HEALTH INFORMATION SYSTEMS IN SMALL COUNTRIES OF THE WHO EUROPEAN REGION: REPORT FROM THE SMALL COUNTRIES HEALTH INFORMATION NETWORK

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ABSTRACT

Introduction: The WHO European Region has established a Small Countries Health Information Network (SCHIN) in recognition of the many specific challenges and opportunities that small countries encounter in the governance of their health systems. This is particularly important, as the need to sustain highquality health information systems is a key prerequisite for the effective implementation of Health 2020. SCHIN held its first meeting in Malta during March 2015. This paper reports on the health information features and issues of eight small-state health information systems. **Methods**: Participants of SCHIN answered a questionnaire before the meeting. The findings from this survey were analysed and are reported in this paper, together with additional information provided by the participants during the meeting.

Results: Most small states maintain relatively well-developed health information systems based on registers, surveys and routine data sources. Good linkage between health information and policy, national coverage and a high level of data completeness are common strengths. Lack of expertise and administrative capacity for data collection and health information analysis, as well as reporting, is a common overarching challenge. There are also important technical issues in ensuring robust data associated with the small population size. **Conclusions**: There is added value in networking between small states to increase opportunities for comparable benchmarking activity, to advocate for a reduction in reporting burden as well as to provide innovative technical solutions to deal with the problems of small numbers. The World Health Organization Regional Office for Europe has an important role to play in facilitating and supporting the sustainable development of quality health information systems in small states.

Keywords: HEALTH INFORMATION SYSTEM, SMALL STATES, NETWORKING, WHO EUROPEAN REGION

INTRODUCTION

Health information is the foundation for the development of health systems. Health information systems (HIS) have been described as "infrastructures for the monitoring of health activities, population health outcomes, and policies with a significant impact on health. They encompass the people, institutions, legislation, interinstitutional relationships, values, technologies, content and standards that contribute to the different stages of data processing" (1).

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The implementation of Health 2020, including the assessment of health systems performance, is among the key priorities for health policy-makers in Europe. The development of robust, high-quality HIS is a vital mechanism to assist policy-makers in achieving their objectives and delivering information that forms the basis of robust policy.

There is no global definition of "a small country" or, as better described in the relevant literature, a "small state". It is noteworthy that the size of a country can be measured in various ways. These can include gross domestic product, political power and surface area (2). For the purposes of this paper, small states shall refer to the countries included in the WHO Small Countries Initiative, which incorporates countries with a population under 1.5 million (in line with the definitions of the United Nations, World Bank and Commonwealth), namely, Andorra, Cyprus, Iceland, Luxembourg, Malta, Monaco, Montenegro and San Marino. The WHO's 2014 first high-level meeting of small countries of the WHO European Region on the implementation of the Health 2020 vision (in San Marino) concluded that despite the rapid development of HIS in Europe, not all HIS are progressing equally and small countries appear to be lagging behind (3). Small countries may have a closer cooperation between HIS stakeholders as well as a higher coordination of their HIS. Additionally, implementing change in their national HIS is argued to be easier for small countries (4). On the other hand, fewer health researchers appear to be present in small countries. Small size creates challenges associated with public administration, the most important of which is probably a small human resource base from which to draw experienced and efficient administrators. Very often, specialists can only be trained overseas in larger countries without a guarantee that their services will be needed on their return. Therefore, many specialists originating from small countries decide to emigrate to larger countries where their services are better utilized and where remuneration for their services is better (5). Small countries, not only because of emigration but also because the HIS staff is very limited and requests for reporting are numerous, appear to lack the resources for data management and therefore do not always provide the same level of health information as larger countries. This lack of resources is of particular concern to small countries because of the effects of economies of scale where, for instance, adding or removing a

health information expert can have a large influence on the whole data analysis process in the HIS (4). For small countries, the availability of valid, comparable health status and health system indicators is essential, as progress must continuously be monitored against external benchmarks. The use of health information for the purposes of external benchmarking appears to be greater in small Member States than in larger Member States (6). Small countries regularly compare their health information with neighbouring countries using data from international organizations.

Although all countries face issues in ensuring the sustainable development of accurate and valid health information, there is evidence to suggest that small countries face specific challenges. A study that investigated factors likely to be associated with missing data in the WHO Health for All database found that an inverse relation between population size and data availability of statistical significance for only 27 indicators, or 5.36% of the total indicators studied. In other words, small states are more likely to have missing data in these 27 indicators (7). Such indicators include those concerning less common diseases (e.g. congenital anomalies, Down Syndrome, poliomyelitis) or events that are relatively rare (e.g. early neonatal deaths, maternal deaths) from a European health perspective. This difference was not observed for indicators pertaining to common occurrences and highly prevalent diseases. There are several implications for missing data. Most important, missing data have a negative impact on evaluation of performance and ability to forecast and plan future services. It can also limit the possibility of applying for grants and research funding. It may also limit countries in the reporting of Health 2020 indicators, which were agreed by all Member States of the WHO European Region in 2013 through a Regional Committee resolution. HIS may suffer loss of reputation due to a negative public perception. In some scoring systems, missing data may lead to penalization in rankings and, for European Union Member States, inability to provide data may even lead to legal sanctions.

Small states therefore have come together under the auspices of the WHO European Region to establish a Small Countries Health Information Network (SCHIN). The overall objective of this network is to enable the smaller states within the WHO European Region to work together to strengthen and improve their HIS by sharing experiences and good practices. This paper reports on the health information features and issues that have been identified through an analysis of HIS of eight small states.

METHODS

The first meeting of the focal points of the SCHIN took place in Valletta, Malta on 3–4 March 2016. It was jointly convened by WHO Europe's Division of Information, Evidence, Research and Innovation, and the Division of Policy and Governance for Health and Well-being of the WHO European Office for Investment for Health and Development. It was hosted and chaired by the Ministry for Energy and Health, Malta.

The focal points of SCHIN were provided with a template containing instructions for data collection before the meeting (Annex A). The template contained a series of questions to enable comparable presentations to be made during the meeting. This facilitated the analysis of the HIS of the members of SCHIN. The focal points of SCHIN were required to provide an overview of their HIS, including its legal and institutional governance, data availability, data sources and flows, and its impact on knowledge translation. They were also asked to describe the strengths and weaknesses of their HIS as well as their expectations from SCHIN.

RESULTS

Most small countries have relatively well-developed HIS (Table 1). They base their data collection on a mixture of routine data sources, registers and surveys. While a number of health information databases are common to all countries, there are some unique databases that are present only in one or two countries. This may be due to specific contextual epidemiological factors or political priorities. It may also be a result of differences in the organization and management of their health systems. The differences between countries provide an opportunity for knowledge sharing if other small countries wish to develop such databases. Bilateral twinning arrangements between small countries may be more feasible and offer a higher degree of system transferability than those between larger and smaller countries.

A specific health information strategy exists only in Andorra and Cyprus. Other countries such as Montenegro are in the process of preparing a national health information strategy. In several countries, the health information strategy forms part of the overall national health strategy. This is not surprising, as the elaboration of a specific strategy is resource-intensive and may be too costly for small administrations to pursue. Nearly all countries describe the existence of a legal framework for the operation of their HIS. For European Union (EU) Member States, this is based on EU legislation. A number of common strengths emerge from the assessment of the respective HIS.

National coverage and a high level of data completeness characterize HIS in small countries. A potential opportunity is timely availability of data so that trends may be picked up earlier. Close collaboration with national statistical offices and other sectors was also described. Assets included personal contacts and easy access to health information brokers or data owners, including clinical service leaders. These assets lead to the key opportunity that arises from the close relationship and short distance between health information offices and policy-makers. Most SCHIN health information focal points therefore perceive that there is a strong link between health information and health policy development in their country. It should, however, be stated that sometimes there may be conflicting interests for people who work in both sectors - health research as well as health policy. Additionally, most small countries do not have an autonomous public health institute and this is perceived as a challenge in some instances.

The main challenges may be broadly divided into two groups – challenges linked to the lack of technical and administrative capacity, and lack of a legal and strategic framework; and those that arise as a direct consequence of specific population characteristics, including the small population size. These have an effect on the data collection process and data interpretation, analysis and dissemination. These features are summarized in Table 2.

The lack of technical and administrative capacity is both a quantitative and a qualitative one. Specialized expertise for complex analyses or modelling may not be present and this often leads to dependence on larger institutions in other countries, particularly for some of the very small states. As a result of this lack of capacity, there may be underreporting and underutilization of the data collected. Small countries experience a disproportionate reporting burden, especially when it comes to reporting to international organizations. Often multiple requests differ slightly and require a different data submission. Moreover, certain questionnaires repeat similar requests or are not specifically tailored for small administrations.

The small population size leads to some specific problems for small states. Oversurveying and resultant survey fatigue can lead to difficulties in achieving the required numbers for surveys, particularly when one considers that for countries such as Luxembourg and Malta, the minimum survey population may be the same as that required for Lithuania or Ireland, which although small, have tenfold larger populations. These difficulties are often compounded by the fact that some small countries tend to be multilingual and face the administrative burden of producing questionnaires and reports in more than one language. The World Health Organization Regional Office for Europe has therefore recently established an important internal gatekeeper function to reduce the number of data requests going from the Regional Office to Member States and affecting small states disproportionally.

Many small countries exhibit particular population denominator effects. These could be due to a smaller resident population compared with the population actually consuming certain goods, resulting in higher per capita consumptions. This situation can arise due to a relatively high day-commuting workforce as well



| | AND | СҮР | ICE | LUX | MLT | MNC | MNE | SNM |
|--------------------------------------------------------------|-----|-----|-----|-----|-----|-----|-----|-----|
| Cancer register | | | | | | | | |
| Cardiovascular (coronary events) | | | | | | | | |
| Causes of death | | | | | | | | |
| Cerebrovascular disease | | | | | | | | |
| Communicable diseases | | | | | | | | |
| Congenital anomalies | | | | | | | | |
| Dementia | | | | | | | | |
| Diabetes | | | | | | | | |
| Financial and administrative data, including human resources | | | | | | | | |
| Health behaviour in School Children survey | | | | | | | | |
| Health examination survey | | | | | | | | |
| Health interview survey | | | | | | | | |
| Hospital discharges | | | | | | | | |
| Injuries/accidents | | | | | | | | |
| Maternity and birth | | | | | | | | |
| Medicines | | | | | | | | |
| Primary care | | | | | | | | |
| Rare diseases | | | | | | | | |
| Screening | | | | | | | | |
| Transplants | | | | | | | | |
| Vaccination | | | | | | | | |

AND: Andorra; CYP: Cyprus; ICE: Iceland; LUX: Luxembourg; MLT: Malta; MNC: Monaco; MNT: Montenegro; SNM: San Marino Shaded boxes represent availability of data.

TABLE 2. STRENGTHS AND CHALLENGES IDENTIFIED IN SUSTAINING QUALITY HEALTH INFORMATION SYSTEMS BY MEMBERS OF THE SMALL COUNTRIES HEALTH INFORMATION NETWORK



HIS: health information system

AND: Andorra; CYP: Cyprus; ICE: Iceland; LUX: Luxembourg; MLT: Malta; MNC: Monaco; MNT: Montenegro; SNM: San Marino Shaded boxes represent availability of data.

as a high tourist population that can result in data distortions and merits further in-depth analysis by the SCHIN members.

The small numbers also lead to sharp data fluctuations and wide confidence intervals. This tends to undermine confidence in the quality of the data submitted. The health information focal points called for specific solutions such as moving averages (e.g. mid-year populations) and aggregate data (e.g. pooling years) to minimize precision problems. The World Health Organization Regional Office for Europe is now working with small states to establish such rolling averages for selected indicators. Capacity-building initiatives to address specific issues encountered by small countries can also be of value.

The small population size also provides specific challenges in ensuring data protection, as identification of persons is easier than in larger countries. This calls for additional measures to be taken to safeguard anonymity and poses yet another burden on the limited human resources.

CONCLUSIONS

Small countries recognize the added value of networking at the international level. It is expected that the SCHIN would help in dealing with the numerous common data challenges, focusing on ways to reduce multiple, uncoordinated data requests by international bodies to Member States, harmonization of valid comparable data and potential joint reporting of indicators. The establishment of a minimum dataset for small countries as well as the development of a mini health system performance assessment were described as potential benefits. While it is acknowledged that small countries have different HIS and each country exhibits certain unique strengths and challenges, nonetheless there are several common elements and issues that can be better addressed in a joint manner. There is added value in networking small states to increase opportunities for comparable benchmarking activity, to advocate for reduction of reporting burden as well as to provide innovative technical solutions to deal with the problems of small numbers. The World Health Organization Regional Office for Europe has an important role to play in facilitating and supporting the sustainable development of quality HIS in small states. Results from the activity from SCHIN could be of relevance to regions of comparative size in larger states, and there is an opportunity for joint initiatives, including comparative analysis, to be undertaken between regions and small states.

LIMITATION

The results reported in this paper are based on the individual country presentations as well as the deliberations that took place during the meeting. The conclusions drawn are dependent on the individual perspectives of the respondent, which may or may not accurately reflect the position in that country.

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REFERENCES

- Vershuuren M, Achterberg PW, Kramers PGN, Van Oers H. Monitoring the health of the population. In: Rechel B, McKee M, editors. Facets of public health in Europe. European Observatory on Health Systems and Policies Series. Maidenhead, United Kingdom: Open University Press; 2014:23–42 (http://www.euro.who.int/en/aboutus/partners/observatory/publications/studies/facets-ofpublic-health-in-europe, accessed 24 June 2016).
- 2. Thorhallsson B, Wivel A. Small states in the European Union: what do we know and what would we like to know? Camb Rev Int Aff. 2006;19(4):651–68.
- Meeting report of the First High-level Meeting of Small Countries. Copenhagen: World Health Organization Regional Office for Europe; 2014 (http://www.euro.who. int/__data/assets/pdf_file/0005/259799/Meeting-reportof-the-First-High-level-Meeting-of-Small-Countries. pdf, accessed 24 June 2016).
- Brand H, Achterberg P, Wilkinson J, Michelsen K. Promoting better integration of health information systems: best practices and challenges. Copenhagen: World Health Organization Regional Office for Europe; 2015 (http://www.euro.who.int/__data/assets/pdf_ file/0003/270813/Promoting-better-integration-of-HIS-best-practices-and-challenges.pdf, accessed 24 June 2016).
- Briguglio L, Cordina G, Farrugia N, Vella S. Economic vulnerability and resilience: concepts and measurements. Oxford Development Studies. 2009;37(3):229–47.
- 6. Rosenkötter N, van Bon-Martens M. Public health reporting and monitoring: maintaining and improving the evidence-base. Eurohealth. 2015;21(1):17–20.
- Thijssen S. Does size matter? The challenges and strengths of health information systems (HIS) in small EU Member States and their provision of health information to international requests and agreements [dissertation]. Maastricht University; 2015.