HEALTH METRICS NETWORK

Framework and Standards for Country Health Information Systems

SECOND EDITION



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Preface

The Health Metrics Network (HMN) was launched in 2005 to help countries and other partners improve global health by strengthening the systems that generate health-related information for evidence-based decision-making. HMN is grateful for funding support from the Bill and Melinda Gates Foundation, the UK Department for International Development (DFID), the Danish International Development Agency (DANIDA), the Netherlands Ministry of Foreign Affairs, the United States Agency for International Development (USAID), the European Commission (EC) and the World Health Organization (WHO), which also serves as host to HMN.

HMN is the first global health partnership that focuses on two core requirements of health system strengthening in low and low-middle income countries. First, the need to enhance entire health information and statistical systems, rather than focus only upon specific diseases. Second, to concentrate efforts on strengthening country leadership for health information production and use. In order to help meet these requirements and advance global health, it has become clear that there is an urgent need to coordinate and align partners around an agreed-upon "framework" for the development and strengthening of health information systems.

It is therefore intended that by 2011, this *Framework and Standards for Country Health Information Systems* (the "HMN Framework") will be the universally accepted standard for guiding the collection, reporting and use of health information by all developing countries and global agencies. This will only be achieved by fostering agreement on the goals and coordinated investments now needed by country health information systems.

The HMN Framework will serve two broad purposes. Firstly, at country level, it will focus investment and technical assistance on standardizing health information system development, and serve as a benchmark for baseline system assessments. As part of this, a roadmap is described for strengthening health information systems, and putting in place ongoing monitoring and evaluation. Second, the HMN Framework will permit access to – and better use of – improved health information at the country and global levels.

The HMN Framework is not intended to replace existing guidelines that provide detailed information on health information system elements. Instead it will seek to identify appropriate and existing standards and promote them. This dynamic approach is expected to evolve over time as it incorporates new developments, country experiences and partner inputs. This second edition has already been informed by a wealth of input on different aspects of health information systems obtained through consultative meetings and country visits. Its adaptation is intended to be iterative as HMN progresses and country health information systems mature. It is intended that the HMN Framework will be instrumental in forging consensus around the vision, standards and processes required of a health information system.

Introduction

Since the 1990s, knowledge and understanding of the global public health picture have improved following important investments in data collection. Despite this, a huge gap remains between what public health professionals actually know and what they need to know to improve the health of the world's population. The Health Metrics Network (HMN) is founded on the premise that better health information means better decision-making, leading to better health.

The goal of HMN is to increase the availability, quality, value and use of timely and accurate health information by catalysing the joint funding and development of country health information systems. It is intended that this goal should be achieved by:

Developing and elaborating upon the harmonized HMN Framework for country health information systems described in this document.

Supporting developing countries in adapting and applying the HMN Framework to improve their health information systems; providing technical support; and acting as a catalyst to secure funding.

Improving the quality, value and use of health information by developing policies and offering incentives to enhance the dissemination and use of such data at local, regional and global levels.

Reliable and timely health information is an essential foundation of public health action and health systems strengthening, both nationally and internationally. This is particularly

so when resources are limited and funding-allocation decisions can mean the difference between life and death. The need for sound information is especially urgent in the case of emergent diseases and other acute health threats, where rapid awareness, investigation and response can save lives and prevent broader national outbreaks and even global pandemics. Furthermore, the requirements of the 2005 *International Health Regulations* (IHR)¹ impose additional demands on often weak health information systems for the accurate and timely notification of any public health emergency of international concern (PHEIC).

Reliable and timely health information is an essential foundation of public health action and health systems strengthening, both nationally and internationally.

Despite all this, few developing countries have sufficiently strong and effective health information systems even to permit adequate monitor-

ing of progress towards the United Nations Millennium Development Goals (MDGs). Indeed, it is often in countries with the greatest need that reliable and timely information is not available, owing to chronic under-investment in systems for data collection, analysis, dissemination and use. Even when data are available, they are often out of date, rendering the challenge of assessing trends even more difficult. Decision-makers do not have the

¹ World Health Organization. International Health Regulations (2005): Areas of work for implementation. Geneva, World Health Organization, 2005 (WHO/CDS/EPR/IHR/2007.1). <u>http://www.who.int/csr/ihr/IHR_Areas_of_work.pdf</u>

information required to identify problems and needs, make evidence-based decisions on health policy and allocate scarce resources optimally.

Difficulties in collecting good public health data are tied not only to financial constraints – measuring health is conceptually and technically complex. Statistical, public health and biomedical knowledge and expertise unique to specific diseases or programme areas are also required. Accurate measurement depends upon the availability of disease-specific biometric tests, clinical diagnoses, and the feasibility of measuring behaviours and population-based indicators. Thus, health statistics may vary greatly in terms of their reliability and validity, usability and timeliness.

At the same time, the presentation of epidemiological data is generally aimed at specialists and other experts. Too often, little effort is made to make the information understandable to policy-makers, frontline health workers, non-health specialists or the public. As a result, there is a widely established perception that health information is obscure, unclear and sometimes contradictory. Public demands for accountability and evidence-based decisionmaking is increasing, while the involvement of multiple donors in the public health sector has created a greater awareness of the need for good data to avoid misguided interventions that waste efforts and resources, and result in the loss of credibility.

A key component of health information systems is public health surveillance which focuses mainly on defining problems and providing a timely basis for action. This is especially so when responses need to be urgent, as in the case of epidemic diseases. Epidemic and emergent disease surveillance produces information linked with public health action. The need for timeliness of reporting and response, and the requirement for effective linkages to those in authority with the responsibility for disease control, impose additional requirements on health information systems. Often in the past, totally separate systems for surveillance and for general health information have been established, leading to fragmentation and competition for resources.

In addition, health information is produced and used by many different institutions (including ministries of health, national statistics offices, the private sector, civil society organizations, donors and development agencies). Health information systems have thus evolved in a haphazard and fragmented way following administrative, economic, legal or donor pressures. Health information systems have been further fragmented by the demands of

Health workers are overburdened by excessive data and reporting demands from multiple and poorly coordinated subsystems. disease-focused programmes, often caused by diverse donor requirements and international initiatives directed to specific areas. The capacity of country health information systems can easily be overwhelmed by these multiple parallel information demands.

In the context of health sector reform and decentralization, health systems are managed as closely as possible to the level of service delivery. This shift in function between the central and peripheral levels has generated new information needs and led to a profound restructuring of information systems, with changing requirements for data collection, processing,

analysis and dissemination. Health sector reforms also magnify the need for standardization and quality of information, presenting a further challenge to national health authorities. Data are often collected without being analysed critically or turned into information that can be used for day-to-day management or longer-term planning. Meanwhile, health workers are overburdened by excessive data and reporting demands from multiple and poorly coordinated subsystems.

The resources now needed for strengthening health information systems will typically come from constrained national budgets, and countries will have to sustain the long-term investments required. Health information systems should be made responsive to the needs and requirements of all institutions concerned, within one comprehensive plan developed

with widespread collaboration. Controlling major diseases should also be approached in a comprehensive and coherent manner that binds together individual and community health interventions.

Another essential step in strengthening health information systems will be to link information production to use. Users of health information include those delivering care and those responsible for managing and planning health programmes both within countries (health and finance ministries) and outside (donors, development banks and technical support agencies). At the same time, decision-making around country health priorities

necessarily involves the wider community, including civil society. A good health information system should therefore present and disseminate data in appropriate formats for all audiences. Sound health information is a global public good and requires public and media support to ensure continued investment. Country plans to improve health information systems can help bring together international organizations, governments, donor agencies, health planners and statisticians, communities and health providers in a shared mission to create or strengthen systems to generate the health information needed by all.

Another essential step in strengthening health information systems will be to link information production to use.

This will be a technically and politically demanding challenge, and knowledge and experience must increasingly be pooled if progress is to be made. Across all sectors broadbased consensus-building will be crucial as much of the data needed by the health sector is generated by others. The requirements and difficulties outlined above in generating, analysing, sharing and using data are common to many countries and regions. At the same time, the objective of a health information system is also common to all – to produce relevant and quality information to support health interventions. HMN is actively seeking the strong political endorsement and consensus-building required for adoption of the HMN Framework (**Fig. 1**) for general use. Key stakeholders include WHO Member States, the United Nations Statistical Commission, the High Level Forum on the Health Millennium Development Goals, and the forums and board meetings of other partners and alliances. At the 60th World Health Assembly in May 2007, Member States urged stakeholders ranging from international bodies, the public and private sectors, and health information and statistical communities to use the standards and guiding principles of the HMN Framework in the "strengthening of [health] information systems".¹

This document – the HMN Framework and Standards for Country Health Information Systems – is divided into three parts:

Part 1: Rationale, Approaches and Vision – focuses on the rationale, approaches and vision required for strengthening health information systems. A new approach to health information systems strengthening is described and specific solutions proposed to the problems identified. The key role of global health partnerships and HMN is discussed.

■ Part 2: Components and Standards of a Health Information System – describes the components and standards of a health information system, as shown in the left-hand column of **Fig. 1**. These are health information system resources, indicators, data sources, data management, information products, and dissemination and use. Desirable standards to be attained when strengthening or establishing each health information system component are reviewed. Data-management methods are proposed and subsequent practical use of the information generated is discussed.

Part 3: Strengthening Health Information Systems – Principles, Processes and Tools – guiding principles for health information system development are outlined, and practical

¹ 60th World Health Assembly, Resolution 60.27 Strengthening of health information systems, http://www.who.int/gb/ebwha/pdf_files/WHA60/A60_R27-en.pdf

steps for implementation proposed. As part of the "Processes" of strengthening health information systems (shown in the right-hand column of **Fig. 1**), three implementation phases are identified, which are all accompanied by continuous evaluation and improvement.



Fig 1. The HMN Framework

PART 1

Rationale, Approaches and Vision



In Santiago, Chile, Alejandra Landabur enters information from death certificates into a database. She records 100 forms daily. PHOTO: WHO/ALIOSHA MARQUEZ

1.1 Rationale for strengthening health information systems

1.1.1 Improving health – the reason for better health information

Although reliable and timely health information is the foundation of public health action, it is often unavailable due to under-investment in systems for data collection, analysis, dissemination and use. Consequently, decision-makers cannot identify problems and needs, track progress, evaluate the impact of interventions and make evidence-based decisions on health policy, programme design and resource allocation. It is not the case that countries with insufficient resources should forgo good health information. Indeed, they are the ones that can least afford to be without it.

1.1.2 The challenge of measuring health

Measuring health is conceptually and technically complex, requiring statistical, public health and biomedical knowledge and expertise unique to each disease or programme area. Accurate measurement depends upon the availability of disease-specific biometric tests, clinical diagnoses, and the feasibility of measuring population behaviours and the coverage of health services. As a result, health statistics may vary greatly in terms of scientific soundness, usability and timeliness.

1.1.3 Poor performance of health information systems

Health information systems have evolved in a haphazard and fragmented way as a result of administrative, economic, legal or donor pressures. The responsibility for health data is often divided among different ministries or institutions, and coordination may be difficult due to financial and administrative constraints. For example, counting births and deaths

Health information systems have evolved in a haphazard and fragmented way as a result of administrative, economic, legal or donor pressures. – a basic building block of a health information system – is generally undertaken by planning or interior ministries. Special efforts are therefore needed to ensure adequate coordination and sharing of information between health ministries and other sectors.

Health information systems are further fragmented by disease-focused demands that often relate to donor requirements and international initiatives directed towards specific areas such as malaria, HIV/AIDS or tuberculosis. Intense pressure for the rapid availability of data often contributes to the establishment of disease-specific information systems driven by performance-based funding. Countries then risk being overwhelmed

by multiple, and often parallel, information demands that can stretch available resources beyond their limits. Within the health sector itself, health workers are overburdened by excessive reporting requirements from multiple and poorly coordinated subsystems that cannot deliver timely, accurate and complete data. Although a vast amount of data may be collected, only a small proportion is synthesized, analysed and used.

In recognition of the potential damage caused by fragmentation along specific disease lines, many countries and donors are seeking a greater degree of integration. For example, in Africa, integrated strategies have been adopted to improve the performance of surveillance activities at all levels of the health system, often in order to deal with multiple diseases using similar structures, personnel and processes.

Data are often collected and presented in crude formats, without any attempt at the synthesis or analysis required for proper day-to-day management or longer-term planning. There is little point in engaging in the time- and resource-consuming process of data collection if there is no commitment to analysing the data, disseminating the resulting information and using it to improve health system functioning. In addition, the presentation

of epidemiological data is frequently aimed at specialists and other experts. Little effort is made to present the information in formats that are relevant and comprehensible to policy-

makers, the public or those working in sectors other than health. As a result, there is a widely established perception that health information is obscure, unclear and sometimes contradictory.

Increased data demands compound the fragility of health information systems, especially when coupled with administrative pressures to cut costs and increase efficiency. When data are not available in response to user needs, there may be a loss of credibility. When the public loses confidence in the reliability and integrity of data emanating from the health information system, a vicious cycle of under-investment and further decline ensues.

Decision-makers at all levels of the health system need information that is relevant, reliable and timely. Unfortunately, even when high-quality

information is available this does not guarantee its appropriate use in the decisionmaking process. The literature abounds with anecdotal accounts of the underutilization of information – a situation that has led to the conclusion that:

Much of the material remains unprocessed, or, if processed, unanalysed, or, if analysed, not read, or, if read, not used or acted upon.¹

1.1.4 Drivers for change

The recognition of health information system weaknesses is not new. However, a number of forces have recently converged to accelerate the push for strengthened health information systems. There is broad consensus that improved health outcomes cannot be achieved without strengthening health systems (including health information systems) as a whole, rather than focusing on discrete, disease-focused components. Few countries have sufficiently strong and effective health information systems in place to permit adequate monitoring of progress towards the United Nations Millennium Development Goals (MDGs). Even where data are available, they are often outdated, rendering the challenge of assessing trends particularly difficult.

It is now apparent that modern health information systems must be able to address emerging diseases and urgent health threats, whether natural or manmade. This will

require comprehensive surveillance, capable and rapid detection, and investigation (including laboratory and epidemiological analyses) of unusual events that might represent a threat to health. Appropriate response measures will then need to be implemented.

The need for better health information has also arisen from demands to improve accountability, and ensure evidence-based decision-making. The need to make better use of limited resources is a strong driver for improving the quality of health data, particularly to assist evidence-based policy development, and the planning, management and evaluation of health services. The ability to report on progress towards specified targets The need for better health information has also arisen from demands to improve accountability, and ensure evidence-based decision-making.

has become more important with the introduction of performance-based disbursement by a number of international initiatives. These include the Global Alliance for Vaccines and Immunization (GAVI), the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the President's Emergency Plan for AIDS Relief (PEPFAR). More resources, coupled with increasing recognition of the complexity of health challenges and interventions, has

Few countries have sufficiently strong and effective health information systems in place to permit adequate monitoring of progress towards the United Nations Millennium Development Goals (MDGs).

¹ Chambers R. Rural development: putting the last first. New York, Longman, 1994.

created a demand for better data without which there is a serious risk that interventions will be misguided and efforts and resources wasted.

In the context of health sector reform and decentralization, health systems are managed as closely as possible to the level of service delivery. This shift in function between the central and peripheral levels generates new information needs, and calls for the restructuring of information systems to collect and use information for decision-making at local, district, provincial and national levels. This in turn drives a need for the careful assessment of what is required for data collection, processing, analysis and dissemination. Health sector reforms also present major challenges in achieving standardization and ensuring the quality of information – challenges which must be addressed at the central level.

Shifts in the way health services are organized and managed are also leading to greater attention being paid to the need for better statistics for monitoring and evaluation. The rapid growth of the private sector in almost all countries has policy, regulatory and operational implications. It is essential to ensure that non-state health-care providers are included in the health information system. At the same time, the health information system provides an important tool for ensuring supervision.

There are also drivers for change outside the health sector. Governments and development partners are increasingly adopting results-based approaches (for example, in the design and implementation of national poverty-monitoring strategies) as part of their efforts to achieve the MDGs and other national development goals. Such approaches – as promoted by PARIS21¹ and the Organisation for Economic Co-operation and Development (OECD)² – significantly increase the demand for improved quality, coverage and use of statistics.

1.1.5 Global standards and harmonization of health information

A sound health information system depends upon organized processes for gathering, sharing, analysing and using health-related data for decision-making. To achieve this, country institutions and management structures must be strengthened by adopting and adapting global health information standards that are aligned to broader efforts to improve the availability and quality of statistics. To support this, development partners must harmonize their efforts in each country in which they operate and align themselves around a sound national health information system. The HMN Framework outlines the global standards for health statistics and indicates how they can be integrated into country health information systems. At the same time, it also invites disease-focused initiatives to identify and subscribe to harmonization and alignment opportunities.

To achieve this, HMN will seek engagement on two levels. First by engaging HMN partners and donors in broad-based harmonization activities, and second by supporting the immediate and specific alignment of health data stakeholders and infrastructure in focus countries. These two levels of engagement will be coordinated to produce a global set of standards for health information.

1.1.6 A unifying approach to health information system development

HMN is the first attempt to develop a unifying framework that facilitates the efficient coordination and joint action of all subsystems in a health information system. Health information systems involve complex processes and relationships that go beyond the responsibility of

¹ <u>http://www.paris21.org/pages/designing-nsds/NSDS-reference-paper/</u>

² OECD Development Assistance Committee (DAC) Guidelines and Reference Documents, Poverty and Health, 2003: <u>http://www.oecd.org/dataoecd/16/36/33965811.pdf</u> and OECD Paris declaration on aid effectiveness, 2007: <u>http://www.oecd.org/dataoecd/11/41/34428351.pdf</u>

any single government agency. Multiple institutions produce and use health data, including health ministries, national statistics offices, the emergency response sector, the private sector, civil society organizations, donors and development assistance agencies. Because health information system development is not the domain of a single entity, a comprehensive and collaborative plan is needed to reform health information systems.¹

1.2 Approaches to health information system strengthening

1.2.1 Introduction

Despite the explicit demand for quality health information, health information system performance in many developing countries consistently falls short of requirements. The goal of a health information system is often narrowly defined as the production of good-quality data. However, the ultimate goal is more than this – it is to produce relevant information that health system stakeholders can use for making transparent and evidence-based decisions for health system interventions.

Health information system performance should therefore be measured not only on the quality of data produced, but on evidence of the continued use of data to improve health system performance, to respond to emergent threats, and to improve health. Improving health information systems in terms of data availability, quality and use often requires interventions that address a wide range of possible "determinants of performance". Researchers and global initiatives such as PARIS21 and the IMF Data Quality Assessment Framework² concur that the sustainable production and use of good-quality health information are not only affected by technical factors such as data-collection tools and processes, IT devices and data analysis. Environmental, organizational and behavioural factors also play a major role.³

Motivating data collectors remains a challenge despite training on data-collection registers and questionnaires. Negative attitudes among clinicians and health workers - such as data collection is a useless activity or a waste of care-provider time - are detrimental to data quality. The knowledge and skills required for data processing, analysis, interpretation and problem-solving are usually not given due attention, which affects the ability to use information. Data collectors and users work in specific environments and organizational cultures, and are influenced by them. The perceptions and attitudes of senior management towards health information system design and implementation will have a determining influence on system performance. For example, the value of collecting information may be questioned if senior health managers do not allocate resources based on evidence and information. If senior managers fail to promote evidence-based decision-making and the use of information for transparency and accountability then a culture of information is unlikely to be fostered. It is therefore crucial to examine the perceptions, attitudes and values of senior managers and other organization members in relation to informationrelated functions. Such an assessment can comprise tools from various disciplines, including epidemiology, performance improvement, behavioural change and policy analysis. These tools collect subjective and objective information and identify performance gaps between what is perceived and what actually exists, leading to the development of interventions to bridge these gaps.

¹ Lippeveld T. *Routine Health Information Systems: the glue of a unified health system.* Keynote address at the workshop on issues and innovation in routine health information in developing countries, Potomac, 14–16 March 2001.

² International Monetary Fund Data Quality Assessment Framework (DQAF), 2003. <u>http://dsbb.imf.org/Applications/web/dqrs/dqrs/dqrs/dqrs/</u>

³ Lafond A, Field R. *The Prism: introducing an analytical framework for understanding performance of routine Health Information Systems in developing countries.* Presented at a workshop on enhancing the quality and use of health information at the district level. Eastern Cape Province, South Africa, 29 September–4 October 2003.

Coordinating dataproducing agencies, sharing data and disseminating statistics all depend upon the legal and institutional environment.

All major stakeholders should

participate in assessing and

planning health information

system strengthening

Coordinating data-producing agencies, sharing data and disseminating statistics all depend upon the legal and institutional environment. The effectiveness of the information system also depends upon the decisions of policy-makers and donors, and upon health sector structures, functions and procedures.

Broader analysis of all these categories of determinants of health information system performance can identify the opportunities and constraints in effective and strategic data collection and production, and in the use of information for decision-making.^{1,2} Strategies to improve performance can then be developed.

1.2.2 Convening stakeholders and undertaking performance assessments

Country health information system strengthening must start with a broad-based assessment of the system's own environment and organization, responsibilities, roles and relationships, and of the technical challenges of specific data requirements. The health information system should be assessed in order to:

 allow objective baseline and follow-up evaluation – assessment findings should therefore be comparable over time;

inform stakeholders – for example, of aspects of the health information system they may not be familiar with;

build consensus around the priority needs for health information system restructuring; and

mobilize joint technical and financial support for the implementation of a national strategic plan.

HMN has developed a tool³ designed to guide such an assessment. All major stakeholders should participate in assessing and planning health information system strengthening. Stakeholders include finance providers and the producers and users of health information and other social statistics – at both subnational and national level. Essential health

information is generated from a range of data sources and a wide array of stakeholders is involved in different ways with each of these sources. For example, information or planning units in ministries of health are usually responsible for data derived from health services records, while separate disease control units manage notifiable disease surveillance and response systems. National statistics offices are usually responsible for the conduct of censuses and household surveys. Responsibility for vital statistics including births and deaths may be shared between the

National Statistics Office, the Ministry of Home Affairs/Local Government and the Ministry of Health.

1.2.3 Identifying data requirements and indicators

The many types of data that a health information system should generate can appear overwhelming. But for policy-makers and planners, some types of information are more important than others. A key step in reforming health information systems is for

¹ Hozumi D, Aqil A, Lippeveld T. *Pakistan Health Information System situation analysis*. MEASURE Evaluation Project, USAID, 2002.

² Aqil A et al. *Determinants of performance of routine health information system (RHIS): evidence from Pakistan and Uganda*. Presentation at the American Public Health Association Conference, December 2005.

³ HMN assessment tool, version 2: <u>http://www.who.int/healthmetrics/tools/hmn_assessment_tool_ver2.xls</u>

stakeholders to identify the data needed for proper management, disease control and response, strategic decision-making and policy development. Such data must then be made available in a timely and reliable manner. Consensus is now needed on a core set of indicators that are meaningful, action-oriented and appropriate to a particular country situation and to collaborating partners.

1.2.4 Describing data requirements and tools at different levels

A key element in strengthening health information systems is to determine what data should be collected, at which levels of the system and by whom. Decisions should be made on what data need to be reported upwards and for what purpose, with consideration given to a limited set of indicators to avoid overburdening the system. Summary indicators are needed especially at facility and district levels to plan, manage, procure and supervise, but at every level of data collection there are corresponding information needs and tools (**Fig. 2**).



Fig 2. Information needs and tools at different levels of data collection

Feedback from the national to more peripheral levels is crucially important, and encourages the creation of a culture of data generation and use. In decentralized systems, innovative approaches need to be found to make representative and disaggregated data available at district levels and below. Another challenge results from data-collection tools designed with national-level data needs in mind, such as household surveys. Very few national household surveys have sufficient power to permit data disaggregation at peripheral levels. Disaggregation may be possible at regional/provincial/state levels or for very broad categories such as urban/rural differences. As countries seek to strengthen their health information systems, they will need to decide on the degree of disaggregation required for policy purposes, as well as on the data tools best suited to generating such disaggregation efficiently.

1.2.5 Matching data requirements to data sources

An essential function of the health information system is to match the data item or indicator with the most appropriate and cost-effective tool for generating it. The range of sources for health-related data comprises service-generated data, disease and behavioural surveillance, civil registration and other sources of vital statistics, financial and management information, household surveys, health-facility surveys, censuses, modelling, estimates and projections, and research. Each source has its own strengths and weaknesses when generating health information. There are many examples of inappropriate methods being used to generate health data and of the underutilization of some data-collection tools.

1.2.6 Ensuring the quality of health information system products

Standards are needed to assess whether the statistics available to decision-makers are comprehensive, timely, accessible and reliable. The General Data Dissemination System (GDDS) guidelines¹ developed by the International Monetary Fund (IMF) provide a comprehensive set of such standards. The GDDS framework is built around four dimensions – data characteristics, quality, access and integrity. It takes into account the diversity of a broad range of countries, their economies and the developmental requirements of statistical systems. While not developed specifically for health-related data, its fundamental principles are applicable to health and deal with issues such as coverage, periodicity (the frequency of compilation) and timeliness (the speed of dissemination).

1.2.7 Synthesizing, analysing and using information

Data alone do not reveal the full situation – meaning is only acquired when data are analysed and interpreted. Data also need to be synthesized, analysed and interpreted within the overall context of the health system and delivery of health interventions. In

Data alone do not reveal the full situation – meaning is only acquired when data are analysed and interpreted. this way data is transformed into information, evidence and knowledge for action. A vital aspect of analysis is synthesising data from multiple sources, examining inconsistencies and contradictions, and summarizing health situations and trends to produce consistent assessments. This will include the burden of disease, patterns of risk behaviour, health service coverage and health system metrics. Despite its importance, such data analysis capacity is often lacking at peripheral levels where the results of generated data are needed for planning and management. Developing

this capacity will require careful planning and investment by multiple stakeholders.

After analysis comes use of data for management, decision-making and policy development. Technical rigour, while essential, does not lead automatically to appropriate information use. There are many examples of information systems where the indicators are sound, data-collection forms are well designed and data-analysis capacity available, but where information tools are not available, and information is not routinely used to make evidence-based decisions. Information packaging is a key requirement for influencing decision-makers.

Motivational and organizational factors can also undermine evidence-based health action. For example, in health systems using normative rather than strategic planning, decisionmakers follow traditional resource-allocation patterns based on set formulas. Even the availability of accurate and timely health data cannot guarantee that evidence becomes the basis of decision-making. Easy access to information for country leaders, executives and managers will be essential in creating a culture of evidence-based decision-making.

¹ <u>http://dsbb.imf.org/Applications/web/gdds/gddshome/</u>

For this to occur, the health information system must be carefully designed to support direct and user-friendly access by decision-makers. For data to be used consistently, the entire health system must place a high value on health information and leadership.

1.2.8 Aligning partners and bringing data and users together

Another essential step in strengthening health information systems is to link data production to data use. Users comprise care deliverers and those responsible for managing and planning health programmes – including those financing health-care programmes inside countries (health and finance ministries) and externally (donors, development banks and technical support agencies). Users of health-related data are not confined to health-care

professionals or statisticians. Indeed, decision-making around country health priorities necessarily involves the wider community, including civil society, and policy-makers at senior levels of government. These different information users have different needs in terms of the detail and technical specificity required. Thus the health information system will need to present and disseminate information in appropriate formats for various audiences.

Another essential step in strengthening health information systems is to link data production to data use.

1.3 The power of partnership – the Health Metrics Network (HMN)

1.3.1 The HMN vision

HMN uses the strengths of a global network to stimulate the coordination and alignment of partners around a harmonized framework to develop and strengthen country health information systems. However, putting the recommendations of this HMN Framework into practice is not a simple matter. Existing health information systems are institutionally and historically complex, with multiple partners involved in different ways and at different levels in generating, analysing, sharing and using data. Experience has shown that good collaboration between investors and local stakeholders has been difficult to achieve and time-consuming. Many of the problems experienced appear to be common to many countries and regions. There is now wide acceptance of the need to do better, and awareness that collaborative health information system investments will be more efficient and effective than individual initiatives.

The potential of HMN to catalyse and accelerate health information system reform derives from the synergies created among its partners, none of whom would be able to undertake the task alone. The reach of all the different partners working on various aspects of health information at global, national and subnational levels is very broad.¹ Partners collaborating with HMN include both producers of health information in the health, statistics and research communities, and users of information such as the media, donor and development agencies, funds and foundations. Other networks with mandates in the area of enhancing statistical capacities and building better health information systems include PARIS21² which aims to improve statistical capacity in developing countries; the Routine Health Information Metwork (RHINO)³ focusing on improving capacities to generate and use health information derived through service-delivery systems; and the INDEPTH Network⁴ working to strengthen and harmonize methods for vital event monitoring in resource-poor settings.

¹ Details of HMN Board members, partners, countries and Secretariat are available on the HMN web site at: <u>http://www.who.int/healthmetrics/partners/en</u>

² Partnership in Statistics for Development in the 21st Century <u>http://www.paris21.org/</u>

³ Routine Health Information Network <u>http://www.rhinonet.org</u>

⁴ International network of field sites with continuous demographic evaluation of populations and their health in developing countries <u>http://www.indepth-network.org/</u>

1.3.2 Global health partnerships and HMN

Global health partnerships – such as initiatives to combat HIV/AIDS, malaria and vaccinepreventable diseases – offer extraordinary opportunities to advance public health in poor countries. But there is typically a high expectation of rapid implementation and scaling-up, supported by disease-focused funding. In response to such pressures, global health partnerships often require countries to implement vertical and programme-specific monitoring

> and evaluation. Such approaches may fragment and disrupt the health information system of the host country, rather than strengthen, adapt and utilize existing systems.

Global health partnerships offer extraordinary opportunities to advance public health in poor countries.

In addition, each host country has different health data technical standards and systems. Without the technical capacity to adapt their indicators in a multitude of country health information systems, global health partnerships have virtually no means of achieving their targets through proper incorporation into national systems.

HMN can overcome this by:

Establishing a comprehensive set of globally agreed and linked technical standards for health information in least developed countries (LDCs). This will help global health partnerships to define their information and monitoring needs once – not repeatedly for each country in which they function.

Promoting the incorporation of HMN technical standards into a critical mass of health information systems and mechanisms in LDCs. Incorporating new global health partnership data-support and monitoring needs into HMN will be technically straightforward and relevant in many countries.

Helping to create a context in which global health partnerships can use state-of-the-art technical support to translate specific data needs into the HMN Framework.

Strengthening health information system components and systems in LDCs to meet global health partnership information needs.

Defining a reasonable and transparent process – and the proportion of global health partnership resources required – to strengthen and use country health information systems for specific global health partnership information and monitoring needs.

Establishing a unified front of participating countries, donors and technical partners committed to supporting and reinforcing this model in ongoing and new global health partnerships.

1.3.3 Goal and strategic objectives of HMN

The overarching goal of HMN is to improve health by increasing the availability, quality, value and use of timely and accurate health information by catalysing the joint funding and development of country health information systems. To achieve this, HMN will pursue three key objectives:

- To elaborate a harmonized HMN Framework for developing country health information systems.
- To support developing countries in adapting and applying the recommendations and standards contained in the HMN Framework to improve their health information systems; and provide technical support, and act as a catalyst to secure funding to this end.
- To improve the quality, value and use of (and access to) health information by developing policies and offering incentives to enhance data dissemination and use by all those concerned at local, regional and global levels.

PART 2

Components and Standards of a Health Information System



In Freetown, registered deaths are archived without being entered into a database and analyzed. PHOTO: WHO/DAVID LUBINSKI

2.1 Introduction

2.1.1 The six components of a health information system

There is clear value in defining what constitutes a health information system and how its components interact with each other to produce better information for better decisions and better health. This part of the HMN Framework describes the six components of a health information system and the standards needed for each. There is clear value in defining what constitutes a health information system and how its components interact with each other to produce better information for better decisions and better health. In addition to its six components, a health information system can be further subdivided into its *inputs*, *processes* and *outputs*. Inputs refer to resources, while processes touch on how indicators and data sources are selected and data is collected and managed. Outputs deal with the production, dissemination and use of information. Accordingly, the six components of a health information system are:

Inputs

 Health information system resources – these include the legislative, regulatory and planning frameworks required to ensure a fully functioning health information system, and the resources that are prerequisites for such a system to be functional. Such resources involve personnel, financing, logistics support, information and communications technology (ICT), and coordinating mechanisms within and between the six components (SECTION 2.2).

Processes

- Indicators a core set of indicators and related targets for the three domains of health information outlined in SECTION 2.3 is the basis for a health information system plan and strategy. Indicators need to encompass determinants of health; health system inputs, outputs and outcomes; and health status.
- 3. Data sources can be divided into two main categories; (1) population-based approaches (censuses, civil registration and population surveys) and (2) institution-based data (individual records, service records and resource records). A basic set of standards for each source and strategic elements in achieving these standards are described in SECTION 2.4. It should be noted that a number of other data-collection approaches and sources do not fit neatly into either of the above main categories but can provide important information that may not be available elsewhere. These include occasional health surveys, research, and information produced by community based organizations (CBOs).
- 4. Data management this covers all aspects of data handling from collection, storage, quality-assurance and flow, to processing, compilation and analysis (SECTION 2.5). Specific requirements for periodicity and timeliness are defined where critical as in the case of disease surveillance.

Outputs

- Information products data must be transformed into information that will become the basis for evidence and knowledge to shape health action (SECTION 2.6).
- Dissemination and use the value of health information can be enhanced by making it readily accessible to decision-makers (giving due attention to behavioural and organizational constraints) and by providing incentives for information use (SECTION 2.7).

For a health information system to function, various policy, administrative, organizational and financial prerequisites must be in place. Supportive legislative and regulatory environments are needed to enable confidentiality, security, ownership, sharing, retention and destruction of data. Investment from domestic and international sources is required to strengthen ICT, and provide human resources to run these systems. Expertise and leadership at national and subnational levels must also be provided to enable the monitoring of data quality and use. And there must be infrastructure and policies in place to transfer information between producers and users both inside and outside the health system.

Limited national resources and capacities may affect how far countries can apply the full standards described in the following sections, and how this may be achieved. In countries where standards do not currently exist, they are likely to evolve over time as countries adapt, use and learn from the HMN Framework.

For a health information system to function, various policy, administrative, organizational and financial prerequisites must be in place.

2.2 Health information system resources

2.2.1 Health information system coordination and leadership

Developing and strengthening health information systems depends upon how key units and institutions function and interact. These include the ministry of health central health information unit, disease surveillance and control units, and the central statistics office. These are responsible for designing, strengthening or supporting data collection, transmission, analysis, and reporting and other dissemination. Institutional analysis can be useful in identifying constraints that undermine policy or hamper the implementation of key strategies for developing the information system. Constraints include those related to reporting hierarchies or relationships between different units responsible for monitoring and evaluation.

A representative national committee comprising key stakeholders from health and statistics constituencies is needed to guide the development and maintenance of a health information system, and to ensure that data is shared across programmes and institutions. This committee should include high-level representatives of key programmes within ministries of health, statistics offices, academia, NGOs and international multilateral and bilateral agencies. The chairmanship may alternate between health and statistics. It should, as much as possible, build upon existing coordinating mechanisms and fit into broader statistics strategies. It should be associated with the development of the national strategic plan for statistics, within which the health sector is an important area. In countries with poverty-reduction strategies, it will be essential to build upon existing structures as part of a national poverty-monitoring masterplan.

The committee should agree upon and sanction national and international demands and requirements for reporting data from health programmes, donors and other national stake-holders. It is crucial that the country health information system environment encourages local innovation and entrepreneurship among stakeholders. The overall system and, as far as possible, each subsystem should be able to accommodate, within standards-based frameworks, extensions to various datasets and systems.

A national health information system strategic plan is also essential for coordination. This can guide health information system investments, with indications of the timeline and anticipated activities budget to be completed in the short term (1–2 years), intermediate (3–9 years) and long term (10 years and beyond). The strategic plan should provide for the maintenance,

strengthening and coordination of key health information system components – vital statistics, household surveys/censuses, health service records, reporting and response to health risks and events, and resource tracking. It will also be important to emphasize the integration of data from different sources at national and subnational levels.

A national health information system strategic plan is also essential for coordination.

2.2.2 Health information system information policies

The legal and regulatory contexts in which health information is generated and used are important as they enable mechanisms to be established to ensure data availability, exchange, quality and sharing. Legislation and regulation are particularly significant in relation to the ability of a health information system to draw upon data from both the private and public health services, as well as non-health sectors. Particular attention to legal and regulatory issues is needed to ensure that non-state health-care providers are integral to the health information system, including the use of accreditation where appropriate. Existence of a legal and policy framework consistent with international standards, such as the *Fundamental principles of official statistics*,¹ enhances confidence in the integrity of results. A legal framework can also define the ethical parameters for data collection, and information dissemination and use.

The health information policy framework should identify the main actors and coordinating mechanisms, ensure links to programme monitoring, and identify accountability mechanisms. There should be an institutional policy defining the respective roles of health and statistics institutions to ensure the independence of data from external influences, and to facilitate accountability.

The revised IHR (2005)² provide a unifying policy framework and establish legally binding reporting requirements with regard to public health emergencies of international concern caused by new or re-emerging diseases with epidemic potential or by acute chemical or radionuclear event. The IHR define practices and procedures for prompt notification to WHO of global health risks. Countries are obliged to nominate a national focal point to communicate detailed public-health information to WHO, including case definitions, laboratory results, number of cases and deaths, and the conditions affecting the spread of disease.

2.2.3 Health information system financial and human resources

Little research has been undertaken into the investment levels needed to ensure a sound health information system – which can vary according to a country's overall level of development. Estimates of the annual cost of a comprehensive health information system range from US\$ 0.53 to US\$ 2.99 per capita.³

Improvements to health information systems also require attention to be given to the training, deployment, remuneration and career development of human resources at all levels.

Improvements to health information systems also require attention to be given to the training, deployment, remuneration and career development of human resources at all levels. At national level, skilled epidemiologists, statisticians and demographers are needed to oversee data quality and standards for collection, and to ensure the appropriate analysis and utilization of information. At peripheral levels, health information staff should be accountable for data collection, reporting and analysis. Too often, such tasks are given to overburdened care providers who see this as an unwelcome additional task that detracts from their primary role.

Deploying health information officers within large facilities and districts (as well as at higher levels of health-care systems) results in significant improvements in the quality of data reported and in the understanding of its importance by health-care workers.

¹ United Nations. Fundamental principles of official statistics. New York, United Nations Statistics Division, 1994. Principles include impartiality, scientific soundness, professional ethics, transparency, consistency and efficiency, coordination and collaboration.

² World Health Organization. *International Health Regulations (2005): Areas of work for implementation*. Geneva, World Health Organization, 2005 (WHO/CDS/EPR/IHR/2007.1). <u>http://www.who.int/csr/ihr/IHR_Areas_of_work.pdf</u>

³ Stansfield SK et al. Information to improve decision-making for health. in: Jameson et al. eds. *Disease control priorities for the developing world*. 2006, April, chapter 54.

Appropriate remuneration is essential to ensure the availability of high-quality staff and to limit attrition. This implies, for example, that health information positions in ministries of health should be graded at a level equivalent to those of major disease programmes. Within statistics offices, measures should be taken to retain well-trained staff. Establishing an independent or semi-independent statistics office should allow for better remuneration and subsequent retention of high-level staff.

Targeted capacity development is needed, and training and educational schemes should be used to address human resource development in areas such as health information management and use, design and application, and epidemiology. Such training should be for all levels of competency, ranging from the pre-service training of health staff and continuous education, to public health graduate education at the Masters and PhD levels.

2.2.4 Health information system infrastructure

The infrastructural needs of the health information system can be as simple as pencils and paper or as complex as fully integrated, web-connected, ICT. At the level of the most basic record keeping, the health information system needs the ability to store, file, abstract and retrieve records. Many countries describe overflowing storerooms filled with mouldering patient records, facility logbooks and paperwork that is never sorted or analysed.

Emerging technologies can help countries to dramatically increase their storage and performance capacities and accelerate the processing time-frames previously required. As a result, the availability, quality, dissemination and use of health-related data can be radically improved by ICT. While information technologies can improve the amount and quality of the data collected, communications technology can enhance the timeliness, analysis and use of information. A communications infrastructure is therefore needed to fully realize the potential benefits of information that may already be available.

At both national and subnational levels, health managers should therefore have access to an information infrastructure that includes computers,

e-mail and Internet access. Although access to the Internet is increasingly essential, basic telephone (landline or mobile) facilities still remain highly useful. Similarly, national and regional statistics offices should be equipped with transport and communications equipment to enable the timely collection and compilation of data at subnational levels. All facilities need such levels of connectivity, but in most developing countries this is a long-term objective, and implementing new technology is complex and requires careful planning and training.

In many settings, computers are already used in discrete vertical health information programmes and electronic medical records systems, resulting in many non-compatible systems being used within countries. This often aggravates rather than alleviates duplication and overlap. Coherent capacity building in electronic and human resources throughout the health system is a far more effective and cost-efficient approach. This must be supported by clear data-management policies that protect privacy and confidentiality – the issue of data management is addressed below in SECTION 2.5.

2.3 Indicators

2.3.1 Domains of health information

The boundaries of a health information system are not confined to the health sector alone and overlap with information systems in other fields. Health information systems should offer data for various needs, including information for the provision of services to individual

Emerging technologies can help countries to dramatically increase their storage and performance capacities and accelerate the processing timeframes previously required. clients, statistics for planning and managing health services, and measurements for formulating and assessing health policy.

As shown in Fig. 3, core indicators are needed to assess change in three major domains:

Determinants of health – these include socioeconomic, environmental, behavioural, demographic and genetic determinants or risk factors. Such indicators characterize the contextual environments in which the health system operates. Much of the information is generated through other sectors, such as agriculture, environment and labour.

Health system – indicators include inputs to a health system and related processes such as policy, organization, human resources, financial resources, health infrastructure, equipment and supplies. There are also output indicators such as health service availability and quality, as well as information availability and quality. Finally there are immediate health system outcome indicators such as service coverage and utilization.

Health status – indicators include levels of mortality, morbidity, disability and wellbeing. Health status variables depend upon the efficacy and coverage of interventions and determinants of health that may influence health outcomes independently of health service coverage. Health status indicators should be available stratified or disaggregated by variables such as sex, socioeconomic status, ethnic group and geographical location in order to capture the patterns of health in the population.

2.3.2 Defining core indicators

The core indicators of a health system should reflect changes over time in each of the three health information domains shown in **Fig. 3**. As with any indicator, health indicators should be valid, reliable, specific, sensitive and feasible/affordable to measure. They must also be relevant and useful for decision-making at data-collection levels, or where a clear need exists for data at higher levels. Carefully selected and regularly reviewed core indicators are vital to strengthening a health information system and can be viewed as the backbone of the system, providing the minimum information package needed to support macro and micro health system functions.

Fig 3. Domains of measurement for health information systems



All countries therefore need a nationally defined minimum set of health indicators used regularly in national programme planning, monitoring and evaluation. The reporting frequency may vary depending upon the type of indicators and likelihood of change. Although core indicators may include those in the MDGs,¹ more-detailed information will

also be needed to manage specific programmes and services. The precise list of indicators will vary according to the epidemiological profile and development needs of individual countries. Core health indicators and related data-collection strategies must be linked to a broader national statistics strategy, and notably a poverty-monitoring master plan in countries with a poverty-reduction strategy paper (PRSP).

The main challenge will be to identify a small set of indicators. Individual programme areas will each have a defined "minimal" list of indicators, often at the instigation of external partners and donors. When combined, these indicators can create a huge burden in terms of data collection,

All countries therefore need a nationally defined minimum set of health indicators used regularly in national programme planning, monitoring and evaluation.

analysis and interpretation. A rational selection of a minimum set of core health indicators is therefore essential. A compendium of standard definitions and measurement issues for 40 core indicators has recently been produced.¹

A framework for choosing core indicators is needed to ensure that they make the comprehensive monitoring and evaluation of health and health systems possible. This framework should identify key management functions and strategic decisions, and then classify them according to whether they involve inputs/resources, processes, outputs and results. When choosing an indicator and its attributes (such as frequency of measurement and level of disaggregation) consideration must be given to national and subnational measurement capacities – indicators for which no statistic can be generated will be of little use.

National sets of core indicators may not necessarily be the same as subnational sets. But for some indicators, subnational data collection (for example, through health service provision records) provides the basis for national statistics. For other indicators, a national household survey may be used when subnational data collection is not feasible (for example, to record child-mortality rates).

Although health indicators are needed to monitor local and national priorities, indicator definitions must also meet international technical standards. Moreover, national indicators should be consistently linked and harmonized with key indicators in major international and global initiatives, such as the MDGs, GFATM and GAVI. Targets should be set for the number of core indicators that match national plans or international goals. Long-term targets and intermediate benchmarking are useful, but should be guided by existing data and well-established baseline statistics. National and international stakeholders should take part in defining the core indicators.

2.4 Data sources

2.4.1 Health information data sources

As shown in **Fig. 4**, health information system data are usually generated either directly from *populations* or from the operations of health and other *institutions*.

Population-based sources generate data on all individuals within defined populations and can include total population counts (such as the census and civil registration) and data on representative populations or subpopulations (such as household and other population surveys). What these data sources have in common is that they relate to the whole

¹ http://www.who.int/mdg/publications/mdg_report/en/index.html

² World Health Statistics 2005. Geneva, World Health Organization, 2005.

Fig 4. Health information data sources



population, not only to groups using institutional services. Such data sources can either be continuous and generated from administrative records (such as civil registers) or periodic (such as cross-sectional household surveys).

Institution-based sources generate data as a result of administrative and operational activities. These activities are not confined to the health sector and include police records (such as reports of accidents or violent deaths), occupational reports (such as work-related injuries), and food and agricultural records (such as levels of food production and distribution). Within the health sector, the wide variety of health service data¹ includes morbidity and mortality data among people using services; services delivered; drugs and commodities provided; information on the availability and quality of services; case reporting; and resource, human, financial and logistics information.

Health research should also be recognized as an essential source of information for health decision-making. Most data on the provision of clinical services or health status at the time of clinical encounters are generated "routinely" during the recording and reporting of services delivered. Health facility surveys² provide another important methodology for collecting data on health services and for validating routine health service data by observing service delivery, inspecting facilities, interviewing staff and clients, and reviewing archives.

Health research should also be recognized as an essential source of information for health decision-making. As listed in a joint publication³ of the

Council on Health Research for Development and the Global Forum for Health Research, research typically covers the following broad spectrum:

¹ Health service data sources have been variously equated with terms such as health management information system (HMIS), routine health information system (RHIS), management information systems (MIS) or occasionally Health Information System (HIS). In order to avoid confusion, the term "health service data sources" is used in the HMN Framework, while "HIS" is used exclusively to describe the total information system, incorporating both population-based and institution-based sources.

² A health facility *survey* involves visiting and collecting data from a representative *sample* of all health facilities in a country or geographical area. Alternatively, a health facility *census* involves collecting such data from *all* health facilities in a country or geographical area. Health facility surveys and censuses should not be confused with the entirely distinct "population-based" surveys and censuses shown in **Fig. 4**.

³ IJsselmuiden C, Matlin S. Why Health Research? Research for Health: Policy Briefings, Vol. 1, October 2006.

- biomedical;
- public health;
- health policy and systems;
- environmental health;
- social and behavioural sciences; and
- operations research into health ICT as part of general "science and technology".

Research has increasingly focused on health problems with a global dimension or on those which disproportionately affect poorer countries and marginalized populations.

Research is also essential for improving the performance of health systems. Generating the evidence required to guide service-delivery strategies and improve the management of human resources will require collaboration between the research institutions of rich and poor countries. The Alliance for Health Policy and Systems Research (AHPSR) is working to promote the generation, dissemination and use of knowledge to enhance the performance of health systems.¹

Although surveillance is sometimes also considered as a data source, the HMN Framework emphasizes instead the importance of regarding surveillance in much broader (and more integrated) terms as a special set of methods for handling data from a wide range of different data sources (BOX 1).

It is clear that no single data-collection or research method can provide the broad range of information required by countries. The most appropriate data sources will depend upon the information required and the cost-effectiveness and feasibility of individual methods. Country health information systems should draw on a set of core data sources. The contribution of each source will vary due to differences in the types of data best collected. In many cases, using a combination of sources will lead to better quality information while maintaining efficiency. In other cases, it will be more efficient to avoid duplication. The optimal choice will depend upon a range of factors, including epidemiology, specific characteristics of the measurement instrument, programme needs, cost and the human and technical capacities required to collect, manage and disseminate data.

The following sections (2.4.2-2.4.7) describe the key features and desirable standards for the leading sources of health and health-related data shown in **Fig. 4**, along with the strategic elements that countries need to consider when implementing approaches to meet these standards.

2.4.2 Censuses

The population and housing census is the primary information source for determining the size of a population and its geographical distribution, plus the social, demographic and economic characteristics of its people. Censuses have been undertaken in most countries in recent decades, and in some places for more than a century. Censuses should ideally be held every 10 years, and can provide vital statistical data on population and housing situations at even the smallest administrative levels (**Fig. 5**). The Statistics Division of the United Nations Department of Economic and Statistical Affairs (UNDESA) has developed principles, recommendations and manuals for population and housing censuses available from their web site.²

¹ Alliance for Health Policy and Systems Research. *Strengthening health systems: the role and promise of policy and systems research*. Geneva, 2004.

² <u>http://unstats.un.org/unsd/demographic/sources/cwp2010/docs.htm</u>

Box 1. Surveillance of health information data sources – a new synergy

"Surveillance" is frequently used to refer to systems for detecting, reporting and responding to specific notifiable conditions – usually epidemic-prone communicable diseases. In this context, surveillance involves establishing case definitions, promoting awareness of the need to report, enhancing systems for laboratory investigation, strengthening systems for reporting and analysis, and responding appropriately to early warning signals. Surveillance systems for acute communicable diseases are mainly based on routine health and disease records. Such systems can detect events rapidly, manage outbreaks, support the response, and document outcomes in an integrated manner.^a Surveillance for chronic diseases (such as HIV/AIDS, and tuberculosis) also draws mainly on health and disease records. Sentinel surveillance systems use selected health facilities or defined subsets of populations to monitor disease trends over time, trading off monitoring the disease everywhere with the provision of more intensive and careful data collection in targeted settings. Behavioural monitoring draws more on survey data sources, and in most countries annual surveillance rounds are recommended.

For certain diseases or health events that need to trigger urgent public health action, and for other health conditions to which special resources are dedicated, special separate surveillance systems or monitoring and evaluation strategies have often been developed. These include targeted surveillance systems, cancer registries, specialized clinical care systems for diseases of special significance (such as tuberculosis) and often elaborate and distinct ("vertical") monitoring and evaluation strategies for diseases of great global interest (such as HIV/AIDS or vaccine-preventable diseases).

However, surveillance is not only about tracking epidemics but is also relevant for monitoring public health trends or epidemiological "situational awareness and monitoring". In this context, surveillance draws on many data sources (**Fig. A**) – these are both population-based (such as mortality surveillance in sentinel populations) and institution-based (such as disease surveillance in sentinel health facilities). Thus, rather than being linked to one data source, surveillance now includes specialized approaches to monitor vital events, frequent and increasing use of survey

methods (for example, HIV/AIDS surveillance in antenatal care surveys) and analysis of health service records. Surveillance also now includes measuring risk behaviours (for example, tobacco use or unsafe sex) through household surveys, monitoring administrative systems (such as surges in the purchasing of particular pharmaceuticals) and monitoring rumours or lay reports of unusual illness patterns reported in the media or unusual query activity on the Internet.^b

Although specialized or vertical systems have often been extremely successful, when several disease-specific programmes each incorporate



a surveillance system, district and other local health staff quickly acquire multiple and time-consuming reporting requirements. It is now becoming increasingly clear that the appropriate reconnection of the surveillance community with broader health information systems has much to offer to each. Investment in health systems in poor countries is accelerating and the standardization and integration of surveillance across diseases could become a model for the much broader standardization and integration of health information across data sources which is the goal of HMN.

^b For example, see the Global Public Health Intelligence Network at: http://www.phac-aspc.gc.ca/media/nr-rp/2004/2004_gphin-rmispbk_e.html

^a For further information, please refer to: http://www.who.int/csr/labepidemiology/projects/surveillance/en/index.html and http://www.cdc.gov/epo/dih/Eng_IDSR_Manual_01.pdf





From the health perspective, information on population numbers and distributions by age, sex and other characteristics is essential for national and local planning, estimating target population sizes and trends, and evaluating service-coverage rates and future needs. Information on major determinants and risk factors, such as poverty, housing conditions, water supply and sanitary facilities may also be included. The nature of the census allows for small-area estimation and disaggregation by key stratifiers, such as socioeconomic status. The census can also provide additional information on health and mortality.

The disadvantage, however, is the small number of health questions that can be included. Asking women of reproductive age about children ever born and children still alive has been used extensively to estimate child mortality. Censuses could include questions on recent household deaths, providing information on age and sex patterns of mortality at national and subnational levels. The usefulness of including mortality questions in the census depends upon the availability of data from other sources. For instance, if mortality data are available from vital statistics systems with high levels of coverage (over 90% of deaths) then no mortality questions should be added. However, if data on mortality levels and trends are limited, censuses should include mortality questions. One major issue is to accurately estimate, and correct for, the level of underreported recent deaths, which generally occurs on a fairly large scale. Some censuses have included information on causes of death, particularly those that can be clearly defined, such as pregnancy-related deaths or deaths due to injuries.¹ A recent review and update of the *Principles and Recommendations for Population and Housing Censuses*² makes explicit mention of the

Stanton C et al. Every death counts: measurement of maternal mortality via a census. Bulletin of the World Health Organization, 2001, 79:657–664; and Measuring maternal mortality from a census: guidelines for potential users. MEASURE Evaluation. Chapel Hill, University of North Carolina, 2001.

² United Nations Statistical Division. Principles and Recommendations for Population and Housing Censuses, Revision 2, 2007.

census as a possible source of maternal mortality data. The advantages of using the national census to estimate maternal mortality in countries lacking accurate conventional sources

HMN is working with technical experts to build country capacity in evaluation and correction methods. of data are considerable. The census is the only household-level survey large enough to support the measurement of spatial and socioeconomic differentials in maternal mortality. Standard methods exist for evaluating and, under certain conditions, adjusting the data on overall deaths. HMN is working with technical experts to build country capacity in evaluation and correction methods.

Analysis of the most recent census is ongoing in many countries and should include detailed projections of population age and sex characteristics for

small geographical areas for health sector use. Furthermore, it is important that census microdata become easily accessible for analyses, such as determining health service access or health worker distribution.

2.4.3 Civil registration

Civil registration is:

... the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events (live births, deaths, foetal deaths, marriages and divorces) and other civil status events pertaining to the population as provided by decree or regulation, in accordance with the legal requirements in each country.¹

The primary purpose of civil registration is the establishment of legal documents as required by law, and its strategic objectives have also been described in full.² However, the records generated also provide a major – and arguably the most effective – source of vital statistics on births, deaths and changes in marital status.³ When the civil registration system is coupled with medical certification of cause of death using the principles and standards set out in the *International Statistical Classification of Diseases and Related Health Problems* (ICD),⁴ obtaining accurate data on cause of death is possible.

From a demographic and epidemiological perspective, the most important advantage of civil registration is that it ensures universal and continuous registration of vital events and enables the routine production of vital statistics essential for improving health outcomes,

Vital statistics are a key input for policy-making and planning in human development. as well as the provision of small-area data. Vital statistics are a key input for policy-making and planning in human development. Timely knowledge of the size and characteristics of a population is a prerequisite to socioeconomic planning. Information on the number of live births over time, classified by various characteristics of the mother, constitutes the basis for analysing reproduction dynamics. Data on deaths, classified by various characteristics of the deceased, especially age and sex, is necessary to calculate life tables and estimate the probability of dying at

various ages. Such information is invaluable for assessing and monitoring the health status of populations, and planning interventions.

¹ United Nations Statistics Division. Principles and Recommendations for a Vital Statistics System. Revision 2, Series: M, No.19/Rev.2. New York, United Nations, 2001. Sales No. 01.XVI.10. <u>http://unstats.un.org/unsd/publication/SeriesM/SeriesM 19rev2E.pdf</u>

² For example, see the Global Public Health Intelligence Network at:

http://www.phac-aspc.gc.ca/media/nr-rp/2004/2004_gphin-rmispbk_e.html ³ AbouZahr C et al. Who counts? The way forward. *Lancet*, 2007 (forthcoming).

⁴ World Health Organization. International Statistical Classification of Diseases and Related Health Problems (ICD). 10th Revision, Second Edition. Geneva, World Health Organization, 2005. http://www.who.int/classifications/icd/en/

Operating and maintaining a civil registration system requires the accurate and continuous registration of population vital events from birth to death, recorded when they occur and under strict national standards. In many settings, particularly low and lower middle income countries, civil registration is weak or non-existent and cannot serve as the source of vital statistics.^{1,2}

Improving these processes may begin with the systematic examination of civil registration and vital statistics processes, as well as their external relationship with other systems. The legal mandate and financial limitations determine its organizational structure and should also be examined. Day-to-day system operations must be monitored continuously, including registration and statistical reporting functions, the network of registration offices, personnel issues, equipment and supplies, and other facilities. Cooperation and coordination with other government agencies and the public to facilitate the functioning of civil registration and vital statistics systems should be developed, strengthened and enlarged. In support of all these activities, specific suggestions for early-stage, intermediate-term and long-term activities have been outlined elsewhere.³

The HMN Framework draws attention to the need for national governments and the international community to give high priority to putting in place policies that will upgrade civil registration systems so that all countries will enjoy the benefit of a solid empirical base for health sector planning. The "gold standard" is a civil registration system providing a complete births and deaths record (100% coverage) that includes medically certified causes of death (**Fig. 6**). However, experience has shown that making improvements is slow process and cannot be achieved overnight. The number of countries with death registration regarded as "complete" (by the not very rigorous standard of 90%) increased by only seven from the 1970s to the 1990s.⁴ It requires investment not only in administrative systems but also in public awareness. In the meantime, interim substitutes are needed to provide national and subnational estimates of vital rates and cause-specific mortality. The various interim approaches proposed have different strengths and weaknesses, and include targeted questions in population censuses, sample registration systems, demographic surveillance sites and household surveys.⁵

The governments of China and India have introduced sample vital statistics systems that have been shown to work quite effectively. In addition, packages such as Sample Vital Statistics with Verbal Autopsy (SAVVY) have the potential to considerably improve knowledge of basic population health statistics. Demographic Surveillance Systems (DSS) focus on specific populations for a prolonged period and offer another valuable data source in countries lacking vital statistics, even though they are not part of a national sample. Finally, in some countries (notably those with low levels of medical certification of causes of death) verbal autopsy (VA) can be used to ascertain the probable cause by standardized interviews with the relatives of the deceased. However, the diagnostic accuracy of cause and the ability to detect cause-specific mortality trends through verbal autopsy varies.

In countries with very low civil registration coverage and poor cause-of-death data, at least one urban and one rural sentinel demographic surveillance system must be established to get an overview of population-level causes of death, and to build capacity in cause-of-

¹ Coullare F et al. Vital Statistics Obtained from Civil Registration: Quality Assessment and Current Status. *Lancet*, 2007 (forthcoming).

² Mathers CD et al. Counting the dead and what they died from: an assessment of the global status of cause of death data. *Bulletin of the World Health Organization*, 2005, 83:171–177.

³ For example, see the Global Public Health Intelligence Network at:

http://www.phac-aspc.gc.ca/media/nr-rp/2004/2004_gphin-rmispbk_e.html

⁴ Mahapatra P et al. Civil Registration Systems and Vital Statistics: successes and missed opportunities. *Lancet*, 2007 (forthcoming).

⁵ Hill K et al. Interim measures for meeting health sector data needs: Births, deaths and causes of death. *Lancet*, 2007 (forthcoming).

Fig 6. Civil registration – minimum standards for data-collection methods



death identification and coding. Later, as capacity extends, countries can consider making the system more representative by adding a broader sample registration system such as SAVVY, as implemented in China. At this stage, routine civil registration coverage should be steadily improved using the sentinel or sample systems to validate or calibrate the results. Once routine coverage exceeds 80%, the sentinel/sample systems may be phased out (**Fig. 7**).

Fig 7. Improving availability of vital statistics


HMN has developed a resource kit that provides easy and user-friendly access to HMNendorsed technical documents relating to civil registration, sentinel and sample civil registration with verbal autopsy, and demographic surveillance. Following peer review, the resource kit it will be made available to countries on CD-ROM and online.

2.4.4 Population surveys

In many developing countries, population surveys are the single most important source of population health information. Of the 23 health-related MDG indicators, 17 are currently generated through household surveys, such as the USAID-supported Demographic and Health Surveys (DHS) and the UNICEF-supported Multiple Indicator Cluster Surveys (MICS). Such surveys are used to generate data on:

child and maternal mortality and health, nutrition, service use, and knowledge and practices related to health care; In many developing countries, population surveys are the single most important source of population health information.

health status evaluations, descriptions and determinants;

 knowledge, beliefs and practices related to disease prevention and transmission (especially of HIV);

- household expenditures on health; and
- inequalities in health outcomes and access to health services.

Household surveys have recently added biological and clinical data collection (health examination surveys) providing much more accurate and reliable data on health outcomes than self-reports. Numerous countries, especially in Asia and Latin America, conduct national household surveys on health or include health questions in economic and demographic surveys. By linking surveys focused on health to those directed towards other issues, it is possible to generate important data on the links between health and socioeconomic determinants. Surveys are the prime data sources on risk factors such as unsafe sex, smoking, substance abuse and poor nutritional status. They are less efficient when it comes to measuring relatively rare events such as adult deaths.

Population surveys conducted to assess non-health issues (such as incomes and expenditures, the labour force, agriculture or education) may also generate statistics on factors of major importance to human health. While some of these data can be derived from institute-based sources, population-based sources are less subject to bias and more representative of the population. Many indicators are also tracked through sample and sentinel surveillance systems referred to in SECTION 2.4.3 as part of improving civil registration.

A recent innovation in population surveys is the use of data on household assets as a proxy of wealth that can be used to disaggregate survey results into wealth quintiles. For only a marginal extra survey cost, this provides an important and often unique insight into the equity of the health system.

The very success of the household-survey approach for generating data on key health indicators (such as the MDGs) has created its own problems. Programme donors now tend to require a household survey in order to measure progress, resulting in a plethora of overlapping surveys, and overburdening the capacities of country statistical systems. For this reason, the HMN gold standard is a well-integrated and demand-driven household-survey programme that is part of national health information and statistical systems, and that generates regular and essential high-quality data on population, health and socioeconomic status (**Fig. 8**). As such, national surveys become major national planning and evaluation instruments. It is therefore important that international standards and norms are adhered to.

Fig 8. Population surveys – minimum standards for data-collection methods



Several steps are needed for a health information system to obtain a well-functioning survey system. Detailed assessments of what the data needs (core indicators) are for the next decade should be followed by a feasibility analysis of which data sources can meet the demand. Mapping past and planned population-based surveys is essential. This should lead to a 10-year country plan in which all major national population surveys are scheduled, and the roles of national and international stakeholders and partners indicated. Integrating population surveys into an overall health information system involves planning in several dimensions including:

careful consideration of which health data can be collected as part of non-health surveys (such as economic surveys) which tend to be more frequent and larger in sample size;

a recognition of surveys as essential sources of validation and calibration of routine data sources (such as immunization records or HIV/AIDS prevalence derived from antenatal care surveillance);

careful weighing of data collection on certain topics (such as mortality and causes of death) against other options (such as civil registration systems) – some options may not have immediate results, but in the long term may generate more frequent and complete data; and

the recognition that large-scale national household surveys are costly and complex undertakings that are rarely feasible or cost-effective to conduct more than once every 3–5 years – household survey data are also subject to margins of uncertainty owing to sampling and other errors, illustrating the importance of triangulating data sources.

Population surveys should follow internationally agreed standards with regard to sampling, questionnaire design, field supervision, consent and confidentiality, data processing, body-fluid collection and analysis, and reporting. Also the data should be publicly available within

a reasonable timeframe. In order to deliver these standards, a country needs adequate human resources and infrastructure capacities. Although national statistics offices are usually the prime survey organization in countries, close collaboration will be essential with health ministries, especially as biomarkers and health examination surveys become increasingly integrated into large population surveys.

The demand for subnational data on population health indicators should also be taken into account. Large surveys may provide reliable subnational estimates for some indicators, but this is often impossible at district levels where budget allocations are made. Further work is needed to determine whether simple local surveys can provide sufficiently accurate data to that level.

2.4.5 Individual records¹

Individual health records (Fig. 9) typically consist of:

 documentation of the provision of health services (for example, of growth monitoring, or antenatal and delivery care) to individual clients;

case reports and disease records routinely produced by health workers (of consultation and discharge); and

information held in special disease registries (such as those for cancer).

Such records should also include the notification and documentation of individual cases of disease and other health events captured by surveillance systems and vertical disease programmes.

One of the main purposes of individual records is to help care providers to deliver health services to individuals in a facility, or through outreach activities in the community. The content and format of these records vary depending upon the services to be provided, which include:

- preventive services for children under 5 or pregnant women;
- acute curative care;
- follow-up of chronic diseases;
- inpatient care in a hospital setting;
- laboratory or radiographic examinations (requests and results); and
- referral of the patient to other care providers.

of individual records is to help care providers to deliver health services to individuals in a facility, or through outreach activities in the community.

The outpatient management of many acute health problems is often recorded by the health provider using simple diagnostic and treatment notes, either on plain paper or simple medical record forms. These notes then act as a memory aid to the provider if the patient returns. However, for some health services (such as antenatal care, the outpatient management of chronic disease or inpatient care) more-extensive data or more-carefully designed recording formats are required to permit:

- identification of risk factors;
- organization of continuity of care; and

Iongitudinal tracking of patients with chronic illness (for example, AIDS or tuberculosis) to monitor treatment outcomes.

¹ Based on: Lippeveld T. Routine data collection methods. In: Lippeveld T, Sauerborn R and Bodart C, eds. *Design and Implementation of Health Information Systems*. Geneva, World Health Organization, 2000, chapter 6.

Fig 9. Individual records – minimum standards for data-collection methods



Paper forms will continue to play a key role in recording individual health service information for the foreseeable future. Therefore the design and production of such forms is an important consideration in health information system strengthening activities. For example, one way of helping health staff to make correct clinical decisions is to organize the record forms in an action-oriented manner. This might include listing clinical options next to a data item. For example, when a particular risk factor during pregnancy is identified, the recommended options for action in the immediate or longer term can be provided on the prenatal record form. Medical record forms can also be optimally organized to guide care providers during clinical examinations – disease-focused or problem-focused checklists are often pre-printed on the record forms. This not only reduces the time needed to fill them in but also makes them more legible. In terms of form production, the general rule is that the thicker the paper used to make the form the longer it will last but the more expensive it will be to produce. The thickness of each paper form will thus be a compromise between longevity and cost.

Entering medical records into an electronic database can greatly facilitate the storage, retrieval, transfer and analysis of essential client information. This is especially important where large numbers of clients must receive complex and long-term care, such as antiretroviral therapy. The proper combination of paper-based and electronic medical records will depend upon the human and financial resources and ICT available.

Client-retained cards (such as those included with a "road to health" chart) can also be used to record essential information on curative care. This permits some information to be recorded and shared even when the service provider lacks a system for storage and retrieval of medical records – and even when the client seeks care from multiple providers (including community health workers). Client-retained immunization records also play an important role when determining immunization coverage through a population survey. However, there are significant limitations on the amount of information that can be recorded on client-retained records. In addition, because cards may be lost or destroyed, a strong argument can be made for prioritizing investment in systems for the recording, storage and retrieval of facility-based records, even at the smallest and most under-resourced of health facilities.

There are significant limitations on the amount of information that can be recorded on client-retained records.

2.4.6 Service records

Service records (**Fig. 10**) cover not only the records of health service providers but also the records of events with important health consequences produced in other sectors. These include records made by the police, veterinary services, environmental health authorities, insurance companies and occupational health agencies. The type of events covered will include unintentional injuries, homicides, suicides, road traffic accidents, environmental and meteorological incidents and alerts on food and product safety. It is essential to capture the service statistics from the private sector and from community and civil society organizations as well as public sector institutions.



Fig 10. Service records – minimum standards for data-collection methods

The focus of health service records is typically on subnational information used to manage health services. These records are based on service-generated data derived from health facilities and patient-provider interactions covering care offered, quality of care, treatments administered, and so on. A major characteristic and strength of health service statistics is their local use for facility management. Where appropriate, such service statistics may be used to develop population-based estimates of immunization coverage, maternity care, etc. Such estimates provide a regular source of information that can be validated periodi-

cally with statistics from occasional household surveys. They can however be imprecise due to the need to estimate denominators and the possibility of under- or double-counting.

Service quality should be assessed regularly as part of the health information system. Supervisory systems can be used to collect standardized and systematic data, and to provide comparisons over time and between clinics and regions. Additional data may be collected through a health-facility survey, which is usually based on a sample of clinics. Such a survey may consider different aspects of service quality, such as the availability of drugs, commodities and trained staff. Special techniques, such as record review, observing client-provider interaction and using mystery clients, add considerable value to the assessment. But they also increase the costs and complexity. Data collected from record reviews and staffing inventories can be used to validate routine administrative statistics on the volume of services delivered and on the availability and geographical distribution of human resources.

Only limited data should be collected with the main aim of producing national summaries. Such summaries of district information can however provide data useful for national-level planning, monitoring and evaluation.

Sentinel systems use selected health facilities to monitor disease trends over time. Sentinel sites allow the provision of more intensive support to data collection. For some diseases, a special effort to collect additional data over a specified period of time (for example, HIV testing on residuals of blood samples collected for syphilis testing among pregnant women attending antenatal clinics) is conducted in sentinel clinics.

Health service based mortality or morbidity data are rarely sufficient to make estimates of population prevalence, incidence of disease or causes of death unless service coverage is close to 100%. They may, however, provide useful information on trends and on the relative importance of diseases and causes of death. Rankings of causes of death in hospitals or cancer registries are examples of such information. Correcting for some of the biases of such data may further enhance their utility.

2.4.7 Resource records

Resource and administrative records focus on the quality, availability and logistics of health service inputs (**Fig. 11**). This includes data on the density and distribution of health facilities, human resources for health,¹ budgets and expenditures, drugs and other core commodities,² and key services.

The minimum requirement is a database of health facilities and the key services they provide. Further development will involve mapping facilities, human resources, budgets and expenditures, core commodities and key services at national and district levels.³ This typically involves the use of Global Positioning System (GPS) equipment and Geographic Information System (GIS) software to determine the location of service delivery sites and administrative boundaries and place these on a computerized map.⁴ Mapping the availability of resources, specific interventions, and disease patterns can then provide important data from an equity perspective, and promote efforts to ensure that needed interventions reach peripheral areas and do not remain concentrated in urban centres.

¹ The information subsystem used routinely to manage the health workforce at various levels is sometimes referred to as the human resources management information system.

² The information subsystem used routinely to manage supply logistics is sometimes referred to as the logistics management information system.

³ Maps are also important for illustrating the geographical distribution of risk factors and health events such as disease outbreaks.

⁴ Service Availability Mapping, WHO/MHI

http://www.who.int/healthinfo/systems/serviceavailabilitymapping/en/index.html accessed 8 August 2007



Fig 11. Resource records – minimum standards for data-collection methods

Information on human-resource levels and distributions of key staff is also essential and should be monitored at central, district and facility levels. Such data on doctors, paraprofessional clinicians,¹ midwives, nurses, nurse auxiliaries and laboratory technicians should be complemented by further information such as health worker attrition through mortality, resignation and possibly migration, plus outputs from health-training institutions.

As part of the management of health services, budget and expenditure data are routinely provided by financial management information systems. For policy development and strategic planning, financial data is compiled using the methodology for national health accounts. This system provides information on the amount of financial resources available for health and their flows across the health system. The breakdown of data into private and public sector categories is an important feature requirement in this area. In addition, the disaggregation of financial information by major disease or health programme area is possible, but rarely done. At subnational levels, budget information tagged to health system functions (and in particular health interventions) is needed as a minimum for performance budgeting. Information on actual expenditure is more difficult to obtain but is crucial in understanding the performance of the health system.

Finally, the availability of information on core commodities and drugs can be assessed through facility reports or administrative records from medical stores within the health system. This may include essential medicines, condoms and emergency obstetric care kits.

¹ Referred to variously as medical assistants, clinical officers, physician assistants and nurse practitioners.

2.4.8 Linking indicators and data sources

Each essential indicator identified should be linked with one or more suitable data sources (**Table 1**). Sometimes there will be only one gold-standard data-collection method for a given indicator. More often, data for particular indicators can be generated from more than one source, as in the use of vital statistics or household surveys to measure maternal mortality.

Table 1. Sources of data for health indicators by domain

	Determinants of Health	Health Systems		Health
		Inputs and outputs	Outcomes (coverage and use)	status
Censuses	•	•		•
Civil Registration	•			•
Population Surveys	•	•	•	•
Individual Records	•	•	•	•
Service Records		•	•	•
Resource Records		•		

In such cases, one method may be superior or more cost-effective than another. Alternatively each measurement strategy may have relative advantages and disadvantages. For example, data on child mortality or immunization coverage can be generated from health services statistics and from household surveys. However, the use of different sources generally results in different values for the indicators and this can lead to confusion among policy-makers. Each source has its advantages and limitations. Service records are available on a continuous basis but are subject to bias because they cover only the populations using health facilities. Population surveys are considered to be more representative but they are time-consuming and expensive. As a result they are generally conducted only occasionally (every 5 years or so) and generate results often spanning several years rather than the immediate past.

If no suitable data sources exist for some indicators, a proxy may be needed. For example, routine statistics on the administration of the third (final) dose of the diphtheria, pertussis (whooping cough) and tetanus vaccine (DPT3) are used as a proxy for assessing full immunization coverage when household survey measurements cannot be used. For other indicators, there may be only one practical measuring method.

The reconciliation of statistical values arising from different sources and measurement techniques is necessary when there is no single best data source. Several health statistics can be obtained from multiple data sources, and reconciliation of the data is needed to obtain the best estimate of rates and trends. Population surveys generally do not generate yearly data or provide information for small geographical areas. Although limited to clinic users, health-facility data can provide frequent data on small populations if special investments are made to ascertain data quality and completeness. Population survey results need to be used to adjust the rates and trends seen in health facilities.¹

A good example of this is the measuring of HIV prevalence among adults in countries with generalized epidemics. Antenatal clinic based surveillance systems provide annual data

¹ Boerma and Stansfield. Health statistics now: are we making the right investments? *Lancet*, 2007. 369:779–786.

on HIV prevalence trends among pregnant women, but this is a biased population sample. Through nationally representative household surveys that include HIV testing, unbiased estimates can be generated that cover all regions in a country and include non-pregnant women and men. However, cost considerations preclude annual population-based surveys of HIV prevalence. Antenatal surveillance results are used to monitor progress and occasional household survey results provide data to calibrate and adjust

surveillance findings. The precise combination of different data sources depends on the indicator in question and the methodologies available to generate the data.

These considerations form the basis for a data-collection plan for the coming decade, which should specify the method and frequency of data collection for each core health indicator. A budget should be developed for this period and the data-collection plan should indicate likely financing sources and levels.

The precise combination of different data sources depends on the indicator in question and the methodologies available to generate the data.

2.5 Data management

2.5.1 Data storage

Routine paper data recorded and collected through registers, cards, aggregation or reporting forms are likely to remain the dominant format for the foreseeable future in less-developed countries. Ensuring the proper storage and accessibility of such data over the medium to long term will facilitate its validation (accuracy, timeliness, completeness and reliability); analysis of disease trends; assessment of quality of care; comparison of different service performance; and ultimately the equitable distribution of resources.

Patient medical records provide one of the best examples of the importance of data storage. These are vital in managing disease trajectory and for clinical decision-making in individual cases. Medical records should be classified and coded during (or immediately after) clinical visits, then properly kept in an appropriate location in a way that makes them easily retrievable. Hospital and health-facility archives can vary in size from a single room to a dedicated floor, but should always be well organized by:

restricting access to authorized staff to protect the confidentiality and privacy of the patient/client;

- coding the system to make records retrievable;
- following clear procedures for record distribution and re-filing; and

observing mandatory rules for the minimum period of maintenance and dispatch times at ward, hospital and facility level, and in national archives.

Data registers and reporting forms should be filed and stored properly at each administrative level and classified according to date, geographical location, title and/or national code. The unified storage of different forms in a single setting facilitates retrospective investigations and studies, and supervisory activities.

Various periodical or ad hoc reports derived from surveys, statistical summaries, epidemiological bulletins, special research studies and evaluation reports should also be carefully stored in a dedicated library or other resource centre. These documents and publications frequently represent the major reference source for programme and intervention evaluation. A uniform system (for example, universal library codes) should be used to classify such documents at all levels – from Ministry of Health headquarters to the most peripheral district office.

At the same time, the evolution and dissemination of ICT devices in less-developed countries has been rapid and an increasing number of hospital and peripheral health facilities now

have at their disposal well-maintained hardware and basic IT skilled staff. ICT applications are now used in some pilot and other settings to enter electronic HIV/AIDS patient data, and

A differentiated approach should therefore be adopted, using multiple communication models at the same time in the same country. to immediately digitize community survey or routine facility data using PDAs and pocket PCs. Nevertheless, although ICT infrastructures in lessdeveloped countries are expanding and Internet access increasing, the digital divide continues. The percentage of fixed broadband subscribers in the African continent was a mere 0.2% of the population in 2004 and 0.7% in all low-income countries in 2005.¹ Connectivity is often not stable and is unequally distributed in poor countries. Electrical power failures and difficulties in maintaining hardware and software undermine the stability of any network information system. A differentiated approach should therefore be adopted, using multiple communication models at

the same time in the same country. Capital cities and developed areas with permanent access can use Internet (and Intranet) technologies, while less-equipped areas can use LAN and/or standalone PCs.² In all cases, transforming paper-based data into digitized data is easier when it is performed as early as possible in the data-to-information cycle (recording, reporting, aggregating, storing, analysing and using). Experience has shown that "it is impossible to migrate data from one database to another manually".³ When a sustainable ICT environment is available at peripheral, hospital and district levels, staff should therefore be encouraged to promptly move routine data from paper to digital format for aggregation, dissemination and reporting.

2.5.2 Ensuring data quality

A wide range of policies and process are needed to ensure data quality. One guiding principle is to reduce the necessary amount of information to a "minimum dataset". This will then reduce the burden of data collection and this alone should improve data quality. Other management actions to improve data are regular local quality control and data-use checks, the use of clear definitions of data elements, up-to-date training, and frequent feedback to data collectors and users. When electronic communication facilities are available, data can be entered at decentralized locations to provide immediate reporting to all levels.

One guiding principle is to reduce the necessary amount of information to a "minimum dataset". Strong health information systems ensure that data meet high standards of reliability, transparency and completeness. It is important to assess source data and the statistical techniques and estimation methods used to generate indicators. Building on the IMF Data Quality Assessment Framework (DQAF)⁴ and IMF General Data Dissemination System (GDDS),⁵ the following criteria can be used to assess the quality of health-related data and indicators:

timeliness – the period between data collection and its availability to a higher level, or its publication;

periodicity – the frequency with which an indicator is measured;

¹ ITU-UNCTAD. World Information Society Report 2007, Beyond WSIS, Figure 2.6, p. 22–26. <u>http://www.itu.int/wisr</u>

² Piotti B, Macome E. Public health care in Mozambique: strategic issues in the ICT development during managerial changes and public reforms. *International Journal of Medical Informatics*. Vol. 76, Supp.1, June 2007, p. 184–195.

³ Lungo JH, Nhampossa JL. The Impacts of Legacy Information Systems in Reporting Routine Health Delivery Services: Case Studies from Mozambique and Tanzania. International ICT Workshop 2004, Dar es Salaam, United Republic of Tanzania.

⁴ International Monetary Fund Data Quality Assessment Framework (DQAF), 2003. <u>http://dsbb.imf.org/Applications/web/dqrs/dqrs/dqrs/dqrs/</u>

⁵ International Monetary Fund General Data Dissemination System (GDDS), 2003. http://dsbb.imf.org/vgn/images/pdfs/gdds_oct_2003.pdf

consistency – the internal consistency of data within a dataset as well as consistency between datasets and over time; and the extent to which revisions follow a regular, wellestablished and transparent schedule and process;

representativeness – the extent to which data adequately represent the population and relevant subpopulations;

disaggregation – the availability of statistics stratified by sex, age, socioeconomic status, major geographical or administrative region and ethnicity, as appropriate; and

confidentiality, data security and data accessibility – the extent to which practices are in accordance with guidelines¹ and other established standards for storage, backup, transport of information (especially over the Internet) and retrieval.

2.5.3 Data processing and compilation

The essence of data processing and compilation is the extracting and integrating of data. This involves extracting data from data sources, ensuring data consistency and quality, and achieving conformity through data transformation so that data from separate sources can be used together. Data transformation may include aggregation, calculation, cleaning, normalizing or merging tables, translating code values, or transposing values. Data can then be delivered to an integrated data repository in formats that allow various query methods to generate tangible outputs that health information system actors can use to inform their decisions. The whole process of data extraction and transformation adds significant value to the source data by:

- removing mistakes and correcting for missing data;
- providing documented measures of degree of confidence in data;
- capturing the flow of transactional data for safe keeping;
- adjusting data from multiple sources to allow them to be used together;
- structuring data to be usable by end-user tools; and

tracking all the above actions to tangibly support data-quality assessments.

be used a backdrop of changing national conditions or new technological developments.

The needs of health

information system actors may change over time, and

Whatever the source of a data item, it is essential to pay special attention to the activities and subsystems concerned with data collection, storage, analysis and dissemination. The aim is to carefully assemble data from a variety of disparate sources – both within the health system and beyond – and to ensure its quality by cleaning and checking prior to releasing information to a broader public.

The outcome will be rigorous relational data structures containing data for monitoring, evaluation, management and research. This aspect of data processing plays a major role in ensuring dataset quality, traceability and comparability with similar information from other sources. Data from one health process or activity should also match with that from another. If two performance measures have the same name, then they must mean the same thing. Such consistency leads to higher quality information with the clear implication that data is accounted for and complete.

The needs of health information system actors may change over time, and this may take place against a backdrop of changing national conditions or new technological developments. Data-processing systems must therefore be designed to handle change. Existing

¹ For example, the OECD Guidelines for data protection at:

http://www.oecd.org/document/18/0,2340,en_2649_34255_1815186_1_1_1_1,00.html

data, applications or health information system processes should not be disrupted when health information system actors ask new questions, or when new data sources are added. These and other changes are more effectively taken into account by modification of the "metadata" in the system.

Metadata is *data about data*. It covers definitions of data elements/variables, their use in indicators, data-collection method, time period of data-collection, analysis techniques used, estimation methods and possible data biases. Metadata is captured and managed within an integrated data repository to support the disparate needs of the technical, administrative and health user groups of the data-management system. It is essential for providing accurately described common data-element definitions and for ensuring that other vital information is understood (such as data time periods, geographical designations and other dimensions). To relate data from multiple sources, it is essential to develop common definitions and to understand the characteristics of each data element.

Data processing and compilation also has a number of other broad requirements, among which are ensuring that relevant and appropriate information is made easily accessible and its contents understandable. At the same time, this also means securing¹ and protecting the information assets of the system. For example, a system may contain disaggregated patient information which may be affected by privacy and security considerations. It is therefore essential to control access² to confidential information.

The results of data processing and compilation are a variety of reporting mechanisms that may be generalized to include both online and conventional reports. Where Internet access is available, the system reporting mechanisms can be accessed directly. Conventional reports can be produced where online access is not yet practical or appropriate to provide sophisticated data analysis and presentation tools developed centrally and benefiting from data-quality procedures. The reports may contain comparative information from other areas or programmes to improve understanding of the data and promote their use.

To meet all these and other requirements when designing and updating comprehensive data-management approaches demands significantly more than ICT skills or the broad deployment of ICT equipment and applications. At best, ICT itself is simply a means to an end

Data extraction and integration should ideally be implemented using ICTbased data warehousing techniques. within an integrated health information system. Nor should data management necessarily be manifested as a centralized solution or even centralized in one government entity. Nevertheless, the conceptual model for data management shares many traits with what is more generally known as data warehousing or integrated data repositories. Data extraction and integration should ideally be implemented using ICT-based data warehousing techniques. However, more-traditional data-aggregation methods can sometimes be used depending upon the situation.

In its implementation using ICT, this component is more generally known in the data warehousing community as Data Access Tools. The ultimate impact of data processing and compilation however is measured by the extent to which it can provide targeted information for action. Reporting mechanisms should therefore be designed with intuitive interfaces for accessing information, tuned to the particular needs of key health information system actors.

As shown in **Fig. 12**, the HMN Framework proposes the creation of an "Integrated Data Repository" which:

can hold data from all sources in a consistent and comparable way;

[&]quot;Secure" implies securing information from nefarious use and/or robust data storage and retention practices.

² "Access" may apply to both ICT security policy, and broader governing policies around health information.



Fig 12. Health information system

can exist in more than one location – especially in environments where physical security is not assured or multiple actors across government would benefit from being in proximity to all or some subset of the data;

records quality information and the transactional history of the datasets contained therein; and

both collects and manages information, and facilitates the key task of distributing the now consistent and comparable datasets throughout a country and to government and international partners.

Developing such an integrated information storage area offers many important benefits, including making best use of complementary data and synergies from multiple sources. Facilities, districts and programmes can view their own data and compare them to information from other sources at the same level. Districts can compare facilities within their area and against facilities in other districts. Similarly, information can be aggregated at national level to give an overall picture or to compare regions. Since the repository contains all information from every level, various tasks are possible. These include aggregating data, examining more-detailed information at local level, and comparing areas. The repository also provides an ideal tool for the immediate feedback of information to facilities and district levels. It use will improve data access and use at local levels by providing immediate access to high-level data-analysis tools. Nationally, the repository provides a convenient central location where all data are available for analysis, evaluation and research, thereby influencing policy, planning and management decisions.

An integrated data repository can amass data from many sources, including routine service statistics, surveys, civil registration, censuses, and financial, human resource and geographical information. At the country level, efforts should be made to include appropriate indicator data or raw source data from vertical programmes. Even if the data are a subset over time, vertical programmes may come to rely on these national core indicators, and realize that collecting separate datasets is not necessary for effective monitoring and

evaluation. Often, a core indicator set in combination with episodic surveys of vertical programmes provides better-quality and more-complete information. Developing a data-

Data must be intuitive and obvious to health information system actors. management system in a country can therefore be an opportunity to examine the information systems of vertical programmes and ultimately rationalize their data collection. However, many vertical programmes may have an established mandate and rigid data procedures, and active engagement at the global level may be required to promote harmonization activities.

Ultimately, the aim of data storage, quality-assurance, and processing and compilation is to present relevant information in credible, consistent and relevant ways. Data must be intuitive and obvious to health information system actors.¹ Such understandability implies legibility – the contents of the data-management system must be meaningfully labelled. Health information system actors may also want to separate and combine data in the system must be simple and easy to use and return query results within minimal wait times.²

2.6 Information products

2.6.1 Transforming data into information

The HMN Framework has so far dealt primarily with the components of a health information system in the context of data. Although data are the raw materials of a health information system, they have little intrinsic value in themselves. Only after data have been compiled, managed and analysed do they produce information (**Fig. 13**).³ Information is of far greater value, especially when it is integrated with other information and evaluated in terms of the issues confronting the health system. At this stage, information becomes evidence that can be used by decision-makers. This synthesis of evidence becomes even more powerful when it is formatted for presentation, communication or dissemination to decision-makers in a form that changes their understanding of health issues and needs. This is the process of transforming evidence into knowledge, and once applied can result in decisions which will directly impact upon health and health equity. The actual impact on health can then be monitored by the health information system by measuring changes in health indicators. This is how HMN visualizes the enabling of a culture of iterative and evidence-based decision-making built on a comprehensive country health information system.

At present, the health information systems in many low- and middle-income countries tend to be "data-rich" but "information-poor". This is a consequence of the belief that data can be used directly for decision-making without the value-added approach outlined in **Fig. 13**. In reality, raw data alone are rarely useful. The point of a health information system is not just to generate high-quality data and hope that it will be used, but to convert it into credible and compelling evidence that informs local health system decision-making. High-quality data stored in a well-structured repository is of little value if it cannot be accessed by users to generate information for decision-making.

If data are extracted and then integrated into a data repository as outlined in SECTION 2.5.3, they can be synthesized and triangulated with other sources and compiled into usable statistics and information for deeper analysis and comparison. A key aspect of this is the integration, synthesis, analysis and interpretation of information from multiple sources, examining inconsistencies, identifying and accounting for biases, and summarizing health

¹ HIS actors are potential entities using or benefiting from information managed within the system.

² Wait times here may imply delays due to data processing, or delays in delivering health information to peripheral HIS actors via offline and/or paper methods.

³ Adapted from de Savigny D, Binka F. Monitoring future impact on malaria burden in sub-Saharan Africa. *Am J Trop Med Hyg*, 2004. 71:224–231.



Fig 13. Transforming data into information and evidence

situations and trends. Such analysis provides estimates (such as knowledge of disease burden, risk-behaviour patterns, health service coverage, trends in indicators, and health system performance). These can then be made available through user dashboards, reports, queries and alerts (see **Fig. 12**). Such formatting or packaging of information for decisionmakers is a core function of the health information system in demonstrating the value of the data it contains. There have been many recent ICT innovations in preparing complex information and evidence in formats that can catch the attention of decision- makers and effectively communicate the messages embodied in information. Some approaches take advantage of web- or computer-based access to repository or observatory data served in an interactive format. Some new computerized analysis tools generate standardized reports rich in graphical (and even cartographical) representation of information. Standardized reporting formats, profiles and briefs are also highly effective. Such formats should guide decision-makers by providing interpretations based on the potential consequences of alternative decisions and scenarios. Information can also disseminated through workshops, medical journals, peer meetings and the media.

In these and other ways, the data held by a health information system can be extensively tapped to transform what is generally perceived to be "merely data" into information and evidence for action. However it must be emphasized that although reliable information is an invaluable tool for improving health, its availability alone does not guarantee that it will be used for improved decision-making. Once the health information system has started converting data into information, the information produced should be used regularly at meetings and displayed where staff and the public can see it. Following such use, the health information system and the quality and usability of its information can gradually be improved by a cyclical learning process. Hands-on experience can identify problems, define new needs and add features to be refined and improved upon in the next cycle. This conversion of primary data to information and evidence requires an appropriate and simple toolkit of targeted methods aimed at providing relevant feedback. HMN is working to identify and develop tools and best practices for each step in this cycle.

Establishing an information architecture as a shared resource at national, subnational and district levels is an essential step in improving information practices and enabling the

necessary high-quality analyses. It is from this level of analysis that results are used for policy development and strategic planning. Such analysis, interpretation and advocacy do not take place spontaneously. They require the formatting, communicating and dissemination of evidence in a presentation and language accessible to senior level policy and executive decision-makers – a generally neglected aspect of most health information systems.

2.7 Dissemination and use

2.7.1 Use of information for decision-making

Information is used at various levels of the health system for health service and system management, planning, advocacy and policy development. Each level has a broad range of

A principle of HMN is that country information should be made a core part of the day-to-day management of health system planning and delivery. users from different technical disciplines and vocations with associated vocabularies and communication methods. A principle of HMN is that country information should be made a core part of the day-to-day management of health system planning and delivery. Thus, access and use should be integral to health information system strengthening activities.

The dynamic links between demand, supply and quality of information should be addressed by encouraging a culture in which information is demanded and its use promoted. In practical terms, this will require the establishment of institutional mechanisms and incentives to create a culture of evidence-based decision-making. Experience shows that the

most effective mechanisms involve linking data/information to actual resource allocation (budgets) and developing indicator-driven planning.

After the packaging and communications stage, information should be used for decisionmaking. However the capacity for data analysis is often lacking at peripheral levels where the data are generated and results should be used for planning and management. Bringing together a comprehensive analysis of the health situation and trends with data on health inputs (such as health expenditure and system characteristics) is particularly important. Developing such analytical capacity requires planning, investment and tools.

One important function of the health information system is to connect data production with its use. Those responsible for collecting data should also benefit from its use. Users comprise those delivering care and managing and planning health programmes. More broadly, users include those financing health-care programmes both within countries (health and finance ministries) and externally (donors, development banks and technical

One important function of the health information system is to connect data production with its use. support agencies). Users of health data are not confined to health-care professionals, managers or statisticians. Decision-making around country health priorities necessarily involves the wider community (including civil society) as well as policy-makers at senior levels of government.

Among the many advantages of developing a culture of evidence-based decision-making is that diverse types of users can all benefit from the country health information system in line with their own needs and requirements. Health-care planners and managers responsible for track-

ing epidemiological trends, and the response of the health system generally, need moredetailed data than policy-makers who require it for broader strategic decision-making and investments.

2.7.2 Institutionalizing information use and demand

It is simplistic to assume that a linear relation exists between evidence and policy – that good data will automatically lead to better decisions that will in turn result in enhanced health.¹ In practice, no linear sequence necessarily exists from good data to better health.²

Various types of data are obtained at different levels of the health system, to be used by several actors for many reasons. Providers generate and use information in the context of patient care; managers need data to enhance efficiency and effectiveness; planners rely on statistics for operational decisions; and policy-makers use information to prioritize and allocate resources (see **Fig. 2**). At the level of clinical practice, good quality of care is greatly facilitated by well-kept records of patient characteristics and provider responses. Yet good clinical record-keeping remains far from universal.³

As we move up the health-system pyramid, the link between data and decision-making seems more tenuous, and many factors come into play when strategic decisions on resource allocation are made. In a large and complex society, policy-making is fragmented and decisions are sometimes difficult to make because of the competing interests of different players and agencies. The Routine Health Information Network has even postulated that the scarcity of evidence-based decision-making is not the result of technical issues related to data generation but of institutional and behavioural barriers that impede the effective use of information. The PRISM framework and tools allow countries to assess such factors prior to intervention(s) to improve use of information, and to later evaluate the change brought about by the intervention(s).

Examples of organizational and behavioural interventions for improving the use of information in decision-making and planning are:

 mechanisms linking data/information to actual resource allocation (budgets and expenditure);

indicator-driven, short- (1 year) and medium-term (3–5 years) planning;

organizational routines where managers are held accountable for performance through the use of results-based indicators at all levels of the health system;

a programme addressing behavioural constraints to data use, for example through applying incentives for data use, such as awards for best service delivery performance, best/most-improved district or best health information system products/use; and

a supportive organizational environment that places a premium on the availability and use of well-packaged and well-communicated information and evidence for decision-making.

¹ Marston G, Watts R. Tampering with the evidence: a critical appraisal of evidence-based policy-making. In: *The Drawing Board: an Australian review of public affairs*, vol 3 no 3:143–163.

http://www.australianreview.net/journal/v3/n3/marston_watts.pdf (accessed 25 January, 2007).

² AbouZahr C et al. From data to policy: good practices and cautionary tales. *Lancet*, 2007. 369:1039–1046.

³ Wyatt JC, Wright P. Design should help use of patients' data. *Lancet*, 1998. 352:1375–1378.

PART 3

Strengthening Health Information Systems – Principles, Processes and Tools



Chaloay Wanathong, 69, signs a certificate registering the death of his father at 95, at Ban Pong District Registration office in Rachaburi Province, Thailand, 14 September 2007. PHOTO: WHO/JEROME MING

3.1 Guiding principles for health information system development

3.1.1 Introduction

Implementation of the HMN Framework should be based upon a set of common principles – empowerment, leadership and ownership; a focus on the needs of individual states; building upon what already exists; broad-based consensus-building; and an incremental approach to health information system development. These are the principles reflected in the Paris Declaration endorsed on 02 March 2005 by more than 100 ministers, agency heads and senior officials committing their countries and organizations to increased efforts to harmonize, align and manage aid for results with a set of monitorable actions and indicators.¹

3.1.2 Principle of country leadership and ownership

The process of strengthening country health information systems is by its very nature focused on empowering countries to undertake broad health system strengthening activities. It is therefore essential that any given national leadership is engaged and owns the implementation process. The role of partners will be to offer flexible support, information and guidance, as well as to actively engage in the HMN harmonization process, which has been globally informed by country experience.

3.1.3 Principle of responding to country needs and demands

Strengthening country health information systems should always begin with recognition of the need for this process by the country itself. The process should then focus on the needs of health information users. It is important that implementation takes into account what

can be achieved within available resources and capacities. A key step in this is the development of a comprehensive vision of health information that:

 addresses institutional and organizational constraints (including human and financial resources);

serves as a coherent framework for international support in improving health information; and

is flexible enough to change in response to changing needs.

3.1.4 Principle of building upon existing initiatives and systems

Wherever possible the implementation process should build upon existing initiatives, systems and knowledge. Strengthening country health information systems should not take place in a vacuum but should be linked to (and build upon) similar initiatives, especially national and international strategies for the development of statistics.² Examples of current efforts include:

the work of the United Nations Statistics Division (UNSD) to support censuses and vital statistics;

promotion of statistical capacity-building by the World Bank (WB) and the Organisation for Economic Co-operation and Development (OECD) through the Partnership in Statistics for Development in the 21st century (PARIS21);³ and

It is important that implementation takes into account what can be achieved within available resources and capacities.

Paris Declaration. http://www.oecd.org/document/18/0,2340,en_2649_3236398_35401554_1_1_1_00.html

² PARIS21 Secretariat. A Guide to Designing a National Strategy for the Development of Statistics (NSDS), 2004. http://www.paris21.org/pages/designing-nsds/NSDS-reference-paper/

³ http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATISTICS/ and http://www.paris21.org/pages/advocacy/why-statistics/index.asp#credits

the work of the International Monetary Fund (IMF) on data-quality improvement.¹

Coordination mechanisms for the strengthening process should use any appropriate existing structure, and initial assessments of the health information system should draw on all available information.

3.1.5 Principle of building broad-based consensus and stakeholder involvement

Broad-based consensus-building is a crucial first step because much of the data needed by the health sector is generated by other sectors, and the resources required to strengthen health information system generally come from constrained national budgets. Although the inputs of external partners and donors are initially important to catalyse action, countries themselves must sustain the necessary longer-term investments.

3.1.6 Principle of a gradual and incremental process with a long-term vision

Strengthening country health information systems is best approached as a gradual and incremental process. It need not entail major structural Although the inputs of external partners and donors are initially important to catalyse action, countries themselves must sustain the necessary longer-term investments.

change or an immediate and total overhaul of the existing system – although this may be necessary in countries where the system is completely dysfunctional. It is generally more effective to deal with one aspect of the system at a time (such as a subsystem for disease surveillance or household surveys) or to address a specific need (such as introducing indicators related to a new health intervention treating, for example, HIV/AIDS). Once improvements have been secured, the strengthening process can then identify a further set of priorities for action.

Whether the scope is narrow or broad, the long-term goal (by 2015) should be a balanced, coherent and comprehensively developed health information system. This will require consistent long-term investment.

3.2 Implementation processes for health information system strengthening

3.2.1 Introduction

The scope, form and content of the implementation processes needed to strengthen a country health information system depend upon specific local factors, such as the structure of government, the level of development, institutional capacities and financial considerations. Whatever the circumstances, the process of implementing the HMN Framework should include the following activities:

 identifying a lead sponsor and country champion for health information system strengthening;

establishing consultation and coordination mechanisms that bring together all key stakeholders, including those working in health and statistics, and all producers and users of health data;

establishing a steering committee to provide ongoing oversight and coordination of health information system strengthening activities;

creating one or more country action teams, depending upon the circumstances, focusing upon a specific area of health information system strengthening;

¹ <u>http://unstats.un.org/unsd/statcom/doc04/data-quality.pdf</u>

- assessing the current situation, including any current work to improve health statistics
 the assessment template should also provide the basis for monitoring improvements;
- reaching agreeing on a shared vision and goals for the health information system;
- defining minimum standards of data availability, timeliness and quality;
- identifying strategic actions to achieve the agreed-upon vision, including the prioritizing of tasks;
- producing a detailed and costed action plan (with a timetable and clear allocation of responsibilities) to achieve the desired outcomes;

synthesizing, analysing and using country evidence to inform planning, resource allocation and evaluation;

 developing and using implementation monitoring-and-evaluation mechanisms, leading to reprogramming; and

providing a dissemination and communications plan to keep all stakeholders (including civil society) involved throughout the strengthening processes, and to report back on results obtained, especially at the evaluation and reprogramming stages.

In order to accelerate the strengthening of health information systems worldwide, the three-phase implementation process shown in **Fig. 14** is proposed.

■ Phase 1 – *leadership, coordination and assessment* are the first steps in activating the health information system strengthening process by securing the involvement and support of key country stakeholders. The assessment process allows stakeholders to

Leadership, coordination and assessment are the first steps in activating the health information system strengthening process by securing the involvement and support of key country stakeholders. collaborate across disciplines and establish a common understanding of the concepts, benefits and current capacities of the health information system in the country.

■ Phase 2 – *priority-setting and planning* builds upon Phase 1 by engaging stakeholders in a vision for evidence-based decision-making and planning. This sets the stage for the development of a strategic plan for achieving the vision in concrete and measurable steps over time. This plan will include consideration of the resources needed both within the country and externally (and how these can be secured) to implement strengthening.

■ Phase 3 – *implementation of health information system strength*ening activities includes addressing ICT capabilities as well as the

policies, human resources and processes that create access to actionable country health information. Countries will have very diverse capabilities and the HMN Framework that comprises Phase 3 must be flexible enough to adapt to existing environments. The country health information system will evolve but include basic data sources, methods for creating them and tools to integrate them and visualize information for evidence-based decision-making. A key aspect of Phase 3 will be the active engagement of donors and global partners in aligning and harmonizing data collection and reporting with the least amount of duplication.

The process of strengthening will become a continuous cycle in which implementation is followed by evaluation and reprogramming. Monitoring and evaluation of the application of the HMN Framework in-country will enable stakeholders to measure progress, document lessons learned and reprogramme future iterations of the country health information system. Ultimately the desired results of the strengthening process are the improved availability and greater use of quality health information. A similar process is already being





promoted by PARIS21 in its support for the integrating of sectoral components into national strategies for the development of statistics (NSDS).

3.2.2 Phase 1 – Leadership, coordination and assessment

The leadership, coordination and assessment phase is essential both for the successful launch of the process and for subsequent support. Many diverse actors have key roles to play, and consensus is needed to determine priorities and to agree upon the methods for addressing them.

Leadership

Practical success in health information system strengthening depends largely upon the personal commitment and dedication of those involved, in particular senior decision-makers such as government ministers and managers. To ensure this, it is vital to make the case that health information makes a difference.

The PARIS21 consortium has focused strongly on advocacy for statistics and evidencebased policy-making. In support of this, it has established a process for identifying key stakeholders in the assessment stage, and provided materials on the importance of using statistical information in the policy making process.¹ Its advocacy guide – *Why statistics*² – notes that to use advocacy materials effectively:

... it will be important to analyse the targets to be reached.

The following specific points are made:

An advocacy campaign targeted at government, parliament or senior civil servants will probably be most effective using speeches, reports or material produced for specific occasions (for example, a parliamentary hearing of the chief statistician). This can make use of information and examples from other countries and their official statisticians.

Leaders of public opinion, regional organizations, pressure groups, academia and the research community can be targeted via publications that periodically summarize the work of the statistics office. With the spread of the Internet, online dissemination will become ever more important.

The national business community is particularly aware of the importance of statistics, and of the need for timeliness and sectoral and local disaggregation, and should be reassured on issues such as the burden of providing statistics, and confidentiality.

PARIS21 materials can also be useful in training staff by equipping them with effective arguments on the nature and necessity of a good statistical system.

Obtaining a high-level policy commitment is a key initial step and signals a clear decision that action is needed. It is also crucial to identify a high-level influential country "champion" with decision-making powers to lead the process. They must be able and willing to invest

time and effort into convening stakeholders, involving different partners (internal and external) and moving the process forward.

Obtaining a high-level policy commitment is a key initial step and signals a clear decision that action is needed.

Coordination

Establishing a broad-based coordinating mechanism with links to relevant ministries, research institutions, NGOs, technical support agencies and donors is another crucial step. It should be the body charged with the goal of reaching agreement to pursue the HMN Roadmap (**Fig. 14**)

and developing a national plan. If a suitable body does not exist, a coordination steering committee under high-level leadership should be constituted to ensure coordination. It should convene regularly, mobilize technical advice, provide guidance and oversight, and disseminate progress reports to all stakeholders. The precise nature of the operational arrangements for taking action will vary depending upon the individual country context.

Such a steering committee should involve donors and development partners such as multilateral and bilateral agencies. Other users and stakeholders may include NGOs, academic institutions, professional associations (medical, statistical) and users of health-related information such as parliamentarians, civil society (including health-related advocacy groups) and the media. In countries with decentralized systems, the process should be clearly articulated and involve managers and representatives of care providers at peripheral levels (districts) as well as stakeholders at the central level. This process of consensus-building will also identify country health information systems strengths and weaknesses, gaps and opportunities for improvement, resources, barriers to health information generation and use, and key actors to be involved.

¹ Partnership in Statistics for Development in the 21st Century. <u>http://www.paris21.org/</u>

² <u>http://www.paris21.org/pages/advocacy/why-statistics/index.asp#credits</u>

Assessment

The assessment process is a mechanism that directly engages stakeholders and reinforces the commitment to broad-based consensus-building. The HMN *Health Information System Situation Assessment Tool*¹ lays out the means to undertake a first baseline assessment and subsequent monitoring. An overriding aim of any statistical system assessment is to arrive at an understanding of:

...users' current and perceived future requirements for statistical information; their assessment of the adequacy of existing statistics and of where there are gaps in existing and planned data; their priorities; and their ability to make effective use of statistical information.²

The coordination steering committee should draw up terms of reference for the baseline assessment, identify the composition of the assessment team, and mobilize the required human and financial resources. The purpose will be to assess the extent to which the health information system and its various subsystems are currently meeting user needs. This includes its capacity to provide the sound and timely data needed for public health action, including priority indicators of national and global health interest.

Such an assessment is complex, as overall system performance depends upon multiple determinants – technical, social and organizational and cultural. Assessment therefore needs to be comprehensive in nature and cover the many subsystems of a health information system, including public and private sources of health-related data. It should also address the resources available to the system (inputs), its methods of work and products (processes and outputs) and results in terms of data availability, quality and use (outcomes). Important "inputs" to assess include the legal and institutional environment, and the volume and quality of financial, physical, ICT and human resources. In assessing the later it is useful to review the competence and professionalism of staff and whether their behaviours and practices are oriented by clearly stated and written ethical standards. In terms of "outputs" the integrity of data is also determined by the degree of transparency of procedures, and the existence of well-defined rules, terms and conditions for collection, processing and dissemination. Assessing "outcomes" should include quantitative and qualitative approaches, such as document reviews and interviews with in-country stakeholders at central and peripheral levels, and with external actors.

In many settings, assessments of the health information system or its individual components may already have been conducted and should be built upon, not duplicated. The findings should provide the foundation for an analytical and strategic assessment of current strengths and weaknesses. Once endorsed, assessment provides the baseline against which future progress in health information system strengthening should be evaluated. The assessment report and its recommendations for action should be made accessible to all stakeholders, including health professionals and civil society.

During the assessment process, workshops must be conducted to build broad-based consensus among key stakeholders in the following three stages:

- 1. First, a workshop is held to mark the launch of health information system reform, the first stage of which is leadership, consensus-building and assessment activities.
- A second workshop then follows to initiate assessment of the health information system, supplemented by follow-up visits to key stakeholders. Another key function of the second workshop is to assess, and open dialogue on, the strengths and challenges of the existing system.

¹ This and other tools may be downloaded from: <u>http://www.who.int/healthmetrics/tools/en/</u>

² PARIS21 Secretariat. A Guide to Designing a National Strategy for the Development of Statistics (NSDS), 2004. http://www.paris21.org/pages/designing-nsds/NSDS-reference-paper/

 The third workshop coincides with the end of the assessment phase and is used to share and discuss findings, highlight existing weaknesses and map a way forward for the planning process.

3.2.3 Phase 2 – Priority-setting and planning

Vision

The HMN *Health Information System Situation Assessment Tool* described above does more than simply assess the strengths and weaknesses of the elements and operations of a national health information system. The mere process of conducting the assessment reaches and engages all stakeholders in the system. Some of these will interact for the very first time through the assessment process, which is intended to be both catalytic and synergistic. It should move stakeholders towards a shared and broader vision of a more coherent, integrated, efficient and useful system. The gap between the existing system and this new vision will be an important stimulus for moving to the next stage of planning health information system reform. At this stage, stakeholders are now better prepared to articulate and argue for a new vision of how a health information system would benefit the country, lead to stronger health system performance, and ultimately to improved public health. This vision will then set the context for establishing strategic goals for system performance over the long term.

Priority-setting

Continuing stakeholder involvement is important when moving from assessment to the development of strategic and operational plans which necessarily requires the setting of priorities. In most settings, a subset of the wider stakeholder group or steering committee will be tasked with organizing workshops and consultation exercises, and with ensuring that key tasks are completed in accordance with the agreed allocation of roles and responsibilities.

Even in the strongest systems, the assessment is likely to reveal relative weaknesses in each component of the health information system (resources, indicators, data sources, data management, information products, and dissemination and use). Priorities will therefore need to be set. The underlying philosophy of priority-setting should be that strengthening will be incremental, with step-by-step implementation of key actions, and gradual scalingup as resources and capacities permit. Inevitably, some types of activities will require more time to accomplish than others. For example, policy reforms related to the role of the private health care sector in health information or civil registration are likely to require legislative action and intersectoral collaboration that cannot be achieved overnight. But this need

The process of prioritysetting should be inclusive and transparent. not preclude more rapid movement on other fronts, for example, making better use of existing data by strengthening analytical skills.

The process of priority-setting should be inclusive and transparent. A national stakeholder workshop should be convened as part of bridging the assessment and planning processes to ensure open discussion of the assessment report and broad-based involvement in the setting of aims,

objectives and priorities. Determining priorities involves first describing the options for addressing the issues raised in the assessment phase. Following further discussion and consensus-building, decisions can then be made on what is essential and what is feasible given current capacities and resource-mobilization opportunities, and the sequence in which issues should be addressed. Integral elements of the priority-setting process include identifying the core indicators (SECTION 2.3), reaching agreement upon the data sources to be used (SECTION 2.4), and ensuring the appropriate and effective application of the information produced. Data needs will vary according to the epidemiological profile and development

needs of each country and on the specific uses of data, whether for high-level policymaking and resource allocation or for district-level management (**Fig. 2**).

Strategic plan

The process of priority-setting goes hand in hand with the setting up of a long-term (10-year) strategic plan which should be closely aligned with other relevant health and development plans. These will include national health plans, poverty reduction strategies and national plans for the development of statistics. The long-term plan sets the broad goals and major objectives, as well as the timeframe into which the identified priorities are mapped, to build up an incremental approach to strengthening and scaling the health information system. Such objectives need to be carefully crafted and SMART¹ (i.e., strategic, measurable, attainable, results-based, and time-bound). Consensus-building around the plan is important to ensure its relevance to all stakeholders over the long term. Advocacy for the plan will also be needed at the highest levels of government, stressing the importance of sound statistics to underpin evidence-based decision-making. Experience shows that without high-level commitment, fundamental challenges such as the allocation of roles and responsibilities among institutional partners will not be adequately addressed. Advocacy and consensus-building efforts should also involve civil society, the media, parliamentarians and health advocates who have the most to gain from better informed public health decision-making.

Action plan and budget

With the priorities established, and the context of the broad, long-term strategic plan agreed, a detailed budgeted national action plan (or "operational plan") needs to be developed, preferably with a short timeframe (3 years). This is done under the overall guidance and leadership of the steering committee. Each of the groups identified as having specific responsibilities in delivering the defined outputs can then develop a detailed activity-specific workplan. A further national workshop should be convened to finalize the national action plan and to allocate roles and responsibilities. The outcome of this should then be endorsed at the highest level. The duration of the national plan will depend upon existing

planning cycles in each country. Some countries have adopted a threeyear rolling plan scheme while others work within an annual timeframe. The national action plan should also be attuned to the calendar of healthsector operational plans. Each strategic intervention identified should be accompanied by a defined product (output) to be delivered, with the specific responsibilities for ensuring delivery clearly set out.

Finally, the national action plan will need to be costed and financing plans and resource-mobilization strategies discussed. Costing should cover both capital and recurrent costs, including the training of existing and

new human resources. The costs of external technical assistance should also be included. Where possible, selecting which data-collection methods to use where alternatives exist (for example, special surveys as opposed to ongoing vital statistics to measure mortality rates) should be based upon cost-effectiveness estimates. Many development partners, including global health partnerships focused around specific diseases such as HIV/AIDS, tuberculosis or malaria, are ready to invest in strengthening health information systems but have not done so because of a lack of strategic assessments and comprehensive plans. HMN has developed tools and model examples to help bridge the assessment and planning processes, and to develop and cost national action plans.

HMN has developed tools and model examples to help bridge the assessment and planning processes, and to develop and cost national action plans.

¹ Conzemius A, O'Neill J. The Handbook for SMART School Teams. National Education Services, 2002.

3.2.4 Phase 3 – Implementation of health information system strengthening activities

Initial implementations of health information strengthening activities will, by their very nature, be pragmatic, iterative and heavily learning-based. It is vital that active and direct guidance on implementing the national action plan is provided through the coordination steering committee. The continuing participation of its high-level leadership, and the active involvement of stakeholders, will help to maintain momentum and commitment. As activity patterns and best practices are developed, ongoing consultation among the coordination steering committee, development partners and donors will continue to be needed.

The initial implementations will require additional dedicated core team members and adequate resourcing. To the maximum extent possible, external technical assistance should be focused upon the transfer of knowledge and skills to country human resources. Each initial implementation should draw on the leadership and guidance of the coordination steering committee when making decisions on issues such as the priority indicators to be used, and which initial datasets to include.

Initial implementation activities will benefit capacity-building for subsequent and morecomplex implementation activities, as well as signal progress towards strategic goals in the national action plan. It is likely that most plans will require action in a number of domains including policies, resources and processes. Almost all countries will need to reassess their core indicators and the data sources for each in light of the integration requirements described in this framework document. Initial implementation activities may also need to be small and easily managed steps towards health information system strengthening.

At some point, most countries will be ready to move beyond paper systems and to take advantage of the extraordinary developments in ICT. Some will be able to capture data electronically at source, or soon after, and to move towards data extraction, transformation

Extracting, transforming and loading can be complex due to variations in source data quality, update cycles and the transformation process. and loading into an integrated data repository providing reports and analyses on demand at all required levels (**Fig. 14**). However, the datasets involved and the tools used to populate an integrated data repository will immediately raise operational issues. As new data are collected and reported, they should be extracted, transformed and loaded into the repository. This could take place daily, weekly, monthly or less often depending upon the data-collection schedule. To the extent possible, these processes should be automated. Extracting, transforming and loading can be complex due to variations in source data quality, update

cycles and the transformation process. Although software tools are available to facilitate all these processes, these must be carefully adapted.

The operation of the repository is not solely a technical undertaking. Sociopolitical factors will both influence and constrain the process. Operational questions to be considered include:

Is the repository in a single physical site or replicated at multiple sites?

Is the repository created and maintained perpetually or is it created on demand as required?

- Who should manage the repository or repositories?
- How should it be managed?
- How is it secured?
- Who has access to the data?

Human resources are also required to set up and maintain the repository, including:

- a professional designer with database experience;
- a database administrator;
- a query and report designer;
- a managing board with representatives from data-source organizations; and
- a stakeholder group.

Once initiated, the repository will become an ongoing project that will develop as data become available and needs evolve. It will require continuous maintenance to load updated data, and to add new types of data, queries and reports. The stakeholder group should convene regularly to keep information sources up to date and to communicate their information needs.

3.2.5 Continuous evaluation and improvement

National action plans for strengthening health information systems should also include a monitoring and evaluation framework with specific indicators used to track progress. The indicators chosen should cover the spectrum of inputs, processes, outputs and outcomes, and be able to demonstrate impact in terms of the availability and use of sound health information. Six-monthly monitoring reports on the progress of activities and funding disbursements should be provided to the coordination steering committee to enable corrective action and modifications to the national action plan if necessary. The milestones achieved – and the difficulties encountered and addressed along the way – should be reviewed and discussed annually by stakeholders.

A full evaluation of implementation progress should also be undertaken at appropriate intervals. It may be helpful to undertake a first full evaluation within three years of the start of implementation. The evaluation should include a reassessment of the health information system using the same HMN assessment tool used originally to allow for comparison of improvements against the baseline. The evaluation should specifically consider the availability, quality and use of important health information, and the extent to which there have been any improvements in the ability to measure and monitor inequities in health and to take action based on these measurements. Evaluation should also permit an assessment of the degree to which there is improved coordination between country and external partners, and greater coherence in overall information demands. The evaluation should lead into a renewed cycle of prioritization, planning and implementation. A national workshop should be convened to finalize and endorse the reprogrammed action plan.

The strengthening process may also involve research and development elements when major gaps have been identified that available methods cannot address. Operations research and the introducing of new approaches should be seen as integral elements of strengthening that can be facilitated by discussions with partners such as HMN. Examples of topics for a research agenda include:

costing of health information system strengthening;

assessing the effectiveness of various targeted interventions (such as training, supervision, feedback and incentive schemes) in improving data quality;

 assessing the effectiveness of different information-dissemination methods to enhance information use;

characterizing the sociocultural factors and constraints affecting information use;

 field-testing and validating sentinel methods of vital-events monitoring and cause-ofdeath attribution;

- validating verbal-autopsy tools for use in diverse settings;
- developing methodologies to merge data from multiple household surveys;
- developing simple methods to evaluate the completeness of reporting systems; and

involving communities in the analysis of data/indicators, and in using the results to improve health care seeking behaviour.

3.3 Evolution of the HMN framework

3.3.1 The way forward

The standards and guidelines described in this document are based upon existing accepted standards and the opinions of experts obtained by HMN. In the coming years HMN will continue to build consensus around the standards and norms required for the collection, management, synthesis, analysis and use of health information – and to support the implementation of activities to achieve its aims in these areas. Equally important will be a series of piloting, testing and validating activities conducted in countries where these accepted or emerging standards will be applied.

The HMN Framework will be greatly informed by these two core activities and implementing it successfully will require a continuous learning process informed by contributions and findings over the next decade from implementation experience of country health information systems. At the same time, best practice is being defined through implementation research and a careful assessment of efforts already made to strengthen health information systems.

It is now the responsibility of HMN Framework members and users at both country and global level to contribute to the growing body of knowledge that will further enhance and refine the approaches now needed to achieve the standards for country health information systems set out in this document.

Glossary of terms

- **Causes of death** the causes of death to be entered on the medical certificate are defined as "all those diseases, morbid conditions or injuries which either resulted in or contributed to death and the circumstances of the accident or violence which produced any such injuries".
- **Civil registration** defined by the United Nations as: "the continuous, permanent, compulsory and universal recording of the occurrence and characteristics of vital events (live births, deaths, foetal deaths, marriages and divorces) and other civil status events pertaining to the population as provided by decree or regulation, in accordance with the legal requirements in each country. Civil registration establishes and provides legal documentation of such events. These records are also the best source of **vital statistics**."¹
- **Data management** a set of procedures to collect, store, analyse and distribute data. Once data are collected, a sound management approach is essential. Firstly, a metadata dictionary is necessary to accurately describe the data elements. Next, effective datastorage procedures require a well-designed logical structure to permit data retrieval and analysis. Data analysis and presentation include calculating indicators and preparing tables and graphs. Finally, the data should be made available to all those who can use and act upon them.
- **Data warehouse** an integrated information-storage area that consists of a data repository bringing together multiple databases from various data sources, and a reportgenerating facility.
- **Demographic surveillance system** (DSS) the continuous demographic monitoring of a geographically defined population with timely production of data on all births, deaths and migration. DSS sites cannot provide nationally representative indicators because of their circumscribed geographical representation. Efforts are being made to provide estimates that can be generalized using several existing DSS sites as resources for training, quality control and supervision.
- **Enumeration** distinct from registration; 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. Enumeration is anonymous and does not provide any direct benefit to the individual.
- **Information and Communications Technology** (ICT) includes the computers, software, data-capture devices, wireless communication devices, and local and wide area networks that move information, and the people that are required to design, implement and support these systems.

¹ United Nations Statistics Division. *Principles and Recommendations for a Vital Statistics System*. Revision 2, Series: M, No.19/Rev.2. New York, United Nations, 2001. Sales No. 01.XVI.10. <u>http://unstats.un.org/unsd/publication/SeriesM/SeriesM_19rev2E.pdf</u>

- International Statistical Classification of Diseases and Related Health Problems (ICD)¹ a classification 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, collection, processing, classification, and presentation of statistics.
- **International Standard Classification of Occupations** (ISCO)² one of the main international classifications, for which ILO is responsible. ISCO is a tool for organizing jobs into a clearly defined set of groups according to the tasks and duties undertaken.
- **Medical certification of cause of death** medical practitioners or other qualified certifiers use their clinical judgement to diagnose the cause(s) of death to be entered on the medical certificate.
- **Metadata (dictionary)**-metadata is "data about data". To relate data from multiple sources, it is essential to develop common definitions and understand the characteristics of each data element. The tool for achieving this is the metadata dictionary. It covers definitions of data elements/variables, their use in indicators, data-collection method, time period of data-collection, analysis techniques used, estimation methods and possible data biases.
- Microdata non-aggregated data about the units sampled. In the case of population and household censuses and surveys, microdata consists of records of the individuals and households interviewed.
- **Mortality rate** the ratio of the number of people dying in a year to the total mid-year population in which the deaths occurred. This rate is also called the crude death rate. The mortality rate may be standardized when comparing mortality rates over time (or between countries) to take account of differences in the population. This rate is then called the age-standardized death rate.
- **National Health Account** (NHA) a tool for the systematic, comprehensive and consistent monitoring of resource flows in a national health system. It provides a framework with standard definitions, boundaries, classifications and a set of interrelated tables for standard reporting of expenditures on health and its financing. NHAs are designed to capture the resource flows for the main functions of health-care financing, namely: resource mobilization and allocation; pooling and insurance; purchasing and providing of care; and the distribution of expenditures by disease, socioeconomic characteristics and geopolitical areas.³
- Sample registration system longitudinal enumeration of demographic events, including cause of death via verbal autopsy, in a nationally representative sample of clusters such as exists in China and India.
- Sample Vital Registration with Verbal Autopsy (SAVVY) proposed by MEASURE Evaluation and the International Programs Center, United States Census Bureau to generate data needed to estimate mortality. Builds on experience from both sentinel demographic surveillance and sample vital registration systems. SAVVY uses a validated verbal autopsy tool to ascertain major causes of death, including those from HIV/AIDS.⁴

¹ World Health Organization. International Statistical Classification of Diseases and Related Health Problems (ICD). 10th Revision, Second Edition. Geneva, World Health Organization, 2005. <u>http://www.who.int/classifications/icd/en/</u>

² <u>http://www.ilo.org/public/english/bureau/stat/isco/index.htm</u>

³ <u>http://www.who.int/nha/docs/English_PG.pdf</u>

⁴ MEASURE Evaluation, Carolina Population Center, University of North Carolina at Chapel Hill, USA. <u>http://www.cpc.unc.edu/measure/leadership/savvy.html</u> accessed 08 August 2007.

- **Sentinel demographic surveillance system** the longitudinal enumeration of all demographic events, including cause of death via verbal autopsy, in a geographically defined population.
- Statistical Data and Metadata Exchange (SDMX)¹ an organization of interest promoted by the IMF, WB, UNSD, EUROSTAT, FAO, OECD, BIS and ECB, and the Global Administrative Unit Layers (GAUL).
- **Underlying cause of death** (a) the disease or injury which initiated the train of morbid events leading directly to death; or (b) the circumstances of the accident or violence which produced the fatal injury.
- **Verbal autopsy** a structured interview with caregivers or family members of households after a death occurs; used to determine probable cause(s) of death where most deaths occur outside of health facilities, and where direct medical certification is rare.
- Vital event defined by the United Nations as: "the occurrence of a live birth, death, foetal death, marriage, divorce, adoption, legitimation, recognition of parenthood, annulment of marriage, or legal separation."²
- Vital registration all sanctioned modes of registering individuals and reporting on vital events.
- **Vital statistics** data on vital events drawn from all of sources of vital events data. Particularly in developing country 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 estimates of vital statistics.²
- **Vital statistics system** as defined by the United Nations: "the total process of (1) collecting information by civil registration or enumeration on the frequency of occurrence of specified and defined vital events as well as relevant characteristics of the events themselves... and (2) of compiling, processing, analysing, evaluating, presenting and disseminating these data in statistical form."²

¹ <u>http://www.sdmx.org/</u>

² <u>http://www.who.int/nha/docs/English_PG.pdf</u>

Abbreviations and acronyms

AHPSR	The Alliance for Health Policy and Systems Research
APHRC	Africa Population and Health Research Center
AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
СВО	Community based organization
CDC	Centers for Disease Control and Prevention
DANIDA	Danish International Development Agency
DFID	UK Department for International Development
DHS	Demographic Health Survey
DOTS	Directly observed treatment – the internationally recommended strategy for tuberculosis control
DPT3	Diphtheria, pertussis (whooping cough) and tetanus vaccine
DSS	Demographic Surveillance System
EC	European Commission
GAVI	Global Alliance for Vaccines and Immunization
GDDS	General Data Dissemination System
GHP	Global health partners
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIS	Geographic Information System
GPS	Global Positioning System
HIS	Health information system
HMN	The Health Metrics Network
HR	Human resources
HIGH	Harvard Initiative for Global Health
HIV	Human immunodeficiency virus
ICD	International Statistical Classification of Diseases and Related Health Problems
IDSR	Integrated disease surveillance and response
ІСТ	Information and communications technology
IDR	Integrated data repository

IHME	The Institute for Health Metrics and Evaluation
IMMPACT	Initiative for Maternal Mortality Programme Assessment
ISCO	International Standard Classification of Occupations
IHR	International Health Regulations
IMF	International Monetary Fund
LAN	Local area network
LDCs	Least-developed countries
LSMS	Living Standard Measurement Study
MDGs	Millennium Development Goals of the United Nations
MICS	Multiple Indicator Cluster Survey
МоН	Ministry of Health
NHA	National Health Account
NGO	Nongovernmental organization
NSDS	National strategies for the development of statistics
NSO	National Statistics Office
OECD	Organisation for Economic Co-operation and Development
PARIS21	Partnership in Statistics for Development in the 21st Century
PC	Personal computer
PDA	Personal digital assistant
PEPFAR	President's Emergency Plan for AIDS Relief
PRSP	Poverty-reduction strategy paper
SARS	Severe acute respiratory syndrome
SAVVY	Sample vital registration with verbal autopsy
SIDA	Swedish International Development Cooperation Agency
SPA	Service provision assessment
SRS	Sample registration system
ТВ	Tuberculosis
UNDESA	United Nations Department of Economic and Statistical Affairs
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNSD	United Nations Statistics Division
USAID	United States Agency for International Development
VA	Verbal autopsy
WB	World Bank
WHO	World Health Organization

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