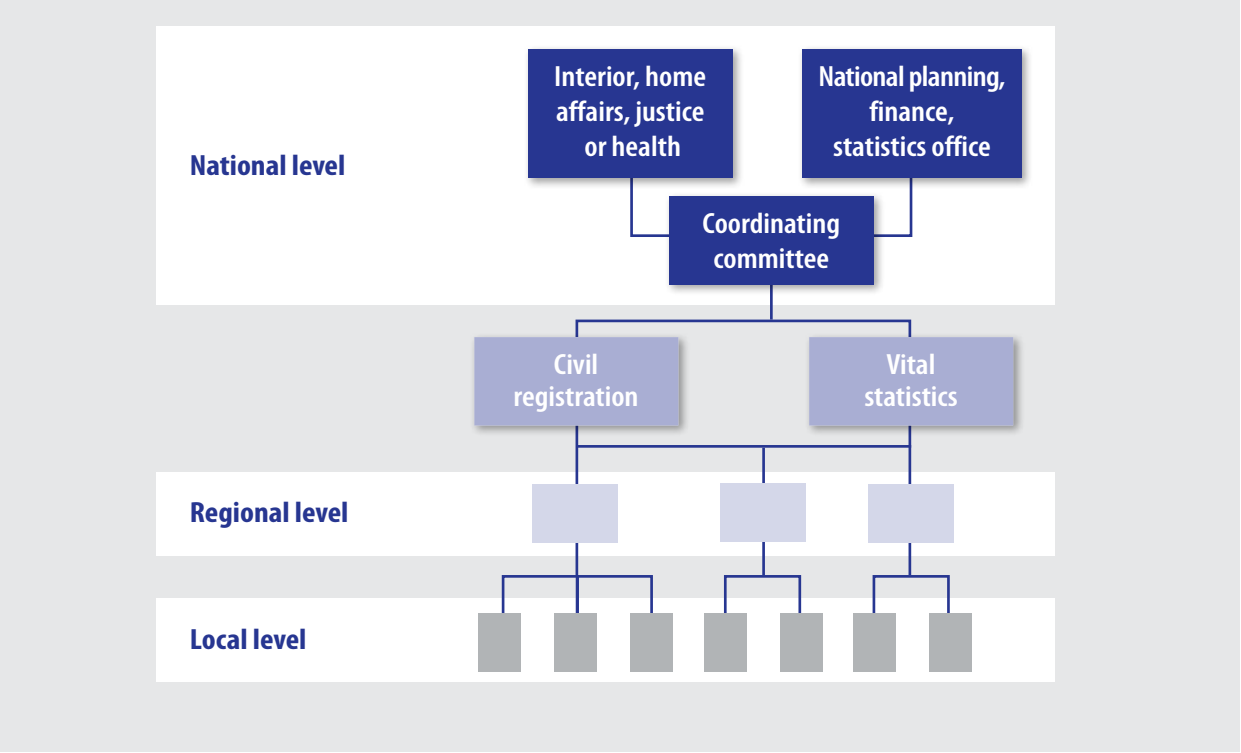


Figure 4c: Decentralized system with legal oversight

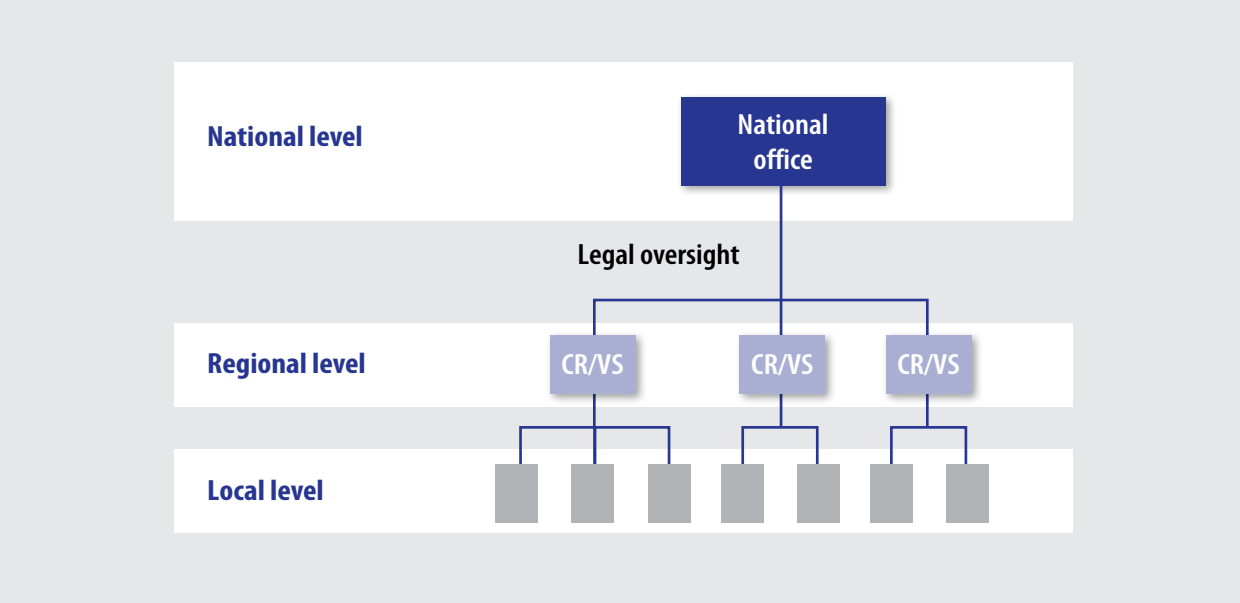
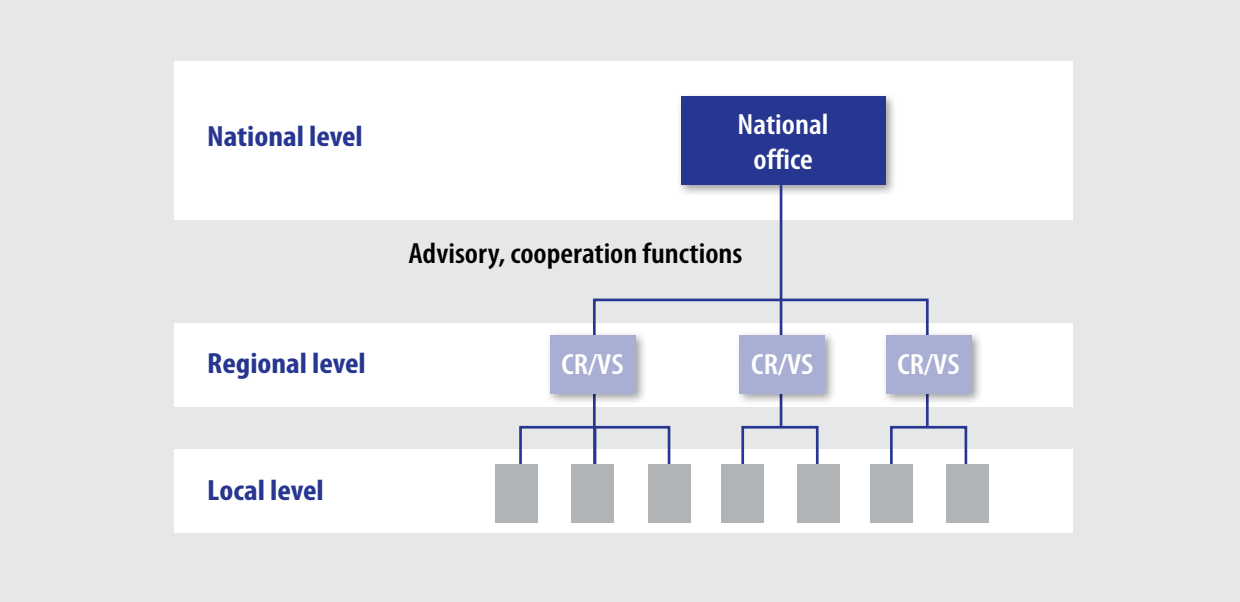


Figure 4d: Decentralized system with advisory function



When preparing a flowchart, it is important to consider which types of vital events may currently not be adequately registered, and to incorporate this into the mapping process. In this respect, reference can be made to Figures 3.1 and 3.2 of the comprehensive assessment tool described in Module 1 (11) which present examples of flowcharts produced in Mexico. These show how certain vital events may fail to be registered and medically certified. This is more likely to happen when births and deaths take place outside health facilities, but even within such facilities deaths in particular may not be properly certified and registered. When preparing the flowchart for death registration, particular attention should be paid to the role of those involved in burials, including undertakers, religious authorities and cemetery officials. Flowcharts should show all the relevant administrative structures of national CRVS systems, how data flow and how all the different system components interact.

Producing the necessary flowcharts may not be simple or straightforward but will be well worth the effort. Different stakeholders tend to view systems from their own perspective and may have only a limited understanding of the roles and challenges faced by others. Bringing together all stakeholders to produce the flowcharts is an important step in identifying where problems lie and how they can be solved. As a result all key players should be involved, including representatives from poor, remote, disadvantaged or minority groups who can provide important perspectives on why births and deaths are not always registered.

Improve coordination

The administrative model used will largely depend upon historical precedent, political and judicial structures, and existing administrative infrastructures. In all cases, good coordination between all the different ministries, agencies and administrative levels is essential. Whether the organizational structure is centralized or decentralized, coordination and integration processes must be built into CRVS systems (25), (27) (see paragraphs 329–340). In centralized systems, a central agency should have responsibility for directing, coordinating and monitoring nationwide civil registration. This can help to ensure adherence to national standards and uniform registration procedures. The role of the central office is to provide administrative and technical oversight, set up local civil registration offices, provide needed guidance materials and coordinate registration procedures. The central office should also coordinate with other relevant governmental agencies, including those in the health sector. In decentralized systems, it is important to have uniform legal provisions and procedures for civil registration in place. Mechanisms should be set up to enforce minimum standards of practices and procedures so that comparable vital statistics are produced across the country. Mechanisms to ensure that uniform standards are applied to the registration process and to the collection and management of data across all local area registration units are a crucial aspect of ensuring coherence at national level.

Where different agencies are responsible for collecting information on vital events and producing vital statistics, a formal communication mechanism should be established. Coordination and collaboration are essential to ensure the use of standard concepts, definitions and classifications, and to avoid duplication of responsibility (25), (34). Poor communication between civil registration and statistical offices can result in data not being incorporated into the system and/or used, even though registration is occurring. In South Africa, for example, the exchange of data between the registration authorities and Statistics South Africa was stalled for several years because of a lack of cooperation and communication, resulting in a large backlog of unused data (35).

Many countries also cite weak links between the health sector, which reports births and deaths in health facilities, and the civil registration system which relies on individual reporting. This is unfortunate because the health sector has the potential to play an important role in the notification and registration of vital events, especially in settings where many births and deaths take place in health facilities. In recent years, the role of the health sector in CRVS systems has been changing, driven by four developments:

- Growing demand in the health sector for accountability, and resulting pressures to generate better statistics on health outcomes such as adult mortality levels to inform

policies for preventing premature deaths due to noncommunicable diseases, and on the progress made in attaining the health-related Millennium Development Goals (MDGs).

- Increasing reach of health services, even in remote areas, and their improved organizational and technical ability to provide information on births and deaths as increasing numbers of such events occur in health facilities or in the presence of medical personnel.
- Increasing use of electronic medical records which incorporate unique individual identifiers, such as those available in legal documents or provided by the civil registration system.
- Growing availability and reach of information technologies in health, including the use of hand-held devices such as mobile phones to monitor vital events, in particular pregnancy outcomes such as perinatal deaths, live births and maternal deaths.

Collaboration across multiple sectors should not be left to chance or to individual action. A proactive approach is required through the establishment of a stakeholder committee with well-defined responsibilities to promote and monitor coordination. Membership of the committee should be drawn from the health department, hospitals, coroners, police, funeral agencies, religious authorities, researchers and civil society.

Develop human resources

The shortage and ill-defined roles of registrars, especially in rural areas, is often highlighted as a major contributing factor to low levels of registration coverage. In some countries, registrars only work part time on registration activities, sometimes in an honorary capacity. The quality of registration will be enhanced when registrars are treated as professionals with important responsibilities. Registration officials should be carefully recruited and trained. They should be literate, have completed secondary (high-school) education, and demonstrate a sound understanding of the purpose and rules of registration. Registration officials should be independent of the elected government, with strict legal duties and responsibilities to protect the integrity of the data collected. They should also be treated with trust and respect, and motivated by an awareness of the importance of their work. As a last resort, penalties can be introduced for non-compliance with the established rules and regulations.

In addition to registrars, the human resource base of CRVS systems should include statistical clerks, coders and medical records officers to convert individual records to useful public health data. In Ghana, for example, a shortage of staff able to complete the coding and analysis of registration returns meant that the Bureau of Statistics was unable to analyse data submitted by registration offices for several years. Competent staff are also vital in completing critical feedback loops between data generation and data use.

Both pre-service and in-service training are essential for health workers with responsibilities for ascertaining cause of death and issuing death certificates. Currently, medical curricula do not devote a significant amount of time to training in the use of ICD as a public health tool. As a result, death certificates are often poorly completed and valuable public health information is lost.

Define roles and responsibilities

The duties and responsibilities of registration officers at national and local levels should be clearly described, and poor performance or corrupt behaviour (such as asking for "under the table" payments at the time of registration) should be made punishable. The duties and responsibilities of registration officers include:

- recording vital-events information in accordance with established rules and procedures;
- ensuring compliance with registration law;
- ensuring the accuracy and completeness of each record;
- ensuring that the public are informed of registration procedures and requirements;
- taking custody of records;
- ensuring the preparation of summary statistics on each vital event, and transmitting this information to the relevant agency for data processing and analysis;
- issuing certificates and copies as requested;
- providing registration and certification services to the public.

It is essential to ensure the smooth flow of information from vital-events registration up until the compilation and dissemination of statistical reports. Each level of the system has an important role to play in checking for missing or incorrectly completed forms. Initial verification, querying, and error identification should take place at the first administrative level before the microdata are transmitted to the higher district, state, regional or national levels. The national statistics office can play an important role by providing statistical oversight of the quality of information collected during registration.

All roles and responsibilities at different levels of the system need to be clearly specified and allocated across different agencies. The existence of unclear or overlapping responsibilities will adversely impact upon the smooth operation of the system. Duplication is also a waste of resources. In some countries, multi-stakeholder committees bring together representatives from the health department, hospitals, coroners, police, funeral agencies, religious authorities and other organizations. These committees need to be active and to have decision-making authority in order to resolve any problems identified.

Revise data-collection forms

The civil registration system is an administrative system that focuses on collecting basic information on births and deaths for legal purposes. The recommended minimum information requirements of both birth and death registration are shown in **Box 5**.

For public health purposes, more-detailed information is required, such as the circumstances of a birth or the cause of a death. For example, to be of most use, the form for registering birth information should include an attachment for recording details of the birth, the baby and the mother. This information is important for improving maternal and child health care. Birth records can be used to identify high-risk infants and mothers for subsequent follow-up. In addition to the basic details of the birth itself, data should also be collected on prematurity, birth order (for multiple births), method of delivery, complications arising during delivery, stillbirth and the date of the mother's most-recent delivery or abortion/miscarriage.

BOX 5. Recommended list of high-priority characteristics to include in birth and death registration information

It is recommended that during the registration of a birth or death, information should be routinely collected on a range of specific characteristics of the event and of those involved. The following characteristics have been selected for inclusion because of their potential importance in efforts to support national policy and programme development, and to promote the regional and global comparability of data.

Live births

Characteristics of the event:

- Date of occurrence
- Date of registration
- Place of occurrence
- Place of registration
- Locality of occurrence (derived)
- Urban or rural occurrence (derived)
- Type of birth (single, twin, triplet etc.)

Characteristics of the parents:

- Date of birth and age (derived) of both parents
- Marital status of both parents
- Educational attainment of both parents
- Place of usual residence of both parents
- Locality of residence (derived)
- Urban or rural residence (derived)
- Children born alive to mother during her entire life (to date)
- Children born to mother and who are still living
- Fetal deaths to mother
- Date of last previous live birth
- Date of marriage and duration (derived)

Characteristics of the child:

- Sex
- Birth weight

Deaths

Characteristics of the event:

- Date of occurrence
- Date of registration
- Place of occurrence
- Place of registration
- Locality of occurrence (derived)
- Urban or rural occurrence (derived)
- Cause(s) of death
- Certifier and type of certification (derived)

Characteristics of the deceased:

- Date of birth and age (derived)
- Sex
- Marital status
- Place of usual residence
- Locality of residence (derived)
- Urban or rural residence (derived)

In addition to the content of forms, their layout should also be considered. Forms should be uncluttered, and easy to properly complete in as little time as possible. When designing collection forms, it should be borne in mind that the information needs to be presented in a standard format to allow comparable national figures to be compiled. The setting of standards for data-collection forms and for coordinating data collection should be undertaken at the national level. If there are various data-collection systems at sub-national levels, ensure that these can be coordinated when forms are being designed (25). Information from forms should be easily transferrable into data-collection systems to reduce the risk of error during the transcription process from the form to the database. For example, information from the form could be scanned and electronically transferred to the database. If manual methods are used to transfer information, it is better to use drop-down menus to ensure maximum standardization. To support the goal of universal coverage of data collection, forms should also be available wherever possible in all national languages.

Modernize data collection, storage and retrieval

Civil registration systems must be able to store, file, abstract, archive and retrieve records. The way in which data are initially collected has implications for all these activities. Records of vital events can be kept in a number of ways, including ledgers or book registers, card registers and electronic records (25). Although paper-based systems require more space than electronic systems, many countries have become adept at storing and managing paper-based archives securely. In other settings, however, there are overflowing storerooms filled with paperwork that is never sorted or analysed. In addition, shortages of basic commodities, such as paper, pens, and simple calculators or computers, make it difficult to obtain copies of birth or death certificates, which in turn can discredit the reputation of CRVS systems and make communities reluctant to comply with their requirements. In many developing countries, computers are not used at the local level where events are initially registered, and this can make the transfer of microdata to higher administrative levels cumbersome and subject to error.

In many countries, computerization at all levels of the system has greatly facilitated the managing and maintaining effective registration systems, with the increasing use of relatively inexpensive information and communications technology (ICT) helping to solve many of the issues involved. The use of ICT can also speed up the compilation and availability of vital statistics. At different levels of CRVS systems, databases and spreadsheets can be used to collect, compile, transmit, validate, store and analyse data using statistical programmes. Although the use of electronic records will not automatically improve data quality, it can greatly simplify the process of checking for errors or inconsistencies in raw data, and can help to identify problems such as large fluctuations in the numbers of births and deaths registered from year to year, or increases in the proportion of deaths without a specified cause. These and other improvements have been made in a number of countries that have made large investments in ICT over the last decade or so, including Bangladesh, Chile, India and Thailand. Concerns have however been raised about security and confidentiality, and problems experienced with long-term retrieval due to the rapidly changing nature of computer hardware and software (25).

One important advantage of electronic records is that they permit cross-matching and linking, for example across birth and death registers. Although record linking can be done manually, it is an arduous process usually undertaken for special research purposes only.

Electronic record linkage enables large numbers of records to be linked and scanned, and has proved to be a valuable tool for improving the ascertainment of causes of death. In the United States, for example, linking the death certificates of reproductive-age women to birth and fetal death records helped to identify maternal deaths, which are often under-reported in civil registration records (36), (37), (38). Electronic record linkage has also allowed for more-complete ascertainment of deaths among people with HIV/AIDS, and for more-accurate estimations of HIV/AIDS prevalence (39). However, record linkage does need to be very carefully managed, especially in terms of optimizing its use, and defining roles and responsibilities in areas such as managing access, ensuring confidentiality and data application (40). Record linkage is greatly facilitated when all individuals each have a unique identifying number such as a social security number or PIN. A limiting factor in many countries, however, is a shortage of suitably skilled computer analysts to develop the systems and interfaces needed.

As the cost of storing and processing information in digital formats has fallen, it has increasingly become possible to inexpensively archive all registration forms and accompanying documentation. Recent advances in communication technologies, including mobile phones and other hand-held devices capable of data collection such as laptop computers and personal digital assistants are revolutionizing the way in which data are collected, especially in remote areas. Consideration should be given to the ways in which such devices could potentially facilitate data collection, bearing in mind the importance of long-term sustainability and the need to adhere to international standards for recording vital events (25).

The use of ICT has also delivered benefits in data transfer, with internet and wireless technologies significantly shortening the time needed to transfer microdata and aggregated data. Nevertheless, technological developments should not be seen as a "quick fix" and their use should be regulated by clear policies and procedures. Contracts with commercial organizations providing hardware and software should explicitly stipulate the legal penalties that will extend well beyond the expiration of the contract for any security breaches by employees.

Ensure consistency between registered events and vital statistics

Systems should be introduced to ensure that all registered vital events are counted in the vital statistics system, with no data leakage occurring between systems. To prevent the loss of data on registered events to vital statistics processes, an audit system should be introduced with clearly delineated responsibilities set out for logging what is sent and received. As part of the civil registration process, checks should be made to ensure that:

- all expected reports from local offices have been received and included in the monthly batch reports;
- data received from local and district offices are checked against expected transmissions;
- delayed registrations and coronial and police cases are included in the transmitted data.

As part of generating vital statistics, a logging system can help to ensure that expected monthly or quarterly reports have arrived, and that the totals shown are consistent with results obtained during similar periods in previous years. The use of these procedures can rapidly reveal if data are missing or are inconsistent with expected values.

Regular monitoring of any delays between the occurrence of a vital event and its registration can provide insights into the extent of under-reporting in previous periods, which might be indicative of the current situation. The proportion of births or deaths that are registered late may be used as an indicator of whether the system is improving or deteriorating. This type of monitoring can be done by place of birth or death, or by place of occurrence (inside or outside health facilities) thereby providing insight into spatial variations and potential problems.

Monitor access, coverage, completeness and accuracy

Regular monitoring will be needed of the extent to which civil registration systems are accessible and complete. Access and completeness are closely related concepts as events cannot be registered if people do not have access to registration points. As accessibility increases, it is likely that the degree of completeness will also increase.

Access to registration is however a complex concept that covers a range of issues, including the availability of registration points, the distance to be travelled, affordability, and cultural and social acceptability. A simple measure of availability ("coverage") is the percentage of people living in census enumeration districts that have at least one civil registration office or other facility to register births or deaths (11).

Completeness is the percentage of actual births and deaths registered in the civil registration system. Completeness can be assessed by monitoring statistical returns from local registrars and identifying gaps or discrepancies in trends over time which could indicate a breakdown of the reporting system. At the national level, completeness can be assessed by monitoring the total number of vital events registered over time. There should be no major variations from year to year, except in cases of war or major disasters. Seasonal variations are to be expected but these should follow a regular pattern over the years. In order to estimate completeness, the number of children less than one year old recorded during a population census can be compared to the number registered.

Births and deaths that take place in health facilities are more likely to be reported. Countries that have civil registrars located in hospitals and that have introduced a midwifery reporting system have made substantial improvements in the registration of births and deaths. More generally, matching reported events from hospitals and health facilities with registered vital events provides an estimate of the extent of non-registration – as occurs for example when early neonatal deaths reported by a hospital are not reported to the civil registration system. However, as noted previously, the reporting of births and deaths that occur in private institutions may be poor where such reporting is not made compulsory by law. Delayed registration should also be tracked because it is indicative of under-reporting in previous time periods. Ongoing measurement of the delay between a vital event and its registration can indicate whether the system is improving or deteriorating (25).

The completeness of civil registration can also be evaluated using demographic techniques. Some methods ("capture–recapture" approaches) are based upon the direct comparison of data from independent sources, while other indirect analytical methods rely upon assumptions made concerning the population–age distribution. Various indirect demographic techniques are available for estimating the completeness of death

registration, including the Bennett–Horiuchi method (41), (42); the Chandrasekaran–Deming technique (43); and Growth Balance methods (44), (45). These methods are often used by national statistics offices or academic institutions to estimate the completeness of registration (25).

A simpler estimate of completeness can also be made by dividing the *actual* number of registered births (or deaths) in a country by the total *estimated* number of births (or deaths) for the same period and multiplying by 100 to give a percentage. An independent estimate of the total number of births (or deaths) should be used for this calculation. If a reliable national estimate is not available, then an international estimate can be used. For example, each year the United Nations estimates birth and death rates in its Member States using various sources and demographic estimation techniques (46). The reliability of such calculations of registration completeness depends upon the quality of the independent estimates of crude birth rate and crude death rate.

The accuracy of civil registration records will be adversely affected by errors in data transmission and in the recalling or reporting events, by misunderstandings, and by errors in editing and coding. Accuracy can be evaluated directly by matching a sample set of registration reports with an independent set of records. For example, birth and death records can be matched against other lists, such as school enrolments, hospital records, and baptism and burial records. Lists based on the registration of electors, on taxation, on identity-card applications and on the customer files of public utility providers (such as water, electricity and telephone companies) can also be used to assess the quality and accuracy of the register. However, the manual matching of records is complex and time consuming, and such studies are best carried out in collaboration with an academic institution with considerable demographic expertise (46).

Consider the use of incentives and penalties

People are more likely to register vital events if they are aware of the benefits that registration brings. In most settings, registration papers are the key to:

- obtaining identity papers needed for all government services;
- establishing citizenship by showing the place of birth and origin of parents;
- obtaining proof of age in relation to rights and obligations that are conditional upon reaching a certain age, such as schooling, military duties and pension entitlements;
- obtaining proof of place of birth and place of registration;
- providing evidence of identity for marriage;
- obtaining a passport or other travel documents;
- obtaining evidence of death for use by the heirs of the deceased;
- obtaining evidence of cause of death for insurance or legal purposes.

These incentives are usually more effective in urban areas where government services are available and in demand. Incentives tend to work better for births than deaths, especially where neither life insurance nor inheritance is common. In some countries, for example the Cook Islands, there are small cash incentives for families to register births. In Brazil, maternity wards are given small monetary rewards for each child they register. In Nauru, families receive financial support for funeral arrangements when they register a death.

Another strategy to increase registration is to more broadly share the onus of registering. Traditionally the family is responsible for registering a vital event. However, in some countries, the responsibility for registration is shared, for example where funeral directors are assistant registrars and register the death as part of their services. By linking death registration with permission to transport the deceased to the burial place, there is a direct incentive for the funeral director to register the death quickly. Relatives later receive the legal papers from the local civil registrar. Similarly, registry office staff may be located in health facilities so that the family can register a birth directly at the hospital before taking the baby home, or arranging the funeral in the case of a death. It is also common for hospitals to report births to the civil registration office, and to provide the necessary papers for the family to forward to the civil registration office. Regular information and communication campaigns are also an important way of encouraging people to register vital events (25), (47).

Individuals should never be charged a fee to register vital events. Fees are a strong disincentive to public cooperation, particularly among poor and marginalized people. To encourage families to register, many countries issue an abridged copy of the birth or death certificate free of charge at the time of registration. However, it is reasonable to request payment for subsequent additional copies of birth and death certificates. In many societies, copies of birth certificates are commonly required for administrative purposes, and the income generated from issuing copies contributes to the running costs of the civil registration service.

In order to enforce civil registration law, many countries impose penalties for late registration or failure to register. However, it is important to monitor the unintended and potentially adverse effects of such penalties. For example, families may misreport dates of births or deaths to avoid penalties, resulting in inaccuracies in the resulting data, especially where a publicity campaign has led to a sudden increase in late registrations. In practice, penalties may discourage timely registration and can lead to false declarations which distort the data (25).

Build public trust

The success of civil registration depends upon the willingness of individuals and families to register vital events. No matter how good the laws in place are they cannot guarantee public participation. Collaboration with civil society organizations can help to promote the benefits of registration, and foster public trust in the system. Civil registration must be accepted and recognized as a public good (48). Public trust will be undermined if people have to pay bribes when registering or obtaining a copy of a certificate. The use of an anonymous web site offering a forum for people to record their experiences of bribery and corruption can help to highlight problem areas and procedures that are most prone to corruption (49), and this approach has now been trialled in a number of countries.

Share data with a range of potential users

Gaining the most benefit from CRVS data involves ensuring access to such data by relevant agencies and individuals. However, there are a number of issues which must be considered in order to ensure that privacy and confidentiality standards are maintained. The right

to consult the identifying records of an individual should be restricted to the individual registered, their close family members, and their legal agents, and to public authorities legitimately seeking to verify the identity of a registered individual.

For researchers and others needing to use the data, anonymized or encrypted microdata can be made available for use in economic and regional planning, and to explore trends in vital statistics. Aggregated data in which the risks of identification have been removed can be shared broadly with data users. The relatively small costs involved in maintaining strict standards of confidentiality are far outweighed by the value of ensuring that the system is ethical, trusted and safe (25), (48).

Consider ways of linking civil registration to the population register

Population registers are partly derived and updated from data collected by the civil registration system, and can be considered as civil registration plus both internal and international migration. The population register is continuously maintained and updated with information is collected over the complete lifespan of every individual. Data derived from a population register allow specific cohort analysis to be conducted during an in-depth analysis. However, population registers also have a number of limitations, with fewer vital events related variables typically collected compared to the civil registration system – thus limiting the value of fertility and mortality statistics produced by in-depth analysis (50).

In settings where the basic elements of civil registration are not in place, one potential starting point for developing a population register is the decennial population census. If one has been conducted recently, it can provide information on the names, age and sex of individuals, their place of birth and place of residence, and on the relationship of household members. Information on vaccination histories, schooling and employment may also be available. In 1960, a recently conducted population census served as the starting point for the population register in Norway. However, once it is established, the register will need to be updated by an ongoing civil registration system so that flows into and out of the register caused by births and deaths are taken into account. A population register also requires information on patterns of migration.

Population registers integrate all information on a single individual into one record, identifiable by a unique PIN. This number is issued at birth and is linked to the health records and death certificate of the individual in question. The number must be long enough for permutations of it to be usable for hundreds of years, and must allow for 3–4 generations and for population growth. Numbers should never be re-used within 100 years of a person's death. The use of PINs can significantly improve the registration of vital events and facilitate access to key services. For example, following registration, the PIN number of an infant can be sent to the parents via a text message on a mobile phone. If such a PIN is known to be required to access services such as immunization and school enrolment, this may increase the likelihood of infants being registered. In cases of non-registration at birth, children attending immunization services can be retrospectively registered via mobile phone and can then receive the PIN needed to access the service.

Two different approaches can be used when designing a PIN:

1. The PIN contains information such as date of birth, sex and place of birth. This kind of PIN is used in a large number of Nordic and other countries. The disadvantage of this approach is that the assigned number will need to be changed if it is subsequently discovered that, for example, the date of birth is incorrect. On rare occasions, individuals elect to change their sex and will therefore also require a new number. On the other hand, PINs containing meaningful information are easier to remember and errors may be more easily detected.

2. The PIN is a purely random or serial number, in which the individual digits have no specific meaning. This is now the recommended approach as information-free numbers are less prone to misuse given that no personal information can be deduced from them. All the information required on an individual is then stored in a database – often called the Central Population Register (CPR) – where it is easily available for legitimate use.

The second option also implies the use of a shorter number. An eight-digit number has sufficient permutations to cater for a population of 100 million people. This should be sufficient for most countries, even without recycling the PINs within the recommended 100 years after a person's death. It is important to clearly distinguish between a population register and a national identification system. In principle, the population register should cover the total population in a country (or all residents) from birth to death, while a national identification system might only cover a certain population segment, for example all those 16 years of age or above.

Maintaining a population register requires a highly functioning administrative system as well as sufficient information-technology resources. This is because the constant maintenance and updating of the population register will require more-intensive efforts than maintaining a civil registration system. It will also be necessary to clearly describe how information flows between national population registers and civil registration systems, and to set out in detail which government agency will be responsible for maintaining the national population register.

3.4 Tools and resources

There are two main categories of tools and resources that can be used to help improve civil registration practices, coverage and completeness:

- standards developed by international agencies with mandates in CRVS systems.
- lessons learnt and research undertaken by demographers in agencies, academic institutions and other organizations on specific aspects of civil registration.

International CRVS systems standards

The basic standards for CRVS systems are set by UNSD while WHO is responsible for standards regarding cause-of-death certification (1). UNSD coordinates the International Programme for Accelerating the Improvement of Vital Statistics and Civil Registration Systems. This programme provides technical guidance and support to countries in strengthening their CRVS systems.

- UNSD maintains an online **Civil Registration and Vital Statistics Knowledge Base** (51) which documents and disseminates United Nations methodological guidelines, demographic research articles, and country practices and activities in CRVS. This resource is intended to facilitate the international exchange and sharing of knowledge and information, as well as provide guidance to countries and monitor progress, and can be found at: **http://unstats.un.org/unsd/demographic/CRVS/default.htm**
- In 2001, UNSD issued the second revision of its **Principles and Recommendations for a Vital Statistics System** (25). This document is a key reference and resource, and includes guidelines on the steps needed to strengthen CRVS systems. The document is currently under review and the updated version will be available in 2013. The current version can be found at: **http://unstats.un.org/unsd/publication/SeriesM/SeriesM_19rev2e.pdf**

Guidance on specific aspects of the operations and functions of civil registration systems is also available in a series of handbooks developed by UNSD. These include:

- **Handbook on Training in Civil Registration and Vital Statistics Systems** (29) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_84E.pdf**
- **Handbook on Civil Registration and Vital Statistics Systems: Computerization** (28) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_73E.pdf**
- **Handbook on Civil Registration and Vital Statistics Systems: Developing Information, Education and Communication** (47) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_69E.pdf**
- **Handbook on Civil Registration and Vital Statistics Systems: Management, Operation and Maintenance** (27) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_72E.pdf**
- **Handbook on Civil Registration and Vital Statistics Systems: Policies and Protocols for the Release and Archiving of Individual Records** (52) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_70E.pdf**
- **Handbook on Civil Registration and Vital Statistics Systems: Preparation of a Legal Framework** (20) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_71E.pdf**
- **Handbook of Vital Statistics Systems and Methods, Vol I: Legal, organizational and technical aspects** (53) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_35v1E.pdf**
- **Handbook of Vital Statistics Systems and Methods, Vol II: Review of national practices** (54) available at: **http://unstats.un.org/unsd/publication/SeriesF/SeriesF_35v2E.pdf**
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3.5 Summary

The key actions shown in **Box 6** address a range of practical, procedural and operational issues, and will be crucially important in efforts to strengthening the registration practices, coverage and completeness of civil registration systems.

BOX 6. Key actions for improving registration practices, coverage and completeness

1. Undertake a mapping of the information flows in the current system, starting from the point of registration of a vital event through to the compilation and dissemination of vital statistics. Use this to identify points in the process where vital events may be missed by the registration system and lost to the vital statistics system.
2. Establish formal and functioning communication and coordination mechanisms that bring together all key agencies – including the office of the civil registrar, national statistics office and ministry of health – and other important stakeholders.
3. Ensure that there are sufficient numbers of registrars – especially in rural areas – and that their duties are properly defined. There should also be sufficient numbers of well-trained statistical clerks, coders and medical records officers as these all play a key role in the conversion of individual records to data of public health relevance.
4. Clearly define roles and responsibilities at all the different levels of CRVS systems and allocate these to the various different agencies involved. Unclear or overlapping responsibilities adversely impact upon the smooth running of the system and waste valuable resources.
5. Ensure that information on vital events is collected in a standard format to allow comparable national figures to be compiled.
6. Ensure that all information essential for public health purposes is collected at the time of registration, especially administrative information and information on the important characteristics and circumstances of births and deaths (including cause of death) and that such information is complied and shared with users.
7. Introduce computerization to help ensure the timeliness of different processes – including data production, verification, validation and sharing. The civil registration system must be able to store, file, abstract, archive and retrieve records.
8. Monitor the extent to which civil registration is accessible by different populations, and whether all vital events are effectively and correctly registered. Ensure consistency between registered vital events and vital statistics, and use available guidelines to calculate the coverage, completeness and accuracy of civil registration.
9. Reinforce public education campaigns through the use of incentives, for example by requiring birth or death certificates for gaining access to government services such as school enrolment and health care, and for acquiring inheritance rights.
10. Work with civil society organizations to promote the benefits of CRVS systems and to generate public trust and support for such systems.

As many different agencies and institutions are involved in the day-to-day running of CRVS systems, undertaking reforms will require consensus-building and collaboration. The roadmap presented in **Box 7** outlines the major steps involved in developing a plan for improving civil registration practices, coverage and completeness. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

BOX 7. Basic roadmap for developing a plan to improve civil registration practices, coverage and completeness

Step 1: Constitute an ad hoc committee comprising high-level representatives of all government agencies and departments involved in the functioning of the civil registration system, in the preparation of registration forms, in data storage, archiving and transmission, and in monitoring system coverage and completeness. The group may include members involved in the working group on legal issues (see **Module 2**) and must also include people involved in the day-to-day activities of registration and vital statistics production such as registration officials, health workers, data managers and data analysts. The function of the committee is to:

- critically review the functioning of the current system, using the comprehensive assessment tool (11) as a guide;
- identify the key priorities requiring action.

Step 2: On the basis of the priorities identified in **Step 1**, outline the processes needed to accomplish the key priorities. These processes should include:

- development of a detailed workplan and time schedule for the introduction of reforms;
- drawing up a budget and identifying potential sources of financial support where needed;
- identifying and accessing technical resources to support the required remedial actions.

Step 3: Present the workplan to a broader group of stakeholders including high-level decision-makers in all relevant agencies, researchers and academic institutions that are major users of vital statistics, as well as to civil society groups and NGOs.

- mobilize support for reform among those involved in CRVS systems;
- identify the roles and responsibilities of different stakeholders in taking forward the implementation of the workplan;
- identify training and technical support needs.

Step 4: Implement agreed activities.

Step 5: Establish an ongoing monitoring group to review the implementation of the reforms, identify bottlenecks and problems, and document the lessons learnt. Monitor changes in the coverage and completeness of civil registration, and identify any areas or population groups that are still excluded from the CRVS system.

MODULE 4:
Death certification and cause of death

4.1 Introduction

The only way to obtain good-quality mortality statistics is to have deaths certified by a medically qualified doctor. How well a doctor manages to diagnose the diseases and conditions that led to a person's death depends upon a number of factors discussed in this module. To ensure that doctors are able to competently certify deaths in accordance with ICD guidelines and standards they must receive basic training in death certification and must understand the importance of good cause-of-death information. This module outlines:

- the importance of cause-of-death information
- common problems with death certification and cause-of-death data
- available strategies to improve cause-of-death statistics.

4.2 Background

Importance of cause-of-death information

Cause-of-death information can be used in many ways to evaluate the health of the local, regional and national population. Cause-of-death statistics are commonly used to:

- describe and explain levels, trends and differentials in mortality;
- identify emerging diseases and conditions, and track changes in the burden of disease in different groups;
- guide priorities for intervention programmes;
- contribute to socio-medical and biomedical research;
- monitor the impact of public health programmes;
- allocate and distribute resources within the health sector;
- identify areas requiring epidemiological research.

Information on the mortality patterns of populations is important for health policy and planning (56). Mortality data are commonly used to calculate the burden of major diseases within population groups or across geographical regions. In many countries, the 10 or 20 leading causes of death are regularly included in official statistics.

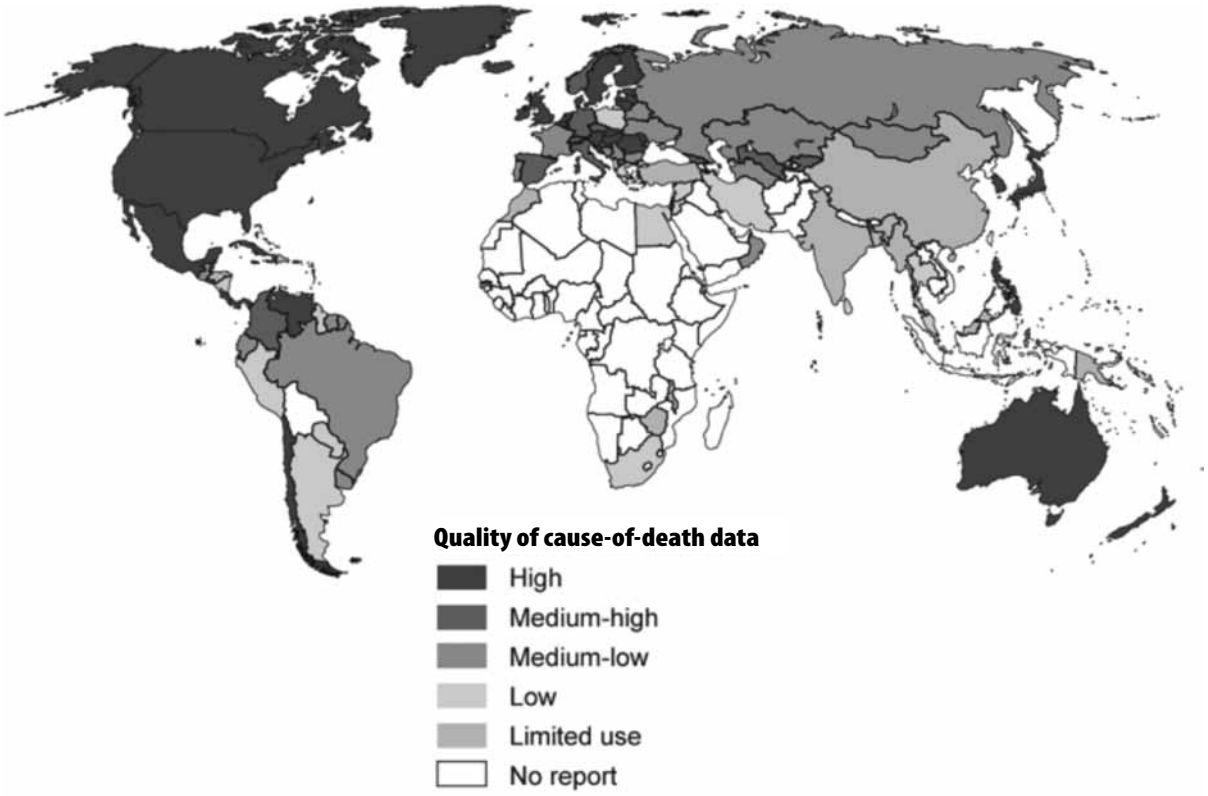
Leading causes of death are defined as the underlying cause-of-death categories or major ICD groupings that usually account for large numbers of deaths within a specified population group and time period. Determining and monitoring the leading causes of death are vital activities as these are primary indicators of the overall health status or quality of life of a population. Because of the many important public health uses to which cause-of-death statistics are put, ensuring their accuracy is vital. This requires that

an accurate diagnosis of cause of death is arrived at by the person certifying the event, and that the underlying cause of death is correctly identified and coded according to international standards.

Global situation

As noted in preceding modules of this resource kit, the percentage of all deaths registered through the civil registration system varies widely between different countries. Because many countries do not have complete registration of deaths – or reliable and accurate registration of causes of death – the quality of cause-of-death data varies even more. According to WHO, only about 70 countries produce cause-of-death statistics of sufficient quality for planning purposes. **Figure 5** summarizes global variations in the quality of cause-of-death data based on the estimated timeliness, completeness and coverage of death registration, and on the proportion of deaths assigned to ill-defined causes.

Figure 5: Quality of globally available information on cause-of-death (11)



In one study of mortality data, it was reported that only 23 countries had cause-of-death data that were more than 90% complete with less than 10% of deaths assigned to ill-defined causes (57). It is therefore not surprising that many national evaluations of health information systems have found significant weaknesses in the generation of mortality statistics. In Thailand, for example, a 2005 assessment of the strengths and weaknesses of the national health information system identified the strengthening of cause-of-death statistics as a priority government action (58).

The first step in improving the quality of mortality data is to assess current mortality registration levels and medical-certification systems using the rapid assessment and comprehensive assessment tools described in Module 1 (10), (11). These assessment processes will help to identify where problems lie. Once completed, the methods or strategies outlined below in this module can be used to improve the measuring and monitoring of cause-of-death patterns and trends. Evidence has shown that improving national mortality and cause-of-death data-collection systems will require:

- a review of medical records and death certificates to assess the current quality of cause-of-death certification;
- the issuing of standard practice guidelines on cause-of-death certification to doctors;
- the training of physicians in death certification according to the rules and procedures of the ICD;
- the training of coders in ICD mortality coding according to the rules and regulations of ICD-10;
- the establishing of collaborative mechanisms between the ministry of public health, national statistics office and local registrars to ensure the collection of better-quality data;
- implementing verbal autopsy (VA) techniques for deaths that occurred in the home and were not medically certified.

Each of these activities is described in further detail in this module, and in modules 5 and 7.

Common problems with death certification and cause-of-death data

The production of good-quality mortality data requires a system in which:

- ***all*** deaths are registered (with an assigned cause of death) by either the civil registration or the vital statistics systems, and that these two systems are integrated;
- ***all*** deaths are medically certified using the WHO International Form of Medical Certificate of Cause of Death (**Figure 6**);
- the underlying cause of death is correctly coded according to the rules and principles of the ICD-10 (1).

Inadequate medical certification of cause of death

For a death to be medically certified, a physician must complete a death certificate and give a judgement on the causes that led to the death. Only a medically trained person can reliably do this, and diagnose the precise cause of death. Mortality statistics are based upon determining the single underlying cause of death, which is the disease or injury that initiated the sequence of events that led directly to death. 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 – as demonstrated in the scenario shown in **Box 8**.

Figure 6: International Form of medical certificate of cause-of-death (1)

INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE-OF-DEATH

	Cause of death	Approximate interval between onset and death
I Disease or condition directly leading to death*	(a)	.....
	due to (or as a consequence of)	
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b)	.....
	due to (or as a consequence of)	
	(c)	.....
	due to (or as a consequence of)	
	(d)	.....
II Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....	.....
	.....	.....

**This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*

Figure 7 shows four factors that are likely to affect the quality of death certification and mortality data. Any problems with each of these different aspects will become apparent following the comprehensive assessment, and should be addressed through a quality-improvement programme.

The medical knowledge and skills of those responsible for certification critically affect the quality of cause-of-death data. Certifiers also need to understand the public health importance of accurate death certification and cause-of-death data, and to receive appropriate training in certification. They also need to be aware of the legal and ethical considerations that may affect the quality of cause-of-death certification, and of ways of addressing them.

Lay certification of cause of death

In many developing countries where a high proportion of people die outside hospitals, the cause of death is not certified by a medical doctor but by a coroner, police officer, village chief, registrar or other layperson without medical training. 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" and "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 health information systems in developing countries.

BOX 8. Cause-of-death scenario

A 50 year old woman is admitted to the hospital with sudden-onset vomiting of blood, and is diagnosed as having bleeding oesophageal varices. Eight weeks previously she had been diagnosed with portal hypertension. The woman had a history of hepatitis B infection diagnosed 2 years ago. Three days following admission she dies.

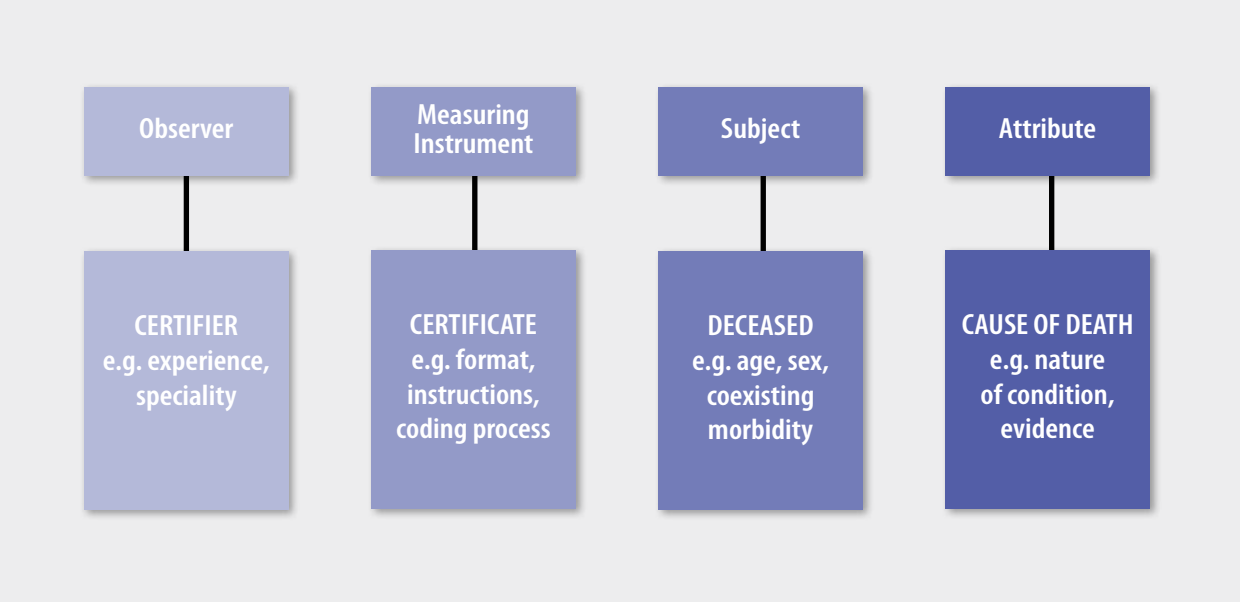
INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE-OF-DEATH

Cause of death		Approximate interval between onset and death
I Disease or condition directly leading to death*	(a) Bleeding oesophageal varices	3 days
	due to (or as a consequence of)	
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b) Portal Hypertension	8 weeks
	due to (or as a consequence of)	
	(c) Hepatitis B infection	2 years
	due to (or as a consequence of)	
	(d)	.....
II Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....	.....
	.....	.....

**This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*

In this case, hepatitis B was the underlying cause of death – not bleeding oesophageal varices, which was the immediate cause of death. Knowing this, public health authorities would be able to react by implementing immunization programmes to prevent such deaths in the future.

Figure 7: Factors affecting death certification and mortality data (59)



Insufficient training in death certification

Although a postmortem examination is the best way to determine the proper cause of death, it is not always feasible and/or practical to conduct such an examination for all deaths. Death certification by doctors is therefore considered to be the "gold standard" for producing cause-of-death data. However, evaluation studies have repeatedly shown that such data are not always of a high quality even when the cause of death has been certified by a physician (60), (61), (62), (63).

In many countries, doctors do not have adequate opportunities to learn about death certification as part of their medical curriculum and training. In addition, some hospitals lack equipment that may be needed to correctly determine the cause of death. Moreover, hospital medical records may be poorly completed and thus inadequate for informing the decision of the doctor responsible for certifying the cause of death (63).

Training in medical certification – which can be delivered in two or three lectures – should cover four areas:

- understanding the sequence of events leading to death and correctly identifying the underlying cause of death;
- completing the death certificate correctly;
- understanding the social, legal and ethical issues that certification may entail;
- appreciation of the public health value of cause-of-death statistics.

Such training can help to avoid the five leading errors in death certification shown in **Box 9**.

BOX 9. Five leading errors in death certification

1. Writing only the immediate cause of death or mode of death in the death certificate, rather than the underlying cause.
2. Documenting multiple causes on one line. Only one condition should be documented per line.
3. Not specifying the site and nature of cancers and other tumours or local lesions.
4. Listing clinically improbable sequences.
5. Not documenting the nature of the injury in the case of deaths due to accidents, and not distinguishing between accidental or intentional injuries.

Inadequate procedures for dealing with "dead-on-arrival" cases

The certification of "dead-on-arrival" cases varies from country to country. In some settings, such cases are passed on to coroners or the police, and sometimes not included in cause-of-death statistics reported by the hospital. Attributing the correct cause of death is difficult because only an autopsy can provide the necessary information and is not always performed. As a result, a high proportion of dead-on-arrival cases are assigned to ill-defined or nonspecific causes, which are of no value for public health purposes.

Lack of clarity in death certificates

The format of the cause-of-death form also plays a role in capturing good-quality data. Ensuring the clarity of the instructions given and specific definitions used is particularly important. If, for example, there is only space on the form to report a single cause of death, it is more likely that doctors will only report the immediate cause of death, rather than the underlying ones. Despite the WHO recommendation to use the International Form of Medical Certificate of Cause of Death (1), many countries use their own certificates which do not follow ICD principles. WHO also recommends that a different certificate is used for perinatal deaths (1) which does not aim to record any underlying cause-of-death information but focuses instead on the main condition of the infant and the main maternal disease affecting the infant – plus information on the outcome of the mother's previous pregnancies.

Characteristics of the deceased

The deaths of infants and of older people are the most difficult to certify correctly. Several studies have shown that the proportion of errors in death certification is considerably higher for older age groups (64). As people age, they often suffer from a number of diseases at the same time, which makes it difficult to ascertain the single underlying cause of death. If reliable medical records and laboratory findings are not available, assigning the correct cause of death may require significant individual judgement. Sometimes the deaths of people above a certain age are considered to be "natural" and assigned a "not known" cause. This is not the correct practice according to the ICD and should not be followed by certifiers.

Nature of the cause of death

The laws and customs of a particular country or culture can affect the willingness of certifiers to report certain causes of death, especially those that may reflect badly on the deceased person or the family, for example by being associated with social stigma. Causes of death that are often associated with stigma include HIV/AIDS, unsafe abortion, tuberculosis, mental diseases and suicide. Relatives might discourage the certifying doctor from recording such causes on the death certificate.

Certifiers need assurances that their conclusions regarding the underlying cause of death and other information on the death certification will not be used against them or their institutions. The availability of legal protection (see Module 2) is particularly important when certain causes of death are subject to a hospital review or "audit" undertaken to identify potentially avoidable factors (1). In countries with a high level of malpractice cases, fear of lawsuits has on occasion led to the abandonment of such investigations.

There may also be financial disincentives to record certain causes of death. For example where life-insurance schemes preclude payment when deaths are due to suicide, or when certain conditions are not included in health insurance reimbursement schemes. One study in South Africa into the level of under-reporting of HIV/AIDS as a cause of death found serious errors in 32.2% of 983 death-notification forms reviewed, with the resulting under-reporting of deaths due to HIV/AIDS estimated to be as high as 53.1% (65). Social scientists and medical professionals need to work together to find ways of avoiding such practices.

Problems related to reporting deaths due to external causes

A common problem in many developing countries is that deaths due to external or unnatural causes are under-reported because many certifiers are unaware of the correct method of certifying such deaths. "External causes" include injury, poisoning or other consequences of external events. In these cases, the certifier must record both the circumstances and consequences of the incident that resulted in death. Although the ICD provides special instructions on how to classify unnatural deaths, certifying doctors are not always aware of the guiding rules and principles. As a result, many doctors report the immediate cause of death rather than the circumstances that led to the death. For example, in the case of an accidental road traffic death, the accident itself should be given as the underlying cause of death, in addition to the immediate cause of death (for example, intracranial haemorrhage).

Another reason for the inaccurate reporting of deaths due to external causes is that in most countries deaths due to accidents and violence must be investigated by the police or coroner. In these cases, the cause of death may initially be registered as "not defined" or "unknown" pending the outcome of the investigation. It is then common for significant delays to occur in finalizing the data with the true cause of death not being accurately reflected in the resulting vital statistics.

Problems related to reporting cancer deaths

From a public health perspective, it is important to know the specific cancer type associated with every cancer death, because prevention strategies differ markedly from one type of cancer to another. For example, preventing lung cancer requires tobacco-control policies, while preventing stomach cancer requires diet-based interventions, aiming for example to reduce salt intake. The death certificate should always state the primary site of the cancer if known as this will help to identify the underlying cause of death. If histology and staging information are also available, this will improve the clarity of the diagnosis and should therefore be included on the death certificate.

Problems related to reporting maternal deaths

The maternal mortality ratio is an important indicator of national health system functioning and level of development. The fifth Millennium Development Goal (MDG 5: improve maternal health) incorporates the specific target of reducing the maternal mortality ratio by three quarters between 1990 and 2015 (66). Despite this, maternal and pregnancy-related deaths remain severely under-reported in many developing countries. According to ICD-10 (1), a maternal death is defined as:

> *…the 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.*

Making accurate estimates of the number of maternal deaths in a country requires:

- complete records for all female deaths
- good attribution of cause of death
- knowledge of the pregnancy status of women of reproductive age who die.

In reality, there are a number of problems in recognizing maternal deaths, including:

- medical certification of cause of death is not available or is inadequate;
- most maternal deaths in developing countries occur at home;
- some causes of maternal deaths are hard to identify, especially when death occurs very early in pregnancy (for example, ectopic pregnancy);
- abortion-related deaths are often missed – particularly in settings where abortion is illegal or stigmatized – because women may hide their pregnancy;
- postpartum deaths are less likely to be reported because, in part, they cannot be linked to reportable birth outcomes;
- maternal deaths at the extremes of maternal age (youngest and oldest) can be missed because of lack of awareness of the possibility of pregnancy at these ages.

Because of difficulties in correctly identifying this cause of death in many developing countries, the ICD-10 introduced an additional category for maternal deaths called "pregnancy-related death" which is a time-of-death rather than a cause-of-death (1). Using this definition removes the need to determine whether the death of a woman of reproductive age women was specifically due to direct or indirect maternal causes. In most settings, the difference between pregnancy-related and maternal deaths is small. However, where the prevalence of HIV/AIDS is high, the difference between pregnancy-related and maternal deaths can be substantial and may lead to the overestimation of maternal deaths (9).

Maternal deaths may be misclassified as non-maternal in cases where the link between pregnancy and death is missed. This can happen, for example, when a recently pregnant woman dies in an emergency department on a specialist ward where she was being treated for complications. The certifying physician may not be aware that the woman had recently been pregnant. To deal with this issue, several countries, including Brazil and the United States of America, have introduced a checkbox on the death certificate to prompt certifiers to find out whether a recently deceased woman of reproductive age was pregnant at the time of death or had recently been pregnant (**Box 10**).

BOX 10. Example content for a pregnancy checkbox on a death certificate

If female:

- ☐ Not pregnant within past year
- ☐ Pregnant at the time of death
- ☐ Not pregnant, but pregnant within 42 days of death
- ☐ Not pregnant, but pregnant 43 days to 1 year before death
- ☐ Unknown if pregnant within the past year

Birth data from health facilities are a good supplementary source of information on maternal death. However, in most developing countries, only a proportion of all births take place in such facilities. Health-facility data are therefore rarely sufficient to make population-based estimates of maternal mortality. Health-facility data may however provide useful information on trends over time, and on specific geographical regions.

It is always better to look at the trends in maternal mortality than to look at the maternal mortality rate for a year. Due to a small number of deaths each year, maternal mortality rates often tend to fluctuate.

There is a growing trend of conducting special investigations of maternal deaths or "audits" in order to identify avoidable factors and take remedial actions to avert future deaths (23). In many countries, the death registration system provides the starting point for identifying deaths among women of reproductive age. These are then investigated using a combination of medical records reviews and interviews with family members and health-care providers in order to correctly identify all deaths associated with pregnancy. Such investigations invariably identify a number of maternal deaths that were not classified as such on the death certificate (67), (68), (69), (70), (71).

Ill-defined causes of death

The best indicator of the quality of national cause-of-death data is the proportion of all deaths that are assigned to "ill-defined" causes. The ICD-10 (1) classification of ill-defined causes of death is a series of vague categories and conditions including:

- symptoms and signs – for example, fever, chest pain or enlarged liver;
- abnormal clinical and laboratory findings – for example, elevated erythrocyte sedimentation rate, impaired glucose tolerance or abnormal blood-gas analysis.

Deaths assigned to ill-defined causes are insufficiently detailed to be of value for public health purposes. At most, these cases reflect overall mortality rates in broad disease or injury groups, or show the number of deaths that may be missing from the other specific categories. The so-called "garbage codes" (**Box 11**) include all the ill-defined or residual categories of major disease groups that do not provide meaningful information on the underlying disease or injury that caused death, such as atherosclerosis or ill-defined primary cancer site (16). It is therefore essential through training programmes and other initiatives to raise awareness among certifying doctors of the need to seek sufficient evidence to assign causes of death to the more-precise categories.

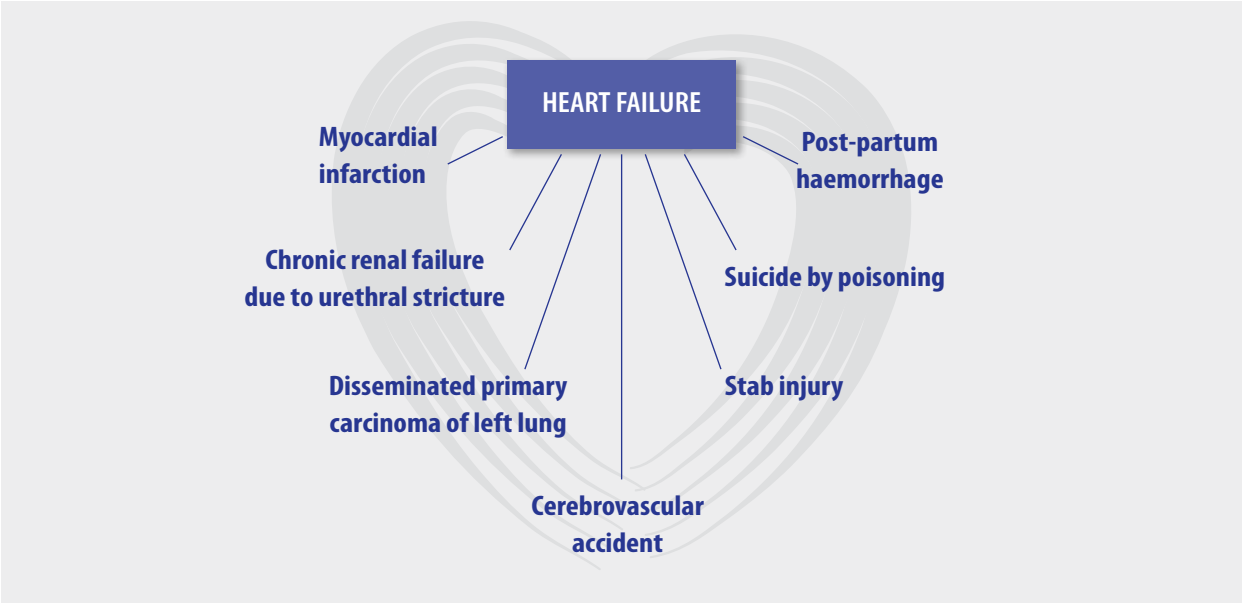
A common error in some countries is to report the "mode of dying" as the cause of death. For example, heart failure, cardiac arrest, shock, brain failure, hepatic failure and renal failure should not be reported as the cause of death because organ failures do not usually occur without a precipitating cause. Therefore, if organ failure is reported on the death certificate, the underlying condition responsible for the failure should also be reported. For example, acute renal failure due to diabetes mellitus or liver failure due to hepatitis B infection. Where only the mode of dying is reported on the death certificates (for example, "heart failure") then a potentially wide range of different underlying causes will be missed (**Figure 8**). As the public health measures needed to prevent these underlying causes are often very different then the key information needed to inform national and local planning and health policy development will be missed.

There will always be individual cases where it is not possible to assign an underlying cause of death due to a lack of information on the events and circumstances leading up to death. However, these cases may be relatively infrequent in most settings and the proportion deaths assigned to ill-defined causes should therefore be monitored. In general, the proportion of deaths coded to ill-defined categories should not exceed 10% of all deaths in the age group 65 years and over, and should account for <5% of deaths occurring in those under 65 years of age.

BOX 11. Ill-defined causes of death (16)

ICD-10 Code	Cause
R00-R99	Deaths classified as ill-defined (except R95)
A40-A41	Streptococcal and other septicaemia
C76, C80, C97	Ill-defined cancer sites
D65	Disseminated intravascular coagulation (defibrination syndrome)
E86	Volume depletion
I10	Essential (primary) hypertension
I269	Pulmonary embolism without mention of acute cor pulmonale
I469	Cardiac arrest
I472	Ventricular tachycardia
I490	Ventricular fibrillation and flutter
I50	Heart failure
I514	Myocarditis, unspecified
I515	Myocardial degeneration
I516	Cardiovascular disease, unspecified
I519	Heart disease, unspecified
I709	Generalized and unspecified atherosclerosis
I959	Hypotension, unspecified
I99	Other and unspecified disorders of circulatory system
J81	Pulmonary oedema
J960	Respiratory failure, not elsewhere classified
J969	Respiratory failure, unspecified
K72	Hepatic failure, not elsewhere classified
N17	Acute renal failure
N18	Chronic renal failure
N19	Unspecified renal failure
P285	Respiratory failure of newborn
Y10-Y34, Y872	External cause of death not specified as accidentally or purposely inflicted

Figure 8: Examples of possible underlying causes of death in cases assigned to heart failure



4.3 Key actions

The key actions required to overcome many of the common problems with death certification, and thus improve the quality of cause-of-death data, are:

- increase awareness among physicians of death-certification practices and improve their skills;
- introduce the International Form of Medical Certificate of Cause of Death;
- conduct regular validation of cause-of-death certification in hospitals;
- increase the proportion of medically certified deaths outside hospitals;
- introduce verbal autopsy procedures when medical certification is not possible.

Increase awareness among physicians of death-certification practices and improve their skills

When a death occurs in a health facility, the treating physician usually certifies the death and diagnoses its cause. The quality of the diagnosis will be influenced by the four factors shown in **Figure 7**. The most-important factors affecting the quality of the cause-of-death data are the physician's knowledge of the illness in the deceased, the physician's experience in certification and the medical history of the deceased.

Improving the quality of death certification requires that physicians have the necessary skills and expertise in international-standard death-certification practices – and that they fully understand the importance of correct certification for public health purposes. Training should be given in both the technical aspects of correct certification and in addressing the key social, ethical and legal considerations outlined above and in Module 2. Two strategies that could be used to provide doctors with more opportunities to learn how to correctly certify and accurately report causes of death are the provision of training in hospitals for practising doctors, and the inclusion of a module on death certification in the medical curriculum. A case study from Thailand illustrates how such measures have been taken (**Box 12**).

BOX 12. Case study – Thailand

Of the 300 000 deaths estimated to have occurred in Thailand in 2000, only 30% occurred in hospitals and were medically certified. It was therefore considered essential to ensure that such deaths were certified as accurately as possible.

An assessment conducted among those responsible for certifying deaths in Thailand showed that 80–90% of doctors did not understand the concept of underlying cause of death and were unsure of how to correctly certify causes of death.

To address these issues and improve the quality of death certification by doctors in hospitals, the following strategies were implemented between 2000 and 2003:

- Development of the first Thai guidelines for death certification.
- Training of approximately 20 000 doctors in death certification at interactive workshops across the country.
- Inclusion of a module on cause-of-death certification in the medical school curriculum.
- Establishment of an audit system for death certification to monitor improvements.

Setting up comprehensive on-the-job training is challenging because it is not possible to include all practising doctors simultaneously. Furthermore, there is often a shortage of trainers with the specialized knowledge needed to teach cause-of-death certification. In these circumstances, it may be more appropriate to offer training in death certification on a recurrent basis so that doctors can attend at different stages of their career. It is also important to set up monitoring and supervision mechanisms to review the sustainability of the improvements made to certification practices following training. Regular feedback to the certifiers will also be helpful in improving death-certification practices and preventing any reversions to flawed certification practices once the training course is over.

The simplest and most sustainable way to train physicians is to add a module on cause-of-death certification to the medical curriculum. Several resources are available to guide the development of an educational module on death certification and on its value to public health. As described in more detail in Module 5, the WHO Family of International Classifications (WHO-FIC) in collaboration with the International Federation of Health Information Management Associations (IFHIMA) has outlined the minimal contents and requirements of a core curriculum for certifiers of underlying cause of death (72). Section 4.4 of this module provides links to these and other tools and resources for training doctors in cause-of-death certification, some of which can be used by doctors for self-learning.

Introduce the International Form of Medical Certificate of Cause of Death

The International Form of Medical Certificate of Cause of Death (see **Figure 6** above) is designed to facilitate the correct diagnosing and recording of the underlying cause of death, and to promote the uniform application of ICD-compliant death certification in all settings (**Box 13**). The use of this form should allow cause-of-death statistics to be comparable across time and place. Volume 2 of the ICD-10 (1) provides guidance and standards for mortality certification, and explains the rules and procedures for selecting the underlying cause of death. It also sets out why the underlying cause of death – rather than the immediate cause of death – should be used to certify deaths, and to produce

BOX 13. Summary guidelines on completing cause of death certification

WHO recommends that the International Form of Medical Certificate of Cause of Death (see **Figure 6**) be used for certifying deaths. This "death certificate" provides a framework for the organization of clinical diagnoses used for public health purposes, and is divided into three sections:

1. **Part I** – including diseases or conditions directly leading to death, and antecedent causes.
2. **Part II** – other significant conditions.
3. 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 I** and **II** 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 I**. These intervals are usually established by a doctor on the basis of available information.

General guidelines for correct death certification

- Always use ***consecutive lines*** – never leave blank lines within the sequence of events.
- Each condition listed in **Part I** should cause the condition above it.
- If there is only one cause of death, it is entered at I(a).
- The entry must be ***legible*** –use ***black ink***.
- Do not make alterations or erasures – if an entry needs to be deleted, a single line should be drawn through it; do not use correction fluid.
- Verify the ***accuracy*** of identification data with the family of the deceased – including the correct spelling of the name of the deceased.
- Do not use abbreviations.
- Enter only ***one disease*** condition or event ***per line***.

statistics that are useful for public health planning and disease prevention. In the case of perinatal deaths, countries are advised to use the WHO definition of the perinatal period – i.e. starting at 22 completed weeks (154 days) of gestation (the time when birth weight is normally 500 grams) and ending seven completed days after birth (1). Correct identification of the cause of perinatal deaths is particularly important in guiding the development of national policies on maternal and child health.

Some deaths result from a sequence of events involving more than one disease or condition. It is important that the certifier records all of the main contributing diseases and conditions, and the length of time for which the deceased had them, to allow the coder to correctly identify the underlying cause of death. As shown in **Figure 6**, space for recording this information is incorporated into the form.

In settings where the International Form of Medical Certificate of Cause of Death is not used and problems are being experienced with the quality of cause-of-death reporting, then consideration should be given to its introduction into the reporting process. Such a step must be coordinated through a wide-reaching information campaign directed at all relevant stakeholders, including:

- medical association
- ministry of health
- ministry of finance and planning
- ministry of justice
- department of the registrar-general
- national statistics office
- other relevant authorities.

Conduct regular validation of cause-of-death certification in hospitals

Most countries that collect mortality information publish an annual summarized list of causes of death. However, very few countries routinely validate the quality of cause-of-death data reported by their CRVS systems. If data are not validated, a reported cause of death cannot be assumed to be correct – even if all deaths are medically certified. Doctors certifying deaths sometimes make mistakes and there may be social, legal or financial pressures that impede the correct certification of certain causes of death.

When physicians certify a cause of death they base their decision on the information available in the medical record of the deceased person. If the medical record has been poorly completed and maintained, it may not provide all the information necessary to certify the death correctly.

One simple way to validate the quality of medical certification is to carry out a medical record review and compare the derived causes of death with those reported by the CRVS systems. In principle, a deceased person's medical records should include details of the circumstances and events leading up to death, and can be used to diagnose the cause of death, and hence assess the quality of cause-of-death certification. Several such studies have now been carried out in different countries to validate the cause-of-death information reported by CRVS systems. **Boxes 14**–**17** summarize studies undertaken in China, the Islamic Republic of Iran, Sri Lanka and Thailand respectively, and illustrate the key principles for conducting such studies, and how to interpret, and act on the findings.

Validation studies can also conducted at the institutional level to help guide hospital administrators on the measures needed to improve the quality of information produced by the hospital. Hospital administrators or heads of health regions can assess the quality of death certification data by selecting a small sample of hospital death certificates and independently verifying the causes of death. If there are significant differences between the institutional data and the results obtained from assessing the original source records then there is a need for the training or re-training of doctors and for stricter hospital processes for certifying causes of death. Evaluations should always be accompanied by an analysis of the types of error arising so that follow-up training can be specifically targeted to these areas.

BOX 14. Case study – China

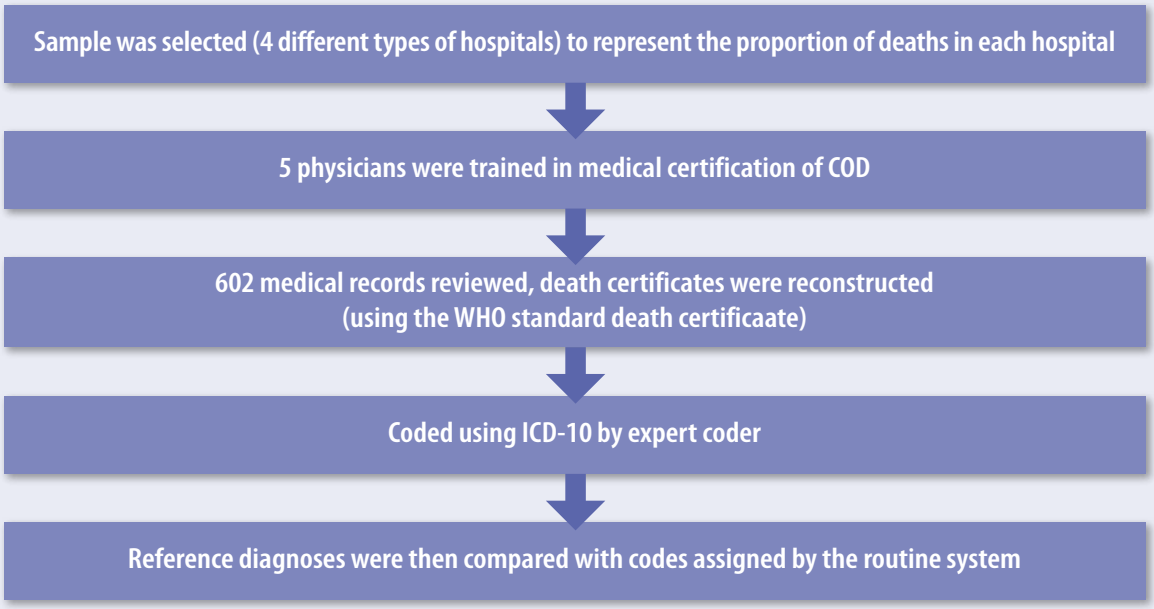
A validation study of cause-of-death statistics from hospitals in six Chinese cities was undertaken in 2007 based upon independent diagnoses obtained by a medical record review of 2917 deaths. The accuracy of hospital diagnoses was found to vary for different causes. In the case of cerebrovascular disease and several site-specific cancers (such as lung, liver, stomach, colorectal, breast and pancreatic cancers) the level of diagnostic accuracy was acceptable. However, the diagnosis of major causes of adult deaths such as ischaemic heart disease, chronic obstructive lung disease, diabetes, and liver and kidney disease was less accurate. Compensatory misclassification patterns were observed between several diseases. It was concluded that although cause-of-death patterns appeared to be compensatory at population level, caution is required in drawing conclusions about particular chronic causes of death in China (60).

BOX 15. Case study – the Islamic Republic of Iran

A medical record review of deaths resulting from ill-defined and vague causes was carried out in the Islamic Republic of Iran in 2008 to assess the extent and patterns of death misclassification in the hospital death registration system. The medical records for 1426 hospital deaths – with either ill-defined or vague causes – were classified into seven groups by the reviewing physicians, and an underlying cause of death was determined using the standard death-certification form. The results were then compared with the original causes of death assigned by the hospital certification system. It was concluded that a significant proportion of deaths in the hospital death registration system were assigned to ill-defined or vague causes of little relevance to epidemiological research or health-policy development. As a result, substantial changes to hospital procedures for diagnosing cause of death were considered to be urgently required (61).

BOX 16. Case study – Sri Lanka

In 2010, an assessment of CRVS systems in Sri Lanka recommended that an evaluation be made of the quality of cause-of-death certification (63). An independent medical record review was undertaken of 602 hospital deaths in the district of Colombo. The results provided valuable insights into medical record practices in Sri Lanka, and revealed the extent and patterns of misclassification in published cause-of-death statistics. The study methodology is shown below.



Although the health authorities in Sri Lanka were aware of problems in the quality of cause-of-death reporting from CRVS systems, they were unaware of the extent of the problem. The assessment confirmed that a high proportion of hospital deaths (30–50% depending on cause) were misclassified. This highlighted the urgent need to better understand and address the problem, for example through the provision of training to doctors in certification practices. It is clear that such studies, despite requiring only limited resources, can generate vital evidence for use by health and civil registration authorities, while also helping to identify the essential interventions needed to improve the quality of cause-of-death data (63).

BOX 17. Case study – Thailand

According to one study, about 15% of hospital deaths in 2005 were assigned to nonspecific diagnoses – despite the potential for greater accuracy using information available from medical records (62). The same study also reported the findings of a medical record review of 4644 hospital deaths. Compared to the original CRVS data, the review showed an increase in deaths due to stroke, ischaemic heart disease, transport accidents, HIV/AIDS, diabetes, liver disease and chronic pulmonary obstructive disease. It was concluded that cause-of-death reporting by the hospital death registration system would require regular validation before it could be used for research or for public health planning and policy development. The study also recommended streamlining the procedures for death certification and coding of underlying causes of death to improve the reliability of data.

Increase the proportion of medically certified deaths outside hospital

Deaths that occur outside hospitals are certified in different ways, depending on the circumstances of the death, the region or the country. In the case of patients who are dead on arrival (DOA), certification practices are usually guided by national practices and regulations. To reduce the number of DOA cases that are certified to ill-defined conditions, verbal autopsies conducted with relatives are recommended. There may also be records arising from previous hospitalizations that could be consulted to provide useful information on the medical history of the deceased.

In developing countries, a high proportion of all deaths occur at home. Such deaths are often certified by family physicians or other general practitioners, who should therefore be encouraged to provide a cause of death wherever possible. In some countries, doctors outside hospitals do certify the cause of death but use plain stationery to do so. This is not good practice and doctors should be encouraged to use a standard form to ensure standardized death-certification practices. The standard form should be issued free of charge to all family physicians, general practitioners and private hospitals. In addition, the incorporation of a cause-of-death module or related training into professional development activities can help to ensure that family physicians and general practitioners know how to correctly report causes of death.

Introduce verbal autopsy (VA) procedures when medical certification is not possible

The idea of assessing cause of death through the use of retrospective interviews originated in London in the 17th century, when "death searchers" would visit the houses of people who had died to make enquiries about the death – especially where this was thought to be due to a communicable disease. By the 19th century, modern systems of death registration had replaced this practice across Europe (73). 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 (17). The use of VA procedures is described in more detail in Module 7.

4.4 Tools and resources

This section lists a number of tools and resources that have been developed to support the implementation of strategies for improving death certification and cause-of-death data.

- **ICD-10 Volume 2** (1)

Chapter 4 of ICD-10 Volume 2 provides general guidance on ICD-compliant death certification and mortality-coding practices, and can be found at:
http://www.who.int/classifications/icd/icdonlineversions/en/index.html

- **WHO ICD online training tool** (74)

WHO has developed this interactive and self-training online tool to improve understanding and enhance the use of the ICD-10. Specific paths for different users include a fast track

for people such as managers, and an in-depth training path for coders. The tool also has a module on cause-of-death certification to promote and support the use of approved death-certification practices by doctors. The tool can be found at: **http://apps.who.int/classifications/apps/icd/icd10training/**

A useful two-page quick-reference guide on cause-of-death certification (75) is also part of the online training tool, and can be found at: **http://apps.who.int/classifications/apps/icd/icd10training/ICD-10%20Death%20Certificate/html/ICD-10_Resources/causeofdeathflyer.pdf**

Please note that the first page of the quick-reference guide is deliberately shown upside down so that the document prints correctly.

• Handbook for doctors on cause-of-death certification (76)

Developed by the University of Queensland HIS Hub, this handbook is written for doctors and medical students in developing countries. It can be read and used as provided, or it can be used as the basis for training in interactive workshops. The handbook is part of a package of resources which includes a workbook of case studies and references for self-learning, and a trainers' manual for running workshops. These resources have been specifically developed for adaptation to individual country contexts. The handbook can be found at: **http://www.uq.edu.au/hishub/docs/Handbook/HISHUB-Handbook-for-doctors.pdf**

Physicians' Handbook on Medical Certification of Death (77)

This handbook provides guidance for physicians and medical students in the United States on how to complete death certificates. Although it covers the basic knowledge required for certification, it is mainly based on the death certification system used in the United States. Although its applicability to developing countries may be limited, the examples it contains may be useful for understanding the main principles of death certification and developing confidence in its importance. The handbook can be found at: **http://www.cdc.gov/nchs/data/misc/hb_cod.pdf**

• Cause of Death Certification – Information Paper (78)

This information paper is specific to the Australian system and provides guidance to medical practitioners on completing medical certificates of causes of death. It provides the basic information and principles covering correct death certification, as well as useful examples of what to do and what not to do. It also contains information on which cases should be dealt with by coroners. The paper can be found at: **http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/FF2D66033DF42F32CA257030007790BD/$File/1205055001_2004.pdf**

• Core Curriculum – Underlying cause of death coders including Learning objectives (72)

Developed through a collaborative effort involving the WHO-FIC Network and IFHIMA, this international core curriculum describes the minimum content requirements for training courses in certifying underlying causes of death. Its purpose is to provide a basis for such training in all countries. The curriculum and further information on the WHI-FIC IFHIMA collaboration are available at: **http://www.ifhima.org/whofic.aspx**

• Checking the quality of cause of death data

The University of Queensland and WHO have jointly developed this tool for checking the quality of mortality data, including cause-of-death data (see Module 6). The tool is available at: **http://www.uq.edu.au/hishub/wp13**

• Maternal Mortality Measurement – resource site

The web-based collection of methods, techniques and applications for measuring maternal mortality is aimed at both experienced and new personnel working in the field of maternal mortality measurement. For more information please see: **http://www.maternal-mortality-measurement.org.uk/**

• Beyond the Numbers: Reviewing maternal deaths and complications to make pregnancy safer (23)

This WHO document provides information on why maternal deaths occur and provides guidance on how they can be averted. The document is directed at health professionals, health-care planners and managers working in the area of maternal and newborn health, and who are striving to improve the quality of care provided. The document is available at: **http://www.who.int/making_pregnancy_safer/documents/9241591838/en/index.html**

4.5 Summary

Disease prevention and control efforts are targeted towards specific causes of death. Reliable information on leading cause-of-death patterns in populations – and how these are changing – is therefore a critically important aspect of rational health policy development and planning. However, many countries are unable to produce cause-of-death data of an acceptable quality and completeness. To improve this situation, it is vital that cause of death be certified only by a doctor or other medically trained person. **Box 18** summarizes the key actions for improving cause-of-death certification. Based on a comprehensive assessment of their CRVS systems (see Module 1), countries will be aware of which of these strategies are the most relevant and necessary for making improvements.

BOX 18. Key actions for improving cause-of-death data

1. Increase awareness among physicians of death-certification practices and improve their skills.
2. Introduce the International Form of Medical Certificate of Cause of Death.
3. Conduct regular validation of cause-of-death certification in hospitals.
4. Increase the proportion of medically certified deaths outside hospitals.
5. Introduce verbal autopsy procedures when medical certification is not possible.

Box 19 outlines a basic roadmap showing the main steps to be followed in developing a strategy for improving the quality of cause-of-death-certification. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

BOX 19. Basic roadmap for developing a strategy for improving cause-of-death certification

Step 1: Form an ad hoc committee with senior representation from physicians, medical educators and trainers, public health practitioners, health statisticians, legal and ethical experts and civil-society representatives. The function of the committee is to:

- gather information on the current status of cause-of-death certification
- identify priority actions needed, and prepare a workplan and schedule of activities
- identify resources needed and sources of technical and financial support
- report regularly on progress to relevant agencies and institutions.

Step 2: Review existing death certificates and related forms and modify as required to ensure alignment with international standards. Review available guidance materials and manuals and revise and/or improve as necessary – ensuring that these address not only the technical aspects of cause-of-death certification but also its legal and ethical aspects. Ensure that the updated guidance materials are widely distributed and disseminated to all medical professionals.

Step 3: Through discussions with hospital administrators and physicians, draw up an action plan – with timelines – for the ongoing training of physicians in medical certification.

Step 4: Through discussions with universities and medical training establishments, draw up a plan for incorporating information on the purposes and content of the ICD in medical curricula.

Step 5: Discuss with public health researchers and the medical establishment the possibility of introducing verbal autopsies for deaths occurring outside health facilities.

MODULE 5:
Coding mortality data

5.1 Introduction

Module 4 discussed issues related to the medical certification of cause of death, and the importance of diagnosing death correctly for producing reliable mortality statistics to guide planning and policy. However, it is also essential that the coding of cause-of-death data is performed correct and is compliant with ICD standards. Certification and coding are two distinct and sequential processes in which the latter is highly dependent upon the former. If certification is poorly done, and the death certificate is incomplete or incorrect, then coding cannot be done correctly.

The international standards for coding provide rules for selecting the cause of death most important or relevant to public health – that is, the underlying cause that gave rise to the chain of other conditions associated with the death. Coding translates diseases, health problems and procedures from text to alphabetic or numeric codes for the purposes of storage, retrieval and analysis. Thus, certification and coding are distinct but closely related elements that are both essential for the production of reliable and useful data on causes of death within populations. High-quality coding requires coder training and skills development. Where the importance of correctly coding mortality data is not understood, crucial information needed for the development of health policies will be lost.

The purpose of this module is to support efforts to improve ICD-based mortality-coding practices in countries. Some of the common problems with mortality coding experienced by countries are discussed, and key actions proposed in the following areas:

- mortality coding practices
- mortality coder qualifications and training
- quality of mortality coding.

A number of key tools and resources for facilitating good coding practices are then outlined.

5.2 Background

Once a death has been correctly certified by a medically trained person, the cause of death has to be coded correctly according to international rules and standards. The ICD-10 (1) managed by WHO provides a universal approach for coding that is used by more than 100 countries. The ICD is a statistical classification that groups similar diseases into mutually exclusive categories using an alphanumeric code. Coding involves assessing records to select and extract data, and then applying ICD-coding rules to a given medical diagnosis. The correct and consistent application of ICD standards and rules ensures that cause-of-death patterns can be compared for different populations or over time in the same population.

Mortality coding involves two components – the correct assignment of ICD codes to the conditions reported on death certificates, and the correct application of mortality-coding rules when selecting the cause of death. The ICD provides rules for selecting the cause of death that is most relevant from a public health perspective. This is the disease or injury that initiated the sequence of events that led directly to death. In ICD terminology, this is the "underlying" cause of death. Although the immediate cause of death or mode of dying will have been of interest to a clinician trying to avert the death, this does not generate the information needed for public health decision-making because it says nothing about what led to the death – even though this may be amenable to public health action. Moreover, as many deaths are associated with multiple medical conditions – all of which may have contributed to the death – it is essential to identify, among these, the underlying cause in the sequence leading to death; with other causes listed as being contributory rather than causative.

The ICD is currently in its 10th revision (2nd edition), and this is the version currently recommended for use by countries. Updates to the ICD involve corrections and quick fixes to identified problems, the insertion of further details, the adding of new terms and the harmonization of content. Cumulative updates then lead to the issuing of a new edition. In contrast, revision of the ICD is a major process that involves structural changes and the introduction of new changes – for example, during the planned revision of ICD-10 to ICD-11 in 2015. As not all countries have yet introduced the latest version of the ICD, "bridge coding" between the different revisions has to be used when making international comparisons. Some countries now use national-language versions of ICD-10, which enhances understanding and application of ICD rules by coders who are able to work in their own national language.

A thorough knowledge and clear understanding of the purpose and structure of the ICD is vital for the correct coding and interpretation of cause-of-death information by coders and statisticians. Applying ICD principles and correctly following ICD selection and modification rules are vitally important in accurately identifying the main causes of death in populations. Without the coding of death records and subsequent compiling of statistics, countries would lack reliable data on their particular cause-of-death patterns and would have little evidence on which to base public health planning and programmes.

Common problems encountered

Accurate coding and correct selection of the underlying cause of death according to ICD rules and procedures is a specialized task that requires training and skills development. Commonly encountered problems in mortality coding are mainly related to coding practices, coder qualifications and training, and the quality of mortality coding.

Mortality coding practices

A common problem in many countries is that the death certificate does not provide enough information for the coder to select a valid underlying cause of death, as only the immediate cause of death is reported. Some death certificates show only a single cause of death documented on line 1a. From the perspective of the coder, these certificates can easily be dealt with as all that is required is to code the single cause. In practice, however, most deaths result from a sequence of conditions, all of which should be noted on the

death certificate and all of which should be taken into account when selecting and coding the underlying cause of death. The problem of insufficiently detailed death certificates can only be resolved by querying doctors for further information. However, few countries have a query system in place, and deaths are therefore often coded either incorrectly or to an ill-defined category for convenience. Coding the immediate cause of death as if it were the underlying cause will mean that the results of the aggregation stage will be misleading and distort the true cause-of-death distributions.

Where multiple causes are reported on the death certificate, the recommended practice is to identify the condition or event that started the fatal sequence of events – this is the underlying cause of death without which the patient would not have died. From a public health perspective, this is the most important cause of death because it can be averted or managed through public health interventions. This is fundamentally different from the clinical perspective as clinical therapeutic interventions to prevent death can be taken at any point along the sequence of events. To verify and select the correct underlying cause of death, coders should have access to all the information on the original death certificate, and not simply be provided with the cause of death reported by the certifier. In many countries, even where multiple causes of death are reported on the death certificate, cause-of-death lists are tabulated using only the underlying cause of death. This means that important information on the other causes recorded on the death certificate is lost and cannot be analysed. Where resources are available, it is preferable to tabulate and retain all causes reported as this will provide a much richer dataset on mortality patterns.

Mortality coder qualification and training

Mortality coding is a highly specialized task that requires thorough understanding of the rules for determining the underlying cause of death and for assigning codes. The level of knowledge and understanding of the coder is a key determinant of the accuracy of the resulting data. In many settings, however, coders receive only elementary on-the-job training, which is insufficient for quickly and efficiently developing the coding skills required. Although on-the-job training is important, formal training courses on how to correctly code death certificates based on standardized curricula are thus essential for ensuring the consistency of training and hence the consistency of coding.

In some countries, physicians who certify the cause of death also code the data. However, this is not a good use of their time and skills. More commonly, coding is carried out by specially trained administrative clerks and statisticians. This approach is preferable as it leads to the development of a specialized group of coders with in-depth knowledge of ICD rules and procedures. However, in many countries clinical coding is not a recognized profession, and poor recognition of the skills required and lack of career-development paths have resulted in high levels of coder turnover, negatively impacting upon the quality of coding. The establishment of career paths, and the improved recognition and formal qualification of coders are thus important elements in maintaining coding standards.

Quality of mortality coding

Mortality statistics are increasingly being used for epidemiological surveillance, health-services planning and policy development, and programme monitoring. This has placed a renewed emphasis on the quality of coding. Coders are often wrongly blamed for the poor quality of some cause-of-death data. In fact, the problem is more often related to poor death

certification rather than poor coding. The accuracy of coding is closely linked to the quality of certification. Mortality coding can also be complex and demands a certain amount of subjective judgement – for example when there is no direct match between what is written on the death certificate and the ICD coding list. This results in coders having to use their own judgment about the code to use for a particular diagnosis. Slight differences in wording or in cause-of-death semantics may also lead to the assigning of incorrect codes, particularly if the coder is inexperienced and/or poorly trained.

Having access to the right tools is vital for good coding. Coders should work from a copy of the three ICD volumes – Tabular list; Instruction manual; and Alphabetic index – to ensure the proper assigning of codes. Many countries now use computer programmes such as the Automated Classification of Medical Entities (ACME) decision tables to help coders select the correct underlying cause of death (see section 5.4 for details of this and other tools). The use of automated coding systems minimizes the number of subjective decisions that a coder has to make, and helps improve the quality of mortality coding by ensuring that all coders consistently assign the same code to the terms used on death certificates. However, even though computerization can help to overcome numerous problems and speed up the coding process, a computer programme cannot be a substitute for an experienced ICD coder. Complex cases will still have to be coded manually irrespective of which automated coding tool is used.

5.3 Key actions

The key actions needed to address some of the common problems encountered with mortality coding are:

- increase training opportunities for coders
- standardize training programmes and certify trainers and coders
- introduce mortality-coding tools
- conduct regular coding-quality assessments
- centralize mortality-coding.

Increase training opportunities for coders

In countries with good-quality coding, mortality coders are generally highly qualified professionals who work in a statistical office or the ministry of health. These coders usually have university or community college qualifications and are employed specifically to code. They know how to extract the relevant data, use the coding rules and guidelines to determine an underlying cause of death, and assign an accurate ICD code. Coders must understand medical terminology and medical science to ensure that the underlying cause of death selected for coding aligns with the requirements of Volume 2 of the ICD-10.

In contrast, in many developing countries, coders may not have any coding education at all and may be expected to learn on the job (79). A number of WHO-FIC Collaborating Centres regularly offer training courses in ICD coding. These training courses can be particularly valuable for trainers who provide national ICD training or when new versions of the ICD are being applied. Upon completion of national training programmes, coders should receive certificates in recognition of their skills and have access to structured career paths in medical

coding to help avoid a high turnover of coders and subsequent loss of valuable coding experience in a profession where consistency and expertise matter.

In addition to WHO-FIC Collaborating Centre training courses, WHO has also developed an electronic training tool for ICD-10. The tool is designed for self-learning, but can also be used in classrooms. The modular structure of the tool allows users to select specific subject areas for study and training. The United States National Centre for Health Statistics (NCHS) training portal also provides web-based training on determining causes of death. Details of these and other training tools and resources can be found in section 5.4 below.

Standardize training programmes and certify trainers and coders

To ensure consistency in the level of skills, training curricula and courses should be standardized both nationally and internationally. Institutions that provide training on mortality and morbidity coding can also apply to have their curriculum assessed by the WHO-FIC Network. Approval will give coders confidence that their education and training programme meets international standards for high-quality teaching and learning.

At present, both training opportunities and training curricula are often inadequate in developing countries. As part of efforts to address this, an international core curriculum for certifiers of underlying cause of death has been developed through a collaborative effort involving the WHO-FIC Network and IFHIMA (see also Module 4). This core curriculum offers a standard basis for education across the world in the form of a nine-module training course covering the objectives shown in **Table 3**. Since the core curriculum is currently only available in English, countries will need to make their own national language versions of the course.

Another useful approach for countries may be to compare their national coder training with the proposed international core curriculum. Following evaluation by the WHO-FIC Education and Implementation Committee, the mortality coder training material used by the National Institute of Health Sciences (NIHS) in Sri Lanka for its ICD-10 training course was found to be compliant with the international core curriculum (80). Instructors from the NIHS now conduct ICD training for several countries in the region.

Details of where to access these and other resources and tools are provided in section 5.4 below, and a list of ICD-10 training materials approved by the WHO-FIC Network is provided in Annex B.

Table 3: WHO-FIC Network core curriculum for training mortality coders

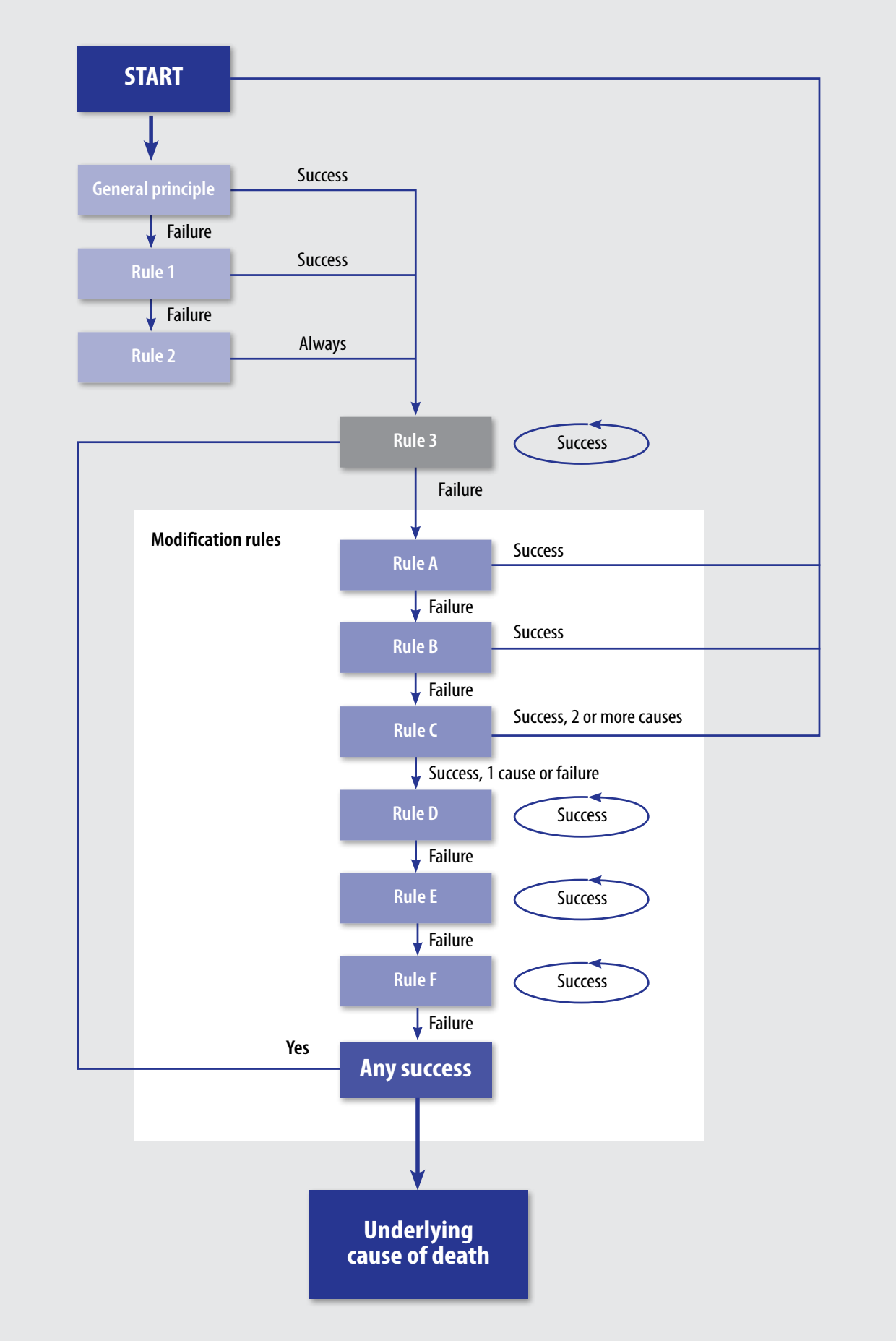
Module	Objective
1. Knowledge of basic medical science	To develop an understanding of the medical terminology used in cause-of-death statements, having an understanding of the structure and function of the human body, and an understanding of the nature of disease.
2. Legal and ethical issues relevant to the country in which coding is being conducted	To introduce the legal and ethical issues applicable to health information, its collection and release.
3. General use of underlying cause-of-death data	To explain the purpose of collecting and using cause-of-death data.
4. Specific use of underlying cause-of-death data	To introduce the specific use of coded mortality data.
5. Users of mortality data	To explain the different groups and stakeholders who use mortality data.
6. Sources of mortality data	To explain the roles of those responsible for reporting data on the deceased, and the sources of that data.
7. The ICD	To develop an understanding of the ICD and to develop the knowledge and skills necessary to assign valid codes for cause of death.
8. How to code	To provide detailed instructions on how to apply the coding rules and assign codes.
9. Quality assurance	To raise awareness of the various factors that influence the quality of coded data, and to describe techniques for ensuring the highest-possible data quality.

Introduce mortality-coding tools

Mortality coding is a complex process. Coders are expected to apply and re-apply mortality coding rules until the final underlying cause of death can be selected. To correctly select the underlying cause of death, coders need to understand the causal relationships among the conditions reported on death certificates. For each case, the ICD selection and modification rules have to be applied in a logical sequence, beginning with the "general principle" and re-applying the rules until a final underlying cause of death is determined (**Figure 9**). Using computerized or paper-based mortality-coding tools enables coders to better determine causal relationships, and ensures the consistent application of ICD selection and modification rules resulting in comparable cause-of-death data. These tools also minimize the number of subjective decisions made by coders when selecting the underlying cause of death.

The most commonly used tool for assisting coders in manually interpreting causal relationships is the ACME decision tables contained within the NCHS Mortality Medical Data System (MMDS) of the United States Centers for Disease Control and Prevention (CDC). Although these tables do not constitute an international standard, they are used by many countries. The MMDS was developed in the United States to suit national needs and can automatically code the majority of death certificates used in the country. For use in other countries – including English-speaking ones – it requires substantial adaptation, thus preventing its easy transfer to other environments, and limiting its use.

Figure 9: Algorithm for application of cause-of-death rules (84), (85)

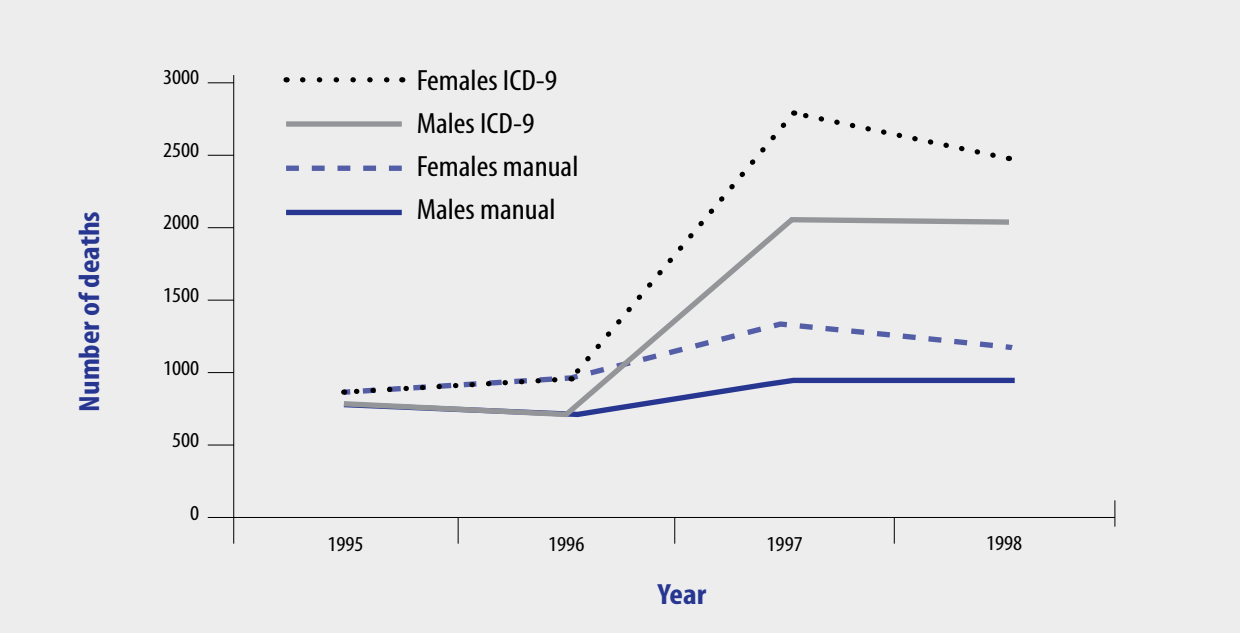


A simpler computer-based system for coding causes of death and for selecting the underlying cause of death is IRIS. The data dictionary required for IRIS is now available in English, French, German and Swedish. Further information on these and similar approaches can be found in section 5.4 below.

Switching from manual to automated coding can often result in significant differences being observed in cause-specific mortality rates. These differences arise specifically from differences in the application of mortality coding rules (81). In one assessment of the impact of changing from manual to automated coding on mortality statistics in Australia (82), it was shown how the recorded mortality rates for pneumonia would have differed in 1997–98 if automated coding systems had not been introduced in 1996 (**Figure 10**). The large data discrepancies observed were partly attributed to the interpretation of mortality coding Rule 3 in automated coding compared to manual coding. Similar increases in deaths coded to pneumonia have been reported in Sweden (83).

These studies indicate that dramatic changes can be seen in recorded mortality trends for some diseases following the introduction of automated coding software. It is important that mortality coders and researchers understand the impact of these changes on mortality data when seeking to account for variations in mortality trends over time.

Figure 10: Effect of the 1996 introduction of automated coding using ICD-9 on recorded pneumonia mortality rates in Australia (82)



Conduct regular coding-quality assessments

Poor coding practices detract from the usability of cause-of-death data and are a waste of resources. To ensure good-quality coding, the work of coders should be systematically evaluated on a regular basis to identify and correct any errors or misunderstandings. This process need not be onerous – for example, a sample of coded certificates could simply be re-coded by different coders and the degree of agreement assessed. If the evaluation revealed a specific problem then an expert coder could deliver targeted training based on the type of errors detected.

In the Netherlands, a "double-coding" study of the reliability of underlying cause of death coding was conducted using death certificates from May 2005 (86). These were then re-coded manually in 2007 by four coders. Reliability was measured by calculating the degree of agreement between coders (inter-coder agreement) and the consistency of each individual coder over time (intra-coder agreement). Evaluation of 10 833 death certificates showed that inter-coder agreement on the underlying cause of death was 78%. The mean intra-coder agreement for all four coders was 89%. The degree of agreement was found to be associated with the specificity of the ICD-10 code (whether at chapter, three-digit or four-digit level); age of the deceased; number of coders; and the number of diseases reported on the death certificate. The study also found that the reliability of cause-of-death statistics was high (>90%) for major causes of deaths – mainly cancers and acute myocardial infarction – but low for chronic diseases such as diabetes and renal insufficiency (70%). It was concluded that statistical offices should provide coders with additional rules for coding causes of death associated with a low level of reliability.

In Taiwan, China, a systematic sample of 5621 death certificates (5% of all the death certificates issued in 1994) was reviewed to assess quality of coding according to ICD-9 (87). The underlying cause of death selected by the reviewer for each death certificate was compared with that selected by the original coder. In both cases, the underlying cause of death was selected according to ACME decision tables. Overall agreement rates between the reviewers and the coders were 80.9% for three-digit ICD categories and 83.9% for two-digit ICD categories. Good agreement was found in cases of malignant neoplasms (kappa = 0.94); and for injuries, and poisoning (kappa = 0.97), but agreement was poorer for nephrotic diseases (kappa = 0.74); hypertension-related diseases (kappa = 0.74); and cerebral infarction (kappa = 0.77). It was concluded that the national administration should undertake routine internal reviews to check on the quality of underlying cause-of-death coding practices.

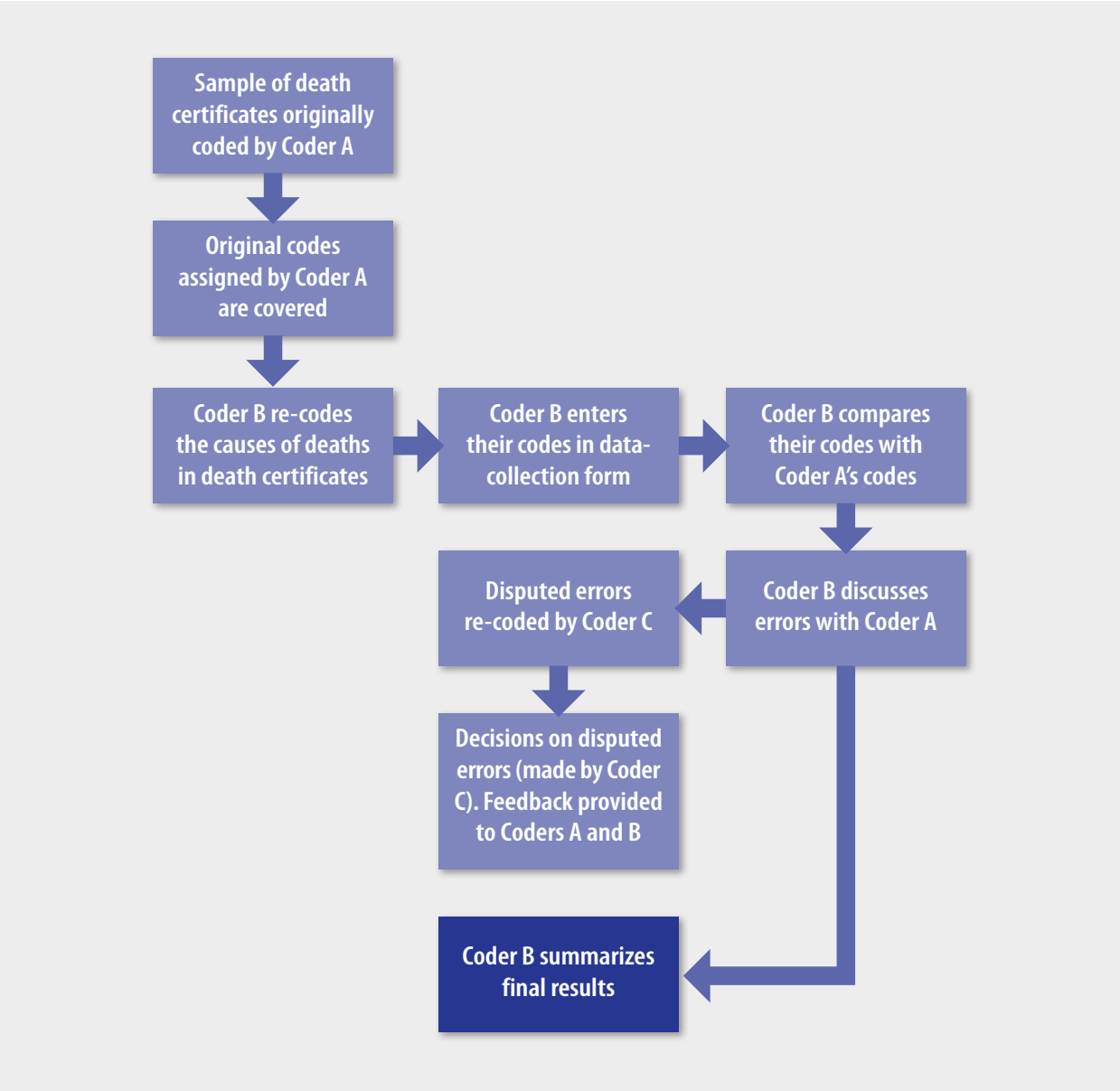
In 2002, 1067 medical records from hospitals in the Colombo district of Sri Lanka were assessed for coding quality using the Australian Coding Benchmark Audit (ACBA). The original records were re-coded, and overall agreement was found to be only 57.6% (88). **Figure 11** shows the auditing procedure used in ACBA. Even though the 2002 study was conducted using morbidity data, the same principles apply to mortality data. ACBA was developed by the National Centre for Classification in Health in Australia in 1998 (89), and recommends the use of a minimum of 40 records or 5% of the total number of records when assessing coding quality. Although ACBA software is no longer available for purchase, the philosophy behind it could usefully be adopted when assessing the quality of mortality coding.

Centralize mortality coding

In some countries, mortality coding is carried out centrally in one place, often in the ministry of health or national statistics office. In other countries, coding is undertaken in the hospital where the death occurred. The centralized coding of cause of death facilitates the consistent application of common standards and procedures. It also makes it easier to carry out quality assessment and to maintain workforce training standards. In addition, few hospitals have enough deaths to justify a specialized mortality coder, and coding is usually undertaken by morbidity coders who are not necessarily familiar with all the

special coding rules for mortality. However, hospital coding makes it easier to access original patient medical records where there is any doubt about the certification. Within hospitals, coders may also have access to the certifier for further clarification, allowing for an informed opinion to be obtained from the certifier rather than relying upon mortality-coding rules, which are more arbitrary (1).

Figure 11: Auditing procedure used by ACBA



5.4 Tools and resources

This section describes tools and resources that can help in the implementation of strategies for improving ICD-based mortality-coding practices.

• International Statistical Classification of Diseases and Related Health Problems (ICD) (1)

The ICD – developed and maintained by WHO – is revised every 10 years with the 10th revision (ICD-10) currently in use. The purpose of the ICD is to allow the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries at different times. The ICD is used to translate written diagnoses of diseases and other health problems into alphanumeric codes in a process known as clinical coding. Once coded, causes of death can be compiled and statistics produced for storage, retrieval and analysis.

The ICD can be used to classify the diseases and other health problems recorded on many types of health and vital-event records. Originally used only for classifying causes of death, the scope of the ICD was extended to include morbidity with the issuing of the 6th revision in 1946. The ICD-10 consists of three volumes:

- **Volume 1** – Tabular list
- **Volume 2** – Instructions and guidelines manual
- **Volume 3** – Alphabetical index.

Volume 1 – Tabular list

Volume 1 of the ICD-10 has 22 chapters, most of which cover particular body systems, special diseases or external factors. There are, however, two exceptions: Chapter XVIII: *Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified* and Chapter XXII: *Codes for special purposes*. The broad chapter titles indicate the wide range of conditions included, with a large number of codes required to cover them all. Each chapter is divided into blocks of related conditions which are then subdivided into three-character categories and four-character (and subsequent) subcategories (**Figure 12**). The use of an alphabetical character at the beginning of each of the three-character codes results n more than 2600 such codes being available – each of which can have up to 10 four-character subcategories.

Volume 2 – Instructions and guidelines manual

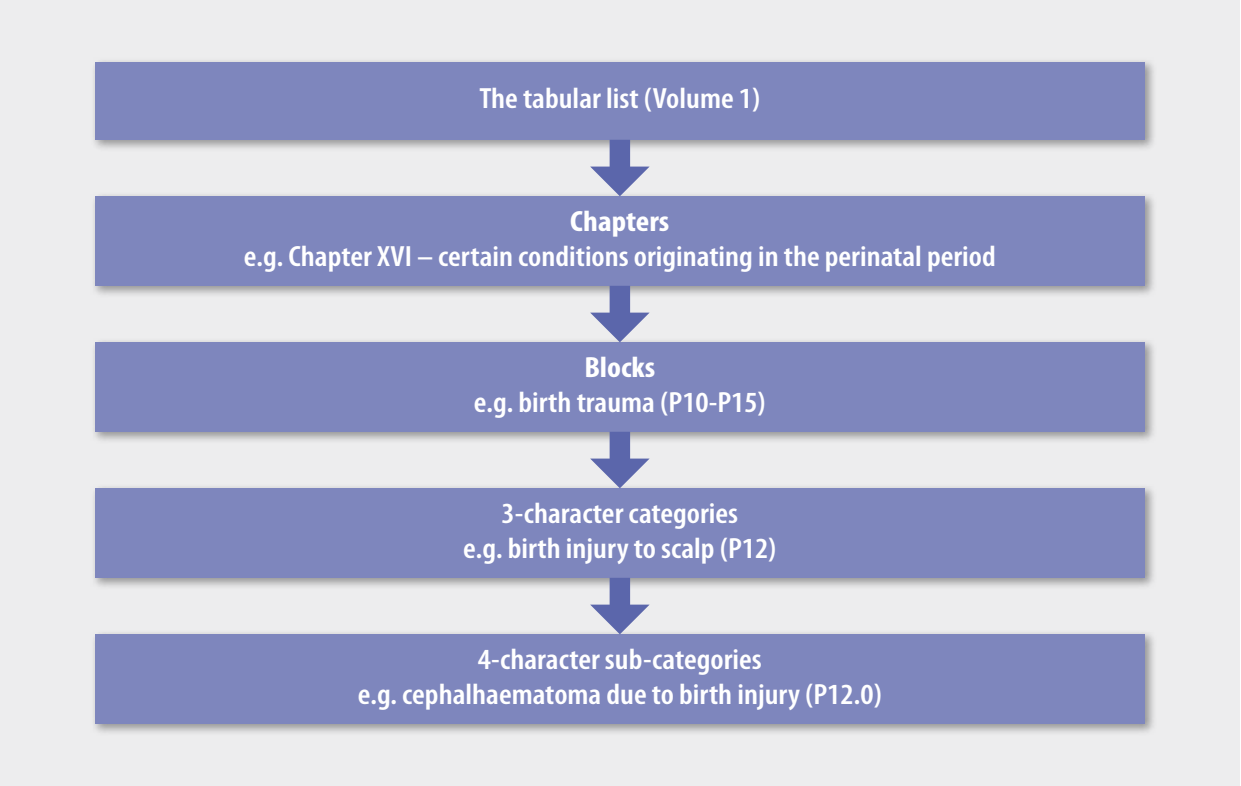
Volume 2 of the ICD-10 is the key to understanding the rules and regulations that govern the classification of conditions. It provides guidance on the use of Volumes 1 and 3, and on the rules of mortality and morbidity coding, and information on the historical development of the ICD. Volume 2 also contains four special "tabulation lists" (**Box 20**) designed for use in settings where the complete three-character ICD list is too detailed. These special lists are primarily intended for the tabulating of data into useful categories which can be compared across populations and geographical areas. Medical doctors should never use the short tabulation lists as a guide to certification and never diagnose cause of death according to categories shown on the lists. When using the special tabulation lists, it is important that the medical certificate be completed in the same way as if coding were done to three or four ICD digits.

Volume 3 – Alphabetical index

Volume 3 of the ICD is a comprehensive alphabetical index of all the diseases and conditions found in the full tabular list of Volume 1. It thus contains far more diagnostic terms than the special tabular lists, reflecting the wide variety of ways in which doctors and other clinical staff describe diseases. Volume 3 consists of:

- Introduction – explaining the purpose of the index, its general arrangement and the conventions used;
- Section I – an alphabetical listing of terms relating to diseases, nature of injury, reasons for contact with health services and to the factors influencing a person's health;
- Section II – an alphabetical listing of external causes of injury, morbidity and mortality;
- Section III – an alphabetically arranged table of drugs and chemicals.

Figure 12: Organization of Volume 1 of the ICD-10



BOX 20. ICD special tabulation lists on mortality

- **List 1**: General mortality – condensed list (103 causes)
- **List 2**: General mortality – selected list (80 causes)
- **List 3**: Infant and child mortality – condensed list (67 causes)
- **List 4**: Infant and child mortality – selected list (51 causes).

It is imperative that Volumes 1 and 3 are used together to accurately assign codes for each clinical case. Volume 1 lists all the diseases or conditions included (or excluded) in many disease categories. Coders should never code straight from Volume 3 (Alphabetical index) or browse the tabular list in Volume 1 looking for a code that seems suitable for the clinical case being coded. Coders need to study the coding conventions, rules, instructions and guidelines described in Volume 2 (Instruction manual) of ICD-10 before starting to code.

Updating the ICD-10

Since the ICD-10 was published, WHO has decided to use a process of continual updating of the classification to keep it as current as possible between major revisions. The aim is to ensure that ICD-10 continues to meet the needs of the international health community for clinically credible up-to-date classifications. It is therefore important that the users update their books and files in line with any changes introduced by the WHO-FIC Updates and Revision Committee. Updates to ICD-10 are effective from 1 January of the year of implementation. Countries should delay updating in a particular year until all coding for the previous year is completed – i.e. all deaths occurring in the same calendar year should be classified using the same version. The ICD-10 can be found at:
http://www.who.int/classifications/icd/en/ with cumulative updates available at:
http://www.who.int/classifications/icd/icd10updates/en/index.html

Training resources and tools

• WHO online ICD-10 training tool (74)

Interactive face-to-face training from a specialist in coding training is considered to be the best approach. However, because not all coders will have the opportunity to undergo such training, a WHO online ICD-10 training tool (74) has been developed as an alternative way of preventing major errors when using the classification. The tool is designed for self learning and classroom use, and is recommended for coders, clinicians and managers. The course materials:

- provide an overview of coding
- focus on the different chapters of ICD-10
- give a the minimum amount of required medical background
- provide short summaries.

The tool allows users to select the desired areas and pace of study. For example, a physician will skip the sections related to medical knowledge, while those at managerial level may choose to gather an overview of ICD-10 by taking a "short-track" route through the training materials. Each chapter has a medical science section covering the relevant anatomy, physiology and diseases of the body. This ensures users who are unfamiliar with the basic medical sciences gain the background knowledge required for studying ICD coding. The tool consists of a user guide and 22 training modules. Special topics such as ethics, confidentiality, statistical presentation, death certification, and rules and guidelines for morbidity and mortality coding are also addressed. For training purposes, the three volumes of the ICD-10 are included. It is possible to translate the materials into other languages and the required permissions and translation guide are available on request.

The tool is available as a download at:
http://apps.who.int/classifications/apps/icd/icd10training or as a CD-ROM on request. The site also includes information on the ICD-10 training tool support group, where those conducting the training can contact expert coders to ask questions. The support group welcomes any question and users are encouraged to forward suggestions for making the training tool more effective.

• WHO-FIC Collaborating Centre training courses in ICD coding

A number of WHO-FIC Collaborating Centres regularly offer coding training courses. These can be particularly valuable for trainers who provide national ICD training or when a new version of the ICD is being applied. Contact information for the Collaborating Centres can be found at: **http://www.who.int/classifications/network/collaborating/en/**

• Core Curriculum – Underlying cause of death coders including Learning objectives (72)

Developed through a collaborative effort involving the WHO-FIC Network and IFHIMA, this international core curriculum describes the minimum content requirements for training courses in certifying underlying causes of death. Its purpose is to provide a basis for such training in all countries. The curriculum and further information on the WHI-FIC IFHIMA Collaboration are available at: **http://www.ifhima.org/whofic.aspx**

Mortality coding tools

• Mortality Medical Data System (MMDS) decision tables

The MMDS decision tables were originally developed by the CDC NCHS in 1967 to automate the entry, classification and retrieval of cause-of-death information reported on death certificates in the United States. They are used to help determine the correct underlying cause of death, and to assign valid multiple cause-of-death codes. The decision tables are a collection of lists that provide guidance and direction in applying the selection and modification rules published in Volume 2 of the ICD-10. Although originally designed for use with automated coding software available from the NCHS, printed copies of the tables are more often used in countries because of their usefulness in helping coders to understand causal disease relationships and to make decisions on acceptable and non-acceptable sequences. Using MMDS decision tables allows people without medical training to determine genuine causal relationships, and ensures the consistent application of selection and modification rules across jurisdictions, thus generating comparable data. MMDS software is free and can be downloaded at:
http://www.cdc.gov/nchs/nvss/mmds.htm – it does however need to be extensively adapted to local language and conditions to be useful.

The automated MMDS consists of the following basic programmes:[4]

- **SuperMICAR** is a text-searching application designed to automatically encode medical cause-of-death data into numerical entity reference numbers (ERNs). The software takes "cause" text and splits it into separate causes ignoring noise words such as "massive", "terminal" and "life-threatening". Where two conditions are reported in one line (for

[4] For further information, please see the Information Paper produced by the Australian Bureau of Statistics (186) upon which this section is based.

example, "myocardial infarction due to hypertension") these are separated into two distinct causes, analysed, and an ERN for each accepted cause of death assigned. SuperMICAR incorporates a thesaurus, dictionary and word list. The thesaurus contains synonyms and other words or phrases for terms which cannot be matched in the dictionary. For example, the word "narrowing" may be recorded instead of the medical term "stricture". The dictionary holds valid descriptions for each ERN. The word list contains words which are to be ignored and words which separate causes. For example, the words "left" and "right" are important for coding in some cases but not in others, while in the above example of myocardial infarction due to hypertension, the term "due to" simply separates the causes. ERNs represent a much more detailed classification than the ICD, and the design of the system enables a smoother transition between ICD versions.

- **MICAR200** performs editing and validation functions using mortality coding rules, which are held in look-up files, together with a dictionary. These rules are applied to the ERNs assigned during the SuperMICAR process to produce ICD multiple-cause codes, not just the underlying cause of death.
- **ACME/TRANSAX** applies WHO mortality coding rules to the ICD codes determined by MICAR200. ACME uses a number of look-up tables to allocate underlying cause codes appropriately. ACME makes implicit linkages (relationships) between multiple causes in assigning ICD codes for underlying cause. TRANSAX identifies the relationship between conditions mentioned on the death certificate, and then assigns an ICD code for any significant combinations.

The MICAR system assigns ICD codes to the medical condition reported by physicians. This process, however, is highly language dependant. Even if MICAR performs perfectly in English, numerous problems arise when it is applied to other languages. However, the use of MICAR in conjunction with ACME can result in overall simplification and reduced data-entry and training costs. The system maintains the order and sequence of events reported by the certifier. ACME then applies the WHO rules to the ICD codes and selects an underlying cause of death. Since ACME requires the input of cause-of-death data in the form of ICD codes, the function is independent of language and is the only MMDS component that can be used in non-English speaking countries (90).

• IRIS – Automated coding system for causes of death

IRIS is an interactive computer-based system for coding multiple causes of death, and for selecting the underlying cause of death based on MMDS software. The system has been developed through a long-standing collaboration between several countries including France, Germany, Hungary, Italy, Spain, Sweden and the United States. IRIS is a language-independent software system based on the use of national dictionaries, and can be operated from a laptop. The main objective of IRIS is to increase the quality and comparability of mortality data at the international level (91).

IRIS can be used in two modes. In "code-entry mode" the user enters ICD-10 codes corresponding to the conditions reported on the death certificate. IRIS then selects the underlying cause. In this mode, IRIS can be used as soon as it is installed. In "text-entry mode" the user enters the causes of death in free text, as they are reported on the death certificate. To operate in this mode, a country-specific data dictionary needs to be created that assigns the corresponding ICD-10 code to the text-based cause of death. English,

French, German and Swedish versions of the dictionary have been developed and may be used freely. The latest version of IRIS (V4.0.38) was released in May 2011. This version has the capacity to process the time intervals associated with diagnoses, and contains additional features for facilitating the work of coders (92).

IRIS is available for free download at:
http://www.cepidc.vesinet.inserm.fr/inserm/html/IRIS/iris_project.htm

5.5 Summary

Good-quality mortality coding is essential for translating death certificates into statistics, and for correctly determining the cause-of-death patterns of a country, region or population. Mortality coding is a specialized task that requires thorough training and skills development. In addition, because coding is based upon the information reported on the death certificate, reliable and correct certification is a precondition for the correct identification and coding of the underlying cause of death. Certification and coding are thus distinct but closely related functions essential in the generation of reliable and useful data on causes of death.

Resources and coder training opportunities are not uniformly available. In most developing countries, only some hospitals are able to provide reliable cause-of-death information and often this is lost because it is not coded or coded so poorly that it is of no use. In contrast to the long-term difficulties experienced by developing countries in building up an adequate number of physicians, coders can be trained in a relatively short time and at low cost, thus allowing countries to benefit from the mortality data collected by the health system.

Box 21 summarizes the key actions needed to address some of the common problems encountered with mortality coding.

BOX 21. Key actions for improving mortality coding

1. Increase training opportunities for coders.
2. Standardize training programmes and certify trainers and coders.
3. Introduce mortality-coding tools.
4. Conduct regular coding-quality assessments.
5. Centralize mortality coding.

The roadmap proposed in **Box 22** outlines some of the major steps for improving coder training and mortality-coding practices. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

BOX 22. Basic roadmap for improving mortality-coding practices

Step 1: Constitute a small group of mortality-coding stakeholders such as ministry of health and other public health institute officials, national statistics office staff, hospital managers and local WHO representatives.

Step 2: Conduct an assessment of mortality-coding practices in the country by collecting information on:

- who trains coders
- the number of trained coders
- the type of training they have received
- the curricula used for training
- organizations using or handling cause-of-death statistics.

Step 3: Identify problems and set priorities. Prepare an action plan that sets out specific activities, responsibilities, resources and expected outcomes.

Step 4: If training is identified as a problem area, conduct a training needs assessment for mortality coding. If necessary, increase training opportunities, and standardize training curricula and education. Identify the components to be taught and be guided by the core curriculum recommended by the WHO-FIC and IFHIMA joint collaboration.

Step 5: If quality or a backlog of coding is identified as problem areas, investigate the feasibility of adopting automated coding or of introducing the manual use of the MMDS ACME decision tables for identifying underlying causes of death. If mortality coding is decentralized to hospitals, investigate any potential efficiency gains in having it performed centrally.

Step 6: Monitor progress by conducting regular coding-quality assessments.

MODULE 6:
Data quality checks, access and use

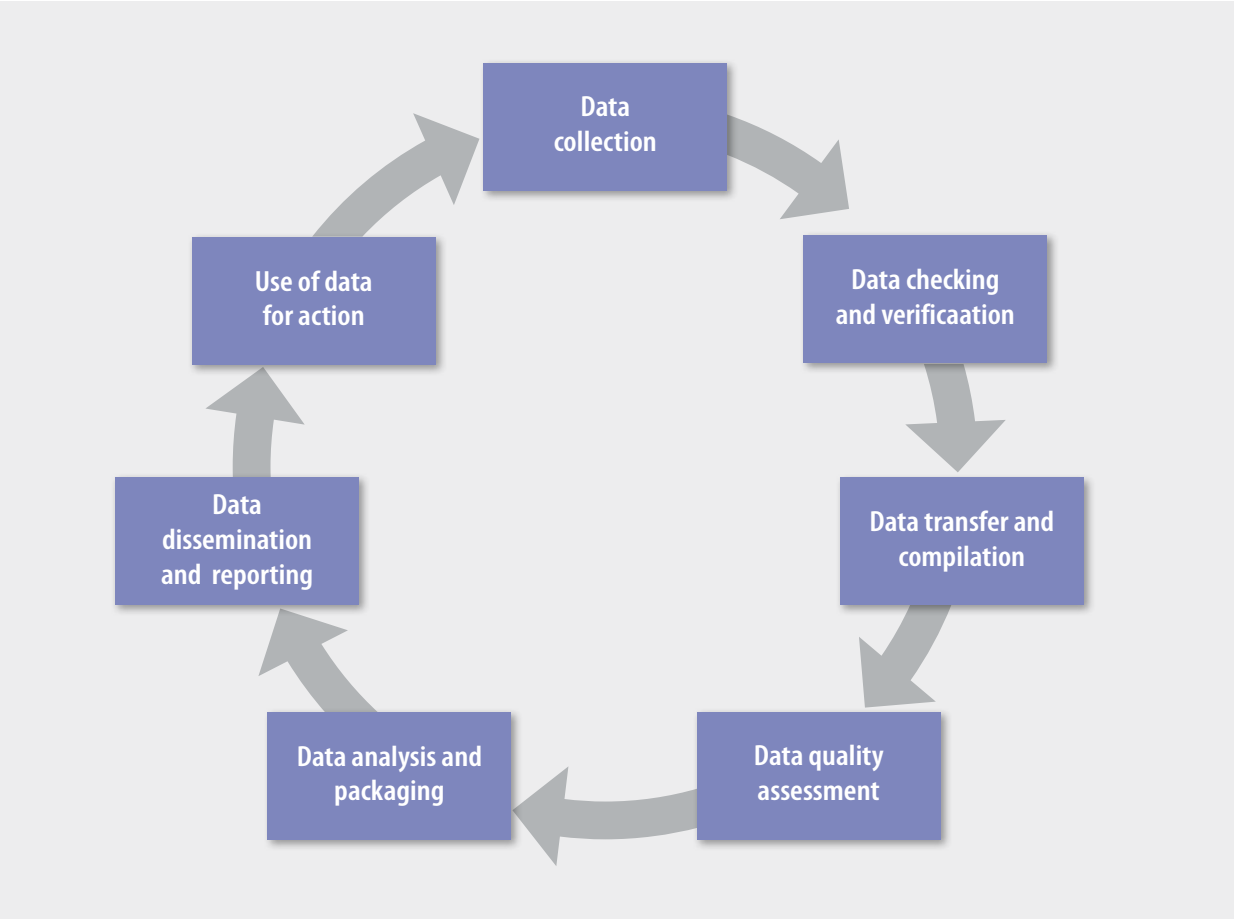
6.1 Introduction

The previous modules in this resource kit have focused on the systems and processes that need to be in place in order to collect information on births, deaths and causes of death. However, data collection is not an end in itself – the data obtained must be used to improve the health and wellbeing of people, and to support social and economic development. This module discusses a number of key actions that can be taken to check data quality and increase data accessibility and use. A number of basic checks of data quality will help to ensure accuracy and reliability – statistics will not be used if they are not trusted. Advice is also provided on how to present and share data with users. Data are of little value unless made accessible to many different users of vital statistics, including decision-makers in health and other sectors, programme managers, health professionals, researchers and the general public. Ensuring that statistics are presented in ways that are meaningful to different users is the best way to ensure that they will be used effectively to improve the health and development of society. Where data are not used, all the effort put into collecting, checking and disseminating them will have been wasted.

Information collected through the civil registration system is raw material that needs to be compiled, managed and analysed to produce information that can be shared with – and communicated to – different technical and non-technical audiences. The quality and reliability of the information gathered must be evaluated if it is to become useful and usable evidence for action. Data should be formatted for presentation, communication and sharing in formats that help users to understand the key issues. Providing summaries of the data, interpreting key findings and presenting complex information in simple charts and maps will greatly assist users. The cyclical process of transforming raw data into knowledge that can be used to support health and development decision-making is shown in **Figure 13**.

Assuring data quality is an essential first step and begins during the data-collection phase of the cycle – the phase where registration data is being collected and transferred for compilation. At this stage of the cycle, the focus is on ***microdata*** – that is, the accuracy and completeness of the information contained in each record. During the later stages of data analysis and packaging through to dissemination, reporting and use, quality-assessment processes will primarily focus instead on the accuracy, consistency and plausibility of the ***aggregated*** data – that is, the total counts of births, deaths and causes of death. This distinction is important since different data-quality assessment techniques will be applied in each case. Data that are perceived to be inaccurate and unreliable will not be trusted and will therefore not be used.

Figure 13: The cycle of data collection, management, analysis, dissemination and use



The availability of high-quality data allows for their conversion into credible and compelling evidence that can inform decision-making by end users. When producing data it is essential to know who will be the end users and what will be their purpose. This will enable data producers to supply data in the most-relevant and useful formats for different users. Data users include health service planners and managers in the public and private sector, insurance groups, government policy-makers, academics, demographers, epidemiologists and researchers, health advocates, the media and civil society organizations. Decision-makers, planners and managers working in health and other sectors often need basic information on population growth and movement, and information on levels and causes of mortality. This type of information is used for fundamental government decision-making concerning resource allocation and programme planning. Academic demographers and epidemiologists use vital statistics as essential inputs into their research. Members of the public are also potential users of vital statistics, especially at the local level. For example, there is often media interest when local area statistics on the patterns and causes of death are published.

Although the health sector generates a lot of information from health facilities, vital statistics on the entire population form the core of health information systems, because they:

- provide the basic data on population size, distribution and trends that are used for health sector planning and for calculating key health-related indicators such as fertility and mortality rates and ratios;

- aid understanding of the level and distribution of mortality due to disease and injury, highlight health inequalities and priorities, and allow for the monitoring of trends, as well as the evaluation of the impact and effectiveness of health programmes;
- provide a reliable method (when timely and complete) for measuring baseline levels and for monitoring progress towards international objectives, such as the MDGs;
- enable understanding of emerging health challenges, caused for example by increases in noncommunicable diseases or injuries;
- allow tracking of the impact of national strategies, for example on health-sector reform, poverty reduction and development;
- support planning, monitoring, and evaluation in decentralized health systems, by providing information on health conditions and status at regional and local levels;
- enable the forecasting of demographic and health trends, which are used for planning in sectors such as education, insurance and employment.

No other source of health information can generate health-outcome (fertility and mortality) data at national and local levels on a continuous basis. The above advantages also allow for the supporting of decentralized planning and monitoring of regional health.

6.2 Background

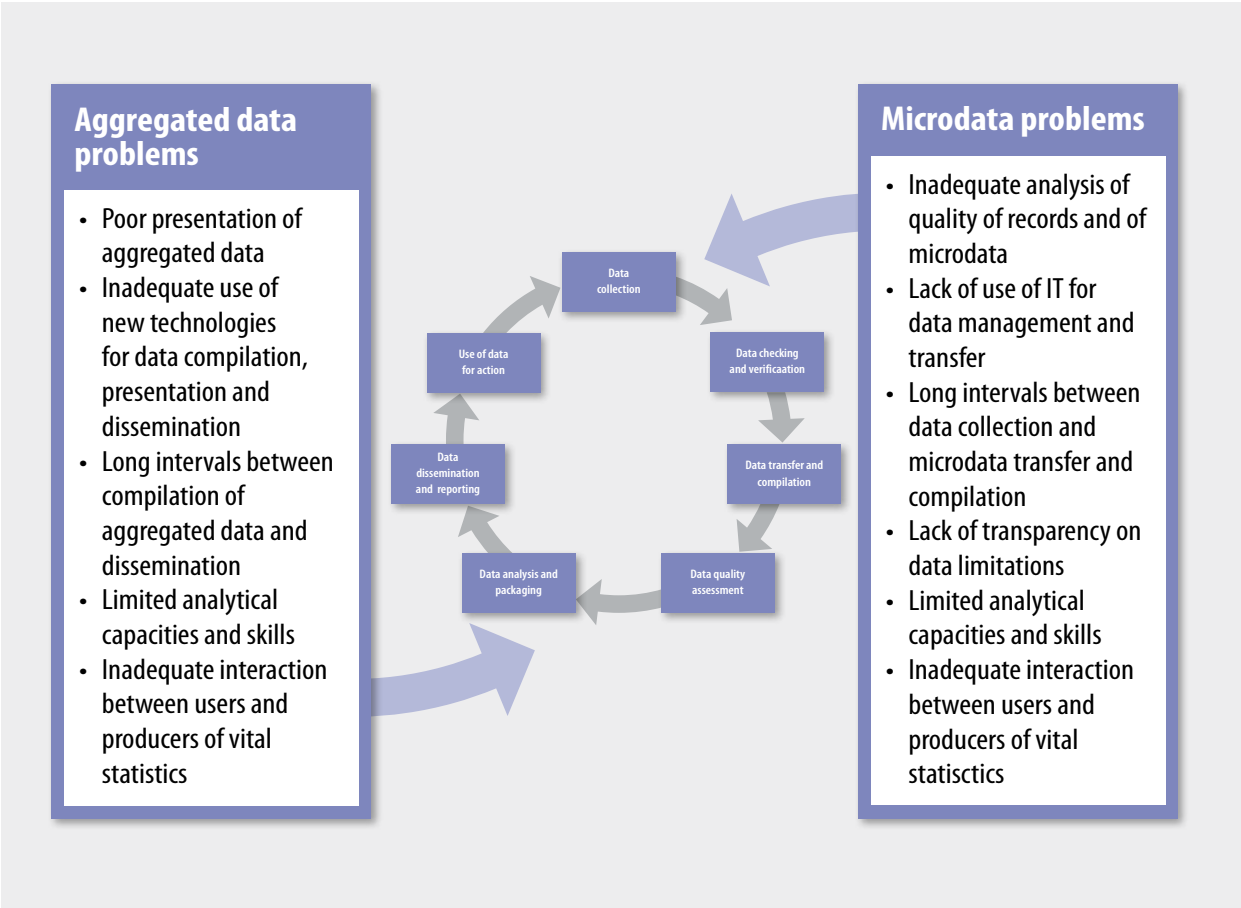
Statistics have been described as "the eyes of the policy-maker" (93). Despite this, health policy-makers are often faced with data that are contradictory, confusing and misleading. All too often, issues of data quality, access and use have been neglected even though these are clearly crucial aspects of any statistical system. The importance of these issues must be recognized – and the common problems encountered in the production and use of both microdata and aggregated data (**Figure 14**) addressed. Otherwise there remains the risk that important information on births and deaths – often collected at great expense – will not be trusted or used, and that decision-making will not be guided by sound evidence.

Inadequate systems for ensuring that microdata are accurate

Just because CRVS systems are operational does not mean that the data and statistics it produces are accurate. There are many potential sources of error in microdata, including the under-registration and misreporting of births and deaths, and incorrect certification and coding of underlying causes of death. Unfortunately, not all countries systematically review their microdata to assess potential weaknesses in quality. In practice, there are some relatively simple data quality assessment methods that can be used, and for which there is considerable guidance available.

Even when the microdata have been gathered and summarized to a high standard, further analysis is usually needed before the information can be shared with, or communicated to, non-technical audiences, or used as the basis for policy-making. Often, what is missing is solid analysis of a statistical dataset that puts information in context, provides interpretation and imparts meaning to the numbers. Such analysis is very important, for example in anticipating and dealing with diverging stakeholder needs and perceptions that could lead to different interpretations of the same dataset. For example, technical

Figure 14: Common problems encountered in microdata and aggregated data production



experts may focus on the microdata that are most complete and scientifically sound, whereas policy-makers may instead focus on the data analysis in tabular form that can bring them political benefits. To cater to both sets of needs, reports should be published with neutral text summaries or interpretations highlighting the important implications of the data.

Lack of transparency concerning data limitations

If CRVS systems are incomplete, and quality assurance is insufficient, the resulting microdata will inevitably be less than perfect. It is better to be open and transparent about their nature and limitations. Microdata limitations such as missing values and potential sources of bias should be described in statistical reporting. It is essential to analyse each vital statistics dataset for the population covered and to adhere to the best standards of data production available.

Limited data management and analytical capacities and skills

Good data management, including quality assessment of the microdata, is essential for the establishment of a useable database of vital statistics. Civil registration office staff should include personnel with the required record-management skills and ability to conduct quality assurance of civil registration records. In many settings, national statistics offices have the analytical capacities and skills needed for in-depth understanding of the quality

of the aggregated vital statistics. Such skills include effective data compilation; assessment of completeness; identification of (and correction for) missing data; understanding of the sources of error and bias; adjusting for under-reporting; and reconciling data from different sources. Given that data reconciliation allows for comparison of the completeness and correctness of microdata, it should be a standard part of all quality assessment. However, these skills are often in short supply in statistical offices because staff members have to deal with multiple demands and have little time to set aside for in-depth quality assessment.

Poor presentation of statistical data

Many vital statistics reports are hard to read, dull, and full of detailed tables and statistics that are difficult to interpret. This places the responsibility for data interpretation and analysis onto the users. As few users will have in-depth skills in data analysis and interpretation, the use of the data will be largely confined to those that do, such as academics and researchers. Decision-makers need simple summary information, such as leading causes of death in different communities and age groups, emerging mortality trends and comparisons with other countries. The mismatch between the production of data that are hardly used and the specific information needs of various audiences often leads to complaints from decision-makers that they do not have the information they need to guide policy and programming. Senior policy-makers want simple summary information that alerts them to those issues requiring policy interventions, such as emerging mortality patterns, progress towards national goals, neglected issues or population groups, and comparisons with other countries.

Inadequate use of new technologies

Information technology can be a useful tool for expanding capacities across the spectrum of activities from data compilation to dissemination. Customized tools have been developed to assist data entry and compilation, data presentation and the production of periodic reports.

Delays between data compilation and dissemination

It is frequently the case that there are long delays between the compilation of the microdata into summarized data tables and their dissemination in the form of publications, web materials and so on. As a general rule, annual dissemination of the total numbers of births and deaths should happen within 12 months of the closure of the records at the end of the calendar year in question, with dissemination of cause-of-death data occurring within 12–18 months. It may be that information on deaths due to external causes cannot be finalized within this time period due to the lengthy legal processes that may be required. In such cases, a note should be made and the data subsequently corrected once the legal outcomes have been determined. In some countries, quarterly or mid-year reports of total numbers of vital events are issued thus helping to promptly track any significant variations that might have occurred, and that may need to be investigated.

Inadequate interaction between producers and users of vital statistics

As noted above, many different stakeholders have an interest in the different aspects of CRVS systems. These can broadly be divided into two groups: those working to produce information (vital statistics) such as government departments responsible for registration, statistics, health and justice; and users of that information such as the media, donors and development agencies, academics and researchers, and funds and foundations. In many countries, consultation and coordination between these two groups is weak or non-existent. This lack of interaction contributes to misunderstandings and hinders efforts to improve data and enhance their use. In most countries, the sharing of information between the producers and users of vital statistics is rare and ways of encouraging collaboration are not functional.

6.3 Key actions

A comprehensive assessment of national CRVS systems (see Module 1) is likely to highlight issues of data quality, access and use – and may naturally lead to ideas concerning potential solutions. Experience has shown that remedial actions do not have to be complex or costly. Often, relatively minor changes in the way that data are compiled, managed and shared can result in significant improvements in both data quality and user access. Support and expertise from the academic community and research institutions may be available when implementing the actions outlined in this section and should be requested. In addition, some key tools, guidance documents and other resources are described in section 6.4.

Assess overall data quality

Undertaking data quality assessment should not be viewed as a fault-finding exercise designed to identify errors and apportion blame. Instead the purpose should be to engage with vital statistics producers and users at all levels in order to identify weaknesses in the data and correct problems. An assessment of microdata quality can start with the information recorded at health-facility level and aggregated up through the reporting chain. Although this can provide important information, it does not cover two important sources of error – unrecorded occurrences and erroneously recorded occurrences. Some of these errors can be detected by studying the data, but not all. Gaining an understanding of what is happening in the process of service delivery and registration of occurrences is an important aspect of studying data quality. To achieve this, it will be necessary to talk to those who deliver services and produce reports at health-facility level.

As ongoing efforts are needed to ensure data quality, the regular assessment of the mortality and vital statistics data quality should be an integral activity of health information and statistical systems. It is almost impossible for data to continuously meet all of the key quality criteria shown in **Box 23**. Inevitable trade-offs will have to be made, for example between timeliness, representativeness and accuracy. Investing a lot of time and effort in ensuring that data are complete and cover the whole population may delay publication. Unavoidable delays also occur where the outcome of a coronial process or inquest into final cause of death is pending. Some countries deal with such issues by releasing "interim" reports as quickly as possible and then publishing the final figures once they become available.

BOX 23. Data-quality criteria

Various frameworks and guidelines for statistical data quality have been developed, such as the Organisation for Economic Co-operation and Development (OECD) Quality Framework and Guidelines for OECD Statistical Activities (179); the International Monetary Fund (IMF) Data Quality Assessment Framework (DQAF) (122); and the World Bank General Data Dissemination System (GDDS) (120). There are also other data-quality frameworks which all use basically similar criteria for assessing data quality, including:

- **Relevance** – data meet the needs of users at different levels.
- **Accuracy** – data correctly estimate or describe the quantities or characteristics being measured; in other words that the values obtained are close to the (unknown) true values.
- **Credibility** – users have confidence in the statistics and trust the objectivity of the data, which are perceived to be professionally produced in accordance with appropriate standards and transparent policies and practices.
- **Accessibility** – data can be readily located and accessed in multiple dissemination formats that incorporate information on the types of data collected and how.
- **Interpretability** – users can readily understand, use and analyse the data, assisted by clear definitions of concepts, target populations, variables and terminology, as well as by information describing the limitations of the data.
- **Coherence** – statistical definitions and methods are consistent and any variations in methodology that might affect data values are made clear. For example, different household surveys using similar wording to generate data on the same indicators.
- **Timeliness** – delays between data collection and availability or publication are minimized, although not to the extent of compromising accuracy and reliability.
- **Periodicity** – vital statistics are shared regularly so that they serve the ongoing needs of policy-makers for up-to-date information.
- **Representativeness** – data adequately represent the whole population and relevant sub-populations.
- **Disaggregation** – data can be stratified by sex, age and major geographical or administrative region.
- **Confidentiality** – data-management practices are aligned with established confidentiality standards for data storage, backup, transfer (especially over the internet) and retrieval.

Be transparent about data limitations

It is inevitable that data will not always meet high quality standards. Data collection is never perfect and there will be missing values and misreported and incorrect information, resulting in incompleteness and inaccuracy. It is better to be open about any weaknesses in data, and to make them explicit, rather than pretend they do not exist. Government decision-makers may be reluctant to acknowledge data limitations as these reflect poorly on the system. However, the existence of such limitations can be used to lobby for additional resources to improve the situation matters.

Describing data limitations should thus be part of any statistical reporting, and such limitations should be communicated to users. For example, information should be provided on the completeness of vital statistics in different provinces or regions.

For areas with completeness levels <85%, users should be alerted to possible serious biases in the data. Poorer and rural and remote population groups may be less likely to be registered and may be missing from vital statistics. If cause-of-death statistics include a high proportions of deaths classified to ill-defined signs and symptoms, this should be acknowledged. The problem may arise following the mixing of data from medically certified hospital deaths with data on deaths that occurred at home and were not medically certified. Non-medically certified deaths are expected to be assigned to much higher proportions of "ill-defined" causes than medically certified deaths.

Being transparent about data limitations also allows for the release of data to the public without the need to wait for complete and totally accurate reporting. Users will understand that certain parts of the country may not be as well covered by CRVS systems as other areas, and can take this into account when using the data. Researchers may be able to help maximize the value of vital statistics by correcting for missing or biased information using demographic and statistical techniques.

As part of efforts to ensure transparency, metadata should also be included in reports. Metadata are data about data, and cover issues such as the definition of data elements and variables; their use in indicators; the data-collection method; the time period of data collection; analysis techniques used; estimation methods; and possible data bias (94). Metadata are essential for accurate definitions and for ensuring that other important information such as data time periods, geographical designations and other dimensions are understood. The WHO Indicator and Measurement Registry (95) describes metadata elements for major health indicators. Metadata should cover basic information such as the population covered, recording and certification practices, adjustments made, and how deaths and births that take place overseas are recorded. Metadata should also be compiled into a data dictionary or centralized metadata repository.

Evaluate data plausibility and consistency

In previous modules, key actions were described that can be taken to improve data quality at the collection stage. These actions include the use of clear and standardized definitions; regular training; frequent feedback to data collectors; and the use of information and communication technologies to compile and transmit data. There are also actions that can be taken following the completion of data collection to better understand and deal with any limitations in the quality of the microdata. For example, data can be critically reviewed and their credibility and reliability assessed through comparison against vital statistics from other sources. Standard demographic and epidemiological techniques can also be applied in the post-collection analysis of data.

Once the initial data have been compiled and tabulated, simple plausibility and consistency checks should be carried out to assess how robust and credible the aggregated dataset is and what it can be used for, before being released to the public. When calculating population rates and ratios, such as birth rates, fertility rates and crude death rates, the denominators used should be population counts and the numerators should relate to the events arising in the population group of interest, such as the population at risk. For most rates, the denominators are usually obtained from different data sources, including population censuses, population registers (if available), and population estimates. It is essential that close attention is paid to the definitions and classifications used in sources of both numerators and denominators to ensure that they are harmonized. Unexpected or sudden variations in rates

compared with previous years should always be investigated, as major population indicators typically evolve slowly over time unless there have been specific events which have caused sudden increases or reductions.

The coverage and completeness of fertility data can be assessed using statistical and demographic techniques for estimating under-reporting or other data biases (11). Simple electronic and other tools for checking mortality data for basic errors are also available (18), (16). By using these tools, problems with cause-of-death statistics caused by poor certification and coding practices can be identified. The tools also incorporate simple quality checks, such as calculating the proportion of deaths assigned to ill-defined cause-of-death categories. Any changes in this respect over time will affect interpretation of the trends in specific causes. Such analysis of mortality data will greatly enhance their value in informing health policies and programmes. Other relatively simple ways of analysing the internal validity and coherence of mortality data include comparison with external sources of mortality data, for example the census or recent household surveys, to assess consistency and reliability.

Tabulate and analyse data

As registration microdata are made available electronically and transmitted upwards through the system, there are some simple quality checks that should be conducted. The first of these should be carried out when the data are compiled from individual records – this typically takes place at the first administrative level of the national system. Initial checks should be carried out for missing data items (such as sex, date of birth and date of death), or data-manipulation errors that can occur when the microdata are compiled. Electronic data capture and compilation can help to avoid some of these errors, but a few simple checks should always be undertaken before data are shared. At national level, further checks for missing values and incorrect classifications should be carried out prior to the production of summary tabulations that allow users to understand the overall levels, trends and changes in fertility and mortality data. There are a number of well-established recommendations on the presentation of data tabulations (25)[5] and on the minimum requirements for data tabulations for live births (**Box 24**).

BOX 24. Data tabulations for live births (1), (25)

As a minimum for public health purposes, the tabulations of birth data should include numbers of live births for a specified year by:

- sex of child, gestational age and birth weight;
- live-birth order and interval between last and previous live births to mother;
- place of occurrence, place of usual residence of mother, and month of occurrence;
- place of registration and month of registration;
- age, educational attainment, and ethnic and/or national group of mother;
- age of father and place of usual residence;
- site of delivery, attendant at birth and month in which prenatal care began.

[5] Please see paragraphs 263–299 and the Annex.

As a minimum, all mortality data should be tabulated separately by age, sex and underlying cause of death according to ICD standards (1). In addition, countries should analyse other variables included in the registration record, such as place of occurrence, usual residence, occupation, education and ethnic group as this generates useful information for national purposes. As the risk of death varies significantly by age, mortality statistics should always be compiled according to the age at which death occurred, and aggregated using the standard age groupings shown in **Box 25**. These age groupings are also used to group population data in the census which provides the denominators for calculating fertility and mortality rates and ratios.

BOX 25. Data tabulations for deaths (25)

As a minimum for public health purposes, the tabulations of mortality data should include numbers of deaths for a specified year by:

- sex – i.e. for males and females separately;
- the age at death using the following age groupings:
  - within the first 24 hours after birth (recorded in minutes or completed hours)
  - between days 1–7 after birth
  - between 7 and 28 days after birth
  - between completed months 1–11
  - between completed years 1–4
  - between completed years 5–9
  - between completed years 10–14 etc. (continuing by 5-year age groups, up to completed years 80–84)
  - completed years 85 and over;
- ICD shortlist of causes;
- geographical area.

The probability of dying also varies substantially at different ages for men and women, and can also vary substantially between different regions within a country. Sub-national tabulations are thus important for revealing geographical inequalities in health status. This information will have implications for health-services planning, and decisions will be needed on what level of geographical disaggregation of birth and death statistics is most appropriate for policy and planning needs.

The United Nations recommends that vital statistics are compiled according to the date of occurrence. In many countries, however, birth and death statistics are compiled according to the 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 backlog of earlier births and/or deaths is suddenly registered, for example following periodic registration campaigns or a natural disaster.

Fertility and mortality data should also be tabulated according to place of occurrence, that is, the geographical location (locality or town) where the birth or death took place. For policy and services planning, it is also important to know the place of "usual residence" of the parents in the case of a birth, or of the deceased in the case of a death. Where significant numbers of people give birth or die in countries other than those of usual

residence, it is important to have a clear definition of what constitutes "residence" and clear operational procedures for determining where the events should be registered. Some countries include the deaths of nationals currently residing outside the country in their tabulations. Where this is current practice, these figures should also be included in national population estimates.

Tabulations should include mid-year population for the same year, sex and age group, which will enable total birth and age-specific birth rates to be calculated, as well as age- and sex-specific mortality rates. Population estimates are generally available from the decennial census and from intercensal projections produced by the national statistics office. Such data can be used to calculate both rates and ratios – as explained below. Where national population estimates are unavailable, estimates developed by the United Nations Population Division (46), (96) can be used – although these estimates are only available at a national level of disaggregation.

Safeguard microdata confidentiality

Any data-collection activity must have the trust of respondents to ensure their continued cooperation. Ensuring confidentiality is the key to maintaining that trust. This is particularly important for CRVS systems, which collect microdata on the life events of individuals. There are many effective ways of safeguarding confidentiality, and provided that appropriate measures are taken, microdata confidentiality requirements need not impede the sharing and dissemination of aggregated vital statistics. Datasets containing personal information can be shared as long as there are clear metadata standards and ways of ensuring that data remain anonymous to safeguard sensitive health information. These standards should be key components of overall data-management activities. Consideration should be given to the development of national legislation, protocols, and codes of practice concerning confidentiality and data dissemination. Guidance is available from UNSD (97), and from the United Nations Economic Commission for Europe and Conference of European Statisticians (98). UNAIDS (99) has also developed interim guidelines on confidentiality issues. Although these guidelines relate specifically to HIV data, they also have broader relevance for other areas.

Foster capacity building

All of the activities recommended for improving data quality and increasing data access and use place demands upon staff working in CRVS systems. Registration offices may not have sufficient resources to assess or follow up on missing microdata. At the same time, statistical office personnel are often faced with multiple demands in relation to censuses, national household surveys and routine administration across multiple data sectors. In addition, within the health sector, capacity for sophisticated data analysis may not be routinely available. Nevertheless, countries should offer training in basic data analysis and presentation based on the tools assembled in this resource kit. The holding of periodic seminars and workshops to exchange views on problems encountered is also recommended in order to supplement formal training (25).

One important strategy for increasing analytical capacities is to draw upon the expertise available in academic and research institutions. These institutions often have the capacity to carry out data analyses using international standards. In many cases, they are already

involved in national processes for reporting data and statistics. Academic and research institutions also have the added advantage of local knowledge, and objectivity and independence from programme implementation. For example, in South Africa, local authorities and academics in Cape Town collaboratively analysed existing cause-of-death information obtained from CRVS systems – particularly on HIV/AIDS and homicide. Despite early official scepticism, the research finding that HIV/AIDS and homicide accounted for most deaths among young adult males led to the mobilization of local communities to address the issues involved (100). This example highlights the value of locally generated data for local decision-making.

Establish and maintain a data repository to enable access to data

At the civil registration department, a central data repository should be established to manage civil registration data and share vital statistics. This central repository should be regularly backed up. Relevant ministries or institutions (such as national statistics offices) that need to access the data repository should be able to do so through an interface based upon appropriate permission levels.

When disseminating vital statistics, it is usually the role of the national statistics office to ensure the availability of data documentation (metadata) as part of overseeing data sharing among organizational units and individual staff members. Data documentation allows users to find the data that they are interested in, understand how data were created and what is being measured, and assess data quality. Good data documentation ensures that users are able to fully understand datasets without having to consult the data producers. International standards for data documentation include:

- The Data Documentation Initiative (DDI) – an international standard for describing data in the social, behavioural and economic sciences.[6]
- The Dublin Core Metadata Initiative (DCMI) – an open organization that develops inter-operable metadata standards that support a broad range of purposes and business models.[7]

Establish mechanisms for data archiving

A data archive is required to ensure the long-term safeguarding and permanent storage of civil registration legal documents. Archiving enables records to be retrieved when registration facilities are destroyed as a result of natural disaster or war. A data archive preserves datasets and their documentation over the long term. However, the timeframe may be reduced if data-archiving hardware and/or software become obsolete, or if damage occurs due to storage-climate conditions, natural disasters, accidents, human error, theft or vandalism.

Data-archive managers should take measures to preserve the confidentiality of the information held on individuals. This can be achieved by anonymizing datasets before they are disseminated, or by providing access to microdata either physically within a secure data centre or through a secured remote connection.

[6] For more information on the DDI please see: http://www.ddialliance.org/

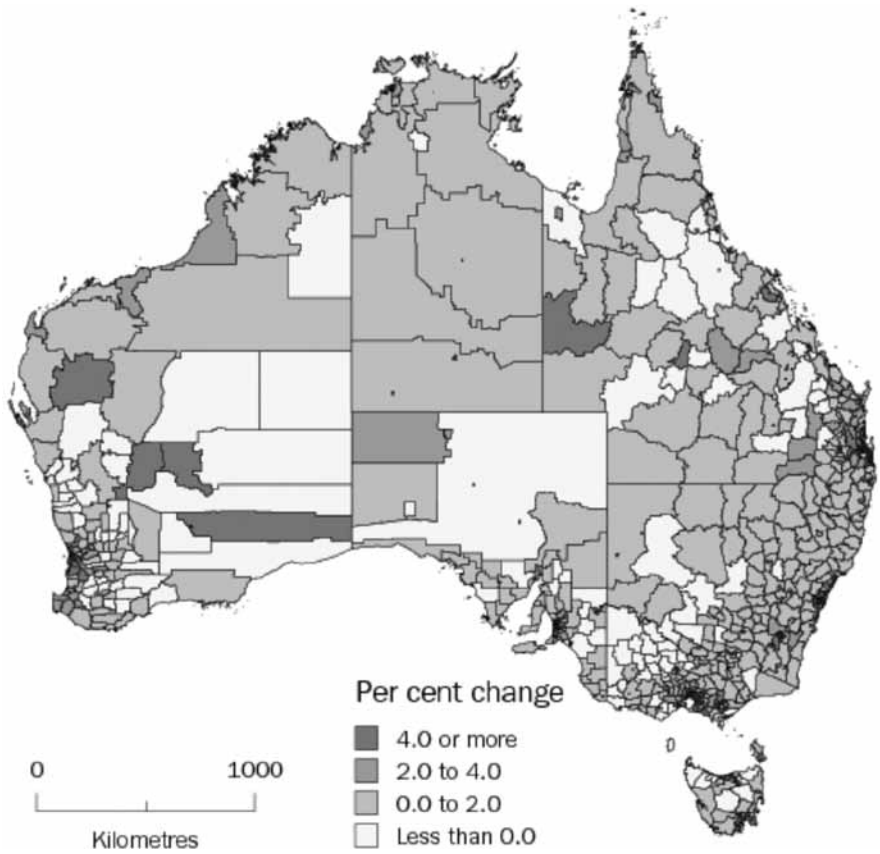
[7] For more information about the DCMI please see: http://dublincore.org/

Present data in ways appropriate to different users

Policy-makers, at both national and global level, are interested in results rather than processes, and greatly appreciate clarity. Policy-makers often have to make decisions quickly and must be able to process information rapidly. Their range of responsibilities means that they cannot possess in-depth knowledge of every issue (48). The way in which data are presented will greatly affect their understanding of the problems highlighted and, by extension, their commitment to addressing them (25).

The presentation of complex information in simple charts and maps enhances the use of data for decision-making. In Australia, for example, vital statistics data are used to identify local areas of population growth or decline (**Figure 15**).

Figure 15: Population change by local government area – Australia, 2009–2010 (101)



In the United States, local area mortality data are used to highlight important inequalities in life expectancy in different parts of the country, reflecting significant socioeconomic disparities (**Figure 16**).

Other simple ways to summarize data can also be used such as "top ten" causes of death, trend analysis and comparative analysis with other countries (18). In South Africa, simple policy briefs were produced to alert decision-makers to the toll of deaths due to homicide, which had remained hidden until the vital statistics data was analysed and clearly presented (**Figure 17**). Good practices in information presentation and dissemination include:

- presenting statistics in different formats depending upon user needs;

- using graphs, diagrams and tables as appropriate, but also including explanatory notes and contextual information to avoid misinterpretation;
- discussing the strengths and limitations of the data openly and honestly (103), (104), (105).

Once microdata have been transformed, the aggregated information should be made widely available. Programme planners and managers should be reminded that vital statistics are essential for their work, and attention should be drawn to ways of improving statistics in documentation and at meetings. In many countries, the national statistics office compiles and publishes annual vital statistics data, while more-detailed analysis is conducted by academics and researchers. Sometimes, specified agencies are given responsibility for data and information sharing. In Thailand, for example, information dissemination is led by the Health Information System Development Office, which produces analytical summaries of important topics such as geographical differences in mortality (107).

As well as improving data presentation, proactive efforts can be made to present findings to different users. Information can be conveyed directly to policy-makers or indirectly through secondary audiences in a position to influence policy-makers, such as academics, researchers, health professionals, parliamentarians and advocacy groups. Communication channels include seminars, workshops, peer-reviewed journals, special events, national

Figure 16: Life expectancy by county of residence – United States, 2009 (102)

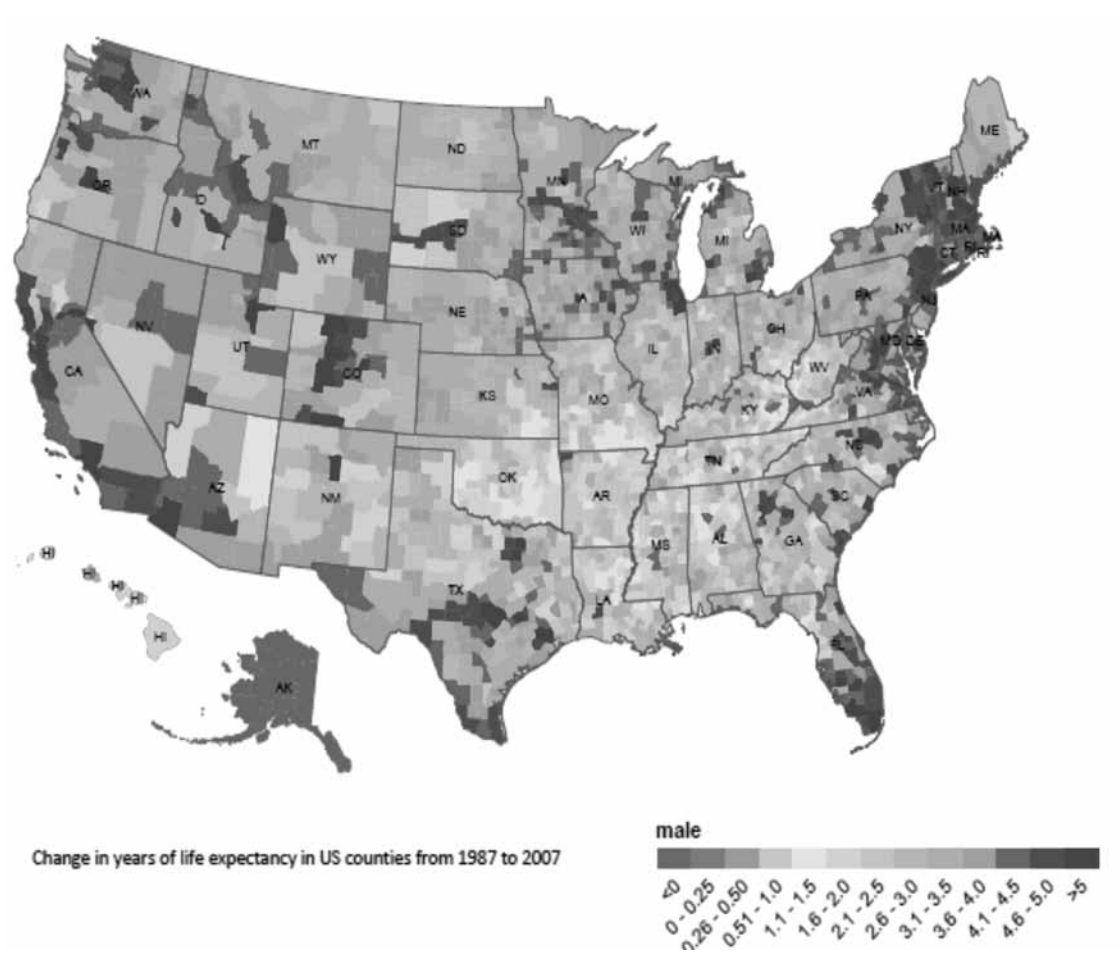
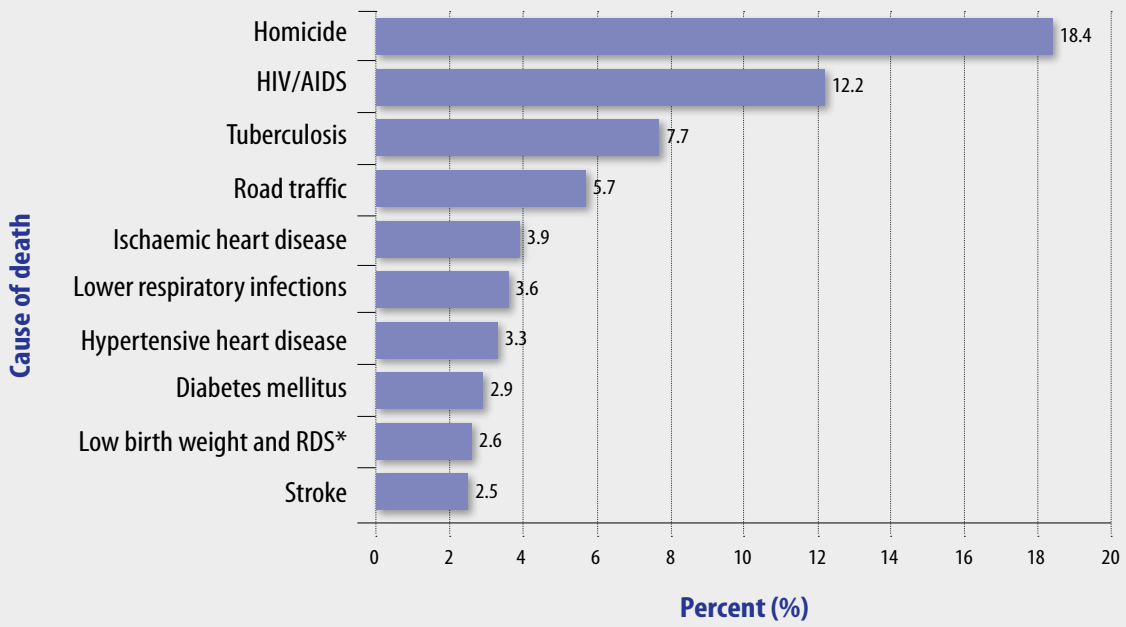


Figure 17: Top ten causes of death – Cape Town, South Africa, 2001–2006 (106)



*RDS: respiratory distress syndrome

and international meetings, and the media (25). The use of standardized reporting formats, country profiles and policy briefs are highly effective vehicles for using aggregated data to reach non-technical audiences. These formats can guide decision-makers by interpreting the data based on the potential consequences of alternative decisions and scenarios. In this way, data become information and evidence for action.

Collaboration with the media should also be welcomed, especially in disseminating findings to the general public. Some countries have set standards and produced guidelines for information dissemination, including on relations with the media. For example, Statistics Canada relies on media coverage to inform the public of its findings, and policies have been elaborated to guide this ongoing relationship (108).

Introduce new technologies

The compilation, presentation and dissemination of data can be greatly improved through the use of information and communication technologies. However, where online access is not practical or appropriate, a mix of conventional and new approaches to data dissemination should be used, including the production of paper-based reports. Where internet access is available, users should be able to access data directly, once it has been aggregated and individual identifiers removed. When data are brought together in an integrated data repository, users can query the data online, download and manipulate the data, and produce outputs that are most relevant to their needs (25). In recent years, advances in electronic data storage and manipulation have made it easier to compile and analyse datasets and to share them widely (109). Compiling data in a microdata repository (110) facilitates data analysis and the reconciliation of data from different sources. A "data dictionary" should also be made available to help users navigate their way through databases by providing a single point of reference for accessing and understanding data

elements and related documents. A good example of this is the Canadian Institute for Health Information Data Dictionary – Users Guide (111).

New information technology tools are also transforming the way large and complex datasets are presented, making them easier to understand. For example, statistical and business manipulation tools can be used to generate standardized reports from the microdata, showing detailed graphics and maps of aggregated data. Increasingly sophisticated software programmes permit the summary of complex information into formats that can attract the attention of decision-makers, and effectively communicate messages derived from the information. For example, data "dashboards" can be used to visually present key data in summary form so that decisions can be made quickly. Dashboards provide an at-a-glance perspective on the current status of a project in the context of its predetermined metrics. The dashboards are also linked to a database so that users can change key inputs to see how that affects the information displayed, and can access the source data to understand the inter-relationships shown. Dashboards also help to manage the large amount of data collected by health programmes by tracking key indicators and displaying trends, thereby allowing users to identify problems and target specific follow-up activities to improve services.

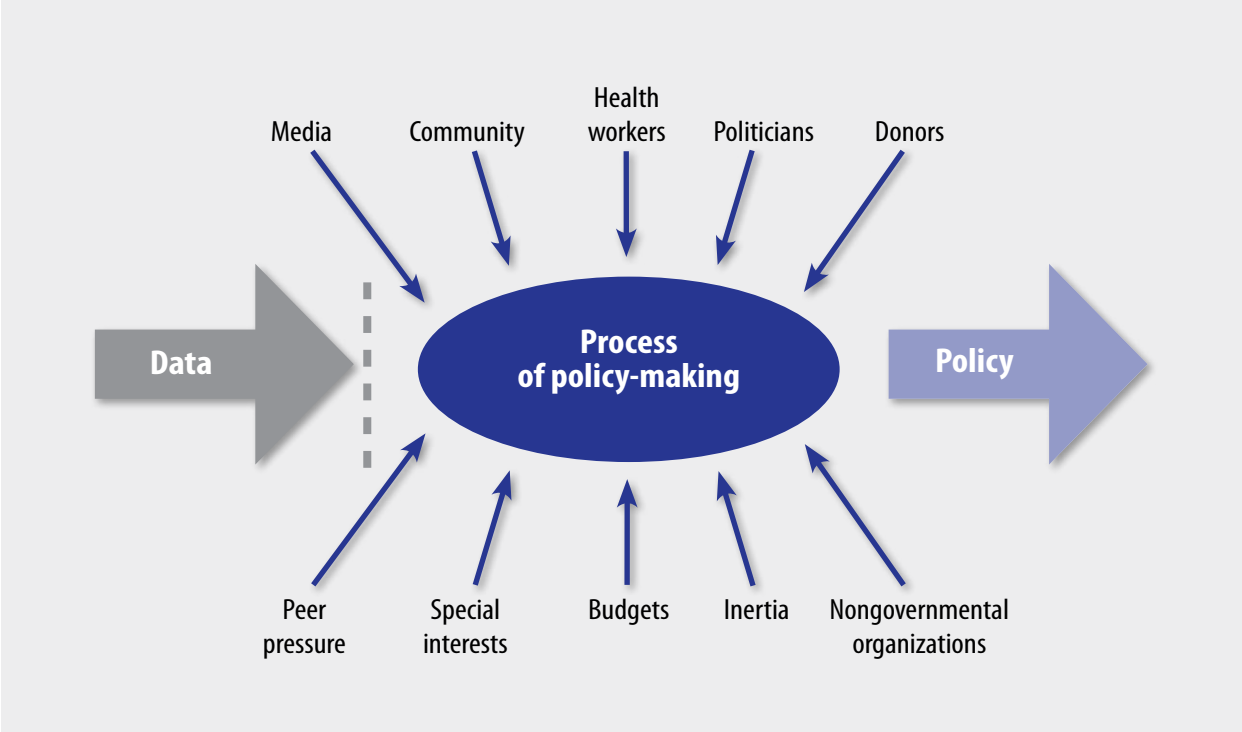
Promote a culture of data use

The overall purpose of improving the civil registration system, enhancing the quality of the vital statistics it generates, and reviewing and packaging data for different users is to ensure that data are used. Potential users of civil registration system data include numerous government departments and private entities. From a governance perspective, civil registration systems generate reliable data and statistics that inform decision-making for policies, programmes and service delivery. These data and statistics are:

- essential for financial planning by governments and other entities, and for formulating and monitoring health, development and social policies and programmes;
- used to determine population estimates and projections in interim years between census collections, and are thus crucial in attracting and distributing funding to government departments and private entities;
- vital for conducting demographic analyses at the smallest geographical and administrative levels;
- vital for managing a population register – the most comprehensive governance tool available, and the basis for issuing individual identity numbers and/or cards;
- the foundations for assessing progress towards national goals in health, education and overall development.

Enhancing the reliability of statistics and making them relevant to the information needs of diverse users are not necessarily sufficient in themselves to ensure that vital statistics will actually be used for policy-making and programming. The availability of data does not automatically translate into data use and better decision-making (48). Many factors influence the strategic decisions made on resource allocation and programme implementation. In most societies, policy-making is fragmented, and decisions are sometimes difficult to reach due to the competing interests of different stakeholders. Decision-making is also influenced by other factors, including special interests and sheer inertia (**Figure 18**).

Figure 18: Barriers to evidence-based policy-making (112)



Although it takes time and political will to develop a culture of evidence-based decision-making, there are some practical organizational and behavioural interventions that can help to improve the use of information. For example, linking data and information to actual budgets and developing indicator-driven planning is very effective (113). There are also a number of potentially resolvable misunderstandings that can arise between policy-makers and technical experts. Policy-makers can be perceived as being too busy, superficial, uninterested in detail, and prone to drawing hasty conclusions and making decisions irrespective of evidence. Technical experts, on the other hand, can be perceived as having little understanding of the policy implications of their work and using too much technical jargon (114). Such misunderstandings are neither new nor confined to the health sector.

In 1991, the United States Agency for International Development (USAID) funded the Data for Decision-Making project, which aimed to increase the use of data in setting health priorities and policies (115). The approach taken was to bring together users and producers of data, and to build skills in epidemiology, problem-solving and communication. The Partnership in Statistics for Development in the 21st Century (PARIS21) consortium has also produced information showing how statistics have been used – or not used – to influence policy-making in health and other sectors (116). A guide to how statistical information can be used to make well-informed policy decisions has also been produced by the Australian Bureau of Statistics (117).

The main users of data should be involved in determining the most appropriate cross-tabulations and regional breakdowns of vital statistics data relevant to their needs. It is important to receive feedback from users on how relevant, useful and reliable are the vital statistics they use. There is little point in producing data that are not used or are viewed as unnecessary. A stakeholder analysis should be undertaken to identify the primary users

of data and to determine what statistics are used for. The timeliness of data is the quality criterion that users rate most highly. This is particularly important in the case of local-level and small-area data. Data-release dates are important considerations for both data producers and users. Keeping to the scheduled release dates allows users to plan their work around the availability of vital statistics. In addition, as discussed above, understanding of vital statistics can be enhanced through the issuing of brief analytical reports based on the data. For example, reports that give a brief account of significant changes in mortality levels, or differences by sex, or trends in leading causes of death are extremely useful as they can be used to summarize key messages for policy use.

The perspectives of data producers and users will differ, as will the level of data they require. Many national-level stakeholders are required, for example, to report national data to international and regional agencies assessing the progress made towards the MDGs. At the other extreme, many countries are actively decentralizing as a key part of their development policy. Therefore, it is also important to address the needs of local governments as data providers and users. Making data available at the local level, where the initial data collection takes place, is one of the most effective strategies for stimulating interest among citizens and promoting the use of data for local planning. The PARIS21 Knowledge Base includes lessons learnt on the use of statistics in local government. Advances in technology can also help to address local data needs more effectively and efficiently than was previously the case. In particular, techniques and processes such as geographical information systems, small-area data estimation and poverty mapping offer opportunities for making data available in readily usable forms at low levels of aggregation (118).

6.4 Tools and resources

The tools and resources for improving data quality, access and use developed by a range of international agencies and technical groups can be categorized as follows:

- Tools to assess and improve vital statistics
- Resources and lessons learnt about data access, dissemination and use
- Tools for general data quality assessment.

Tools to assess and improve vital statistics

• Principles and Recommendations for a Vital Statistics System (25)

In 2001, UNSD issued the second revision of this key reference and resource document which includes guidance on the steps needed to strengthen CRVS systems. Specifically, in the context of this module, it outlines the steps that can be taken to assess and improve data quality. Ways of assessing the completeness and accuracy of register-based vital statistics are described, including direct and indirect assessments, comparison of trends, tracking delayed registration and comparisons with other sources of vital statistics data. The document is currently under review and the updated version will be available in 2013.

The current version can be found at:
http://unstats.un.org/unsd/publication/SeriesM/SeriesM_19rev2e.pdf

• Handbook of Vital Statistics Methods (55)

This 1955 handbook provides more-detailed information on several methods used for producing vital statistics and is available at:
http://unstats.un.org/unsd/demographic/standmeth/handbooks/Series_F7en.pdf

• Improving the quality and use of birth, death and cause-of-death information: guidance for a standards-based review of country practices (11)

This comprehensive assessment tool provides guidance on the detailed assessment of different aspects of country CRVS systems (see Module 1). The focus of the tool is on births, deaths and causes of death because these are the fundamental events that countries need to know about in order to guide public health programmes, monitor population dynamics and measure key health indicators. If the extent of completeness or coverage of vital statistics data is known, then even incomplete information can yield valuable insights into mortality patterns and the main causes of death. The tool include guidance on how to conduct an assessment of data quality and describes some basic reliability checks focused on mortality and cause-of-death data, and can be found at:
http://whqlibdoc.who.int/publications/2010/9789241547970_eng.pdf or can be obtained in its spreadsheet version from WHO at **healthstat@who.int**

• Mortality statistics: a tool to enhance understanding and improve quality (18)

This document is intended to help build analytical capacity for assessing the quality of mortality statistics in order to enhance their value in informing health policies and programmes. It describes simple ways of analysing the validity of mortality data and shows how comparisons with other sources of data can be used to assess consistency and reliability. By carrying out these simple checks, data collectors and practitioners can diagnose weaknesses in their data. The document is associated with an electronic spreadsheet (ANACoD) produced by WHO (16) for facilitating the analysis of available mortality and cause-of-death data. This spreadsheet can automatically calculate indicators that highlight the reliability of data and highlight data-quality problems. When used in conjunction with an assessment of CRVS systems, these tools will help country decision-makers develop and target strategies for improving the availability and quality of mortality data.

• In-house training in statistical organisations

Statistics Norway has gathered information on a number of online training resources for use in statistical training. This document provides recommendations for setting up in-house training aimed at equipping staff with the relevant skills, and is available at:
http://www.ssb.no/english/subjects/00/90/doc_201231_en/

Resources and lessons learnt about data access, dissemination and use

• A Guide to Designing a National Strategy for the Development of Statistics (NSDS) (118)

This PARIS21 guide can be found at:
http://siteresources.worldbank.org/SCBINTRANET/Resources/NSD_Guide-Nov04.pdf

• User-friendly presentation of statistics: Guide to creating a dissemination strategy and dissemination guidelines for developing and transition countries

This PARIS21 handbook has been published in cooperation with Statistics Norway. It covers various aspects of statistics dissemination in relation to practical problems that can arise. Topics covered include how tables and graphs can be made as understandable and correct as possible, how to maintain good media relations and how statistics agencies can use the internet as a dissemination channel. Good and bad examples from statistics agencies throughout the world are provided and the guide is available at: **http://www.paris21.org/node/455** – it is also available in Arabic, English, French and Russian at: **http://www.ssb.no/english/int/pres_stat_en/**

• How to modernise a Civil Registration System: The case of Albania (19)

Albanian authorities and government institutions, the Organization for Security and Co-operation in Europe (OSCE) and Statistics Norway have all cooperated in modernizing the Albanian civil registration system. The former register based on handwritten books has been transformed into a modern electronic population register. The report is available at: **http://www.ssb.no/english/subjects/00/90/doc_201232_en/**

National statistics office resources

Several national statistical organizations, including those of Canada and the United Kingdom, have now developed protocols and codes of practice for enhancing data access. An example of this is the United Kingdom Statistics Authority **Code of Practice for Official Statistics** (119) which is available at: **http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf**

United Nations guidelines

• Principles and Guidelines for Managing Statistical Confidentiality and Microdata Access

This Statistical Commission background document is available at: **http://unstats.un.org/unsd/statcom/doc07/BG-Microdata-E.pdf**

• Managing Statistical Confidentiality & Microdata Access: Principles and Guidelines of Good Practice

Available at: **http://www.unece.org/fileadmin/DAM/stats/publications/Managing.statistical.confidentiality.and.microdata.access.pdf**

The above United Nations guidelines highlight the value of granting microdata access to the research community at both national and international levels. Recognizing the potential risks in microdata release, the guidelines provide principles for managing confidentiality issues and maintaining public trust. They also identify emerging practices whereby developing countries release their microdata for access through data repositories. It is recognized that the precise arrangements for access to microdata will vary from country to country, depending on issues such as legislation, public attitudes and the capacity to provide support to the research community.

Making Data Meaningful and related guides

The United Nations Economic Commission for Europe *Making Data Meaningful* guides are a three-part set of practical tools to help managers, statisticians and media-relations officers in statistical organizations use text, tables, charts, maps and other devices to succinctly and meaningfully convey statistics to non-statisticians:

• **Making Data Meaningful – Part 1: A guide to writing stories about numbers** **(103)** – focuses on the use of effective writing techniques

• **Making Data Meaningful – Part 2: A guide to presenting statistics** **(104)** – aims to help readers find the best way to get their messages across to non-specialists, using the most suitable set of tools and skills now available from an array of communication methods.

• **Making Data Meaningful – Part 3: A guide to communicating with the media** **(105)** – is a practical tool for managers, statisticians and communication and media-relations officers in statistical organizations; particularly those in the process of developing communication strategies. The guide aims to help producers of statistics find the best way to communicate effectively with the media using suggestions, guidelines, and examples rather than strict rules or rigid templates.

The *Making Data Meaningful* guides are available at:
http://unece.org/stats/documents/writing/

The PARIS21 consortium has also published a guide to the user-friendly presentation of statistics, aimed at helping statistics agencies in developing and transition countries to devise strategies and guidelines for the dissemination of statistics. Available at:
http://www.paris21.org/node/455

Data use

Many examples of tools and resources can be found in this area, illustrating the recognized value of statistics in enhancing policy analysis, policy design, and policy outcomes across a wide range of sectors in many different countries.

• **Measuring up to the Measurement Problem: The role of statistics in evidence-based policy-making** **(116)**

This PARIS21 guide has identified a number of lessons to be learnt from case studies, and is available at: **http://www.paris21.org/sites/default/files/1509.pdf**

• **Data for Decision Making Project – Final Report: Overall lessons learned** **(115)**

The USAID-supported Data for Decision-Making project has led to important lessons being learnt about the process of generating and using data for decision-making. Key findings include:

- the availability of data and evidence are necessary but insufficient conditions for policy improvement, though they can help mobilize support for change;
- adequate data and evidence for health-sector reform does not have to be expensive, with most countries already having access to a lot of information that is being poorly used;
- some evidence is better than no evidence and more is usually (though not always) better than less;

- local counterparts must participate in the process of design, collection, analysis and presentation of evidence if decision-makers are to believe, accept or use the results;
- investments in creating data and evidence must be linked with capacity-building investments in both government and non-government organizations to create a potentially sustainable evidence base;
- health-systems evidence and policy development needs to focus more on system changes that make a difference to health outcomes;
- it is possible to develop and maintain adequate information systems in developing countries that are accessible to national and international decision-makers.

This final report is available at:
http://www.hsph.harvard.edu/ihsg/publications/pdf/finalreport.PDF

- **A guide for using statistics for evidence based policy** **(117)**

This ABS guide targets the skills and capacities that data producers and users need to be able to use statistics to make well-informed decisions. These skills are summarized under the overall heading of "statistical literacy" which comprises four areas:

- data awareness – knowing what data are needed, what types of data are available and how to access them, and the overall quality of the data;
- ability to understand statistical concepts – understanding simple and more-complex statistical terminology, applying basic statistical concepts, and understanding and interpreting graphical representations of data;
- analysis, interpretation and evaluation of statistical information – understanding the limitations of data sources, identifying the correct questions needed to obtain the information required, and understanding analytical techniques;
- communication of statistical information – using tables and graphs to present findings, and accurately and effectively writing about the data.

This guide is available at: **http://www.abs.gov.au/ausstats/abs@.nsf/mf/1500.0**

Tools for general data quality assessment

These tools were originally developed to provide standards and guidance in relation to the quality of economic statistics. They are presented here to illustrate the kinds of criteria that should be considered when assessing, sharing and improving the quality of all types of statistical data.

- **General Data Dissemination System (GDDS)** **(120), (121)**

General guidance on data quality assessment has been compiled by the World Bank and IMF which is designed to:

- encourage member countries to improve data quality;
- provide a framework for evaluating needs for data improvement and for setting priorities;
- guide member countries in the provision of comprehensive, timely, accessible and reliable economic, financial and socio-demographical statistics to the public.

The guidance covers four distinct areas or "dimensions":[8]

- data coverage, periodicity and timeliness;
- quality of the disseminated data;
- integrity of the disseminated data;
- access by the public.

In each of these areas, the GDDS describes good practices in developing national data production and dissemination systems. More information on the GDDS is available at: **http://dsbb.imf.org/pages/gdds/home.aspx**

• Data Quality Assessment Framework (DQAF) (122)

The IMF DQAF comprises a set of prerequisites for data quality, and the following five dimensions of data quality:

- assurances of integrity
- methodological soundness
- accuracy and reliability
- serviceability
- accessibility

The DQAF is designed for use during comprehensive assessment of national data quality, and covers institutional environments, statistical processes and characteristics of the statistical products. The DQAF is available at: **http://dsbb.imf.org/pages/dqrs/dqaf.aspx**

• Fundamental Principles of Official Statistics (123)

Developed and endorsed by the United Nations Statistical Commission, this document describes the role of official statistics and lays out the criteria for a good system. The document is available at: **http://unstats.un.org/unsd/dnss/gp/fundprinciples.aspx**

6.5 Summary

This module has discussed the issues and common problems associated with efforts to improve the quality, access and use of data obtained from CRVS systems, and outlined a number of key actions (**Box 26**).

The roadmap proposed in **Box 27** outlines the major steps for developing a plan for improving data quality, access, and use. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

[8] For a more-detailed overview of these four dimensions please see Annex D.

BOX 26. Key actions for improving data quality, access and use

1. Establish a data archive for the long-term safeguarding of civil registration records.
2. Compile and tabulate microdata according to established international standards developed by United Nations agencies such as WHO.
3. Regularly assess both microdata and aggregated data for quality and reliability by conducting assessments of coverage, completeness, accuracy, consistency and plausibility.
4. Be transparent with users about the limitations of data; for example by making such limitations explicit in statistical reporting.
5. Establish mechanisms for data sharing, such as a data repository that is regularly backed up.
6. Develop a code of practice to ensure that standards of confidentiality are maintained without impeding data dissemination.
7. Make data more accessible to users by providing analytical summaries that present data using simple charts and maps.
8. Introduce information and communication technologies to improve data visualization and accessibility.
9. Build skills and capacities by training individuals in data analysis and presentation. Draw upon expertise in academic and research institutions to support the enhanced analysis of available data and to promote broader understanding of analytical techniques.
10. Promote a culture of evidence-based decision-making by increasing collaboration between data producers and users, and encouraging improved mutual understanding.

BOX 27. Basic roadmap for developing a plan for improving data quality, access and use

Step 1: Form an ad hoc committee that brings together those involved in the management and quality assurance of vital statistics and the users of vital statistics. The committee should form two subgroups:

- A data-quality evaluation subgroup consisting of researchers, demographers, statisticians, epidemiologists, programmer analysts, database managers, quality assurance officers and information technology personnel;
- A vital-statistics users subgroup consisting of users such as policy-makers, government officials, representatives of business and the private sector, academic institutions, donors, development partners, media and civil society.

The two subgroups should share their findings as data quality and data use are closely linked. The functions of the committee are then to:

- critically review currently available data, in terms of coverage, completeness, accuracy and timeliness;
- identify priority areas requiring action and develop a data-quality improvement plan;
- identify ways of improving data dissemination;
- identify ways of improving the use of vital statistics for policy and programme development and implementation.

Step 2: Conduct a thorough review of the quality of both microdata and currently available aggregated vital statistics using specially designed tools. Based on the findings of the review, develop a data-quality enhancement plan that clearly assigns roles and responsibilities.

Step 3: Bring together potential users of vital statistics from different sectors and critically review current data-dissemination and sharing strategies. Identify any improvements needed. Obtain information from users on what types of data tabulations and presentations are most relevant to their needs. Ask users about the current relevance, utility and quality of vital statistics, and discuss ways of making data more easily accessible in a variety of formats and presentation methods. Develop an improvement plan.

Step 4: Convene meetings between senior policy-makers, programme planners and managers, and representatives of donor agencies, development partners, media and NGOs to discuss ways of improving the use of vital statistics for policy and programme development and implementation. Establish mechanisms for sharing information between data producers and data users and encourage mutual feedback.

MODULE 7:

Interim methods for generating vital statistics when civil registration is inadequate

7.1 Introduction

In most African and many Asian countries, civil registration coverage is inadequate and the availability and quality of vital statistics are poor – particularly for mortality and causes of death (57). When civil registration coverage is low, vital events are more likely to be missed in poor, rural and marginalized populations, which tend to have different birth and death rates and patterns of causes of death compared with wealthier, urban populations. As a result, vital statistics are not representative of the population and are of little utility in informing policy-makers and health-system managers of trends and patterns of premature mortality in the population as a whole. In low- and middle-income countries, largely avoidable premature mortality constitutes the major and growing portion of the burden of disease. It is therefore more important than ever that countries have the ability to continuously monitor changes in their fertility and mortality patterns, and to track the evolution of cause-specific mortality. Civil registration is the best means of doing this.

Although this resource kit is intended to support countries in improving their civil registration and vital statistics systems, achieving high coverage and quality cannot be accomplished rapidly because of the need for far-reaching administrative reforms and collaboration between multiple partners. In the immediate term, country decision-makers urgently need reliable information on vital events to aid planning, resource allocation and programme monitoring. When civil registration systems are weak or dysfunctional, alternative methods of data collection on births, deaths and causes of death are available and can be used on an interim basis to generate national and sub-national estimates of fertility and cause-specific mortality to support decision-making.

The contents of this module will be particularly relevant to countries with no civil registration or with weak and dysfunctional systems, but where decision-makers need to know something of the levels, trends and patterns of fertility and mortality. This module aims to answer questions such as:

- What methods can be used to generate evidence on levels of mortality by age and sex on an interim basis alongside efforts to strengthen civil registration?
- What techniques are available that can generate information on the causes of deaths that occur outside hospitals?
- What approaches can be used to implement vital events registration among a representative sample of the whole population?

The two interim approaches that can address such questions are:

- **Health and demographic surveillance system** (HDSS) conducted on sentinel populations;
- **Sample vital registration with verbal autopsy** (SAVVY) conducted on statistically sampled population clusters representative of the whole population.

Both of these approaches use verbal autopsy (VA) to determine cause of death. This module provides an overview of the characteristics of HDSS, SAVVY and VA, discusses their advantages and disadvantages, and identifies the detailed technical resources available to guide their implementation.

It must be emphasized that these interim data-collection methods are only intended to serve as temporary sources of information on vital events pending the attainment of full civil registration and medical certification of all deaths. They have been developed in recognition of the crucial role such information plays in national health and development planning. However, these methods should ***not*** be regarded as sufficient to meet country needs for disaggregated health and social statistics covering different population subgroups – nor can they meet the legal and human-rights requirements that only universal civil registration can deliver.

7.2 Background

Role of interim approaches for generating vital statistics

To meet the need for data on births, deaths and causes of death in developing countries, different interim approaches have been developed over the past 40 years. These include innovative strategies both for data collection and for the analytical assessment of the data and estimation of key indicators. Data-collection systems include population censuses, sample vital registration systems, demographic surveillance and sample surveys. Methods of analysis of incomplete information yielding indirect estimates of health and demographic indicators, and statistical modelling, have also been used to fill data gaps. These will not be dealt with in this module which focuses instead on the strengthening of empirical data collection rather than the advanced analysis of collected data.

Although innovations in data collection and analysis have greatly increased knowledge of the demography and descriptive epidemiology of populations in developing countries, significant gaps remain. This is particularly true for adult mortality, which now constitutes the vast majority of deaths in developing countries due to the success of child-survival interventions. Much of the initial impetus for the development and application of innovative data-collection methods came from efforts by the health and development community to monitor population growth and child survival. Investment in census development was a vital aspect of the generating of reliable data on population size, growth and change. Starting in the 1970s, attention was increasingly paid to developing international programmes for decennial censuses and household surveys that could generate reliable data on fertility, child mortality and their determinants. In the first decade of the 21st century, an accelerating demographic and epidemiological transition has led to renewed interest in other systems and methods that can produce data on

adult mortality and causes of death, namely civil registration, surveillance and sample registration with VA.

All of these data-collection methods have their strengths and weaknesses which have been well described (124) and are summarized in **Table 4**. Only civil registration and, to a lesser extent, surveillance and sample registration systems perform well when it comes to generating data on adult mortality causes, levels, trends and differentials. Only civil registration also confers legal benefits to individuals, such as proof of identity. However, other methods are potentially of great value for generating vital statistics in settings where civil registration systems are inadequate. This module focuses solely on primary data collection though sentinel and sample health and demographic surveillance because these methods can generate vital statistics and cause-of-death data on a continuous and ongoing basis on the populations they cover.

Table 4: Comparison of approaches for generating vital statistics (124)

	Level of estimate	Civil registration system	Demographic surveillance sites	Sample registration systems	Population censuses	Household sample surveys
Births	National	Yes	No	Yes	Maybe*	Yes
	Differentials	Yes	Limited	Limited	Maybe*	Limited
Child mortality	National	Yes	No	Yes	Yes∏	Yes
	Differentials	Yes	Limited	Limited	Yes∏	Limited
Adult mortality	National	Yes	No	Yes	Maybe*±	Weak¶
	Differentials	Yes	Limited	Limited	Perhaps* ±	No
Cause of death	All	Yes	Yes§	Yes§	Maybe§	Yes§**

* With assessment and possible ajustment; methods do not always work.

∏ For a recent period by indirect methods.

± For an intercensal period.

¶ Methods measuring parental survival or sibling history.

§ With verbal autopsy.

** For child deaths identified by a full birth history.

Countries with dysfunctional or very weak civil registration systems should consider establishing an HDSS site in selected areas as a first step in efforts to improve the generating of vital statistics. Establishing demographic surveillance sites can help to generate capacity for the enumeration of vital events and the use of VA to ascertain causes of death – however, this will ***not*** yield nationally representative statistics. Countries with several existing HDSS sites – usually established for research purposes and often in rural areas – should build upon them and consider adding additional sites (for example, in urban areas) to enhance representativeness and generate vital statistics on population-based mortality levels and cause-of-death distributions. As capacities and resources increase, sample surveillance sites could be established to generate nationally representative vital statistics on a continuous basis.

The experience of the United Republic of Tanzania in this regard provides a useful example. Starting in 1992, the Ministry of Health and its partner research institutes

have established an increasing number of sentinel HDSS sites. At present, there are five districts running large-scale sentinel sites – representing a critical mass of experience and human-resource capacity for managing mortality surveillance with VA. In addition, this has created demand for such data in other districts that lack sentinel sites. Recently, a decision was taken by the Ministry of Health and its funding partners to continue with the existing sentinel sites for research and evaluation purposes, while also investing in the development of an independent and statistically representative SAVVY system for generating routine vital statistics. The sample registration system now provides data from 23 statistically representative districts, allowing for the production of both locally and nationally representative data on rates and causes of death. While these HDSS and SAVVY sites provide cause-of-death data for the Ministry of Health, efforts are also being made by the Ministry of Justice and Constitutional Affairs to meet its mandated goal of increasing the coverage of routine and continuous CRVS through its Registration Insolvency and Trusteeship Agency. Although experience of running HDSS sites is useful for developing skills, leadership and demand for SAVVY and CRVS, it is not essential. Some countries, for example Zambia, are introducing SAVVY without prior HDSS site experience.

Improving vital events coverage in the population – starting with surveillance sites or sample registration systems – is more likely to be achievable if efforts are made to ensure that enumeration activities in surveillance or sample sites are carried out in collaboration with existing civil registration authorities, particularly in urban areas where some form of civil registration exists in many low- and middle-income settings. This can help to create demand for improved vital statistics on the part of national and local authorities, and to ensure political commitment and resource allocation. Moreover, it can help to raise community awareness of the value of civil registration and vital statistics for local-level planning and programme implementation.

It should be noted, however, that major differences between an HDSS and routine civil registration renders the simple linear progression from surveillance sites to sample and comprehensive registration systems highly unlikely. In particular, HDSS sites use active case finding of vital events through specifically trained community workers. By contrast, civil registration is a passive system that relies upon the willingness of individuals and families to come forward and register vital events. Nonetheless, much can be learnt from effectively functioning HDSS sites when building country capacities for the enumeration of vital events and for the management, analysis and use of the resulting data (125).

National authorities may decide to opt directly for comprehensive civil registration without first introducing either HDSS or SAVVY – as occurred in South Africa (see Case study 3 in Module 8). On the other hand, many countries – such as the United Republic of Tanzania – have found the skills and experiences built up in existing HDSS sites to be of great value when extending surveillance to cover a representative sample of the population or, indeed, the whole country.

It should also be stressed that moving towards comprehensive civil registration need not imply that health and demographic surveillance be abandoned once full registration is achieved. HDSS sites generate a lot more data on linkages between health interventions and population health status than is possible either in SAVVY or civil registration. Sentinel surveillance will continue to serve the needs of health authorities and researchers in understanding the context of changes seen in mortality patterns, but will no longer be the

only source of reliable vital statistics. Surveillance systems can also be used in the quality validation and calibration of data obtained from routine registration systems.

In conclusion, interim data-collection approaches for vital statistics ***cannot*** be considered a permanent substitute for civil registration systems; rather, they offer stop-gap solutions to the lack of vital statistics while providing opportunities for countries to develop capacities in birth and death enumeration, and ascertainment of cause of death. Using the data collected to understand the current health status of the population, and identify potential emerging threats, will help to generate further demand from decision-makers for reliable vital statistics. Interim methods can also be useful in monitoring and validating progress in the scaling up of CRVS systems. They are not required where CRVS systems are in place that have sufficiently high levels of coverage (>90%) and quality.

Health and demographic surveillance system (HDSS)

In 1998, a number of previously independently functioning HDSS sites in developing countries came together to form the International Network for the Demographic Evaluation of Populations and Their Health in Developing Countries (INDEPTH). As of 2012, there were over 40 HDSS sentinel field sites operating in Africa and Asia (**Figure 19**). At these sites, all vital events occurring in contiguous populations of between 50 000 and 200 000 people living in defined rural or urban are being monitored over time. New sites are being established each year – though these often experience unnecessary start-up difficulties and delays because of a lack of timely access to expertise and technical know-how on the practical aspects of establishing and running an HDSS site. At the same time, established sites are increasingly being challenged to provide additional information to serve the intensified efforts of countries to reduce poverty and improve health. For these reasons, INDEPTH has now assembled the best practices and experiences of its existing sites into a technical resource kit maintained on its website.[9]

HDSS sites can answer complex research and evaluation questions because they generate data that are more complex, complete and contextualized than are produced by sample registration or civil registration systems. On the other hand, the relatively small number of HDSS sites in an individual country means that the results obtained may not be applicable to areas that are distant from the site, particularly in large countries with considerable geographical and socioeconomic diversity. In order to generate data that reflect the whole country, it is necessary to select surveillance sites that are statistically representative of the national situation.

Sample vital registration with verbal autopsy (SAVVY)[10]

SAVVY is a generalized form of HDSS in which a larger number of sites – assessed by the national statistics office to be collectively representative of the country – are established to monitor the vital statistics of the populations covered. The overall results are then considered to be statistically representative of the national situation. SAVVY is essentially

[9] For more information please see: http://www.indepth-network.org

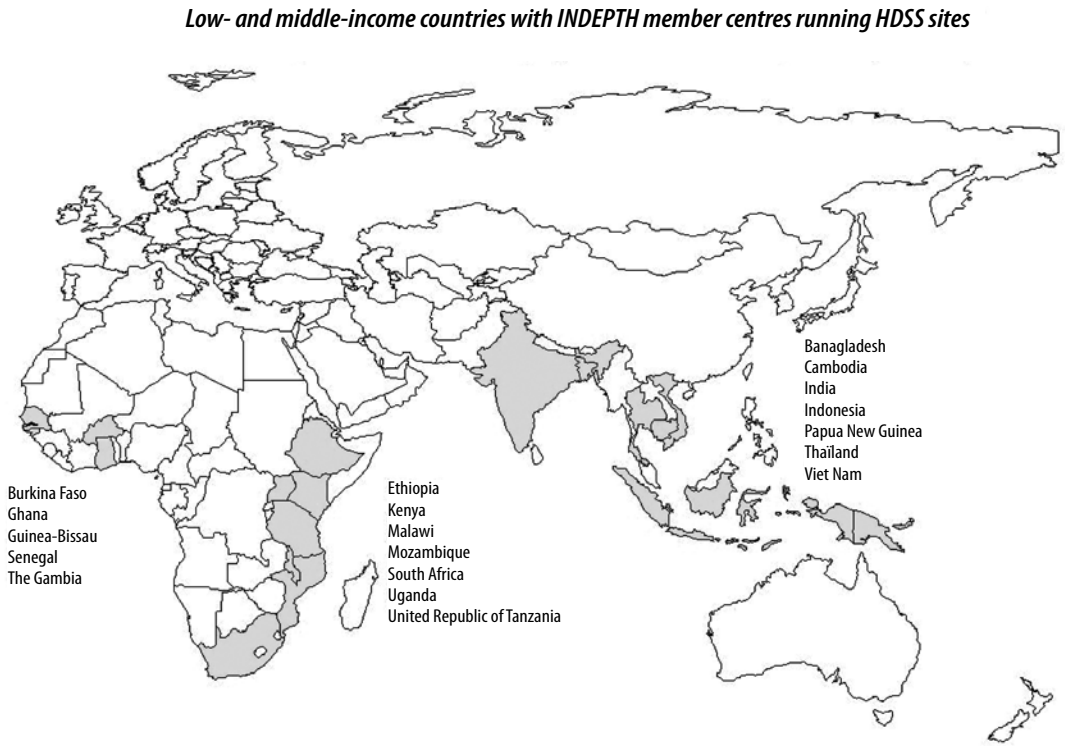
[10] The term "registration" is something of a misnomer here as vital events are enumerated (counted) rather than registered in the legal sense.

natality and mortality enumeration rather than health and demographic surveillance. As a result, follow-up is less intense and the denominators used to calculate population statistics may not be as robust as those in an HDSS site. SAVVY is thus more suited to monitoring fertility and mortality rates and causes of death in populations, rather than functioning as a vehicle for research purposes, and can be very useful for planning purposes. Both SAVVY and HDSS approaches use a common methodology for ascertaining cause of death, namely VA.

The best-known example of SAVVY is the Indian Sample Registration System, which started in 1964 and expanded to cover the whole country by 1970 (126). In approximately 7000 sample areas (covering almost 1% of the population), part-time officials continuously record births and deaths. In addition, twice a year an independent survey team interviews all sample households, specifically asking about births and deaths in the previous six months. The two sets of event records are then matched, and any discrepancies investigated. The final count of events is the total of all matched events plus those recorded only by the officials plus those recorded only during the household interview. Independent evaluation suggests that the system captures about 85% of all deaths (124).

In China, sample registration occurs through the Disease Surveillance Point system which currently covers 160 districts and counties scattered in all provinces, autonomous regions and municipalities. Population coverage is estimated to be 73 million people, representing almost 6% of the total population (127). The system generates about 500 000 death reports annually. In rural areas, about 80% of adult deaths take place at home, with few

Figure 19: **Countries hosting one or more HDSS sites**



occurring in the township hospital or other tertiary hospitals in the vicinity. For deaths that occur at home, the event is reported by a village health worker to the disease prevention unit at the township hospital. A staff member from the unit then visits the household and completes a death certificate on the basis of a VA combined with available documents from the most recent contact with health services. For deaths that occur in the township hospital, disease-surveillance staff members collect the death certificate from the hospital, where it should have been completed by the physician who attended the death. For deaths that occur in other hospitals, relatives of the deceased submit physician-certified death certificates to the disease prevention unit at the township hospital (124).

In India, the sample registration system functions entirely separately from the existing civil registration system and there are no plans for integration. In China, however, there are plans to merge the Disease Surveillance Point and civil registration systems. Although this process could take many years, it is likely to result in significant benefits for the mortality surveillance system.

Verbal autopsy (VA)

In situations where physicians are not available to certify the causes of registered deaths, a very useful option for countries is to use VA. VA is the most practical way of diagnosing the causes of deaths occurring outside hospitals or in health facilities with only limited diagnostic capability. Although the use of VA generates useful cause-of-death information at the population level – i.e. 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 VA cannot be used for legal purposes, which usually require more-rigorous medical certification.

VA is a process for diagnosing causes of death based on responses collected by a health worker from families and/or caregivers to a series of structured questions on the signs and symptoms experienced by the deceased, and their duration. These responses are usually reviewed by a physician to determine the probable cause of death. 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 in widespread use in HDSS sites.

More-recent research has generated new automated techniques that perform even better than physicians – though these techniques need to be field-tested in a range of settings before they can be recommended for universal application. Automated methods have the advantage of speed and reduce the burden on physicians who are generally required to prioritize their clinical responsibilities over other activities.

VA instruments are based on three main assumptions regarding the causes they cover:

- each cause of death has a distinct pattern of signs, symptoms, severity, duration and so on;
- these symptoms can be recognized, remembered and reported by lay respondents;
- it is possible to correctly diagnose deaths, based on the reported information, and to categorize them into groups of causes of death that are useful for public health purposes.

In practice, many factors influence the validity and reliability of VA determinations, especially for adult deaths. These factors include the distribution of cause-specific mortality in the population; the specific VA tools used (questionnaire and diagnostic procedures); and the process of data collection (including interviewer skills) and analysis (128).

The use of VA continues to be an evolving area of research. As a result, there are no definitive questionnaires, data-collection methods or analytical standards. In 2007, WHO brought together researchers and technical experts to compile a standard VA questionnaire and manual (129). After proving to be a useful resource in guiding countries in the application of VA methods and approaches, this instrument was revised in 2012 (17), and will, over time, be applied in HDSS sites and elsewhere. However, the 2007 tool does incorporate a large number of diagnostic categories which may be of interest in some research and other settings. Compared with the 2007 tool, the new instrument includes a shorter VA questionnaire that can more easily be used routinely by countries as they work to achieve complete medical certification of all deaths. The revised manual also reflects new guidelines on the use of automated methods instead of physician review to diagnose cause of death from VA. Adaptation of the revised standard questionnaire will however be required depending upon local epidemiological and socioeconomic contexts. Moreover, if VA is to be used routinely in any data-collection system then the questionnaire should ideally be as short and efficient as possible.

When planning to introduce VA determinations of cause of death, it will be important to access and benefit from the experience of researchers, country officials and populations in using the approach (130). A number of recent experiences have been described in a thematic series on VA (131) and further guidance on this issue is provided in subsequent sections of this module.

Common problems encountered

For all sentinel systems, ensuring representativeness is a major challenge as surveillance sites are not necessarily representative of the national population. In the case of sample registration systems, vital events might be missed entirely due to sampling design or choice of sample population (124). In both sentinel and sample registration systems, the data-collection and checking systems can delay access to results with adverse effects on their timeliness. Delays are then compounded in the case of VA approaches by the need for physician review of questionnaires, which can impose a heavy burden on already overstretched physicians.

As a general rule, existing HDSS sites were established for research purposes such as testing and evaluating interventions to reduce fertility, and infant and child malnutrition and mortality. For example, one of the longest-running sites (in Matlab, Bangladesh) was set up to evaluate interventions to prevent child mortality due to diarrhoeal diseases. More recently, surveillance sites have been established to test interventions for the prevention or management of HIV/AIDS and malaria. Dependence on research funding brings both benefits and risks. It helps to maintain a high standard of demographic enumeration and application of VA techniques, but introduces stresses with regard to continuity of funding.

Both sentinel and sample surveillance systems require active follow-up of vital events, which has important cost implications. The system of disease surveillance points in

China became almost non-functional in 2001/02 because of budget constraints. After an assessment in 2004, and the injection of additional resources, the system was strengthened and adjusted to improve its representativeness (127). Decision-makers considering the introduction of HDSS or SAVVY should therefore include sustainability planning in their proposals.

Another issue requiring further examination is the extent to which HDSS sites are connected to ministries of health, and to what extent the data they generate are actually used to guide national health and development decision-making. While research findings from HDSS sites are well publicized in the academic literature, not enough is known about the use of the statistics they generate by the health sector, national statistics offices or other decision-makers. Sectors with a potential interest in vital statistics include education, taxation, insurance, labour, defence, and the private and business sectors. To help resolve this issue, HDSS sites in some countries are now being taken over or co-funded by the Ministry of Health. For such sites, an annually updated burden-of-disease profile can be produced that summarizes the proportion of the mortality burden that can be addressed by targeted, locally available and cost-effective interventions (132).

In many countries there is a significant backlog of fertility and mortality data produced by the routine civil registration system that have not been compiled and remain under-used because of a lack of capacity and resources in the agencies involved. There would therefore be great benefit in promoting the transference of the enhanced skills developed in HDSS to routine civil registration systems. To avoid duplication of efforts, it will be important that sample registration systems do not function entirely separately from existing civil registration systems. Sample registration should be carried out by, or in close collaboration with, civil registration authorities to ensure effective integration into a full civil registration system, capable of the ultimate goal of producing reliable vital statistics.

7.3 Key actions

Despite these multiple challenges, health and demographic surveillance and sample registration systems remain the best ***interim*** approaches for generating reliable vital statistics on an ongoing basis in countries with weak civil registration systems and no capacity to medically certify deaths occurring outside hospitals. As outlined in Module 1, there are a number of strategic considerations that should inform decisions on the need to establish such interim approaches, and several different options should be considered:

- Countries with no existing HDSS should, as a first step, seek resources to establish at least one rural and one urban HDSS site in order to build skills and capacities, and to start to produce useable statistics – even though these will not be representative of the whole country.
- Countries with existing HDSS sites should examine how these could be further strengthened in order to generate more-complete and representative vital statistics. For example, if a country has HDSS sites only in rural areas, consideration should be given to setting up one or more sites in urban or peri-urban areas so as to better reflect the country situation.

- Countries with an established multi-site HDSS should ensure that the data from all the various sites are integrated into a shared database so as to maximize their potential use in generating sound vital statistics.
- Where existing HDSS sites are working successfully and skills and capacities for enumeration and application of VA methods are available, consideration should be given to establishing SAVVY systems with a random selection of sites that can generate representative population-based vital statistics. SAVVY is by definition a nationwide undertaking, and should be carried out as a multisectoral endeavour with close involvement of the civil registration authorities and the national statistics office.
- Parallel concerted efforts should be made to consolidate all available data on births and deaths that occur in hospitals or other public and private sector health facilities. If the inclusion of all hospitals serving urban populations is not feasible, then the strategy should be implemented in a sample of urban areas, preferably including the capital city. It is vitally important that serious efforts are made to obtain and collate data on ***all*** births and deaths occurring in a defined urban population.
- Once data have been compiled, a detailed evaluation of data quality should be carried out, using established mortality data quality checks (16), (18). These should particularly check for the under-registration of deaths, and for the quality of cause-of-death certification and coding (see Module 5). In principle, it should be easier for countries to collate, check and remedy errors in mortality data generated by hospitals, given that the vast majority of such deaths are likely to have been registered, and certified by a medical practitioner. Particular priority should be given to providing training in the correct certification of causes of death to doctors in urban hospitals that form part of the sentinel system.

It is important that in urban areas in particular, efforts are made to link the HDSS to existing birth and death registration systems, and to health information systems – especially where hospital and health-facility data are produced by medical staff trained in the determination of causes of death. The multisectoral involvement of civil registration, health-system and statistical authorities will promote the long-term sustainability of vital-event recording and data compilation.

Establishing a health and demographic surveillance system (HDSS)

Although there is no manual or textbook for organizing and implementing an HDSS, a wealth of experience in implementing such systems across diverse population sites has been built up over time by the management teams. However, whereas many of the experiences have been published in the peer-reviewed literature, the detailed practical documentation of methods is scattered across multiple "grey" reports, manuals and instruments.

A number of HDSS sites (such as Matlab in Bangladesh and Niakhar in Senegal) have been in continuous operation since the early 1960s. A typical site monitors births and deaths in the entire population of a geographically defined "sentinel" area. The population size required to track trends in the most common causes of mortality depends upon the degree of detail required for cause of death, and the levels of uncertainty that can be accepted in the estimates (133). The area covered by an HDSS site may be based on a cluster of sub-districts or localities, or on a larger single geographical area such as a clearly

defined district. Sites are selected so that households can be reached in all reasonable weather in all seasons. A detailed overview of the principles and operation of an HDSS is available (134).

It is highly recommended that countries with inadequate civil registration maintain at least one urban and one rural HDSS sentinel site, and that larger countries with diverse geographical regions and/or socioeconomic settings should have several rural and urban HDSS sites. Once expertise has been built up in the running of multiple sentinel HDSS sites, countries should consider establishing sample registration systems (see below) (109), while also implementing the improved collation of urban cause-of-death data, as outlined above.

How an HDSS works

An HDSS monitors and reliably records all births, deaths, causes of death, fertility and migration in a specified and clearly defined population. This "catchment" population is determined by a single initial census of all individuals in the sentinel demographic surveillance area (DSA). The initial census should, if possible, geolocate all households using global positioning satellite (GPS) technology, and capture core information on all residents intending to reside in the DSA over the next four months. The census should record the names, sex, age, dates of birth and civil relationships of everyone in each household, assign each of them a unique and permanent alphanumeric identifier, and register them as de facto members of the HDSS. The initial census usually takes about 3–4 months to conclude. From then on, trained enumerators visit each household every four months to update the household register by recording any inward or outward migrations, and any pregnancies, pregnancy outcomes, births and deaths.

The HDSS also typically collects information on events such as marriage and divorce. Other events recorded by the HDSS include change of head of household, formation or dissolution of a household, and the construction or destruction of building structures. Unlike the monitoring of static populations – i.e. populations defined at one point in time, with no new entrants followed up for vital events – an HDSS allows for normal population dynamics such as births, deaths and migration, and therefore allows for the calculation of accurate denominators based on person-time lived in the DSA – an essential aspect of calculating precise birth and age-specific death rates. Another particularly important output of the HDSS is cause-of-death data, which are vital for proper health planning.

Monitoring core HDSS variables

In addition to pregnancies, births and deaths, other core variables that are monitored in every update round of a sentinel HDSS site are:

- Location ID – the unique alphanumerical identification that combines a code for the enumeration area name and the unique household structure number.
- Individual ID – the unique and permanent numerical identification code assigned to registered individuals living in the residential units and household structures; which is appended to the location ID.
- Residency – the state of being physically present in a given residential unit for a defined threshold of time.

- Membership – the state of being a registered individual in the catchment population area irrespective of physical presence.
- Migration – the movement of people across a specified boundary for the purpose of establishing a new or semi-permanent residence. External migration is where the place of residence changes from a residential unit in the DSA to one outside it, and internal migration is where the place of residence changes from one residential unit to another in the same DSA.
- Cause of death – the underlying cause of death for each deceased resident member of the DSA – i.e. resident since the last visit.

Cause-of-death information is a key product of a sentinel HDSS and is derived from VAs conducted into every death within 6–8 weeks of the event. These are conducted using internationally standardized and validated instruments and coding procedures described in more detail below.

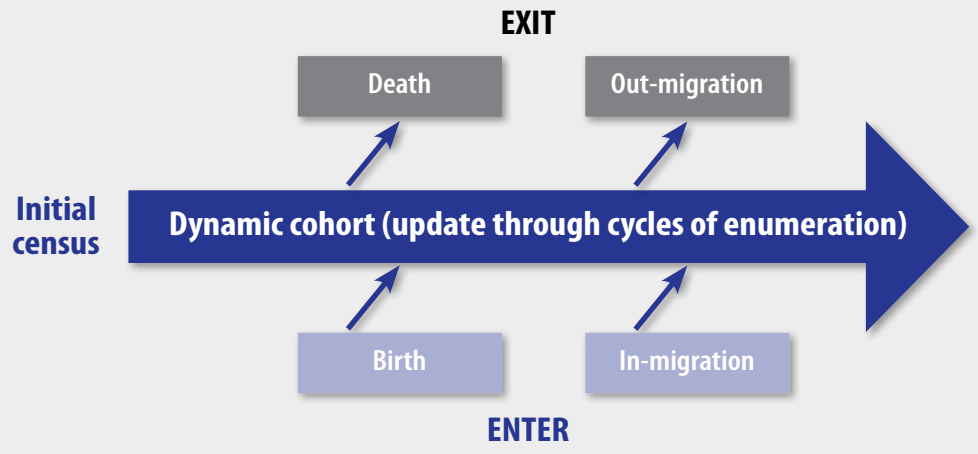
To identify deaths for VA, the sentinel HDSS maintains – in parallel with the cyclical visits of trained enumerators – a large number of "key informants" who are lay residents of the community and who continuously identify births and deaths in their local area. These key informants are visited weekly by supervisors from the HDSS who check if the locally identified events have occurred to registered members. In the case of a death, a VA supervisor will then visit the household after a suitable bereavement interval (2–8 weeks following the death) to conduct the VA. This reduces the "event recall" period for relatives compared to an approach in which deaths are only identified during the four-monthly update rounds. In such an approach, deaths occurring on the last day of a calendar year may not be identified for VA for up to four months into the following year. It could then take several more months to fully certify and code all causes of death (assuming the availability of physicians) and to reconcile all migrations in order to accurately "lock" the annual dataset for analysis, and for production of full and accurate vital statistics.

The ideal frequency of the update cycle is three or four times a year to reasonably allow for the tracking of pregnancies and their outcomes. This is particularly important for obtaining accurate perinatal and neonatal mortality rates. Three four-monthly update rounds per year are adequate for most practical purposes. Any less-frequent updating would be problematic in areas where accurate neonatal and infant mortality rates are needed.

Data from the enumerators and migration supervisors are returned to the HDSS data centre each week, and continuously cleaned and entered into a computerized data system (**Figure 20**) that updates the status of the population, and allows for the calculation of demographic rates, and the integration of cause-of-death data and other contextual variables. A crucial aspect of the HDSS is the need to reconcile the relatively common inward and outward migration of registered members. Some migration will be within the HDSS area and hence such members must continue to contribute person-time to the denominators. Other migration may take members outside the HDSS area for periods exceeding an update-round cycle when their person-time will not count in the denominators. Returning residents retain their unique identifiers and can resume residency in the system. This activity requires dedicated resources in the data centre to reconcile all migrations and maintain the database.

A typical sentinel HDSS site monitors a rural population of 70 000–100 000 people. However, reliably tracking causes of death at the more-detailed levels may require up to 10 times as many people to be monitored. Methods have been provided for calculating required population sizes according to the frequency of the particular causes of death of interest (133). Normally, an HDSS employs approximately 30 field enumerators with bicycles; seven enumerator supervisors; three key-informant supervisors; three migration supervisors; and three VA supervisors with motorcycles; one demographer; one data manager; and five data clerks with one vehicle. The total annualized running costs for a core sentinel HDSS is in the order US$ 250 000 per year. Costs are lower in urban HDSS sites where events are generally easier to track.

Figure 20: The concept of a dynamic cohort* in an HDSS



* Defined as a cohort of individuals identified in the initial census that changes over time due to entrants (births and in-migrants) and exits (deaths and out-migrants), and is monitored through repeated updates.

Major considerations in running a sentinel HDSS site

Before establishing a sentinel HDSS site there are numerous issues to consider, including:

- legal ownership, status, identity and leadership
- governance management and advisory committees
- site strategic plan
- financing and funding partners
- data management and sharing
- users and stakeholders
- networking
- permits, and institutional and ethics approvals.

For example, HDSS data-management systems require a reference data model (RDM) which provides the temporal design for a relational database for the demographic history of a population. The RDM allows for the recognition of key events that determine life

transitions and of key episodes that mark the time intervals between events (such as marriage or residence times). The RDM records and manages membership of social groups, residence times at various locations, "status" observations, observation times, and all of the events needed to define the population under observation and track its basic dynamics (135). Most INDEPTH sites currently use the Household Registration System. New open-source applications such as the Open Household Demographic System[11] have allowed for significant updating of data capture, computing systems and the RDM used. These and other technical and methodological issues related to the running of a sentinel HDSS are fully addressed in the INDEPTH Resource Kit (see section 7.4). The kit also provides financial templates, personnel and administrative manuals (including accounts charts), and tools for estimating HDSS capital investments and running costs.

The 10 key steps in establishing an HDSS site are summarized in **Box 28**.

BOX 28. Ten steps in establishing an HDSS site

1. Establish ownership and governance structures.
2. Develop sustainable funding arrangements.
3. Identify population size, sentinel site and boundaries.
4. Develop design considerations, operational procedures and instruments.
5. Recruit and train staff – establish field office, and acquire capital, equipment and supplies;
6. Initiate community approach and information provision.
7. Conduct initial census and geo-locating of all households, and establish the core database.
8. Conduct the first update cycle.
9. Process data from the first update cycle, including VA questionnaires.
10. Prepare feedback to stakeholders and communities.
11. Full details of each of these steps are provided in the INDEPTH Resource Kit (see section 7.4).

Sample vital registration with verbal autopsy (SAVVY)

The enumeration of births and deaths coupled with VA in sample areas has been conducted in India since 1970 by the Sample Registration System (SRS) of the India Registrar General's Office, and in China since 1989 through the Chinese Disease Surveillance Point (DSP) system. SAVVY can be considered to be a more-generalized version of these methods, and is particularly relevant for countries with weak or absent civil registration systems as it allows for the generation of routine vital statistics in both rural and urban areas.

[11] For more information please see: http://openhds.rcg.usm.maine.edu/

How SAVVY works

SAVVY is essentially a demographic surveillance system built around vital-events monitoring for a representative sample of the population. It operates in a similar way to a sentinel HDSS as described above – but in this case the sample sites are distributed across the entire country to generate statistically representative estimates in urban and rural settings. A two-stage probability sampling method is typically used – with geographical areas sampled first, followed by villages and urban districts within the selected areas. The total sample size of a SAVVY system is normally in the order of 1–2% of the total national population. The system uses repeated total counts or censuses and continuous reporting of vital events to generate information on population, age, sex, household characteristics and migration. SAVVY was originally developed by USAID through its MEASURE Evaluation project[12] and the United States Census Bureau.

The first step engages the national census bureau in identifying sample locations that are statistically selected to provide nationally representative data. As with the sentinel HDSS approach, a complete baseline census is then conducted of all households and residents in the sample areas. Subsequently, the census information on the residents of each sample area is updated by annual or two-yearly repeat censuses – i.e. less frequently than the minimum of three times per year in the HDSS. Following the baseline census and continuously thereafter, lay key informants (rather than trained enumerators as in the HDSS) notify a VA interviewer of all deaths occurring in the sample area. The VA interviewer is typically a trained health worker (but ***not*** a medical doctor) from a health centre in the sample area. The VA interviewer conducts an interview at the household where the death occurred. A physician trained in correctly certifying deaths from the local health centre in the sample area should then review the VA questionnaire to determine the cause of death according to international-standard procedures. The data are then transferred to a local data centre (usually in the health centre). All data are handled in a dedicated computer system called SAVVY CSPro.

A fully implemented SAVVY system should also be capable of producing sub-national data, but in practice this is normally limited to the provincial or regional level, rather than the district level, due to cost considerations. The census and mortality data in SAVVY can be used to monitor and evaluate major disease control programmes at the national level, and thus to monitor progress towards national and international goals and targets, including the MDGs. User-friendly reporting software also permits indicators to be produced separately for age, sex or poverty groupings, and by geographical area. The production of routine SAVVY system outputs can be tailored to support and guide local planning and budgeting cycles. For example, an annually updated profile can be produced showing what proportion of the mortality burden could be addressed by specific locally available and cost-effective interventions.

Most people working to implement SAVVY systems are selected with community input and participation – a key factor for success and sustainability. It is also important that SAVVY be positioned as part of a national vital statistics strategy, requiring long-term commitment on the part of national and local government, and the active participation of the national statistics office, ministry of health, civil registration authority and other relevant partners. It is anticipated that several stakeholders will join together to

[12] For more information please see: http://www.cpc.unc.edu/measure/tools/monitoring-evaluation-systems/savvy/

invest in the establishment and sustained functioning of a SAVVY-based sample vital registration system, and to support its scaling up. Over time, the system should begin to complement the output of a weak civil registration system, thus helping to promote broader understanding of the importance and advantages of both civil registration and vital statistics, potentially leading to increased levels of birth and death registration in the population.

Despite its significant potential advantages in monitoring vital events and causes of death – and positive experiences of its long-term use in China and India – there is relatively little experience of implementing SAVVY in other regions, notably Africa. In Zambia, a sub-national SAVVY pilot study has been conducted (136), and a national SAVVY is in the process of being launched in a number of sample districts in the United Republic of Tanzania **(Figure 21)**.[13]

Figure 21: SAVVY districts in the United Republic of Tanzania

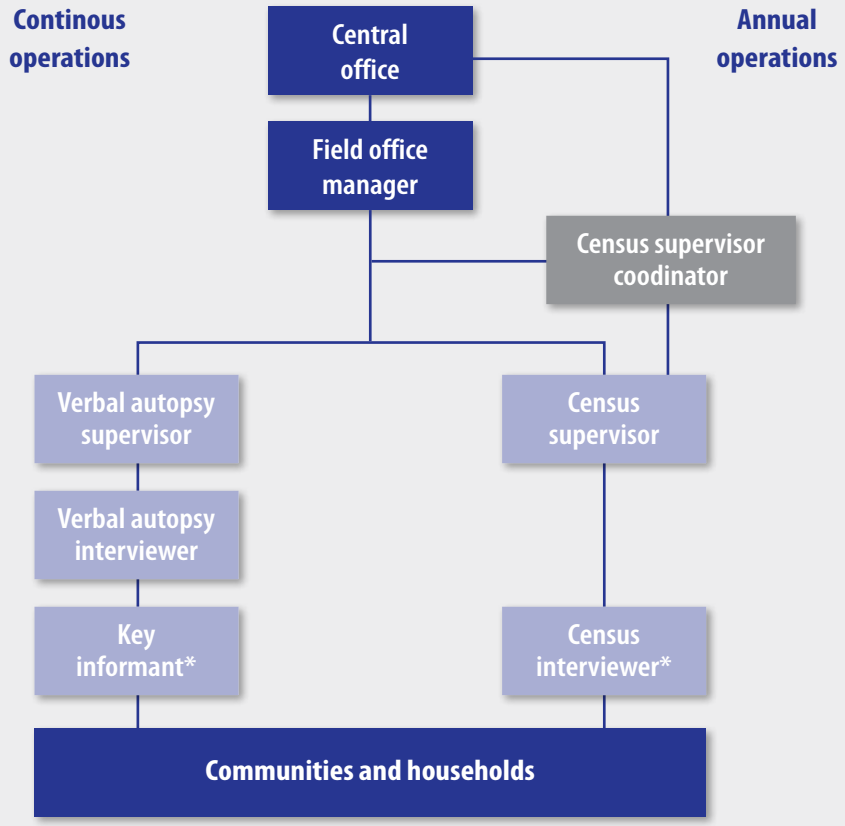
Provided that the sample districts are chosen on a strictly representative basis – i.e. according to the socioeconomic characteristics of the population identified in a recent census – then the SAVVY system should yield representative information on births, deaths and causes of death for the whole country. It is important to avoid choosing sample sites because of convenience and/or cost considerations (for example, wealthier districts with better infrastructure such as roads, or urban areas only). Collectively, the sample districts chosen should be truly representative of national living conditions, access to health care and other factors likely to affect fertility and mortality.

[13] For more information please see: http://www.ihidata.org/spd.php

If it is not feasible to monitor all of the population in a selected geographical district, then a second-stage sampling procedure should be used to identify representative population groups within the selected district (such as those living in a particular village or urban sub-area) that can feasibly be monitored. Where there are doubts about the sampling strategy, it is preferable to choose fewer sampling units (that are still representative of the country) in order to reliably monitor ***all*** events and causes of death.

Figure 22 shows how a typical SAVVY system might operate based upon the roles and reporting relationships of different personnel. Cause-of-death data are collected continuously using VA methods (see next section). In addition, personnel will have to be recruited specifically to carry out the annual census of the populations living in each sample site. Staff responsible for the annual census and those responsible for the continuous collection of VAs should each report to a field office manager whose role is to consolidate the annual vital statistics on births, deaths and causes of death for each site.

Figure 22: Typical operation of a SAVVY system



* If possible, these roles should be filled by a single individual.

The 10 key steps in establishing a SAVVY system are summarized in **Box 29**.

BOX 29. Ten steps in establishing a SAVVY system

1. Establish leadership and secure funding.
2. Obtain buy-in at the national level (including from ministries of health, finance, local government, justice and home affairs) and from advisory and technical governance structures (such as the offices responsible for the census and for national statistics).
3. Develop a sampling strategy in consultation with the statistical office.
4. Sensitize local authorities and establish ownership.
5. Recruit key staff (centrally and in the sample districts).
6. Plan a phased-in approach to inform expansion.
7. Adapt key SAVVY documents and develop data-management systems.
8. Train staff in the areas of census enumeration, VA and reporting of vital events.
9. Collect data and process the baseline census and deaths in sample populations.
10. Prepare analyses and reports, and disseminate.

VA to ascertain causes of death

Both HDSS and SAVVY use VA techniques to ascertain causes of death in the surveillance population. VA is essentially a two-stage process:

- **Stage 1** – an interviewer (***not*** a medical doctor but preferably a trained lay person) visits the household where a death has occurred to interview the family using a predesigned questionnaire, and to record all responses in a standardized manner (17).
- **Stage 2** – the pattern of responses is reviewed by a physician (***never*** a lay person) to determine the probable cause of death based on the signs and symptoms reported by the family. This process can be aided by reviewing information on the events leading up to death provided by the family in their own words (the "open narrative"), as well as any information reported by the family that resulted from contact with health facilities (for example, being told by a hospital that the deceased had a specific disease).

The operational steps in moving from a VA interview to a final underlying cause of death that is likely to be of use for health services policy and planning are shown in **Figure 23**, which also highlights the various factors (in shaded boxes) that are likely to influence the accuracy of underlying cause of death determination, and hence of the resulting cause-specific mortality fractions.

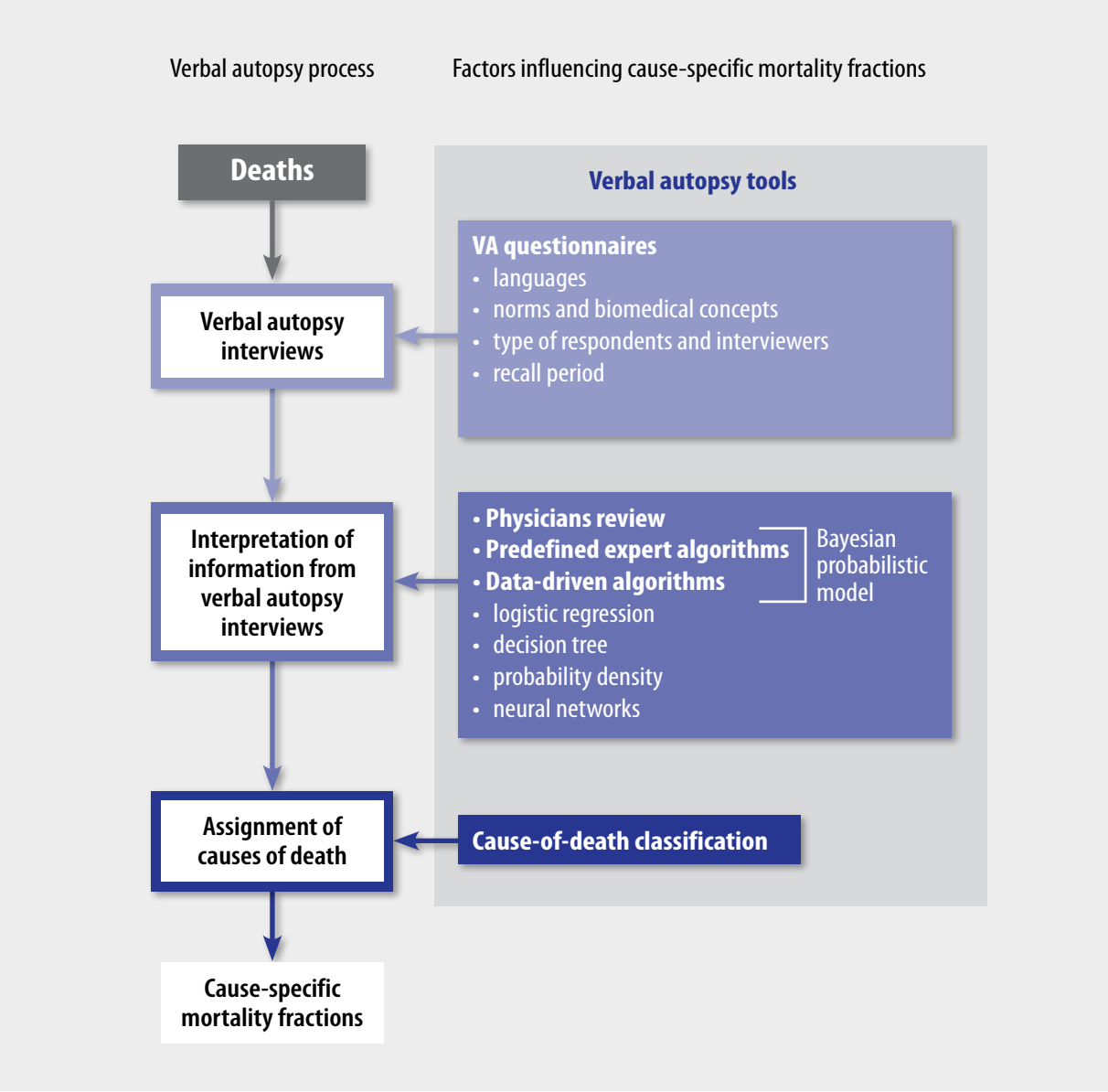
The middle box shown in **Figure 23** refers to Stage 2 of the VA process, and offers an alternative to the more-expensive and time-consuming option of physician review outlined above. This is the use of computer software to read "patterns" in the responses and to come up with a probable cause of death. The strengths and limitations of these two approaches to diagnosis are discussed below. It should also be noted that the three shaded boxes shown: VA questionnaire, diagnostic-assessment (by physician or computer) and a "target" cause of death classification comprise the set of tools required to collect and use VA data. These three tools are described in detail in the WHO VA instrument and manual (17).

VA interviews

Many factors influence how well VA tools will perform in practice in the interview setting, including:

- **Language** – the language used in VA questionnaires and during the interview itself has to be appropriate to the local context to allow the maximum amount of information to be captured. Standard questionnaires may need to be adapted to suit a specific setting, and translated into the local language. Translation has to be done very carefully to ensure that the meaning of each original question is not altered. It may be useful to validate a translated questionnaire in a small area first prior to its wider application.
- **Cultural norms and biomedical concepts** – the norms and biomedical concepts of the local setting need to be considered when selecting appropriate VA questions. For example, if blood loss after childbirth is widely considered to be "normal" then respondents may not report heavy bleeding.

Figure 23: VA process and factors influencing cause-specific mortality fractions



- **Characteristics of respondents and interviewers** – the education, socioeconomic characteristics and expectations of local respondents, as well as the background and training of interviewers, also influence the accuracy of VA data.
- **Recall period** – although the ideal time period for recalling information about a death has not been determined, many studies indicate that the VA should take place less than one year after the death, and preferably sooner to minimize recall errors. In many settings, the VA interview is conducted just after the traditional period of mourning.

Experience indicates that it is preferable to ***not*** use physicians as interviewers. Nurses, other allied health workers and even students can be adequately trained to collect data via VA questionnaires.

Open-ended versus close-ended questionnaires

Variation in the structure of VA questionnaires may lead to different outcomes or responses. For example, open-ended questions require the respondent to recall specific details, while close-ended questions require the recognition of symptoms. Experience indicates that more information is likely to be "recognized" rather than "recalled". The use of open-ended questions may therefore require interviewers to have medical training in order to prompt the recall and recognition of appropriate symptoms and signs that are not voluntarily reported. However, medical training is not necessary for obtaining reliable responses to close-ended questions (130). These two factors would suggest that it is better to use closed rather than open-ended questions. Recent research has suggested that VAs that use both close-ended questionnaires (consisting of a structured set of questions on signs and symptoms) and open narrative (in which the respondent is asked to describe in their own words what happened when the death occurred) perform best (131). However, if automated methods are to be used for determining the cause of death, the open narrative will be difficult to incorporate.

WHO VA standards

Because VA instruments have been developed on an individual basis for application in different sites, there is enormous variation between questionnaires and analysis methods. However, if data derived using VA are to be compared over time and across different regions or countries, it is important to standardize the instruments as far as possible. WHO has developed a manual on VA standards (17) that countries are recommended to use pending further developments. Some local adaptation will be required to take account of different epidemiological and demographic profiles, and the final questionnaire should be field-tested and validated before its widespread use. In addition, WHO recommends the use of the three distinct age-group questionnaires described in **Box 30**.

An adapted version of the standard WHO VA questionnaire is being used as the basis of a research project led by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. This project assesses the performance of various methods for diagnosing causes of death – i.e. the second stage of the VA process shown in **Figure 23**. The adapted questionnaire incorporates advances in medical knowledge since the WHO standards were published in 2007. The Population Health Metrics Research Consortium (PHMRC) questionnaire (137) is based on the WHO model and focuses on the same three broad age groups – i.e. neonates, children and adults.

BOX 30. WHO VA questionnaires (17)

VA questionnaire 1: death of a child aged less than four weeks

Questionnaire 1 distinguishes between stillbirths, early neonatal deaths and late neonatal deaths. It also aims to determine the causes of perinatal events and deaths. In addition to the "signs and symptoms noted during the final illness" checklist, the questionnaire contains extensive questions on the history of the pregnancy, delivery, the condition of the baby soon after birth, the health of the mother and other contextual factors.

VA questionnaire 2: death of a child aged four weeks to 14 years

Questionnaire 2 is designed to ascertain the major causes of post-neonatal child mortality (i.e. starting from the fourth week of life) as well as causes of death through to 14 years of age. The questionnaire includes all of the standard data described above, as well as modules for children aged four weeks to 11 months.

VA questionnaire 3: death of a person aged 15 years and above

Questionnaire 3 is designed to identify all major causes of death for adolescents and adults (i.e. starting at age 15). The questionnaire includes an extensive module for all female deaths, including deaths related to pregnancy and childbirth. Questionnaire 3 also includes a module on behavioural risk factors such as alcohol and tobacco consumption.

Physician-coded VA

Scientifically sound methods for interpreting and analysing VA data are essential if VA methods are to fulfil their potential as valid sources of cause-of-death data. Once a VA questionnaire is completed, the next step is to assign a cause of death using the information recorded. In most VA systems, questionnaire responses are coded against a partial list of the ICD-10 disease codes because it is impossible to define the symptoms and signs for the complete list of causes of death. Most VA systems use a shortlist of 40–50 causes to make diagnoses.

Currently, it is common practice for all VA questionnaires to be assessed by one or more trained physicians who determine the probable cause of death on the basis of the interviewee responses. This is commonly known as "physician-coded VA". In many VA systems, physicians diagnose an underlying cause of death directly from the reported signs and symptoms on the VA questionnaire. More recently, VA systems have followed stricter protocols in which physicians review the VA questionnaire and complete a WHO International Form of Medical Certificate of Cause of Death in which they attempt to identify the sequence of morbid conditions that led to death (see Modules 4 and 5). The certificates are then coded by trained coders. In this approach, physician-coded VA requires inputs from both physicians and coders when coding the death certificate.

The principle underlying the practice of physician review of VA is the assumption that only physicians can correctly interpret the signs and symptoms reported to have been experienced by the deceased, and hence accurately assign the causes of death. In some cases, one physician may carry out the initial review of the VA questionnaire, and their cause-of-death determination is then reviewed by a second, independent, physician. Where the two diagnoses differ, a third physician may be asked to determine the cause of death.

Such requirements for physician (and multi-physician) review frequently lead to major bottlenecks in terms of available human resources and time. In some settings, the analysis of completed VA questionnaires is delayed by months or even years due to the heavy workload or non-availability of physicians. Moreover, a growing body of research has raised serious concerns about the assumed accuracy of physician diagnosis (131). Some of the main findings of this research are outlined below. A more-fundamental and practical concern with physician-coded VA methods is that they are expensive, time consuming and can burden health systems in resource-poor areas by diverting physicians away from their clinical responsibilities. Such concerns have led to efforts to develop and assess the performance of automated methods for coding VA questionnaires that do not rely upon the involvement of physicians.

Automated coding of VA

Computer automated coding of VA is a promising alternative to the traditional approach of physician-coded VA. Computer coding is high speed, low cost and reliable as it removes inter-physician variability and overcomes many of the disadvantages associated with physician-coded VA. Several INDEPTH sites have now switched to the INTER-VA automated statistical algorithm for coding the responses to VA questionnaires.[14] This public-domain method uses a Bayesian probabilistic model to derive the cause of death from input indicators, such as disease history, signs and symptoms recorded in the VA interview.

Although more complex machine-learning methods have also been developed, these have not yet been widely implemented. Based on computer algorithms, these approaches infer patterns from a set of data ("training data set"). In this context, the training data are VA responses for a set of cases for which the true underlying cause of death in each case is already known following the application of rigorous gold-standard procedures. An automated method can then be developed on the basis of the training data set. Performance is then assessed by applying the method to VA responses for an independent set of cases ("test data set") for which the true cause of death is once again known with confidence following use of the same gold-standard procedures.

As outlined in section 7.4 below, PHMRC research on the application of automated VA methods and on the comparative performance of different diagnostic approaches – i.e. stage 2 of the VA process – has been published and usefully compiled (131). A five-year PHRMC study into the use of automated approaches to VA coding is outlined in **Box 31**.

In addition, the IHME web site[15] provides convenient summaries of the methods, advantages and validation characteristics of the various automated methods that can be used for diagnosing VA questionnaires. The so-called "Tariff method" is particularly appealing since it relies on the "strength of the signal" in relation to the symptoms reported in the VA, rather than on a more-complex statistical algorithm. In other words, any symptom reported in the VA that is known to be highly predictive of a particular cause of death ("signal") will have a significantly higher score ("tariff") assigned to it for that particular cause of death, compared with other less strongly associated symptoms ("noise"). The cause of death with the highest total tariff is then automatically selected.

[14] For more information please see: http://www.interva.net

[15] For more information please see: http://www.healthmetricsandevaluation.org/publications/summaries

BOX 31. Outcome of the PHMRC study into the automated coding of VA (137), (180), (181)

In an attempt to address the drawbacks identified in previous VA validation studies, the PHMRC undertook a five-year study (2005–2010) to develop a range of new analytical methods which could be used to diagnose causes of death from VA, and compared the results with those of obtained through the traditional practice of physician coding of VA questionnaires. These methods were tested using data collected at six sites in four countries – India, Mexico, the Philippines and the United Republic of Tanzania.

The study was unique due to the size of the validation dataset (12 542 deaths in neonates, children and adults) and the use of rigorously defined clinical diagnostic criteria. The study also provided new evidence on issues related to physician-coded VA, such as the impact of a second physician on the assigned cause of death, variations in diagnostic accuracy with and without household recall of health-care experience, and the importance of prior information from health services for physicians reading VA questionnaires (137).

The findings confirmed that in nearly all settings in the study, physician-coded VA performed worse than three automated approaches (tariff method, simplified symptom pattern and random forest). These findings are of major importance for countries wishing to use VA methods to determine causes of death in the absence of complete civil registration with full medical death certification. Automated methods are more accurate than physicians in diagnosing the cause of death from VA questionnaires (182). Moreover, automated methods are free, quick and can be made available on platforms such as mobile phones. Therefore, there is little justification for continuing with expensive and time-consuming physician-coded VA.

With the ongoing development of inexpensive, timely and reliable automated methods to determine causes of death in populations, it is now possible, in principle, to apply them to routine vital statistics systems. As of 2012, a number of new methods were being trialled in sample populations in several countries, including China, Mozambique and Viet Nam. This research is likely to provide valuable insights into the feasibility of using automated methods for analysing VA data within the next 1–2 years.

Ten steps to follow when applying VA approaches to the collection of cause-of-death information are summarized in **Box 32**.

BOX 32. Key actions in applying VA approaches to the collection of cause-of-death information

1. Establish a group of stakeholders familiar with the local epidemiological and socioeconomic context to adapt the standard WHO VA questionnaire.
2. Work with a social scientist to determine local meanings and terminology for all signs, symptoms, diseases and conditions.
3. Translate the agreed questionnaire into the local language(s).
4. Recruit and train interviewers (do not use doctors).
5. Pilot the questionnaire.
6. Validate and revise the questionnaire.
7. Develop data-entry screens and a database system.
8. Start conducting VAs, preferably using electronic data capture at point of interview.
9. Code causes of death, preferably using machine-learning methods. Avoid physician coding.
10. Review the quality of cause-of-death results, and prepare annual reports for stakeholders and other users.

7.4 Tools and resources

Establishing an HDSS or SAVVY system

• INDEPTH Resource Kit for Demographic Surveillance Systems

In relation to establishing a sentinel HDSS, this internet and print-based Resource Kit provides complete access to detailed technical guidance, examples of all instruments, a vast array of manuals, tools, software and Stata routines. The available resources are listed in Annex E and can be downloaded at: **http://www.indepth-network.org/index.php?option=com_content&task=view&id=95&Itemid=183**

In relation to SAVVY, a number of other resources are available as training materials, sample forms, job aids, electronic documents, spreadsheets and software. These resources are listed in Annex F.

Applying VA-based approaches

• WHO Verbal autopsy standards: Ascertaining and attributing cause of death (17)

This revised instrument incorporates a number of resources for standard data-collection and cause-of-death assignment, along with general guidelines.
Included are VA questionnaires for three age groups, cause-of-death certification and coding guidelines for applying ICD-10 and related health problems to VA-based approaches, and a cause-of-death list for use in VA with corresponding ICD-10 codes. The full instrument and manual are available at:
http://www.who.int/healthinfo/statistics/verbalautopsystandards/en/

In addition, the original 2007 instrument (129) upon which the revised 2012 version is based incorporates a large number of diagnostic categories which may be of interest in a

number of research and other settings, and is available at:
http://www.who.int/healthinfo/statistics/verbalautopsystandards/en/index1.html

• Verbal autopsy: innovations, applications, opportunities (131)

This comprehensive account of VA-related experiences and potential uses is the summarized outcome of an extensive research project into the comparative performance of six different approaches to the automatic diagnosis of the cause of death from VA questionnaires. In most settings, all six methods performed better than physician coding, thus providing compelling evidence that countries should ***not*** use physicians to code VA forms but should instead adopt automation. Once field testing has been finalized in several countries, widespread access to high-performing automated software will be facilitated by WHO, the University of Queensland HIS Hub and HMN. The document is available at: **http://www.pophealthmetrics.com/series/verbal_autops**y

***• IHME develops fast, affordable ways for countries to better identify causes of death in populations* (News release)**

Available at: **http://www.healthmetricsandevaluation.org/news-events/news-release/ihme-develops-fast-affordable-ways-countries-better-identify-causes-death-p**

7.5 Summary

For many countries, the routine generation of timely, accurate and complete statistics on births, deaths and causes of death will require years of strategic and prioritized investment in civil registration. In the interim, countries need accurate and unbiased data in order to track progress towards improved health outcomes and broader development goals, such as the MDGs, and to identify emerging challenges such as the growing crisis of noncommunicable diseases.

This module has outlined a number of interim approaches that can yield reasonably adequate birth, death and cause-of-death data as countries work to strengthen their CRVS systems. These approaches require the same kinds of skills, capacities and practices as functioning CRVS systems, and generate the same type of information – but for only a sample of the population. By applying rigorous and continuous data collection for a defined and manageable part of the population – i.e. doing "smaller, representative populations well" rather than "larger populations poorly" – biases can be reduced that would otherwise result from missing data, incorrect application of data-management procedures, poor data-quality checking, and lack of medical certification of causes of death.

A key component of this strategy is the routine application of VA methods to the collection of essential cause-of-death data. When properly applied, VA can yield population-based cause-of-death data of comparable quality to data typically collected in hospitals in developing countries. Moreover, the growing availability and accuracy of automated methods for diagnosing causes of death will make it possible to obtain accurate mortality data routinely, cheaply and quickly in resource-poor settings.

The long-term goal of strengthening CRVS systems is to ensure that every birth and death is properly registered, and that causes of death are accurately and medically certified.

In addition, civil registration systems provide individuals and families with the official evidence of the occurrence of vital events needed to obtain legal documentation such as birth and death certificates. Sentinel surveillance and sample registration systems can effectively generate useful statistics on vital events but do not currently provide the documentary evidence for legal certification. However, some sample registration systems, for example in the United Republic of Tanzania, are investigating ways of bridging this gap. Interim data-collection methods are also not well suited to the identification and monitoring of differential mortality rates among different population subgroups – which are central activities in national efforts to reduce health inequalities.

Stakeholders wishing to establish sentinel surveillance or sample registration should therefore work in collaboration with the national and local authorities responsible for civil registration, and should support and promote the formal registration of births and deaths whenever possible. The establishment of sentinel surveillance or sample registration systems should help to strengthen the capacity of the health system to correctly certify causes of death for each decedent (see Module 4). The key actions to be taken when establishing interim methods for generating vital statistics and introducing VA approaches are summarized in **Box 33**.

Many different agencies and institutions will need to be involved in strategies to establish or extend the use of these interim methods (HDSS, SAVVY and VA) in countries where civil registration systems are dysfunctional or weak. The skills and expertise built up in HDSS and SAVVY sites will be an invaluable resource for linking to, and scaling up, the existing CRVS system. The roadmap proposed in **Box 34** outlines some of the major steps to be taken – from an initial mapping of the situation, to the establishment of collaboration and information-sharing mechanisms, and the development of a strategy for action. This roadmap should be regarded as a suggested starting point for subsequent adaption to local circumstances and needs.

BOX 33. Key actions for establishing interim methods for generating vital statistics and for introducing VA approaches

1. In countries with no HDSS sites – consider establishing at least one rural and one urban site in order to generate initial data on births, deaths and causes of death, and to start building the skills and capacities needed for more-extensive future surveillance and registration systems.
2. In countries where HDSS sites are confined to rural areas – establish additional sites that would better reflect the situation in urban areas.
3. In countries with several HDSS sites – introduce sample registration systems so as to generate nationally representative vital statistics.
4. In parallel to establishing one or more HDSS or sample registration sites, make concerted efforts to consolidate all available data on births and deaths that occur in private and public health facilities. If it is not feasible to include all hospitals serving urban populations, then the strategy should be implemented in a sample of urban areas, preferably including the capital city. It is important that serious efforts are made to obtain, and collate data on all births and deaths occurring in a defined urban population.
5. Once data have been compiled, conduct a detailed evaluation of their quality using established checks of mortality data quality. In particular, check for under-registration of deaths, and assess the quality of cause-of-death certification and coding (see Module 5).
6. In settings where cause-of-death information is limited to hospital deaths, introduce VA techniques to ascertain the patterns of mortality at community level.
7. In settings where lay reporting and informal VA methods are used to identify causes of death, review the current instruments used and consider if these need to be adapted or improved.
8. In settings where VA techniques are already in use, review the burden of physician coding and examine the possibility of introducing automated systems for the ascertainment of underlying cause of death.

BOX 34. Basic roadmap for developing a plan to establish or extend interim approaches for the generation of vital statistics

Step 1: Map existing HDSS sites and review available data on births, deaths and causes of death. The mapping process should cover the level of lay reporting of causes of death, and a review of currently used VA instruments.

Step 2: Establish communication and information-sharing mechanisms that bring together staff from existing HDSS or SAVVY sites, local and national civil registration offices, ministries of health, national statistics offices, academia and other relevant stakeholders.

Step 3: Work with academic and technical experts and with government representatives from health, civil registration and statistics offices to develop a strategic approach for establishing and/or extending HDSS sites or, if possible, introducing SAVVY. The strategy should include an analysis of the potential for introducing VA techniques – using either physician coding or available automated methods – as part of the routine notification of deaths. The strategy should be clearly positioned as part of broader efforts to strengthen overall CRVS systems.

Step 4: Present the strategy to a broader group of stakeholders including high-level decision-makers in all relevant agencies, researchers and academic institutions that are major users of vital statistics, and representatives of civil society and NGOs to:

- mobilize support for reform among those involved in CRVS systems;
- identify the roles and responsibilities of different stakeholders in taking forward the implementation of the strategy;
- identify resources, training and technical support needs;
- implement agreed activities.

Step 5: Establish an ongoing monitoring group to review implementation of the strategy and document the lessons learnt.

MODULE 8:

Building support for strengthening civil registration and vital statistics

8.1 Introduction

Each of the preceding modules has identified common problems and weaknesses in CRVS systems and outlined the key actions needed to address them. However, being aware of problems and identifying solutions will not be sufficient where there is no political will to act and bring about change. Moreover, the civil registration system will never function effectively without community cooperation, as people will not register vital events if they are unaware of the necessity to do so, and unconvinced of its value. Similarly, the certification and registration of cause of death are only possible if the medical establishment collaborates, and follows standard death-certification procedures.

Improvement strategies therefore almost always need to include advocacy among different constituencies – whether to bring about legislative or policy change, secure investments for improving CRVS systems or engage civil society. This module is about building support among key groups for the strengthening of CRVS systems in places where their value is not fully understood or appreciated. It discusses approaches that might be useful for convincing government and local authorities of the significant benefits they can derive from improving their CRVS systems. In addition, ways are discussed of harnessing community support for the specific aspects of civil registration that provide significant benefits to individuals and communities. Illustrating the different ways in which data can be used to guide decisions is also part of advocacy. Strengthening CRVS systems can greatly enhance evidence-based policy-making, lead to better decisions and facilitate the fuller realization of basic human rights.

This module addresses questions such as:

- What approaches can be used to effectively advocate for improving aspects of CRVS systems?
- Who is likely to support efforts to advocate for CRVS systems improvement?
- What is the process of advocacy, and what steps should be considered?
- What tools and resources can assist the development of an advocacy strategy?

8.2 Background

Why is advocacy needed?

It is human nature to resist change and anyone who has tried to introduce new procedures into a work environment will have experienced the need to convince staff and co-workers that doing things differently is in the common interest. These issues have given rise to the field of "change management" which deals with how to better plan the implementation of change and overcome resistance (138). Managers faced with the challenge of introducing

new technologies into civil registration systems or other profound organizational changes have to become advocates for change. To increase their chances of success, they should consult the literature on change management and change leadership, which argues that leaders must transform themselves if they are to successfully lead transformation in their organizations. There are several useful toolkits on how to advocate and promote policy change that provide useful practical advice and case studies illustrating different strategies and potential partnerships (see section 8.4).

What is meant by "advocacy"?

There is no agreed standard definition of what constitutes advocacy and the activity can be conceptualized in several different ways. For the PARIS21 consortium advocacy is...*pleading for, defending or recommending an idea before key people in order to obtain a change*. Others have viewed advocacy as the actions, strategies and effective collaborations created to shift public opinion, create political and community support, and influence decision-makers (139); or as being about creating or reforming policies and ensuring that good policies are implemented (140). Whatever definition is adopted, advocacy is about influencing outcomes – including public policy and resource allocation – and convincing policy-makers and other responsible parties to take action.

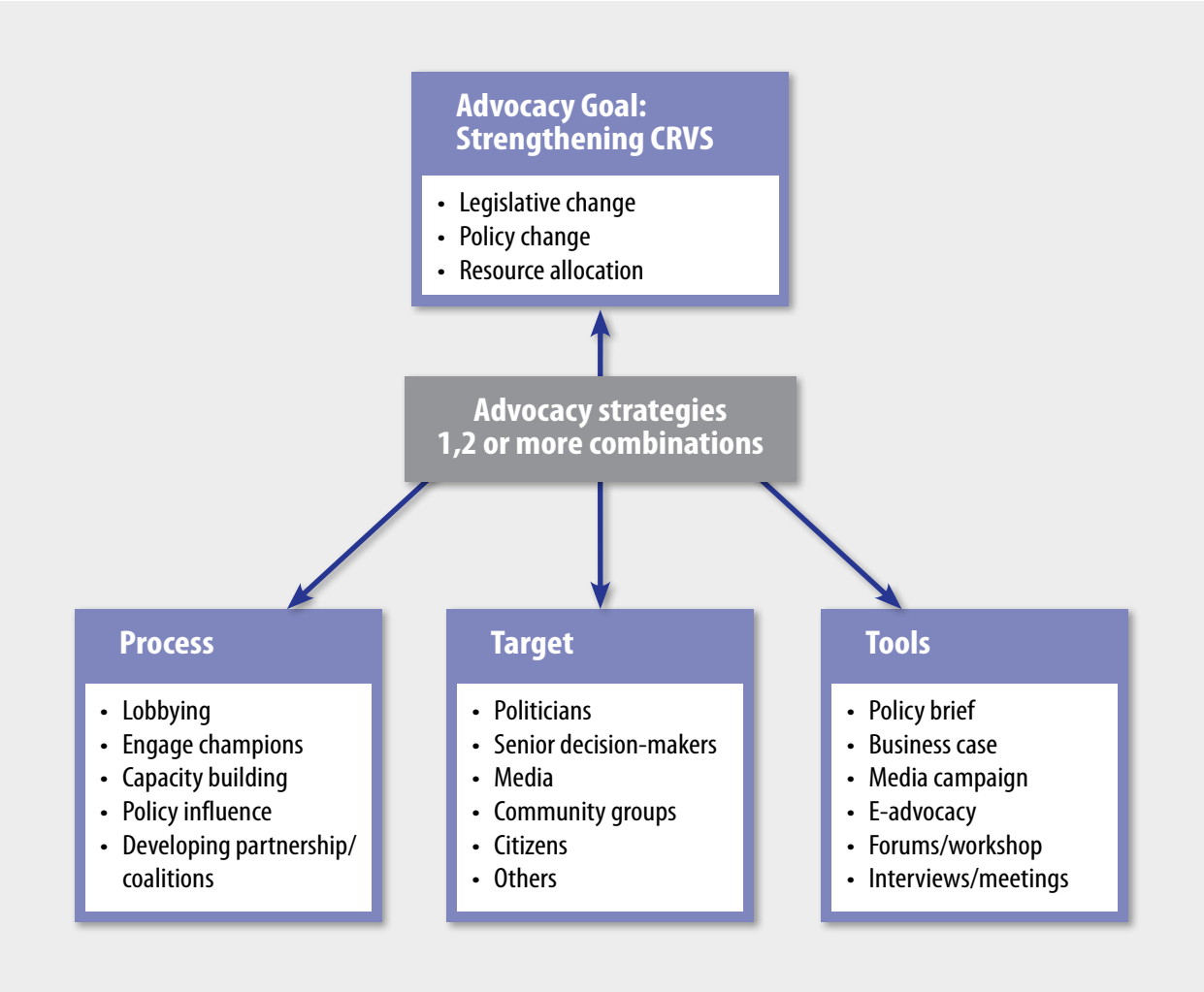
In this module, focus is placed on the use of advocacy to bring about changes in legislation, social policy and resource allocation – with the overall goal of strengthening CRVS systems. To convince politicians, policy-makers, private-sector directors, community leaders, and many others that investing in and improving CRVS systems is necessary and in the best interests of the country, advocacy must be undertaken.

What are the different components of an advocacy strategy?

The three main components of an advocacy strategy are the target audiences, and the processes and tools used to engage and persuade them of the need for change. Together, these three components should comprise the core of an advocacy strategy (**Figure 24**) that can be employed to achieve the set objectives at national and sub-national levels. The development of an advocacy strategy should be informed by a careful policy and stakeholder analysis. The processes required here include lobbying decision-makers and politicians, engaging CRVS champions to inspire and motivate others, and building personnel capacity across government and non-government sectors to influence policy-makers. In addition, partnerships will need to be developed with supportive individuals or organizations.

Reaching different target audiences requires selecting the right kind of communications tools. Tools may include policy briefs on the importance of reliable statistics for health planning; a business case for increased investment in CRVS with a cost-benefit analysis; a mass-media campaign to increase awareness of registration issues; and workshops targeted at specialized groups such as physicians or hospital staff. Other options include television debates and media interviews to deliver key messages and create pressure on politicians for change. As well as externally directed advocacy, internal advocacy within the organizations of those seeking to effect change may be needed in order to build up organizational or institutional support for the improving of policies, services, work routines

Figure 24: Components of an advocacy strategy



or CRVS funding. Anyone, irrespective of their function within an organization, can be an advocate for change if a number of simple rules are followed (139). For example, causes must not be self-serving and must be approached with integrity and adherence to high professional standards if they are to be credible. Some of the general key features which have to be considered when advocating for change are shown in **Box 35**.

BOX 35. Key features of successful advocacy

- **The issue for change** – are people aware that the problem exists or does it need to be explained?
- **The solution suggested** – will it work or how can it be further explored?
- **The target audience** – is there good knowledge of the audience to be influenced?
- **The timing of campaign initiation** – are people ready to listen?
- **The goal** – can it be broken into several smaller goals or interim steps?

An advocacy strategy, whether internal or otherwise, will always be a combination of processes, target audiences and tools – all of which will depend on the nature of the problem and the desired goal. It should usually begin with a thorough analysis of the

problem and of the local political economy. Based upon that, the aspects of the issue that are suitable for advocacy will have to be selected. This first step is best done in conjunction with relevant partners, and should lead to a full understanding of the problem and its underlying causes.

Creating and maintaining partnerships is very important for effective advocacy. A coalition of like-minded individuals and organizations will be needed to help make the case for change. *PolicyMaker* is a policy-advocacy tool for the Windows™ operating system which provides step-by-step guidance on conducting a stakeholder analysis and understanding the political dynamics of policy-making (see section 8.4).

Who advocates for CRVS and what is their focus?

Potential advocates and partners for CRVS strengthening include country NGOs, government ministries and international development agencies. Local organizations are particularly skilled in identifying disparities in access to registration services for minority or disadvantaged groups. Decision-makers in the health, education, treasury and planning sectors, and any agency with an interest in population data, will be likely partners in CRVS advocacy, given their need for solid information upon which to base planning and programming decisions. As a primary user of vital statistics, the health sector has been particularly vocal in calling for improved registration systems and the data they produce. In 2007, for example, a series of papers was published drawing attention to the previous neglect of CRVS systems in developing countries, and the need to redress this – primarily from the perspective of improving death registration and cause-of-death information (141). Likewise, WHO has repeatedly called for greater support to be given to civil registration (142), while HMN has advocated for increased attention to CRVS as part of the overall strengthening of country health information and statistics systems (143).

The United Nations Commission on Information and Accountability for Women's and Children's Health has identified improved civil registration as one of 10 priority actions in its report *Keeping Promises, Measuring Results* (4). UNICEF has for many years advocated for and invested in the strengthening of birth registration in many countries. The Office of the United Nations High Commissioner for Refugees (UNHCR) advocates for the registration of refugees and displaced persons, and regards registration as an essential tool in protecting them. It carries out advocacy with host countries and has developed a handbook with procedures and standards for registering vital events in these populations (21).

Increased advocacy for CRVS has also come from other United Nations agencies. In 2011, UNSD began an in-depth review of its 2001 *Principles and Recommendations for a Vital Statistics System* which incorporated the need to build a stronger advocacy case among both users and producers of vital statistics (50). In addition, a number of regional United Nations agencies such as the Economic Commission for Africa (ECA), the African Development Bank (AfDB), the African Union (AU) and the Economic and Social Commission for Asia and the Pacific (ESCAP) have all helped to mobilize political commitment to the strengthening of CRVS systems (6), (144), (145). Ministerial and regional planning meetings have been sponsored and assistance provided to the development of regional and country plans. The PARIS21 consortium has developed guidance and advocacy strategies to highlight the importance of improved statistics and the use of evidence for policy-making. While PARIS21 has a broad focus on statistics and

does not specifically address the development of civil registration, it has developed a range of resource materials available at its web site[16] that can be adapted to make a case for increased investment in vital statistics and for greater use of these in policy-making.

Civil society organizations such as Plan International have led global advocacy campaigns to improve civil registration, and have extensive experience in advocating for increased birth registration using a variety of strategies (146), (147), (148). In its 2006 campaign report (147), Plan International outlined its success in increasing birth registration over a five-year period in 32 countries. The organization has adopted a rights-based approach to birth registration based on the Universal Declaration of Human Rights (149) and Article 7 of the Convention on the Rights of the Child (150). Plan International has successfully mobilized support and resources for universal registration from stakeholders at many levels, including governments, United Nations agencies, NGOs and corporate partners to change laws and policies in several countries (see Annex A).

UNICEF is another powerful champion of birth registration – the absence of which is a violation of the child's inalienable human right to be given an identity at birth. Children of foreign residents, refugees, the poor and minority groups are the most likely to be excluded from registration. Because of the association of a birth certificate with nationality, which is often granted according to the principle of "jus soli" (law of the soil), many countries are unwilling to register all children born within their borders. Such children often grow up stateless and unable to become full citizens of the countries in which they live. As a result, they are often denied access to social and economic rights such as employment in certain occupations, and access to health, education and other government services.

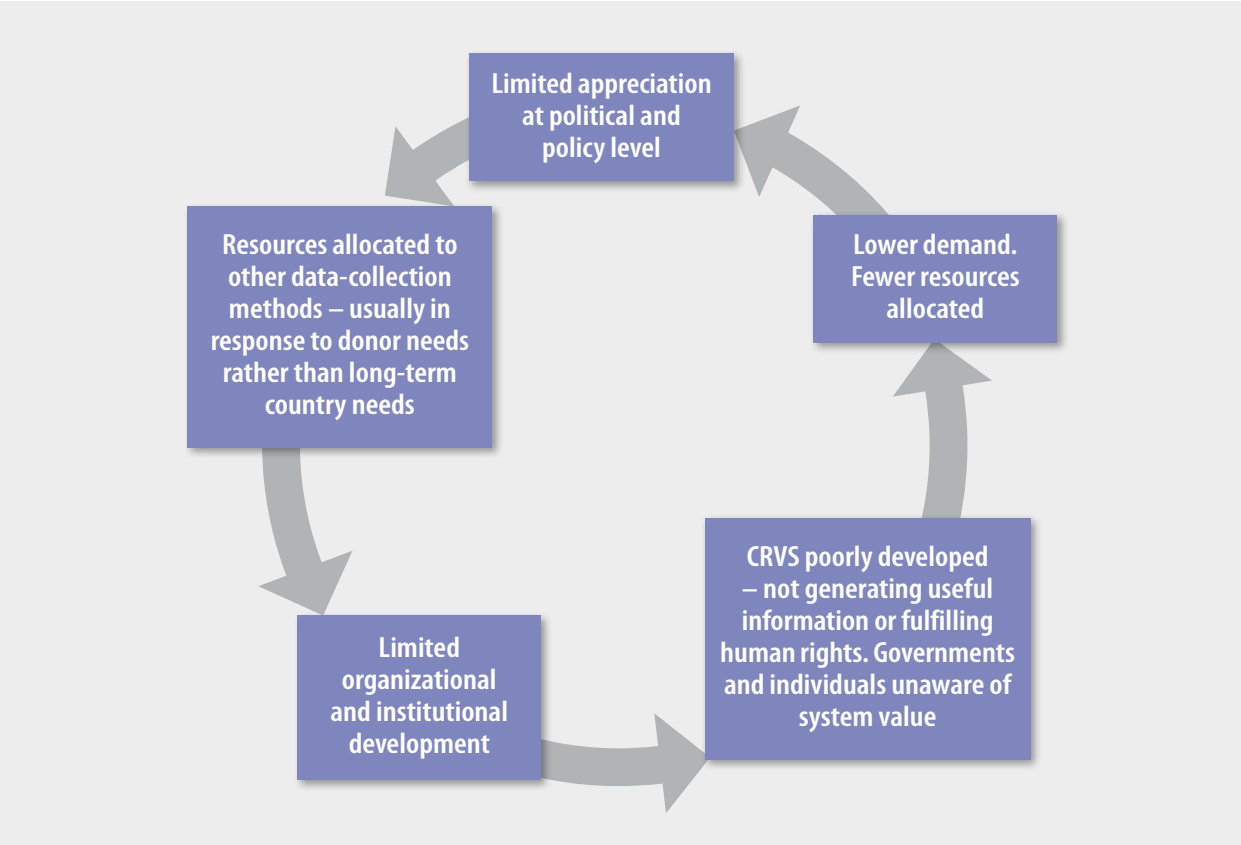
Despite the importance of cause-of-death data for health planning, there was, until recently, a marked absence of champions for death registration. Greater advocacy for death registration is now needed to strengthen the provision of reliable information on the number of people who die and from what. Knowledge of the causes of death in specific populations is essential for determining the public health actions needed to promote and protect health, and to prevent premature mortality (141). In light of the massive increase in noncommunicable diseases and the rapid health transitions which are taking place in many low-income countries, improved cause-of-death data is a pressing need.

Using advocacy to overcome barriers to CRVS

Advocacy is essential in efforts to break the "vicious cycle" of underinvestment in CRVS systems shown in **Figure 25**. Weak and dysfunctional CRVS systems are unable 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 policy-makers fail to see the potential benefits of CRVS systems, they will allocate resources to alternative data-collection methods, not realizing that these have a number of limitations compared to well-functioning CRVS systems. This in turn results in the weak institutional and organizational development of CRVS systems, thus perpetuating the circle of neglect.

[16] For more information please see: http://www.paris21.org/advocacy

Figure 25: Vicious cycle of under-development of CRVS systems (151)



Advocacy can bring about a changed perception – namely, that CRVS systems are a "public good" that every government should provide to their citizens because they clearly benefit individuals and communities, as well as generate reliable and vital birth, death and cause-of-death data.

Advocating for the improvement of CRVS systems can seem particularly challenging because in most countries the responsibility for CRVS is spread across multiple agencies and government departments – usually including the civil registration authorities, the national statistics office and the health department, and sometimes the judicial system. A coordinated approach is crucial in bringing together all the key players needed to make change happen. Experience has shown that collaborative action by several key players can bring about improvements in a short timeframe. In South Africa, for example, the major stakeholders joined forces and the government made a concerted effort to invest in improving vital-event registration, with the result that the completeness of registration greatly improved in a relatively short time (see section 8.3, Case study 3 below). Three government institutions jointly took the lead in tackling the challenge, and academic institutions and researchers made major contributions throughout the improvement process.

At country level, there is an emerging consensus on the pressing need for CRVS advocacy (152), (153). For most countries with poorly functioning CRVS systems, the major challenges that need to be addressed include:

- Political commitment to CRVS is lacking because the current systems do not produce useable data for governance and decision-making.
- Financial resources are insufficient to properly support CRVS systems. Development agencies and donors therefore fund alternative data-collection efforts in order to fill data gaps while regarding CRVS as a government responsibility.
- Legislative frameworks are inadequate or outdated, and there are is no strong legal base to support CRVS.
- Lack of awareness of registration obligations and lack of incentives to register, resulting in low registration coverage and incomplete data.
- Inadequate and unresponsive infrastructures and registration services – which discourages people from registering.
- Lack of clarity concerning roles and responsibilities, leading to inefficiencies and the duplication of tasks by different government agencies.
- Shortages of human resources with the necessary skills and expertise in civil registration in departments such as health and statistics, adversely affecting the quality of both services and data.

A two-pronged advocacy approach is needed that focuses on the benefits for both governments and individuals. Advocacy directed at increasing the demand for vital statistics and encouraging individuals to register vital events will help to break the vicious cycle of under-investment. **Box 36** provides examples of advocacy messages from CRVS champions that taken together illustrate the two-pronged approach required. Overall, the goal is to influence governments to make CRVS a priority, and to ensure that development partners recognize that these systems are vital to successful development (154). Increasing public awareness of the importance of CRVS is also important in obtaining the support of civil society and NGOs in demanding better CRVS systems.

BOX 36. Key messages from advocates of strengthened CRVS 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.

H.E. 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.

H.E Berhan Hailu, Minister of Justice Federal Democratic Republic of 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 of the Statistical Commission for Africa, and Statistician General, South Africa (183)

...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 (184)

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 (154)

...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 of WHO (185)

8.3 Key actions

In this section, the advocacy process is considered and approaches proposed for developing an advocacy strategy and achieving its goals. A conceptual model has now been developed that can guide the design of an advocacy strategy that focuses efforts on those who are best placed to deliver the improvements. This "drivers of change" approach (155) specifically targets those institutions and individuals who can act as key levers in bringing about desired changes in countries, and who need to be convinced to act. If the overall goal is the general improvement of the national CRVS systems (as in Case study 3 below) then improvement will demand a deep understanding and appreciation of the complex relationships within and between all the of agencies and individuals involved. It is therefore essential that all stakeholders take part in developing the advocacy strategy. Participants in this exercise would include representatives of the civil registration office, health departments, national statistics office, and other relevant government departments, as well as civil society representatives. In all cases, the PARIS21 consortium recommends that stakeholders come together to discuss:

- What changes are needed and which ones can advocacy help to bring about?
- What are the social, political, economic and institutional factors impeding change?
- Which organizations, groups and individuals can drive the changes needed?
- How can they be motivated, and what messages will work best?
- How can the messages best be delivered to each stakeholder?

Even when the purpose is overall CRVS systems improvement, the most-effective approach is to focus on a few key priorities, and to use these as the basis for the advocacy strategy. This strategy should incorporate a range of messages and materials developed to suit different target audiences.

The advocacy wheel shown in **Figure 26** illustrates the various options and approaches available when developing a comprehensive advocacy strategy. Each box represents a different approach – for example, using the "media", "champions", or "community education" etc. to advance the overall goal. If, for example, an analysis of the problem has indicated that the most-important drivers of change are government officials and politicians, then it would be most appropriate to use approaches such as media releases, letters to politicians and meetings with politicians. It can also be productive to generate debate and discussion at community level and among civil-society organizations who can be effective allies in bringing issues to the attention of government. It will most likely be necessary to use a combination of approaches to reach diverse audiences.

A detailed description of each of the approaches shown in the advocacy wheel can be found in the tool kit for public health professionals (139) outlined in section 8.4, together with useful tips and case studies illustrating the use of some of these.

Figure 26: The advocacy wheel (139)

Ten steps for developing an advocacy campaign

There are a number of possible steps that could be taken to develop a successful advocacy campaign. The ten steps outlined in this section do not necessarily need to be followed in the order described – several steps may occur simultaneously and may need to be periodically revisited as the campaign is developed. As these steps require a variety of skills from various disciplines, it will be important to work in partnership with others to facilitate access to the necessary skills and experience.

1. **Identify and analyse the problem** – what are the key issues and options for bringing about change? The process of advocacy starts with gathering stakeholders together and identifying a problem or issue that requires policy action, and which can be influenced by advocacy. If a country has undertaken the comprehensive assessment of its CRVS systems described in Module 1 then priority issues needing improvement may already have been identified. The stakeholder meeting can then be used to discuss which of these issues would be best suited to becoming the focus of advocacy

efforts, and to identify the most effective "drivers of change". Having an in-depth understanding of the problems facing CRVS systems, and their underlying causes, makes it easier to define effective strategies and solutions. An analysis of policy and the local political economy can then help to identify any underlying obstacles and causes contributing to the problem. Further information on policy and political economy analysis is available (140), (156), along with the computer software programme, *PolicyMaker 4* (see section 8.4).

2. **Identify the goal** – what change is being aimed for? Is the goal to increase the level of registration of births and deaths by changing legislation? Or, is it to increase government budget allocation to strengthen CRVS systems? For advocacy efforts to succeed, it is important to have a clear goal that is achievable, addresses the problem and has broad support. The multiple actions needed to improve CRVS systems can appear complex and overwhelming. It is therefore essential to set realistic short- and longer-term goals, and to build incrementally on success. Clear objectives and targets related to your overall goal should be defined and should be SMART – Specific, Measurable, Attainable, Reasonable and Time specific) so that progress can be reported on. For examples of goals and related objectives, see the United Nations handbook on developing information, education and communication approaches (47).

3. **Identify target audiences** – who are the people or organizations with influence that can help in achieving the overall goal? Audiences can be categorized into primary and secondary audiences. Primary audiences are those with the direct authority to bring about policy change; secondary audiences are those who can influence the primary audience. Because there are usually several secondary audiences, efforts should be focused on those that have the most capacity to influence the primary audience. Understanding target audiences is vital and begins with the analysis of problems and policy. It is easier to devise an advocacy strategy when there is full knowledge and understanding of those who influence and effect policy change. It can be useful to construct a policy map of your audiences and identify their degree of influence and authority (high, medium or low) in relation to policy change (140).

4. **Identify factors that will promote or hinder change** – what are the social, economic and political factors that will affect the likelihood of achieving the goal? As stated above, gaining knowledge of the political economy and policy environment is a key step in planning an effective advocacy campaign. An understanding of how social, political, economic and institutional factors affect the possibilities for change is necessary, as is information on how policy decisions are made, both formally and informally. It must be determined where the key decisions on CRVS policy are likely to be made, and who makes them. This knowledge is required to guide the selection of advocacy strategies (140) in order to most effectively advocate for policy change.

5. **Develop and deliver key messages** – what messages will motivate the target audiences? And how will the messages be delivered – directly or indirectly? One of the keys to a successful advocacy campaign is the development of concise, persuasive and action-orientated messages for specific target audiences. Tailoring messages to different audiences is vital and helps to ensure that they are understood and more likely to be effective. Messages targeting decision-makers at various levels of government will be different to those targeting businesses or the public (**Table 5**).

Table 5: Key messages for different audiences

Audience	Key messages for investing in CRVS
Heads of government, legislators and national and local administrators	**Civil registration is about governance** • Registration of vital events is a responsibility of the State, a basis for the development and implementation of policies and programmes, and a platform for the delivery of government services to the population. • Civil registration increases the credibility of national and local administrators, and enhances their capacity to deliver services by helping to identify what services are needed and by whom. • Civil registration and the vital statistics they generate enable the monitoring of progress towards development goals and targets such as the MDGs. • Civil registration is the platform for the establishment of population registers and systems of individual identifiers used for purposes such as insurance and security.
Ministry of finance and planning	**Civil registration is about efficiency and effectiveness** • Civil registration systems provide the basis for the production of reliable population statistics to guide development planning and permit the evaluation of government programmes. • Investment in civil registration will pay for itself many times over by improving the targeting of services and increasing the efficiency of resource allocation. • Investment in civil registration will generate more-reliable vital statistics that can be used for resource allocation.
National registrars-general, ministries of the interior and justice	**Civil registration is about human rights** • Civil registration provides individuals with proof of identity from birth and supports the progressive realization of their social, economic and human rights. • Civil registration is central to improving the efficiency and fairness of the justice system. • Civil registration helps avoid identity fraud and ensure that services are correctly targeted. • Civil registration provides the foundation for the production of statistics on key life events – births, deaths, marriages – for the whole population and on a continuous basis. • Investing in civil registration will provide better statistics that will enable better planning and development, and permit the evaluation of government programmes.
Ministry of health, directors of health and medical services	**Civil registration is about health** • Trustworthy statistics on levels and trends in mortality and causes of death enable the identification of emerging health threats and of groups at high risk. • Civil registration systems and the improved statistics they generate support the health sector in determining needed interventions and required resource allocation. • Civil registration generates data on life events that are essential for the calculation of indicators for tracking the health status of the population, and the progress made towards meeting health goals, including the MDGs. • Reliable vital statistics on causes of death have many direct policy and programme implications, for example providing the evidence base for the introduction of seatbelt and crash helmet legislation, drink-driving laws, and measures to reduce tobacco consumption. • Investing in civil registration will provide better statistics on fertility, mortality and patterns of causes of death, and enable the health sector to identify major health threats and vulnerable groups.

Audience	Key messages for investing in CRVS
National statistics office	**Civil registration is about reliable data** • Civil registration generates sound data on population size and distribution, on levels and trends in fertility, and on patterns and causes of mortality. These data are essential for efficient and effective planning and resource allocation across all social and economic sectors, including the business and private sectors. • An effective civil registration system generates data on a continuous basis for the whole population, including at local level.
Other social and economic sectors	**Civil registration is about social and economic development** • The health, education, employment and other social sectors responsible for the provision of public services require accurate vital statistics at the levels of national and local administration, and community service provision. • All social and economic sectors require better statistics to guide programme planning and permit the ongoing monitoring and evaluation of government policies and programmes.
The business sector	**Civil registration is about economic development, business and commerce** • Civil registration benefits companies – and their customers – because they are better able to identify their customers. Banks are more likely to lend money to people who have legal proof of identity. • Civil registration benefits the social insurance sector as it is better able to determine appropriate insurance rates when it has access to reliable data on fertility and mortality.
Civil society, the general public, citizens	**Civil registration is about legal status** • Civil registration provides individuals with legal documentation and proof of identity. • Civil registration brings individuals into the modern economy and enables them to access social security and inheritance rights, obtain passports, open bank accounts, get driving licences, etc. • Civil registration facilitates access to services such as health care, education and social security. • Statistics generated from civil registration provide the means of holding governments accountable for their policies. Citizens will have information on the extent to which government is providing the services required to meet economic and social needs. • Investing in civil registration not only provides individuals with legal documentation and proof of identity, but also generates the statistics necessary for governments to provide the services needed to meet the health and social needs of the population.
Development assistance agencies and donors	**Civil registration is about aid effectiveness** • Development partners, donors and foundations benefit from high-quality statistics that can be used to improve the allocation and monitoring of aid.

6. **Build working partnerships** – who can be invited to support your cause? Effective advocacy is often about building up a critical mass of support from people and organizations. It will be important to develop alliances with credible partners so that a united front can be presented and agreed common messages for change developed. Partnerships with organizations and influential individuals both inside the system (for example, managers of civil registration offices or directors of justice and planning authorities) and outside (for example, representatives of NGOs active in civil rights and birth registration) will increase the likelihood of success. At the same time, while there are many benefits to working in partnerships or through coalitions, it is also important to remember that building these effectively takes time and requires strong leadership (140). The Stakeholder Identification Template shown in Annex G of this resource kit can be used to assist in the identification of relevant stakeholders.

7. **Conduct research** – is there sufficient evidence to back the cause? Researching and using data to support messages is important. For example, the poor quality of existing data could be highlighted along with how outdated the most-recent data are. A number of web sites – such as those maintained by the Population Reference Bureau (see section 8.4) – provide bibliographical databases and directories of population resources that can be a valuable tool for gathering comparative evidence. Having access to accurate, high-quality and documented information also protects from counter attacks from opponents and helps to maintain credibility in the public arena (139).

8. **Secure resources** – what sort of financial and human resources are needed for the campaign? How can these be secured? A common misunderstanding is that a large budget is necessary. On the contrary, many advocacy strategies have proved to be highly effective despite limited funding. Developing coalitions can help in securing resources. Campaign partners may also have access to public-relations specialists, communications experts, political analysts and business managers that can help develop and implement campaign strategies.

9. **Devise an action plan** – covering the activities, roles, timeline and budget of the campaign. As advocacy is a dynamic process, it is important to be flexible when setting timelines. The policy environment can change quickly and outside events may necessitate changes to the scheduling of activities. Similarly, new opportunities may arise following a change of government or personnel, and an immediate response will be needed to take full advantage of the new situation. The action plan must reflect the chosen components of the campaign strategy (see **Figure 24**) and associated activities. It is outside the scope of this module to detail all the possible strategies and activities – such as those shown in **Figure 26** (139). Instead, three case studies are presented below to provide an overview of the range of strategies and activities that can be employed, and the ways in which the steps outlined in this section have been addressed in different settings. Working through these ten steps will assist in the development of an appropriate action plan.

10. **Evaluate advocacy efforts** – has the goal been successfully reached? To answer this question requires the setting of a clear overall goal and associated targets from the outset, and an indication of how success will be measured. This will allow for the planning of monitoring and evaluation activities, and the collection of relevant information for demonstrating success. It is important to show that advocacy strategies

have made a difference – particularly to funding bodies and stakeholders. Evaluation also helps to ensure that lessons are learnt from the experiences of what works and what does not. These lessons should then be used to inform the planning of future advocacy campaigns. A number of publications provide further information on evaluating and improving advocacy campaigns (139), (157).

Case study examples

In this section a series of case studies are presented highlighting the multifaceted, complex and dynamic nature of advocating for improved legal frameworks, policy and resource allocation for CRVS systems. These case studies illustrate several of the issues discussed above, namely:

- the ways in which problems on the advocacy agenda can be addressed
- the stages and steps in the advocacy process
- various strategies and activities for achieving advocacy goals.

Case study 1: Advocating for improved CRVS legislation in Peru

Box 37 outlines a successful legislative campaign conducted in Peru (158). Such case studies can be very useful in convincing potential partners and target audiences of the power of advocacy. The case study also demonstrates the practical application of the 10-step approach described above in developing and implementing an advocacy campaign. The goal of the campaign was to increase birth registrations by changing the existing legal framework which discriminated against unmarried women and their children. The Ministry of Women and Social Development (MIMDES) and the Alliance for Citizens Rights devised the advocacy campaign based on a communication strategy. The success of the campaign was due to:

- Use of a combination of strategies – media advocacy, interpersonal communication and partnership building.
- Delivery of one persuasive message that was attention grabbing, comprehensible, motivational and easily recalled.
- Strategic use of mass media to create supportive opinions to apply pressure for policy change.
- Targeting congress members as the primary audience as they had the power to enable the change in legislation.
- Opportunity and timing.

BOX 37. Case study 1 – Advocating for improved CRVS legislation in Peru

Identify and analyse the problem – in 2004, about 18% of births (110 000 infants) in Peru were not registered. This was partly because unmarried women were not permitted to register the birth of their child with the father's surname if the father was absent at the time of registration. Without birth registration, children in Peru do not have access to social services and are at risk of a lifetime of poverty.

Identify the goal – the goal of the campaign was to remove the legal barrier to birth registration by ensuring support for a bill to amend the Peruvian Civil Code. The bill would enable unmarried women to declare the name of the father at the time of registration, even if he was not present at the registration office.

Identify target audiences – government officials, politicians and congress members were targeted as potential agents of change. Members of congress have the power to influence the congressional agenda to support the bill. Journalists were also targeted because media coverage was part of the advocacy strategy.

Identify factors that will promote or hinder change – the timely use of media to communicate key messages was identified as a potential factor for success. Understanding the reactions and concerns of congressional members regarding the proposed bill, and being prepared to respond to these issues, was also crucial. The context of the proposed bill was also important. In the preceding six years, there had been 16 legislative initiatives introduced in the congress to change the Civil Code on birth registrations and unmarried women. All 16 initiatives were rejected by the Justice Committee of the Congress. This reflected a discriminatory and conservative social structure in Peru, which could have hindered the success of the campaign.

Develop and deliver key messages – the key message of the campaign was that every child has the right to two last names – those of their father and mother – and this was incorporated into campaign posters (see Annex H). The message focused on ending discrimination against children based on parental marital status. Lobbyists were also part of the advocacy team. Their role was to persuade congress members of the social and legal benefits for mothers and children of passing the bill. Communication activities included face-to-face meetings, group sessions, email and phone calls. Mass-media strategies included television, radio, print and public events.

Build working partnerships – the Alliance for Citizens Rights supported the MIMDES campaign. This coalition formed in 2004, and comprised 20 organizations, 13 civil societies, four government organizations and three international groups. The coalition was already working on the issue of lack of identity papers and was increasing awareness of birth registration as a fundamental right. Within the Alliance for Citizens Rights, an advocacy team was jointly formed with MIMDES, Oxfam and Action for Children. This team had credibility, influence and connections in congressional offices.

Do research – formative research identified the knowledge and attitudes of target audiences in relation to birth-registration issues. This helped to inform the key messages. Research showed congress members had a low level of knowledge and poor understanding of the right to a name and the legal affiliation between a father and child. The campaign focused on the rights of infants, rather than the rights of women, as Peru is a very male-dominated society. This helped to minimize the risk of the bill being rejected.

Secure resources – financial support came from Oxfam Great Britain, which was also a member of the Alliance for Citizens Rights.

BOX 37. Case study 1 – Continued

Devise an action plan – mass-media activities were carefully scheduled on a four-week timeline leading up to the congressional debate. Lawyers from the advocacy team met with congress members and gave persuasive legal presentations, and participated in preparatory sessions in the weeks before the congressional debate.

Evaluate advocacy efforts – there were no resources for formal evaluation of the campaign. However, media coverage was tracked and 31 "hits" (print, radio and broadcast) were recorded in the last two weeks of the campaign. Before the start of the advocacy strategy, the bill was ranked as the 42nd matter on the congressional agenda. In the week before the congressional debate, it moved up to become the 6th matter. The combination of partnership and two-pronged communications strategy succeeded when the bill was passed on 30 March 2006.

Case study 2: Advocating for increased awareness and improved delivery of registration services in India

Box 38 highlights the complexity of advocacy efforts when using multiple strategies and activities to achieve diverse campaign objectives, including policy change. In 2000, a civil-society organization– the Society for Participatory Research in Asia (PRIA) – launched a CRVS awareness-raising and capacity-building campaign to increase birth registration in four states in India (159).

Initial sharing of the preliminary research findings with stakeholders helped to stimulate interest in a joint campaign and to delineate roles and commitments to the advocacy goal. Stakeholder partnerships helped the process of developing solutions to improve registration practices. These numerous partnerships also generated the influences that needed to be directed at decision-makers (such as magistrates, subdivisional magistrates, executive officers and district registrars) to effect policy reform. Campaign partners also helped to disseminate messages on birth registration, and provided a support base. The aim of the stakeholder engagement strategy was to ensure that the municipal government was held accountable in terms of meeting its constitutional duty to provide birth registration services to the community over the long term.

A number of campaign features directly contributed to its success, with the key lessons learnt including:

- The role of stakeholders cannot be underestimated in the advocacy process. They can play a key role in delivering targeted messages, and influencing decision-makers to effect policy change.
- Survey and research results are a powerful advocacy tool, and also provide evidence to inform policy change.
- While some policy changes were achieved, there were also a number of recommendations for future policy change – highlighting that advocacy for improving CRVS systems is a long-term commitment.
- Advocates need to be aware of short-term and long-term goals, and of the resources needed for sustained advocacy. Advocates also need to appreciate small victories while also being prepared to be patient in achieving the larger overall goals as this can take time.

BOX 38. Case study 2 – Increasing awareness and improving delivery of registration services in India

This campaign addressed CRVS policy issues related to:
- awareness and demand by citizens
- access to registration services
- clarity of roles and responsibilities of government staff
- human resources to deliver services.

The overall campaign strategy focused on the duel aspects of "demand" and "supply" in relation to birth registration, and on municipal engagement. On the demand side, activities were targeted at increasing the awareness of citizens of the importance of birth registration, and motivating them to register. Spurring citizen action was designed to require the supply side (i.e. municipal offices responsible for registration) to improve their rules and practices ("policy") for registration.

The identified problem was that despite India having an adequate legal framework for birth and death registration (Birth and Death Registration Act 1969), it had the largest number of unregistered children in the world. In some states, more than 90% of births were registered but in others this figure was <30%.

Municipalities are responsible for registering births, but populations clearly face hurdles in getting events registered – especially in the case of poor and marginalized citizens, who are then denied their rights and privileges.

Participatory research and problem analysis were conducted through meetings held in the smallest administrative municipal units ("ward" level) and through informal meetings, workshops, face-to-face interactions and surveys. This research revealed a number of barriers, both for citizens registering births and for government officials providing services.

The demand-side barriers identified were:
- poor understanding of the need to register a birth, and of the associated procedures
- a complex registration process that was not understood by illiterate and semi-literate citizens
- time and other costs discouraged people from registering
- lack of an easy way of registering home births.

The supply-side barriers identified were:
- municipal authorities lacked data on the number of unregistered births;
- officials were unable to correctly apply all birth registration rules, and were often insufficiently trained to properly meet their responsibilities;
- gaps and problems were identified at various levels of government, including lack of stationery, no funds for registration-awareness campaigns, poorly trained staff, and poor monitoring of the quality of records and certificates;
- payments demanded for services that should have been free.

To improve the system, PRIA used two main strategies and a range of associated activities focusing on improving registration services and increasing the number of births registered **(Table 6)**. As well as the two main strategies, an additional strategy running throughout the campaign was stakeholder engagement and the building of a support base through links with local media; academics; elected councillors; government officials; women's community groups; professionals such as social workers, teachers and doctors; NGOs; and civil-society organizations.

Table 6: PRIA campaign strategies for increasing registration service demand and improving supply

Awareness-raising strategy targeting citizens with the aim of increasing the demand for services	Capacity-building strategy targeting officials with the aim of improving the supply of services
• Distributing information materials such as leaflets, posters and booklets on the importance and process of birth registration. • Undertaking a door-to-door campaign conducted by students and members of citizen collectives. • Holding public meetings, targeted at the poor and marginalized, where the Birth Registrar addressed the community on the process of registration. • Holding public rallies to generate curiosity and make people aware of the issues, using slogans, songs and leaflets, and including schoolchildren in the process. • Using folk art to convey key messages in an entertaining way. • Advertising on television. • Placing announcements in places of religious worship, such as temples and mosques.	• Engaging with municipal officials and elected councillors using a participatory research study and follow-up meetings. • Presenting household-survey reports to demonstrate the extent of the problem of birth registration. • Incorporating relationship building as a key activity in the strategy to engage officials in a learning process to improve registration processes. • Supplying copies of the state-specific rules and regulations on birth registration. • Brainstorming sessions to identify solutions for improving the registration process.

Case study 3: Country-level strengthening of CRVS in South Africa

Throughout its colonial era, which started in the 1920s, South Africa had a comprehensive system of CRVS that applied to all citizens. The 1950 Population Registration Act introduced a race identifier into the population register, thus setting the legal basis for the apartheid era (160) and for a registration system that covered selected segments of the population. Henceforward, registration was the means used to produce race-based identity documents, and a foundation for the apartheid policies that greatly influenced the organization of social life, and access to resources and health services (161). The 1950 Act remained in place until replaced by the Birth and Deaths Registration Act of 1992 which requires complete coverage of all people and geographical areas. However, neither Act brought about an inclusive and comprehensive civil registration system.

Nor were civil registration data used as the source of national vital statistics. Some statistical information was available on certain populations, but there was little data on the black African population that constituted over 70% of the population. With the end of apartheid and the emergence of a democratic society during the 1990s, the country embarked on an ambitious series of policy reforms designed to end racial and sexual discrimination, and to build institutions of the state (162). However, national planners and decision-makers faced a dearth of reliable population-based data upon which to take forward this huge social, political and economic transformation. Nor was the climate for promoting registration propitious given the mistrust of registration authorities that had built up during the apartheid era (163).

Nevertheless, South Africa managed within just a few years, between 1997 and 2004, to make birth registration almost universal, while coverage of death registration increased from 63% to 82% (164). The key components of this massive change were leadership; political commitment and advocacy; the formation of partnerships across different

parts of government; and building of community awareness. CRVS champions were active at all levels – in government departments (especially statistics, health and home affairs); among health professionals and academic researchers; and within grassroots organizations working to overcome entrenched inequalities. Working together, these powerful stakeholder groups succeeded in overcoming the long-standing mistrust of the registration system, and fostering trust among communities.

At national level, the tone was set by the Government of National Unity which identified as a key priority the allocation of resources for national information systems to redress the severe inequalities of the apartheid era. Three agencies took the lead in tackling this challenge. The Department of Health constituted a National Health Information System for South Africa and identified reliable and comprehensive data on births and deaths as an essential prerequisite for identifying and redressing inequalities. Statistics South Africa undertook study tours to learn from other countries how to establish universal and sustainable civil registration that would generate reliable data for the whole population. The Department of Home Affairs raised awareness of civil registration, introduced new registration forms and organized outreach efforts among communities and local village chiefs. School enrolment was made contingent upon possessing a valid birth certificate. Each government agency introduced staff training and conducted outreach to peripheral levels in order to create awareness among communities of the importance of civil registration and reliable vital statistics.

Academic institutions and researchers, especially in health, were also major contributors throughout the improvement process. In practice, improving cause-of-death statistics turned out to be a bigger challenge than improving natality statistics, not only because of the technical challenges involved in accurately determining cause of death, but also because of denial about the levels and causes of HIV/AIDS within some parts of the political establishment. In addition, the proportion of deaths occurring outside health facilities (often at home) remained high, notably in rural areas. By 2005, despite improved coverage of death registration, the quality of cause-of-death data remained poor, with 20% of deaths assigned to ill-defined causes, extensive misclassification of HIV/AIDS deaths, and a lack of information on the causes of injury deaths (165). The use of rurally based health and demographic surveillance systems helped to bridge this gap (166), (167), (168), (169).

Throughout the improvement process, researchers played an active role in advocating for change and reaching out to decision-makers and communities by producing easy-to-understand policy guidance and summaries of research findings (100), (106), (170), (171). Cause-of-death data were used to identify the leading causes of deaths, which enabled the government to identify interventions, allocate the health budget and deliver necessary services to the people who needed them (172). Making use of the data ensured that resources continued to be allocated to improving CRVS and to gaining the support and trust of civil society.

Improving civil registration in South Africa has also been identified as important in monitoring and understanding the HIV/AIDS pandemic (173) as it generates cause-of-death information that is crucial to understanding the dynamics of HIV/AIDS in children – including on their age and sex, parental serostatus and the communities into which they were born. Community-level interventions to improve civil registration included working

with village headmen as part of the registration process, and encouraging registration by providing child-support grants for registered births. Mobile facilities were used to facilitate registration for people without easy access to registration facilities – sometimes in partnership with research and development organizations (174).

South Africa identified improved CRVS as central to achieving the national goal of redistribution and improved equity. The Equity Gauge – a national project to monitor progress towards improved equity in health – worked to identify indicators and facilitate the use of information by national and provincial legislators, and local government representatives. In partnership with South African Legislators and the Health Systems Trust[17] Equity Gauge advocated for increased attention to civil registration in order to improve statistics on mortality and causes of death, and permit analysis of the patterns and trends among different ethnic groups and parts of the country. A particular strength of this approach was the close link with parliamentarians, which helped to build capacity for applying an equity lens to policy, institutionalize equity considerations in decision-making and keep equity issues on the political agenda.

South Africa provides a vivid example of the power of advocacy, partnerships and stakeholder involvement to bring about substantial and rapid improvements in CRVS systems. Four elements were considered to be crucial in this success:

- the leadership role exercised by senior government officials in health, statistics and home affairs;
- the sustained involvement of academic institutions and researchers in finding solutions to the challenges identified;
- the explicit efforts made to reach out to community leaders and grassroots organizations;
- the commitment of parliamentarians and legislators to apply an equity lens to the development of policy and legislation.

Advocating for improved resource allocation

A particularly effective approach to raising resources is to carry out a business case study to demonstrate that investment is the most rational and cost-effective decision the government can make. A "business case" is a document used by senior management to assess the justification and options for a proposed project. It is usually developed to:

- gain approval to proceed with a project
- obtain resourcing for a project through internal departmental processes, or
- where resourcing is already available, to document what the project will accomplish.

The purpose of a business case study is to enable those approving the resources to understand the project rationale and assess what impacts it will have (including economic impact), and to compare the assessments against other factors and projects. The business case methodology is frequently used for government projects in Australia, and an easy-to-use template and guidelines have been developed by the Government of Tasmania (175).

[17] An NGO established in 1992 to support the transformation of the health system.

The following section outlines the process of creating a convincing business case for investing in CRVS. Advocating for resources to establish or improve a civil registration system can be a big undertaking, particularly where there is no existing system or tradition of registering vital events. Presenting a business case is particularly appropriate for securing the support of key decision-makers and funders of improvement efforts. In Sri Lanka, for example, a business case was successfully used to fund the Health Sector Development Project for 2005–2010 (176). An example of a recommended business case structure is provided in Annex I.

The business case study presented here sets out research and other issues in order to support a proposal for establishing or strengthening a civil registration system. It has been derived from a working paper on advocating for civil registration (177). In this approach, there are three main phases:

1. Preparing research.
2. Developing the business case.
3. Presenting the business case.

Across these three phases, there are a total of six steps to ensure that the business case is based on good research and evidence, has stakeholder support and presents the arguments in a logical manner. Each step is a simply a guide as most countries will have different legal and government systems, and each business case will be unique.

Phase 1 – Preparing research

Thorough preparation is the first stage of developing a business case, and it is important to have a good understanding of:

- national readiness for a civil registration system
- comparable registration systems, their structure, and costs
- stakeholders who will be important in supporting the business case.

Self-assessment – the first step in preparing research is to understand the current national system for civil registration. Undertaking a rapid or comprehensive assessment of CRVS systems (see Module 1) will help to identify which aspects of civil registration are already in place and how well they are functioning. It will also help identify aspects that need to be further developed.

Prepare evidence for the case – once assessment is complete, it should be possible to present convincing arguments for change and to gain support from the relevant authorities. Decision-makers will need to be convinced of the statistical importance, and policy and planning benefits, of CRVS systems. International experience has clearly shown that information from CRVS systems can be used to measure the success of programmes aimed at controlling specific diseases, to support health initiatives, and to help public administrations function better and provide needed services.

Identify and engage stakeholders – it is important that a range of stakeholders with an interest in supporting the business case are consulted to better inform the project. Once the precise inputs required from stakeholders are understood, the process of identifying key stakeholders can begin (see Annex G). The implementation of a civil registration

system is not only a health, legal or research issue – it is instead a whole-of-government issue that impacts on many government and non-government agencies. Funding proposals for civil registration systems are more likely to succeed when stakeholders:

- recognize the benefits of a civil registration system;
- are committed to supporting the business case, and to promoting it among key decision-makers;
- are willing to address the challenges of implementing a civil registration system.

Phase 2 – Developing the business case

Initial business case – once a clear set of arguments to support the case for a civil registration system have been developed, and stakeholders identified, the business case can be developed. The document should set out the project goal, an assessment of available options, an implementation plan, and cost–benefit and affordability analyses. Resources such as recommended structures for a business case (see Annex I) are available to help in the development and project management of the process.

Modified business case – the business case can be refined after stakeholders have provided information and feedback on the initial document. For example, relevant information can be used to update the business case, which will strengthen the proposal. Once a final version is ready, checks should be made to ensure that it provides decision-makers with the evidence and arguments in a clear and logical manner.

Phase 3 – Presenting the business case

Presenting the business case to decision-makers – each country has its own unique government systems through which important public-policy decisions are made. The business case for a civil registration system will therefore need to suit the relevant decision-making process. When submitting a case, steps must be taken to ensure that decision-makers are made fully aware of all the arguments for a civil registration system, as well the plans for implementing the system. These plans should cover the medium to long term, and should explain:

- how the civil registration system will be supported and operated
- how the capacity of systems and staff will be built up.

When presenting the full business case to decision-makers, an overview of the key message should be provided – the key message should include:

- a convincing case for change, focusing on the decision-makers specific areas of interest, such as health or finance;
- a summary of the facts that clearly identifies all the potential benefits that are being lost as a result of not having a well-functioning civil registration system;
- reference to illustrative case studies that highlight comparisons that will motivate change;
- an appeal for recognition of the relevance and benefits of civil registration – for citizens, these will be the certification of life events and provision of identity, while for countries it will be the opportunities to obtain greatly improved information for use in financial, economic, social and health decision-making.

Developing a business case is resource intensive and relies heavily on good research, planning and commitment from the main stakeholders. The presentation of the case needs to be clear and logical if it is to gain widespread support.

Tips for developing a business case include:

- Keep the assertion of potential benefits simple – focus on what is strategically important. For example, investing in CRVS will provide governments and donors with the high-quality population data that they need to secure more funding and plan more effectively.
- Understand the requirements and operation of the funding body to which the case is directed.
- Take time to conduct a thorough stakeholder analysis.
- Develop and adhere to a stakeholder engagement and communication plan.

8.4 Tools and resources

Tools for developing an advocacy campaign

There is no single approach that can be used for implementing advocacy campaigns. The implementation process will depend upon the type of problems faced, the possible solutions, and the available opportunities and resources for making changes. However, there are a number of manuals, tools and training materials from related fields that can help to outline an appropriate course of action. Even though the focus of the tools and resources listed here is not specifically on civil registration, the processes and elements involved are similar. With some thought, these resources can be applied to advocacy for CRVS systems. The skills and tools for advocacy developed in other disciplines, such as communication, social marketing and political science can also be drawn upon. Inspiration can also be taken from the three case studies presented in section 8.3 above which relate directly to the strengthening of CRVS systems.

• Advocating for the National Strategy for the Development of Statistics: Country-level toolkit (155)

This toolkit focuses on country-level advocacy and is aimed at managers and statisticians in developing countries who need to plan an advocacy campaign to convince policy-makers, civil society, the media, and NGOs of the importance of statistics and related information. It explains the "Drivers of change" approach, gives examples of the advocacy materials produced in developing countries, and provides tips on how to use the media and how to craft a targeted message to different audiences. The toolkit is available at: **http://www.paris21.org/Advocacy-Toolkit**

• Promoting statistics (web site)

Web site containing materials – including the country-level toolkit – that users can adapt for use in their own advocacy efforts. Available at: **http://www.paris21.org/advocacy**

• Advocacy in Action: a toolkit for Public Health Professionals (2nd edition) (139)

Provides a good introduction to advocacy, along with examples of key advocacy strategies and practical tools. The toolkit also offers some very good tips on how to prepare for

advocacy campaigns, what strategies to use with different audiences and what are the best tools to use in each case. It also explains how to conduct internal advocacy for change within an organization. The toolkit is available at:
http://www.phaa.net.au/documents/100114PHAIAdvocacyToolkit%202ndedition.pdf

• An Introduction to Advocacy: Training Guide (157)

Focuses on advocacy for policy change, and is suitable for a variety of audiences. The guide introduces the concept of advocacy and provides a framework for developing an advocacy campaign. It is designed for a workshop setting, but can also be used as a self-teaching resource. The guide is available at: **http://resourcecentre.savethechildren.se/content/library/documents/introduction-advocacy-training-guide**

• Advocacy Tools and Guidelines: Promoting Policy Change (140)

This resource manual was written for CARE programme managers in developing countries and provides a step-by-step guide for planning advocacy initiatives. It lays out a framework for identifying policy goals, creating a plan of action, and effectively building a case for change and implementing it. The guide is available at:
http://www.care.org/getinvolved/advocacy/tools.asp

Communication

• Population Reference Bureau (web site)

The Population Reference Bureau web site – **http://www.prb.org/** – provides a wealth of information and tools that can assist in researching and communicating messages. It provides a list of web sites providing population and health resources, including bibliographical databases, directories of population resources, and information on health in Asia and globally, as well as population policy and development sites.

For those looking for help in developing and communicating population and health research to policy-makers, a training materials section of the web site is available at:
http://www.prb.org/EventsTraining/TrainingMaterials.aspx

The materials include guidelines on creating a window of opportunity for policy change, and on giving effective data presentations in topics such as:

- steps to developing an effective presentation
- delivering an oral presentation
- presentation dos and don'ts
- tips for preparing great slides.

Media strategy

• Handbook on Civil Registration and Vital Statistics Systems: Developing Information, Education and Communication (47)

This handbook provides useful guidance on identifying target groups, developing key messages and using mass media, and is available at:
http://unstats.un.org/unsd/publication/SeriesF/SeriesF_69E.pdf

- **Media Advocacy: Lessons from Community Experiences** (178)

The use of media advocacy as a tool for policy change is discussed in this journal article. It provides helpful tips on using mass media in the context of health issues relating to alcohol and tobacco use. Although it does not deal with CRVS, the lessons learnt can be applied to other contexts. Preview available at: **http://www.jstor.org/discover/10.2307/3343268?uid=2129&uid=3738032&uid=2&uid=70&uid=4&sid=21100998449063**

Policy analysis

Computer software programmes such as *PolicyMaker 4* can be useful tools for analysing and managing the politics of public policy. This particular programme provides step-by-step guidance on conducting a stakeholder analysis and designing political strategies to support policy. The software helps to define policy content, key players, opportunities and obstacles, as well as strategies and strategy impact. The programme provides practical advice on how to manage the political aspects of policy and is promoted as a policy advocacy and lobbying tool. Further details and a tour of the programme are available at: **http://polimap.books.officelive.com/default.aspx**

8.5 Summary

This module has presented the key elements of the advocacy process and the steps to consider when developing an advocacy campaign. Recognizing that well-formulated messages targeting key audiences are crucial for a successful advocacy campaign, a series of carefully developed CRVS advocacy messages has also been included as a resource (see **Table 5** above). There are compelling reasons for engaging in advocacy, particularly as civil registration systems in many countries have progressed very little over the past 50 years. A lack of awareness of the considerable potential benefits for individuals and governments has contributed to a vicious cycle of under-development of CRVS systems. Advocates are needed across a range of sectors to persuade governments to make CRVS a priority, and to work towards obtaining greater political commitment and allocation of resources for establishing and improving systems.

Advocacy for improved legal frameworks and policies that fully support a well-functioning and well-used CRVS system is sorely needed. A selection of tools and resources has therefore been highlighted which can help to initiate campaigns aimed at gaining support for efforts to improve CRVS systems. Some of the key issues that need to be considered when developing an advocacy campaign are shown in **Box 39**.

BOX 39. Guidelines for engaging in advocacy

- Be clear about the goal of advocacy. Be sure it is realistic, achievable and supported by others.
- Be aware of the policy environment, the people who can change policy, and how policy can be changed.
- Timing is important. Be open to opportunities to promote messages for improving CRVS systems.
- Be on the lookout for champions who can motivate and inspire others to support your cause.
- Be well prepared and research both the problem(s) and possible solutions.
- Be strategic and develop an advocacy strategy and plan that uses the most appropriate processes and tools to engage and persuade your target audience.
- Be creative and well-informed when developing key messages.
- Be connected and develop partnerships that provide a strong support base for the advocacy campaign.
- Be persistent and committed in achieving the goal.

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Glossary

Accuracy of register-based vital statistics – the degree to which data items on the statistical report have been correctly and completely filled out with no errors introduced during transcription of vital records data into the statistical report, or during the processing stages (including coding, editing, input and tabulation).

Automated Classification of Medical Entities (ACME) – programme which automates the underlying cause-of-death coding rules. The inputs to ACME are the multiple ICD 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. ACME then applies WHO rules to the ICD codes and selects an underlying cause of death. ACME has become the de facto international standard for the automated selection of underlying cause of death.

Act – in some legal systems, an item of "primary legislation" (law passed in parliament) is known as an act after enactment.

Age – the interval of time between birth and the present, expressed in completed units of solar time. For adults and children, age is usually measured in completed years, while for infants or very young children, in completed months, weeks, days, hours or minutes of life as appropriate.

Attendant at birth – the person who assisted the mother in giving birth; for example, a physician, midwife, nurse, paramedic or lay person.

Bill – before an item of legislation becomes law, it may be known as a bill.

Birth – see "Live birth".

Birth parity – the number of times that a woman has given birth to a fetus with a gestational age of 24 weeks or more, regardless of whether the child was born alive or was stillborn.

Birth rate – the crude birth rate is the number of births over a given period divided by the person-years lived by the population over that period. It is expressed as the number of births per 1000 population.

Born in wedlock – a characteristic of a liveborn infant or dead fetus whose mother and father were legally married (any recognized union according to the laws or customs of the country) at the time of delivery.

Born out of wedlock – a characteristic of a liveborn infant or dead fetus whose mother and father were not legally married at the time of delivery.

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.

Capture–recapture – a type of method that can be used to assess the completeness of registration. Two independent sources of data are used to identify births or deaths, with subsequent determination made of the proportion of cases identified by the second method that were also identified by the first. From this information, the total number of cases can be estimated using mathematical models. Although capture–recapture methods can be used to help monitor trends over time, this assumes closed populations (that is, low rates of migration).

Causes of death – all diseases, morbid conditions or injuries that either 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**).

Census – the total process of collecting, compiling and publishing demographic, economic and social data, at a specific time or times, about all those in a country or delimited territory.

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

Certification of cause of death – the completion by a medically trained person of a death certificate including the cause of death (according to ICD certification standards).

Certifier (of cause of death) – a person authorized by law to issue a medical certificate 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 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).

Citizen – a person who holds the legal nationality of the country they are living in and, as such, benefits from all the constitutional rights of that country, but who is also subject to the obligations and regulations that apply to its citizens.

Citizenship – the legal nationality of a person.

Civil register – a loose-leaf file, ledger book, electronic file or any other official file for the permanent recording, in accordance with established procedures, of each type of vital event and its associated data occurring in the population of a well-defined area (for example, an entire country, county, district, municipality or parish).

Civil registrar – the official charged with the responsibility for civil registration of vital events in a well-defined area (for example, an entire country, county, district, municipality or parish) and for recording and reporting information on those vital events for legal and statistical purposes.

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 of each country. It establishes and provides legal documentation of such events. These records are also the best source of **vital statistics**.

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**).

Civil society – the voluntary participation of citizens in the civic and social bodies that form the basis of a functioning society, as opposed to state and commercial institutions.

Coalition – a group of organizations working together in a coordinated fashion towards a common goal.

Cohort – a group of people sharing a common temporal demographic experience who are observed through time. For example, the birth cohort of the year 2000 comprises the people born in that year.

Completed fertility rate – the number of children born per woman to a cohort of women by the end of their childbearing years.

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, Chanrasekaran–Deming and Brass–Growth Balance methods. These methods are often used by a national statistics office or academic institution to estimate registration completeness.

Confidentiality – a guarantee that information provided by respondents will not be revealed to others.

Coroner – an officer of a county, district, municipality, parish, etc., 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 birth rate – a vital statistics summary rate based on the number of live births occurring in a population during a given period of time. Typically expressed as the number of live births occurring among the population of a given geographical area during a given calendar year per 1000 mid-year total population of the given geographical area during the same year.

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 1000 mid-year 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.

Data documentation – facilitates the effective checking and preservation of a dataset and ensures that the research community will be able to use the data. For more information, please see the Data Documentation Initiative at: **http://www.ddialliance.org/**

Data repository – a means of providing storage and access to datasets and their documentation. The repository can comprise multiple networked data-storage technologies running on diverse operating systems, where data that no longer need to be in primary storage are protected and classified according to captured metadata, processed, de-duplicated and then purged automatically, based on data service level objectives and requirements. In information repositories, data-storage resources are virtualized as composite storage sets and operate as a federated environment.

Date of birth – the day, month and year of birth (and hours and minutes, if required) used to determine **age** in completed units of time.

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 **fetal death**.

Decision-maker – a person with the authority to create or change communal, organizational or governmental policies, programmes and/or laws.

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. Since 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.

Demographic surveillance system – the longitudinal enumeration of all demographic events, including cause of death via verbal autopsy, in a geographically defined population; usually established with the primary purpose of health and development intervention research.

Electronic medical record (EMR) – a computerized medical record created in an organization that delivers care, such as a hospital or physician's office. EMRs tend to be part of a local standalone health information system that allows storage, retrieval and modification of records.

Enumeration – the means by which the presence of individuals in a **household** or other group is recorded; normally used in reference to a census or survey. Distinct from registration, enumeration is anonymous and does not provide any direct benefit to the individual.

Epidemiology – the study of the distribution and determinants of health-related states and events in populations.

Episodes – the meaningful and identifiable segments of time associated with life events such as pregnancies, conjugal relationships and residencies.

Evaluation of a civil registration (or vital statistics) system – an appraisal of the value, worth and importance of individual elements in the operation of the system.

Fertility rate – the total fertility rate is the average number of children born to each woman over the course of her life. In general, total fertility rate is a better indicator of (current) fertility rates than crude birth rate as it is unaffected by the age distribution of the population.

Fetal death – the death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the gestation period; following separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles.

Geographic information system (GIS) – a system designed to capture, store, manipulate, analyse, manage and present all types of geographically referenced data. In simple terms, the GIS is the merging of cartography, statistical analysis and database technology.

Gestational period – the interval in completed weeks between the first day of the last menstrual period of the mother and the day, month and year of delivery, irrespective of whether the product of conception is a **live birth** or **stillbirth**.

Household – an arrangement in which one or more people make common provisions for their own food ("eat from the same pot") or other life essentials. A household may have a common budget, be related, unrelated or a combination of both, and there may be more than one household in a housing unit.

Household surveys – generally unreliable sources of data on adult and cause-specific mortality due to the relative rarity of such deaths and the limitations of sample size. Due to the sample size limitations, reliable estimates are usually only possible at national level and for major subregions. Population-based surveys include more-detailed questions on mortality and fertility that can be asked during a census, and can thus be used to generate estimates of fertility, and of child and adult mortality. DHS, PAPCHILD and MICS are examples of survey programmes that have yielded useful estimates of vital statistics rates, particularly fertility and child mortality.

International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10) – sometimes shortened to the "International Classification of Diseases", this classification system is maintained by WHO for coding diseases, signs, symptoms and other factors causing morbidity and mortality. Used worldwide for morbidity and mortality statistics and 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 deaths – the deaths of liveborn children under one year of age.

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.

Intercensal projection – estimates of population size between official census dates.

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, as well as on the dissemination and publication of vital statistics, with these different aspects potentially coming under different jurisdictions and acts.

Life expectancy – the average number of additional years a person could expect to live should current mortality trends continue for the rest of their life. Most commonly cited as life expectancy at birth.

Life table – a tabular display of life expectancy and the probability of dying at each age (or age group) for a given population, according to the age-specific death rates prevailing at that time. The life table provides an organized and complete picture of a population's mortality.

Live birth – the result of the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, which after such separation breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered to be liveborn.

Maternal death – the death of a woman while pregnant or within 42 days after the termination of pregnancy, irrespective of the duration and 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 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 – see **Certification of cause of death**.

Message – a statement that aims to inform, persuade or motivate an audience.

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.

Migration – the movement of people across a specified boundary for the purpose of establishing a new or semi-permanent residence. External migration is a move from a residential unit in the demographic surveillance area to one outside it, and internal migration is a move from one residential unit to another in the same demographic surveillance area.

Millennium Development Goals (MDGs) – eight social, health and economic development goals endorsed by the United Nations General Assembly in 2000.

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.

Monitoring of a civil registration system (or a vital statistics system) – checking the operation of a civil registration (or vital statistics) system in order to control its efficiency, accuracy, timeliness and coverage on an ongoing basis.

Morbidity rate – the frequency of disease, illness, injuries and disabilities in a population.

Mortality rate – the frequency of deaths as a component of population change.

Neonatal deaths – deaths of liveborn infants during the first 28 completed days of life.

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.

Perinatal mortality rate – the number of fetal deaths after 28 weeks of pregnancy (late fetal deaths) plus the number of deaths of infants under 7 days of age per 1000 live births.

Perinatal period – the perinatal period commences at 22 weeks (154 days) of gestation (the time when birth weight is normally 500 grams) and ends 7 completed days after birth.

Personal identification number (PIN) – the number or other code used to uniquely identify a person in a population database or any other administrative register. The use of a unique identifier for each person avoids duplicate entries and errors in respect to a person's identity.

Policy – a plan, course of action or set of regulations adopted by government, business or other institutions and designed to influence and determine decisions or procedures.

Policy analysis – usually the first step in planning an advocacy initiative. Policy analysis examines plans and regulations set by governments, business or other institutions, and how policies (or lack of policies or failure to implement them) affect specific population groups.

Population – (1) All of the inhabitants of a given country or area (province, city, metropolitan area etc.) considered together; or the number of such inhabitants. (2) In sampling, the whole collection of units (such as people, households, institutions or events) from which a sample may be drawn.

Population-at-risk – (1) for vital statistics purposes, the population that is subject to the occurrence of a vital event, such as the total population in the case of deaths, or the legally married population in the case of divorces. (2) for the calculation of specified vital statistics rates, the number (denominator) by which the number of vital events (numerator) is divided.

Population census – the total process of collecting, compiling, evaluating, analysing and publishing or otherwise disseminating demographic, economic and social data pertaining (at a specified time) to all the people in a country or in a well-delimited part of a country. Data from population censuses can be used to estimate birth and death rates. Also, population censuses can provide the best source of data on at-risk populations (numerators and denominators) in small geographical or administrative areas, and the baseline for sample vital registration.

Population register – a mechanism for the continuous recording of selected information pertaining to each member of the resident population of a country or area, resulting in up-to-date information on the size and characteristics of the population at selected points in time. Because of the nature of the population register, both its organization and operation should have a legal basis. Population registers start with a base consisting of an inventory of the inhabitants of an area and their characteristics (such as date of birth, sex, marital status, place of birth, place of residence, citizenship and language). To help in locating a record for a particular person, household or family in a population register, a unique identification number is provided for each entity. The population register can contain other socioeconomic data, such as occupation or educational level. The population register should be updated with the births, deaths, marriages and divorces recorded by the civil registration system of the country. The population register is also updated using migration records. Thus, notifications of certain events, which may have been recorded originally in different administrative systems, are automatically linked to a population register on an ongoing basis. The method and sources of updating should cover all changes to ensure that the characteristics of individuals in the register remain current.

Poverty mapping – the plotting of information on income, education, health etc. on maps in order to display the spatial distribution of welfare and its determinants. It is also used to simultaneously display different dimensions of poverty and/or its determinants.

Probability of dying – the probability that an individual of exact age x will die before exact age x+n, represented by the symbol nqx.

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.

Record linkage – a process (usually computer-based) that brings together information from two or more data files into a new combined file containing selected information on individuals or events that were not available in the separate records.

Registrar-general – the head of the civil registration office or department, with jurisdiction usually extending over the entire national territory.

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.

Regulation – a law that has been passed not by the parliament but by an executive body of the government (for example, an administration or a ministry). Regulations are as compulsory as laws, and deal with the details of how laws are to be executed.

Resident – see **usual residence**.

Sample vital registration with verbal autopsy (SAVVY) – The MEASURE Evaluation project based at the University of North Carolina at Chapel Hill and the United States Census Bureau has produced a series of SAVVY manuals for mortality surveillance (available at: http://www.cpc.unc.edu/measure/publications/index.php).

Sample registration system – longitudinal enumeration of demographic events (including cause of death via **verbal autopsy**) in a nationally representative sample of clusters, such as that used in China and India.

Small-area data estimation – any of several statistical techniques involving the estimation of parameters for small sub-populations. Generally used when the sub-population of interest is included in a larger survey.

Stakeholders – people or institutions with a shared interest (financial or otherwise) in a given event, process or outcome.

Statistical reporting of vital event data – the transmission of statistical reports on legally recorded vital events to the agency responsible for the compilation of statistics on such events.

Stillbirth – a baby that shows no signs of life when born. Stillbirths may be due to injuries, illness, infections or catastrophic events happening to the mother or to the child while in the womb or during birth. To distinguish this from abortion or miscarriage (for which a **verbal autopsy** is not conducted), the verbal autopsy system includes only births that occur after 28 weeks of pregnancy.

Survey – a canvassing of selected individuals or households in a population usually used to infer demographic characteristics or trends for a larger segment or for all of the population (see **Census**).

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 – the disease or injury that initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which 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 (VA) – a structured interview administered to caregivers or family members of households following a death. The VA 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, fetal death, marriage, divorce, adoption, legitimation, recognition of parenthood, annulment of marriage or legal separation.

Vital event record – a legal document entered in the civil register which attests to the occurrence and characteristics of a **vital event**.

Vital registration – all sanctioned modes of registering individuals and reporting on vital events.

Vital statistical record – a document or record containing the items of information on an individual vital event needed to compile vital statistics.

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 entire system for (1) collecting summary **vital events** data. (2) compiling, processing, analysing, evaluating, presenting and disseminating this data in the form of **vital statistics**.

ANNEXES

Annex A: Examples of Plan International's role in changing law and policy[1]

Country	First step	Plan's contribution	Result
Bangladesh	Plan Bangladesh started working on the birth registration initiative in 2001, working in close collaboration with the Ministry of Local Government and UNICEF.	Plan advocated enactment of the law and prvided input into its drafting.	Birth and Death Registration Act amended in 2004 and enacted in 2006 including free registration for children.
Cambodia	The Ministry of Interior, with the support of Plan Cambodia and UNICEF, organised a national workshop on civil registration.	Ministry requested support from Pan, which brought in an expert to review existing laws against international standards.	Amendments and recommendations have been presented to the Ministry to take forward.
Malawi	In collaboration with the Ministry of Women and Child Development, Ministry of Home Affairs, Malawi Human Rights Commission and UNICEF the drafting of a new bill was initiated.	Plan advised in the drafting of the National Registration Bill, 2005.	The Cabinet has approved the bill, making birth registration compulsory for all children. The bill is awaiting consideration by the Parliament.
Paraguay	Under Paraguayan law, children required a certifiate of live birth issued by a hospital in order to be registered. This was identified as a factor in the non-registration of children, as 40 per cent of births in Paraguay occur at home.	Plan hired a legal consultant to prepare a draft amendment to Article 55 of the Civil Registery Law 1266. Plan lobbied parlamentary authorities and advocated for the amendment to the law.	The law was amended within two months, a record time.

[1] Cody C (2009). Count every child: The right to birth registration. Pages 60–61.

Country	First step	Plan's contribution	Result
Paraguay	Plan's research found that there were a large number of schoolchildren without birth certificates.	Plan supported the Technical Office of the Ministry of Eductation and Culture to draft a resolution requiring education authorities to ensure that all schoolchildren should be registered.	Plan lobbied for the approval of Resolution # 1131-09, calling for all principals of educational centres to ensure that every schoolchild has a birth certificate by the end of the school year.
Togo	The Ministry of Interior with the support of Plan Todo and UNICEF organised a national workshop on civil registration.	Plan participated in the workshop, which led to a process of legal review.	In 2009, a new law on organisation of civil status was adopted by parliament, and includes bringing civil registry centres closer to communities through decentralisation.
Uganda	Workshop held with key stakeholders and government officials to review draft policy document and make proposals to amend the Birth and Death Registration Act.	Plan guided the consultation.	The proposals make during the workshop have been complied into a working document awaiting discussion and cabinet approval.

Annex B: Approved ICD-10 training materials

Country	Materials	Institution	Contact person
Australia	Introduction to ICD-10	National Centre for Classification in Health	Sue Walker **s.walker@qut.edu.au**
Korea	Medical Record/ Health Information Management	Catholic University of Pusan	Professor Bock Hee Im
	Medical Record/ Health Information Management	Korea University	Professor Hyun Sill Rhee
	Medical Record/ Health Information Management	Kyungnam College of Information & Technology	Professor Weon Kim
	Medical Record/ Health Information Management	Jeju Halla College	Professor Hyo Sil Kim
	Medical Record/ Health Information Management	Wonkwang Health Science College	Professor EunHee Cho
	Medical Record/ Health Information Management	Masan College	Professor Jisuk Kim
	Medical Record/ Health Information Management	Yonsei University	Professor Joon H Hong **jh.hong.42@hotmail.com**
	Medical Record/ Health Information Management	Dongduk Women's University	Professor Jae Young Kim
	Medical Record/ Health Information Management	Shin Heung College	Professor Mi Sook Kim
Sri Lanka	Training Coders in Medical Record Practice and ICD-10	National Institute of Health Sciences (NIHS)	Dr Saman Gamage (Course coordinator) **samanhattotuwa@yahoo.com** Dr LT Gamlath Director/NIHS **nihs@sltnet.lk**
USA	NCHS training series Mortality Medical coding with ICD-10	National Center for Health Statistics	Donna Glenn **dgp2@CDC.GOV**

Annex C: Application of data-quality criteria to civil statistics – an example from Australia

Using the data-quality criteria shown in Module 6 (**Box 23**), the Australian Bureau of Statistics (ABS) annually publishes a Data Quality Statement for its Causes of Death publication. For 2010 data, the statement[2] covers the key aspects of:

Institutional environment – Statistics presented...are sourced from deaths registrations administered by the various state and territory Registrars of Births, Deaths and Marriages. It is a legal requirement of each state and territory that all deaths are registered. Information about the deceased is supplied by a relative or other person acquainted with the deceased, or by an official of the institution where the death occurred on a Death Registration Form. As part of the registration process, information on the cause of death is either supplied by the medical practitioner certifying the death on a Medical Certificate of Cause of Death, or supplied as a result of a coronial investigation.

Death records are provided electronically to the ABS by individual Registrars on a monthly basis. Each death record contains both demographic data and medical information from the Medical Certificate of Cause of Death where available. Information from coronial investigations is provided to the ABS through the National Coroners Information System (NCIS).

Relevance – The ABS Causes of Death collection includes all deaths that occurred and were registered in Australia, including deaths of persons whose usual residence is overseas. Deaths of Australian residents that occurred outside Australia may be registered by individual Registrars, but are not included in ABS deaths or causes-of-death statistics.

From the 2007 reference year, the scope of the collection is:

- all deaths registered in Australia for the reference year and received by the ABS by the end of the March quarter of the subsequent year; and
- deaths registered prior to the reference year but not previously received from the Registrar nor included in any statistics reported for an earlier period.

For example, records received by the ABS during the March quarter of 2011 which were initially registered in 2010 or prior (but not forwarded to the ABS until 2011) are assigned to the 2010 reference year. Any registrations relating to 2010 which are received by the ABS after the end of the March 2011 quarter are assigned to the 2011 reference year.

Data in the Causes of Death collection include demographic items as well as causes-of-death information coded according to the...ICD. ICD is the international standard classification for epidemiological purposes and is designed to promote international comparability in the collection, processing, classification and presentation of cause-of-death statistics. The...ICD-10 was used for the 2010 data.

Accuracy – Non-sample errors are most likely to influence accuracy in datasets which constitute a complete census of the population, such as the Causes of Death collection. Non-sample error arises from inaccuracies in collecting, recording and processing the data. The most significant of these errors are: misreported data items; deficiencies in coverage; incomplete records; and processing errors. Every effort is made to minimise non-sample error by working closely with data providers, running quality checks throughout the data-processing cycle, training of processing staff and efficient data-processing procedures.

[2] Australian Bureau of Statistics. Causes of Death 2010. Cat. 3303.0.

The ABS has implemented a new revisions process that applies to all coroner-certified deaths registered after 1 January 2006. Previously, all ABS processing of causes-of-death data for a particular reference period was finalised approximately 13 months after the end of the reference period. The new process enables additional information relating to coroner-certified deaths to be used as and when it becomes available, resulting in increased specificity of the assigned ICD-10 codes.[3]

Accessibility – In addition to the information provided in ABS publications, a series of "data cubes" are also available providing detailed breakdowns by Causes of Death. However, the ABS observes strict confidentiality protocols as required by the Census and Statistics Act (1905), which may place restrictions on access to data at a very detailed level.

Interpretability – The Causes of Death and Causes of Death, Doctor Certified Deaths publications contain detailed Explanatory Notes, Technical Notes, Appendices and a Glossary that provide information on the data sources, terminology, classifications and other technical aspects associated with these statistics.

Coherence – Use of the supporting documentation released with the statistics is important for assessing coherence within the dataset and when comparing the statistics with data from other sources. Changing business rules over time and/or across data sources can affect consistency and hence interpretability of statistical output. The Explanatory Notes in each issue contains information pertinent to this particular release which may impact on comparison over time.

Timeliness – Causes of Death data and Causes of Death, Doctor Certified Deaths are published annually, following the publication of Deaths, Australia (ABS cat 3302.0) in November of each year. There is a focus on fitness for purpose when causes-of-death statistics are released. To meet user requirements for accurate causes-of-death data it is necessary to obtain information from other administrative sources before all information for the reference period is available (e.g. information from finalisation of coronial proceedings to code an accurate cause of death). A balance therefore needs to be maintained between accuracy (completeness) of data and timeliness. ABS provides the data in a timely manner, ensuring that all coding possible is accurately undertaken prior to publication. In addition, to address issues arising from the publication of causes-of-death data for open coroner cases, and to enable the use of additional information relating to coroner-certified deaths either 12 or 24 months after initial processing, data are now subject to the revision process outlined above and in the footnote below.

[3] Further information on the revision process is provided in the Explanatory Notes (35–39) and Technical Notes contained in Causes of Death Revisions, 2006, and Causes of Death Revisions, 2008 and 2009.

Annex D: Four dimensions of the GDDS

The four Dimensions of the GDDS

1. *The Data – coverage, periodicity and timeliness:* Dissemination of reliable, comprehensive and timely economic, financial and socio-demographic data is essential to the transparency of macroeconomic performance and policy.

2. *Quality:* Data quality must have a high priority. Data users must be provided with information to assess quality and quality improvements. The GDDS recommends:
   - Dissemination of documentation and methodology and sources used in preparing statistics.
   - Dissemination of component detail, reconciliations with related data, and statistical frameworks that support statistical cross-checks and provide assurance of reasonableness.

3. *Integrity:* To fulfill the purpose of providing the public with information, official statistics must have the confidence of their users. In turn, confidence in the statistics ultimately becomes a matter of confidence in the objectivity and professionalism of the agency producing the statistics. Transparency of practices and procedures is a key factor in creating this confidence. The GDDS therefore recommends:
   - Dissemination of the terms and conditions under which official statistics are produced, including those relating to the confidentiality of individually identifiable information.
   - Identification of internal government access to data before release.
   - Indentification of ministerial commentary on the occasion of statistical releases.
   - Provision of information about revisions and advance notice of major changes in methodology.

4. *Access by the public:* Dissemination of official statistics in an essential feature of statistics as a public good. Ready and equal access by the public are principal requirements. The GDDS recommends:
   - Dissemination of advance release calendars.
   - Simultaneous release to all interested parties.

Annex E: Contents of the INDEPTH Demographic Surveillance System Resource Kit

Resources shown below can be downloaded from:
http://www.indepth-network.org/index.php?option=com_content&task=view&id=95&Itemid=183

1. Introduction & Navigation

Purpose of the Resource Kit

Navigating the Resource Kit

DSS Terminology

2. Site Startup

Institutional Arrangements

- Legal considerations
- Site identity
- Site leadership
- Site strategic plan
- Management & advisory committees
- Funding partners
- Consumers
- Networking
- Permits

Administration – Personnel

- Typical essential positions & qualifications
- Sample DSS staff organogram
- Sample job descriptions
- Sample job advertisements
- Sample contracts
- Remuneration considerations
- Research fellows & interns

Administration – Financial

- Sample chart of DSS accounts
- Capital equipment acquisition
- Tool to estimate running costs
- Financial guidelines

Site design decisions

- Decisions on definitions
- Site selection
- Update cycle Frequency & timing
- Household, membership and residency
- Migration definition
- Local event calendars
- Local illness terminology
- Data management
- Reference data model
- Core variables
- Additional variables
- Hardware support
- Data document
- Database software platform
- Event questionnaires
- Field – Data flow chart
- Data access, security & confidentiality
- Continuing analysis & quality Control
- Communications & dissemination
- Community feedback
- Web site
- Publications & reports
- V-Sat Internet access

Recruitment and training

- Initial recruitment of managers
- Developing procedures and training manuals
- Piloting instruments
- Field system
- Field staff recruitment & initial training
- Field staff full training
- Community key informants
- Data system
- Data system recruitment
- Data system training
- Data system testing
- Administration
- Administration recruitment
- Administration training

Site management

- Team management
- Field team meetings
- Data team meetings
- Key informant meetings
- Inter-round re-training

Strategic issues
Data sharing and collaboration policies
Sustainability
Influencing policy & practice
Working with INDEPTH
Ethics & confidentiality

3. Core Baseline Round

Census & core parameters

Community approach

Household mapping

Informed consent

4. Core Update Rounds

Registration updated every round

New household registration
Changes in household structure
Pregnancy registration, monitoring and outcome
Birth registration
Death registration
Cause of death registration
Conducting VA
Supervising VA
Reconciling VA
Validating VA
Physician VA Coding
Disease coding ICD10
Migration registration
Internal migration
External migration
Internal movement
Perimeter migration
Geo-referencing
GIS database structures
GPS mapping
Spatial analyses
Access & travel time
Special cases
Urban DSS
Urban Slum DSS
Pastoralists DSS

Registration updated annually

Immunization
Education
Employment
Asset indexing

Quality management

Supervision
Field quality control
Forms logging
Dual entry
Event summary Questionnaires
Repeat visits
Residency reconciliation
Internal & external migration reconciliation
Loss to follow-up
Demographic and statistical logic
Backups and recovery
Data security
Archives
Locking and archiving database by rounds

Financial management

Guidelines for financial management
Projecting annual budgets

5. Optional Modules

Nested morbidity surveys

Physical & cognitive function
Mental health
Anemia

Nested risk factor surveys

Household Food security
Anthropometric status
Anthropometric status indicators
Food security indicators
Measuring food security in survey rounds
Chronic Disease Risk Factors
Sexual behaviour
HIV serostatus
Maternal mortality
Family planning
Twins
Orphanhood
Tobacco
Alcohol and drugs
Domestic violence
Entomologic Inoculation Rates

Nested health system surveys

Service availability mapping
Health service access
Household malaria surveys

ITN coverage
EPI, ANC and TB DOTS coverage
VCT, PMTCT & ARVs coverage
Surveillance for eradicable disease
Catastrophic illness and insurance

Environmental monitoring

Rainfall
Land cover and land use
Weather stations
Water quality

Intervention trials

Management and leadership capacity
Good Trials Practice
Good Clinical Practice
Good Laboratory Practice
Good Data Practice
Trial monitoring
Adverse event reporting
Protocol deviation reporting
Institutional Review Boards and ethics reviews
Controlled Trials Registries

Linking to other databases

Health facility data
Health sector data
Other sectoral data
Civil registration data
Millennium Development Goals

Emerging technologies

Biometrics and smart cards
Electronic data capture
On-line data entry
Optical mark reader (OMR)
Computer coding of Verbal Autopsy
Bar coding
Time stamps & tixels
Off-site electronic archiving

Sustaining the DSS

Community liaison
Staff motivation & retention
Diversifying funding sources
Diversifying information products
Diversifying research approaches
Collaborations and strategic partnerships
INDEPTH membership
Links to DSS donors

6. Resources & Downloads

Manuals

DSS Glossary
Reference Data Model Graphic
Reference Data Model Paper
Sample Data Flow Chart
INDEPTH Census Manual
HRS2 Technical Manual
HRS2 User Manual
Computerized VA Coding
Computerized VA Coding 2
INDEPTH Rainfall Monitoring Manual
Global Positioning Satellite (GPS) Field Manual
Hand Held Computer (PDA) for Household Survey Field Manual
Household Listing Manual
The Fundamentals: Building Visual FoxPro
Sample Interview Guidelines
INDEPTH SES Variables for Cross-site Analyses
WHO STEPS at a Glance
WHO STEPS Guide to Questions
Household Sample Surveys

Software

HRS2 DSS Database System
Stata Routines for building work files
Stata Routine for Residency Event Check File
Stata Routine for Lost to Follow-up
Stata Routine for PCA equity quintiles
Stata Routine for Check Sequence of Events
Excel Tool for Estimating Running Costs

Sample Questionnaires

INDEPTH Verbal Autopsy Instruments
INDEPTH Verbal Autopsy Instruments (French)
Sample VA Transfer Logging Form
Sample Community Form
Sample Initial Census Form
Sample Household Registration Form
Sample Household Registration Form Alternative
Sample Marriage Event Form
Sample Marital Changes Form
Sample Pregnancy Registration Event Form
Sample Pregnancy Outcome Event Form
Sample Birth Registration Form
Sample Death Event Form
Sample Household Malaria Survey Form
Sample Immunization Form
Sample Women's Sexual Behaviour Form

Sample Men's Sexual Behaviour Form
Sample Missed Out Persons Event Form
Sample Change of Residence Event Form
Sample In-migration Event Form
Sample Out-migration Event Form
Sample Changes Form
Sample Insurance Survey Form
Sample Domestic Violence Form
Sample Tobacco Smoking Form
Sample Employment Form
Sample Food Security Form
Sample Anthropometric Status Form
Sample Land Asset Form
Sample Form Logging Form
WHO STEPS Form English
WHO STEPS Form French

Sample Documents

Sample Informed Consent Instrument
Sample Informed Consent Instrument for HIV/AIDS
INDEPTH ICD10 Short List
Sample DSS Health Interventions Profile
Sample Financial Guidelines
Sample Chart of Accounts
Sample Strategic Objectives
Sample Staff Organogram
Sample Job Descriptions
Sample Job Advertisements
Sample Interview Scenarios - Data
Sample Interview Scenarios - Field
Sample Staff Contracts
Sample Equipment List
Sample SOPs for Clinical Trials Policy
Sample Research Operations Matrix

INDEPTH Monograph Volume 1

Introduction, Methods & Life Tables
DSS in East Africa & Southern Africa
DSS in Southern Africa, West Africa & Asia
Appendices: Sample Questionnaires & Bibliography

Annex F: SAVVY Resources

The following resources can be downloaded from:
http://www.cpc.unc.edu/measure/tools/monitoring-evaluation-systems/savvy

- Sample Vital Registration with Verbal Autopsy (SAVVY): An Overview [MS-06-19-OB] provides a concise overview of the SAVVY system.
- Data Processing Manager's Manual [MS-07-26-DPM] provides both an overview and step-by-step discussion of the SAVVY data-processing system.
- SAVVY Budget Manual [MS-07-26-BM] and SAVVY budget spreadsheet template software are used in the budgeting process for SAVVY planning.
- Verbal Autopsy Coder's Manual [MS-07-26-VAC] provides an overview of cause-of-death certification and an outline of the step-by-step process involved in coding information collected from VA procedures. This manual is meant to augment the content of the international standard core VA procedures.
- Field Office Manager's Manual [MS-07-26-FOM] describes the roles and responsibilities of the field office manager, a senior district official responsible for managing the operations of the SAVVY system at the district or province level.

Annex G: Stakeholder identification template[4]

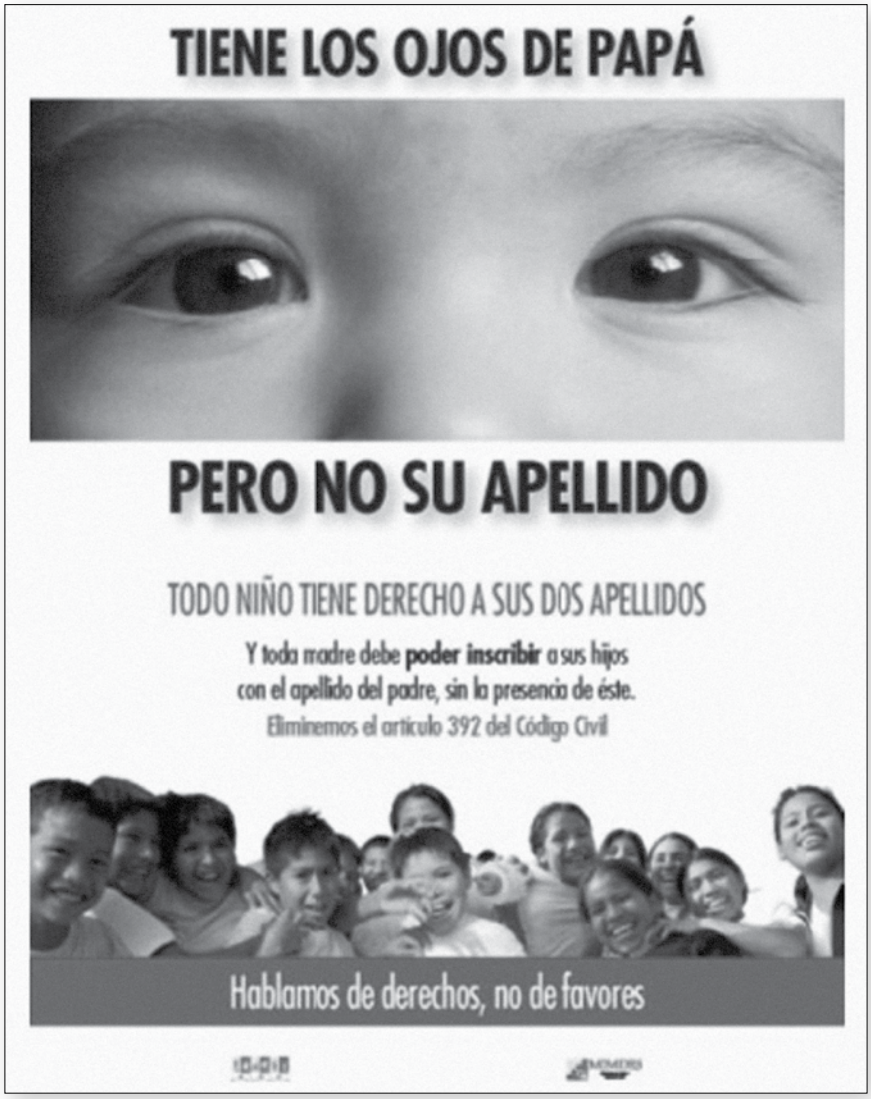
Stakeholder	Nature of Stakeholding
Registration authorities	**Owners** • The prime collection agence for source data • Need for a new legal framework covering registration • Will be required to make significant changes to registration processes • Have an interest in ensuring all of the outcomes expected from a system e.g. legal and statistical are met • Will require ongoing funding for additional staff, training of staff, new functions for the registration processes
National Statistics Office	**Influences and customers** • Have responsability for the production of statistics and statistical standards and frameworks • Will be able to advise on how to incorporate statistical needs into an administrative system • Will have statistical infrastructure in place to assist in implementation • May play a coordinating role
Health Departments	**Customers and beneficiaries** • A prime beneficiary of more complete and timely data on health status in order to deliver services and infrastructure and develop and monitor health programs • May play a large role in the collection of data e.g. cause of death data from doctors, birth data from midwives • May already have infrastructure in place (e.g. health clinics, hospitals, etc.) that could be used in the implementation of a system
Central Agencies - Finance and Tresaury Departments	**Funders and beneficiaries** • Will be required to ensure adequate funds are available for implementation of a civil registration system both in the short and long term • Will benefit from better information enabling more effective resource distribution • Will benefit from better information on development and monitoring of policy and programs
People who cerfify deaths- e.g. doctors, coromers	**Impactees and suppliers** • Will be required to undertake additional training and take on new tasks, howerver will also benefit from the availability of timely local data on health issues
Planning and infrastructure Development Agencies	**Beneficiaries** • Will benefit from better information enabling more effective resource distribution
Health Information Management Professional Association	**Beneficiaries, champions and influencers** • By the nature of their profession are interested in the collation and use of health information • Will have the skills to contribute to implementation

[4] Australian Bureau of Statistics (2010). Advocating for civil registration: guide to developing a business case for civil registration (Working Paper No. 15). Pages 8–9.

Annex G: continued

Stakeholder	Nature of Stakeholding
Academics and Researchers	**Beneficiaries** • Will benefit from better information enabling more effective planning of education facilities and better research information
Education Departments	**Beneficiaries** • Will benefit from better information enabling more effective planning for new schools and education services
Rights agencies and NGOs working for birth registration	**Influencers** • Interested in the correct use of personal data
Civil Liberties/Privacy Groups	**Influencers** • Interested in the correct use of personal data
Community Groups	**Influencers and Champions** • The system must be culturally appropriate • May identify historical cultural aspects which may affect the civil registration system (for example, related to religion or ethnicity) that would need to be addressed with risks identified and overcom • Will be in a postion to promote the value of the system and to educate groups and invididuals about the importance of registration

Annex H: Poster used in communication campaign[5]



"He's got his father's eyes but he hasn't got his father's last name. Every child has the right to his two last names. And every mother shall be entitled to register her children with the father's last name, without requiring his presence. Eliminate Article 392 of the Civil Code. We are talking about rights, not about favors."

[5] Alcantara PB, Edberg M, Morales RV (2007). We call upon the congress: an advocacy strategy on behalf of birth registration rights. Cases in Public Health Communication and Marketing. Retrieved 27 July 2011 from: http://www.gwumc.edu/sphhs/departments/pch/phcm/casesjournal/volume1/peer-reviewed/cases_1_09.pdf

Annex I: Recommended structure for a business case[6]

Purpose: The Business Case is used to obtain management commitment and approval for investment in business change including projects and programs, though rationale for the investment. The Business Case provides a framework for planning and mangement of the business change. The ongoing viability of a project or program will be monitored against the Business Case. The Business Case should contain information covering five key aspects: strategic importance, options appraisal, commercial aspects, affordability and achievability.	
Strategic importance	• Description of the business need and its contribution to the organisation's business strategy • Include results of research and scoping statement
Objectives	• Why it is needed now? • Key benefits to be realised • Critical success factors and how they will be measured
Options appraisal	• High level cost/benefit analysis of (ideally) at least three options for meeting the business need • Include analysis of 'soft' benefits that coannot be quantified in financial terms • Identify preferred option and any trade-offs
Commercial aspects	• This section is applicable where there is an external procurement; this section outlines the potential deal. Most of this information will be produced for the Outline Business Case • Proposed sourcing option with rationale for its selection • Key features of proposed commercial arrangements (e.g. contract terms, contract length, payment mechanisms and performance incentives) • The procurement approach/strategy with supporting rationale
Affordability	• Statement of available funding and 'ballpark' estimates of projected whole-life cost of project • Including departmental costs (where applicable)
Achievability	• High level **implementation plan** for achieving the desired outcome, with key milestones and major dependencies (e.g. interface with other projects) • Outline contingency plans e.g. addressing failure to deliver service on time • Major risks identified and outline plan for addressing them • Provider's plans for the same, as applicable, skills and experience required
Source information	• Procurement documentation • Program/**Project management plans** and documentation • High level requirements • Business Strategy

[6] Australian Bureau of Statistics (2010). Advocating for civil registration: guide to developing a business case for civil registration (Working Paper No. 15). Page 11.

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Millions of people in countries worldwide come into direct contact with their national civil registration and vital statistics (CRVS) systems through their own personal experience of registering a birth or death, applying for a copy of a birth certificate, getting married or divorced, or making arrangements for the funeral of a relative.

Nevertheless, there is often very little awareness that the simple acts of registering a birth, filling out a death certificate or entering a code into a database lie at the heart of larger and crucially important systems that are vital, for example, in providing proof of identity to individuals, or in generating information about whole populations. Such information is the basis of sound governance and the key for responsible planning – not only in health but in other social and economic sectors.

Given the huge importance of well-functioning CRVS systems to both the public and policy-makers, it is remarkable that this issue has received so little attention from the global health and development community. In part, this is because such systems are taken for granted in highly developed countries where all births and deaths are routinely registered and certified. In these countries, vital statistics are thus readily available for governments to monitor and to use for social and economic planning in key sectors such as health, education, employment and housing.

However, governments in low- and middle-income countries have the same need for data for planning their development and ensuring the effective use of limited resources. As a result, there is now a momentum building within these countries and within the global development community towards the strengthening of CRVS systems. In 2007, a series of papers was published under the collective banner "Who Counts?" to help draw attention to the "scandal of invisibility" in which the poorest and most vulnerable people in society go unregistered, uncounted and uncared for.

To help address such ongoing and profound inequalities this collaboratively developed resource kit has been produced to support countries in planning and implementing improvements to their CRVS systems. It has been compiled using critically assessed materials drawn from many sources, and is presented in a user-friendly way that is accessible to both experts and users with a general interest in evidence-based decision-making.

With their primary focus on the need for regular and reliable statistics on births and deaths by age, sex and cause of death, the eight modules and associated resources which comprise the kit will enable all users to identify, locate and make use of core standards, tools, materials and country experiences. Taken together, the resource kit represents a valuable synthesis of the expertise and knowledge gathered during concerted national and international efforts to ensure that everyone counts.

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