

Regional Committee for the Eastern Mediterranean Sixty-first session Provisional agenda item 5(c) EM/RC61/7 September 2014

# Reinforcing health information systems

#### **Executive summary**

1. Reliable and timely health-related information is essential for policy development, proper health management, evidence-based decision-making, rational resource allocation and monitoring and evaluation. While the demand for health information is increasing in terms of quantity, quality and levels of disaggregation, many important gaps exist in Member States.

2. The Regional Office has been working intensively with Member States over the past two years in reviewing health information systems through expert consultations, intercountry meetings and rapid and comprehensive assessments conducted in most countries of the Eastern Mediterranean Region. Currently, no country in the Region is able to report comprehensively on all the core health indicators recommended by WHO. Most countries are in a situation where health determinants and risks are not regularly monitored, cause-specific mortality not reported in a complete and accurate manner, and coverage of interventions and health system performance are not adequately assessed.

3. To support Member States in strengthening health information systems, two parallel but interconnected initiatives are being spearheaded by the Regional Office. The first initiative focuses on improving civil registration and vital statistics, with specific emphasis on strengthening cause-specific mortality statistics. To this end, a regional strategy for the improvement of civil registration and vital statistics systems in the Region was endorsed by the Regional Committee in October 2013. The challenge now for every country of the Region is to mobilize high-level political commitment and engage the relevant sectors in developing and implementing a national action plan based on the directions of the regional strategy.

4. The second initiative aims to reach consensus on the key elements or components of a national health information system and to define what needs to be monitored under each component. Through a series of consultations with Member States, three major components of the health information system were identified: 1) monitoring health determinants and risks; 2) assessing health status including morbidity and cause specific mortality; and 3) evaluating health system performance. The initiative subsequently included intensive work, in 2013 and 2014, with countries and other stakeholders to develop a core list of indicators under each of the three domains as part of a regional plan for strengthening national health information systems. In order to facilitate standardized data collection, analysis and reporting, a detailed indicator metadata registry (now called EMR Indicator Registry) was also developed, based on the WHO global metadata registry, to reflect the regional context.

5. The Regional Committee is invited to discuss the approaches recommended for reinforcing health information systems in the Region, including endorsement of the proposed list of core indicators.

#### Introduction

6. Reliable and timely health-related information is essential for policy development, proper health management, evidence-based decision-making, rational resource allocation and monitoring and evaluation. Regular assessments of health situations and trends and health system performance are integral parts of every Member State's efforts to achieve universal health coverage.

7. While the demand for health information is increasing in terms of quantity, quality and levels of disaggregation, many important gaps exist in Member States. The supply of this information through national health information systems remains generally weak. Monitoring of risk factors and determinants, cause of death patterns, disease incidence and prevalence, and coverage of health system interventions are important priorities which many countries are not fully equipped to support.

8. The Regional Office has been working intensively with Member States over the past two years in reviewing health information systems through expert consultations, intercountry meetings and rapid and comprehensive assessments conducted in most countries of the Eastern Mediterranean Region. The consensus reached through the review is that national health information systems need to focus on three essential components: 1) monitoring health risks and determinants; 2) monitoring health status including morbidity and major causes of death; and 3) assessing health system performance including key health interventions. As will be described in this report, a proposed list of core indicators has been developed for each of the three essential components.

9. The outcome of the assessments conducted in Member States confirm major constraints and weaknesses that impede regular monitoring and reporting on the core indicators in the three components. The limitations were already highlighted in the Annual Report of the Regional Director for 2012. They include fragmentation of health information systems, lack of adequate technical capacity, poor quality of data collection and analysis, significant duplications and ineffective use of available data. Currently, no country in the Region is able to report comprehensively on all the core health indicators recommended by WHO. Most countries are in a situation where health determinants and risks are not regularly monitored, cause-specific mortality not reported in a complete and accurate manner, and coverage of interventions and health system performance are not adequately assessed. A more elaborate description of gaps and constraints is included in the next section.

10. In his report to the 59th session of the Regional Committee for the Eastern Mediterranean in October 2012, the Regional Director included the strengthening of national health information systems as one of the key priorities for reinforcing health systems and achieving universal health coverage. In resolution EM/RC59/R.3 Member States were urged to strengthen national health information systems by improving the reporting of births and deaths and monitoring of exposures to risk factors and social determinants of health, morbidity, cause specific mortality and health system performance and by institutionalizing population-based surveys. Subsequently, the subject was discussed during the 60th session of the Regional Committee, which issued a resolution (EM/RC60/R.8) requesting Member States to develop or strengthen national plans to improve health information systems.

### Situation analysis

11. Two self-administrated questionnaires were sent to national health information focal points in Member States to perform a rapid assessment of the components and functionality of the national health information system and to assess capacity in reporting on the core health information indicators. The questionnaires were followed by telephone interviews and they were supported by desk reviews of national health information systems conducted previously in some countries by the Regional Office and the Health Metrics Network.

12. Across ministries, the national health information systems and civil registration and vital statistics systems tend to be generally isolated, with birth and death data collected by the health department and the registration of these vital events being done by the ministries of justice or interior and national statistics offices. Both the national health information and civil registration and vital statistics systems are fragmented on their own, and the absence of data sharing across them magnifies the problem. Data on human resources, finances, and infrastructure are typically not part of the national health information of cross-cutting indicators.

13. The situation analysis on the country's ability to report on the proposed list of core indicators showed that, out of all core indicators, at least 15% are reported by most countries and nearly 90% are reported in a few countries. As well, not all indicators that are collected are also reported. This gap is as large as 50% in some countries. There is thus an important gap between the ability to collect data and the capacity required to report on indicators.

14. The main gap in reporting indicators on health determinants and risks is related to the behavioural risk factors and biomarkers that are generated mainly from health examination surveys. Health status indicators, especially cause-specific mortality and some communicable and noncommunicable disease indicators such as cancers, are incompletely collected and reported, and whatever reported is frequently of inadequate quality. For cause-specific mortality, between 2008 and 2012, only 11 countries reported to WHO cause-specific mortality statistics, with gaps in annual reporting, and currently only five of them have reported to WHO the mortality statistics for 2012. All these countries except one have a satisfactorily functioning civil registration and vital statistics system. Effective coverage of interventions for noncommunicable disease and maternal, neonatal and child health are not routinely reported with the exception of the very few countries that have conducted Demographic and Health Surveys, Multiple Indicator Cluster Surveys, World Health Surveys or Stepwise surveys.

15. The data sources for indicators include population-based surveys, census, routine facility-based systems, and civil registration and vital statistics. While the stated data source of the majority of indicators is routine facility-based systems, this is not the case in practice, mainly due to the fact that health facility records are often poorly developed, incomplete and of poor data quality. The quality of surveys is questionable in many cases, with problems related to gaps in protocols, standardization and representative sampling. While large and small size household surveys are widespread, these are not always institutionalized or regularly conducted. In addition, health facility assessment surveys are quite limited and focused mainly on emergency settings or post conflict related-assessment.

16. Most indicators are reported at the national level, and there is limited reporting at subnational level. There is a great deal of variation in the reporting frequencies, from quarterly to five-yearly, which may influence comparability and monitoring of results. A potential challenge comes from the limited reporting of private sector data, as some of the core indicators are more prevalent in settings that are more likely to be served by the private sector. This can affect the completeness and the quality of the indicator reports.

17. Given the diversity and the heterogeneity of the countries of the Region, the countries may be divided into three groups based on the levels of health outcomes, health system performance and response and level of health expenditure<sup>1</sup>.

<sup>&</sup>lt;sup>1</sup>Group 1: These countries are where socioeconomic development has progressed considerably over the past several decades, supported by high incomes. Included in this group of countries are Bahrain, Kuwait, Oman, Qatar, Saudi Arabia and United Arab Emirates. Group 2: This group of countries tends to be in the middle-income bracket. These countries have developed extensive public health service delivery infrastructure but face resource constraints. Included in this group of countries are Egypt, Islamic Republic of Iran, Iraq, Jordan, Lebanon, Libya, Morocco, occupied Palestine territory, Syrian Arab Republic and Tunisia. Group 3: This group

18. **Group 1**. All countries have national health information system plans, but some of the plans have limited scope, particularly in data collection, analysis and capacity-building. All have national health information system centres or units with at least five technical staff with an average experience of more than three years. Information from the private sector is not integrated within the national health information system. The national health information systems is computerized in all countries, at all levels, with varying degrees of functionality and integration. Most countries have defined national sets of indicators to report on. All Group 1 countries collect cause-specific mortality data using the International Classification of Diseases (ICD), with different quality and completeness of reporting. Given the high rate of in- and out-migration in this group of countries, population size by age, sex and nationality is not regularly updated. In all countries, basic data quality assessments and feedback are usually performed, but not based on standard tools and procedures. Annual statistics reports are published regularly in print, digital and web formats. The use of the web for dissemination has improved substantially in the recent years.

19. The reporting of indicators on health determinants and risks ranged from as low as 25% up to 90%; however, accuracy and completeness are major issues, as well as the frequency of reporting. For the health status indicators, all countries except one report on the majority of indicators, but cause-specific mortality data are known to be of good quality in only one country. For the indicators on health system response, the reporting ranged from as low as 10% of indicators in one country to around 80% in other countries. Therefore, for all indicators, the percentages of reporting ranged between 25% and 80%. The least reported indicators are "catastrophic health expenditure" and "population getting impoverished".

20. **Group 2**. All countries except one have national and subnational health information system centres. The majority of countries have some sort of health information system plan; however, the staffing is skewed towards information technology rather than public health, epidemiology or biostatistics backgrounds. Most countries have defined core national and programme-specific indicators, ranging from 52 to 152 indicators. With the exception of one country, cause-specific mortality with ICD coding is incomplete and reported at irregular time intervals. Birth and death data are generally incomplete. There are gaps in information on human resources. Data quality assessment practices are limited, including provision of feedback. All countries publish annual health statistics reports, but only two use the web for dissemination. Population surveys such as the Demographic and Health Survey and Multiple Indicator Cluster Survey are conducted regularly in some countries, but other risk factors and programme-specific surveys are not conducted regularly.

21. On average, 50%–60% of all basic health determinants and risks indicators are currently reported by Group 2 countries, compared to around 70% of health status indicators and approximately 50% of health system performance indicators.

22. **Group 3**. All countries except two have a national health information system centre or unit, and a few have national health information system plans that are either out of date or incomplete. Key disciplines such as biostatistics, epidemiology and information technology are not available in most countries. At subnational level there are no health information system units, and adequate staff are lacking at the periphery. Most countries do not have a system of routine reporting, particularly cause-specific mortality data, and ICD coding is not systematically used in all countries. Systematic methods for data quality assurance and analysis are also lacking. No country has an adequate information, communications and technology (ICT) infrastructure, and half of the countries have a unit at the national level responsible for preliminary data analysis. All except one country publish annual health statistics reports with a 2–3 year lag time, while internet and web use for disseminating

of countries tends to be in the low-income bracket. They face major constraints in improving population health outcomes as a result of lack of resources for health, political instability and other complex development challenges. Included in this group of countries are Afghanistan, Djibouti, Pakistan, Somalia, Sudan and Yemen.

health statistics are either not available or inaccessible. Population-based and facility-based surveys are not conducted on a regular basis.

23. With respect to the health determinants and risks indicators, around half are collected and reported. For the health status indicators, few are collected and many are based on global estimates. Of the health system performance indicators, most countries report fewer than half. Overall reporting is low, and indicators not reported include: "insufficient physical activity", "raised blood pressure", "raised blood glucose", "cause-specific mortality", "cancer incidence" and "catastrophic health expenditure", among others. Different data sources are used including surveys, health management information systems, civil registration and vital statistics systems and data from other ministries, while all MDG indicators are estimated.

24. In summary, despite the fact that countries are at different levels of development and that human and financial resources vary between the three groups of countries, there are still major gaps and challenges shared by the three groups that unless adequately addressed, will impede the development of strong health information systems.

- Lack of consensus on the key elements of health information systems and what needs to be monitored as "core".
- Shortage of skilled human resources in epidemiology, statistics and surveillance. All countries have significant constraints in collecting, analysing and reporting on core indicators. This results in lack of accurate data for important indicators and reliance on estimates, which can be misleading.
- Weak joint work and coordination between national stakeholders and fragmentation of health information and civil registration and vital statistics systems, both within and across ministries.
- In the area of health determinants and risks: irregular conduct of surveys; lack of regular reporting; problems with representative sampling and quality of data collection; and fragmentation of data sources.
- Weak and often incomplete reporting of cause-specific mortality data and the use of ICD.
- Low priority and limited capacity in reporting, monitoring and interpretation of health system performance indicators.
- Weak reporting on core morbidity indicators. For example, reliable population-based cancer registries, which are essential for planning cancer prevention and control services, are weak or nonexistent in most countries.
- Lack of data from the private sector in the national health information system of nearly all Member States.
- Ineffective leveraging of opportunities provided by ICT in data collection, analysis and dissemination.

### Progress in strengthening health information systems

25. To support Member States in strengthening health information, addressing the gaps, and in responding to resolution EM/RC60/R.8, two parallel but interconnected initiatives are being spearheaded by the Regional Office.

26. The first initiative, which started immediately after the 59th Regional Committee in 2012, focuses on improving civil registration and vital statistics with specific emphasis on strengthening cause-specific mortality statistics. Initially, a rapid assessment of civil registration and vital statistics systems was conducted in all countries of the Region. This assessment and a more comprehensive assessment subsequently conducted in many countries revealed a clear picture of the current gaps and lack of adequate capacities in monitoring cause-specific mortality, which is an essential component of health information systems. Based on this situation analysis, a regional strategy to strengthen civil registration and vital statistics was developed, in consultation with countries, other regional

stakeholders and international experts. The regional strategy was endorsed by the 60th session of the Regional Committee in October 2013 in resolution EM/RC60/R.7. The overarching aim of the strategy is to guide and support the improvement of the civil registration and vital statistics in countries of the Region over the period 2014–2019. The challenge now for every country of the Region is to mobilize high-level political commitment and engage the relevant sectors in developing and implementing a national action plan based on the directions of the regional strategy to address the gaps shown by the rapid and comprehensive assessments. In countries with major gaps, strengthening mortality statistics will require many years of intensive multisectoral work, and it is important that these countries consider alternative options as a short- or medium-term objective, which might involve improving hospital mortality data and adopting verbal autopsy techniques. WHO will focus in its collaboration with countries during 2014–2015 on assisting countries to develop their action plans and providing technical guidance on short-term solutions.

27. The second initiative aims to reach consensus on the key elements or components of a national health information system and to define what needs to be monitored under each component. Through a series of consultations with Member States, consensus was reached that the three components of the health information system are: a) monitoring health determinants and risks; b) assessing health status including morbidity and cause specific mortality; and c) evaluating health system performance. The initiative subsequently included intensive work, in 2013 and 2014, with countries and other stakeholders to develop a core list of indicators under each of the three domains as part of a regional plan for strengthening national health information systems. The following section will focus primarily on the process followed in implementing this initiative and the recommended way forward.

# Agreeing on a list of core indicators for national health information systems in the Region

28. In May 2013, the Regional Office organized a regional stakeholders' meeting on health information system strengthening, which brought together for the first time participants from ministries of health, interior, justice and the national statistics offices, along with WHO, United Nations agencies and regional and international experts. The specific objectives of the meeting were to reach a common understanding on the design and core components of health information systems, analyse and discuss existing gaps in countries of the Region and develop strategies to strengthen health information programmes, based on current evidence and lessons learned. Throughout the process the Regional Office has consistently promoted the use of an approach that is practical, clear to policy-makers, evidence-based, feasible to implement and responds to the priorities of health development in the Region.

29. A proposed list of indicators was initially drawn from global and regional experiences and intensively discussed by country representatives and WHO experts. The initiative included a thorough analysis of each proposed indicator in terms of definition, tools and methodologies for data generation, analysis and reporting. In October 2013 the draft list was presented to the 60th session of the Regional Committee , which issued resolution EM\RC60\R.8 requesting Member States to review the list and propose additional optional indicators (now known as the expanded list of indicators). Based on the input generated during and after the Regional Committee, an expert task force was established to review the initial version of the list and metadata, identify the challenges and gaps, and advise on finalizing the list and on recommended actions to address the challenges faced by countries in adopting the list and in strengthening their information systems. The indicators and the metadata were also discussed during the recent Regional Director's Technical Advisory Committee. In addition to the core list, an expanded list that was also developed to provide countries and programmes with additional indicators for use as relevant.

30. In order to facilitate standardized data collection, analysis and reporting, a detailed indicator metadata registry (now called EMR Indicator Registry) was also developed, based on the WHO global metadata registry, to reflect the regional context. The registry includes a description of the following

attributes for each indicator: purpose, definition and related terms, main data sources, measurement and estimation methods, data type, expected frequency of data collection and reporting, level of disaggregation and stratification, and any limitations in data collection, measurement, reporting, etc.

31. The adoption and review of the metadata revealed major challenges and gaps in key aspects of national health information systems, namely data sources, measurement methods and reporting. These gaps may be addressed through the approaches recommended below.

## Way forward

32. To address the challenges and gaps identified through the rapid assessments and the review of current status in reporting on the proposed core indicators, Member States are invited to consider the following approaches.

- Endorse and institutionalize the proposed list of core indicators and assess existing capacity to generate data necessary for accurate and complete reporting on each indicator. Using the EMR Indicator Registry, each Member State will need to identify areas where action is needed to address gaps and strengthen data generation, analysis, reporting and use for policy making and health management.
- Identify weaknesses in capacity in the relevant areas of expertise, like epidemiology, statistics, surveillance and information technology, and develop an investment plan to address gaps. The plan should respond to the need for specific training on data collection and compilation, data quality assessment, validation and adjustment, data analysis and review including estimation and statistical modelling.
- Build effective mechanisms for coordination and joint work among the relevant sectors, particularly ministries of interior and planning and national centres of statistics.
- Raise political commitment and initiate concrete action to strengthen civil registration and vital statistics in order to strengthen the accuracy and completeness of cause of death reporting, based on the regional strategy for the improvement of civil registration and vital statistics systems 2014–2019. Use of verbal autopsy is recommended as an interim measure in settings where strengthening of death registration will require a long-term plan.
- Build integrated systems through the architecture of an ICT and web-based platform.
- Address the fragmentation in generating data for the core indicators through different surveys by considering the establishment of sustainable and comprehensive health examination surveys conducted on periodic basis. The Regional Office is embarking on a pilot project in implementing a comprehensive health examination survey in one Member State. Results will be shared with other countries as soon as they become available.
- Strengthen routine facility-based information, including data quality assessment and reporting mechanisms.
- Publish core and country-specific indicators on an annual basis with appropriate level of disaggregation by region and determinants and ensure that such reports reach policy-makers and the various stakeholders on a periodic basis to assist in evidence-based decision-making and in strengthening health systems.