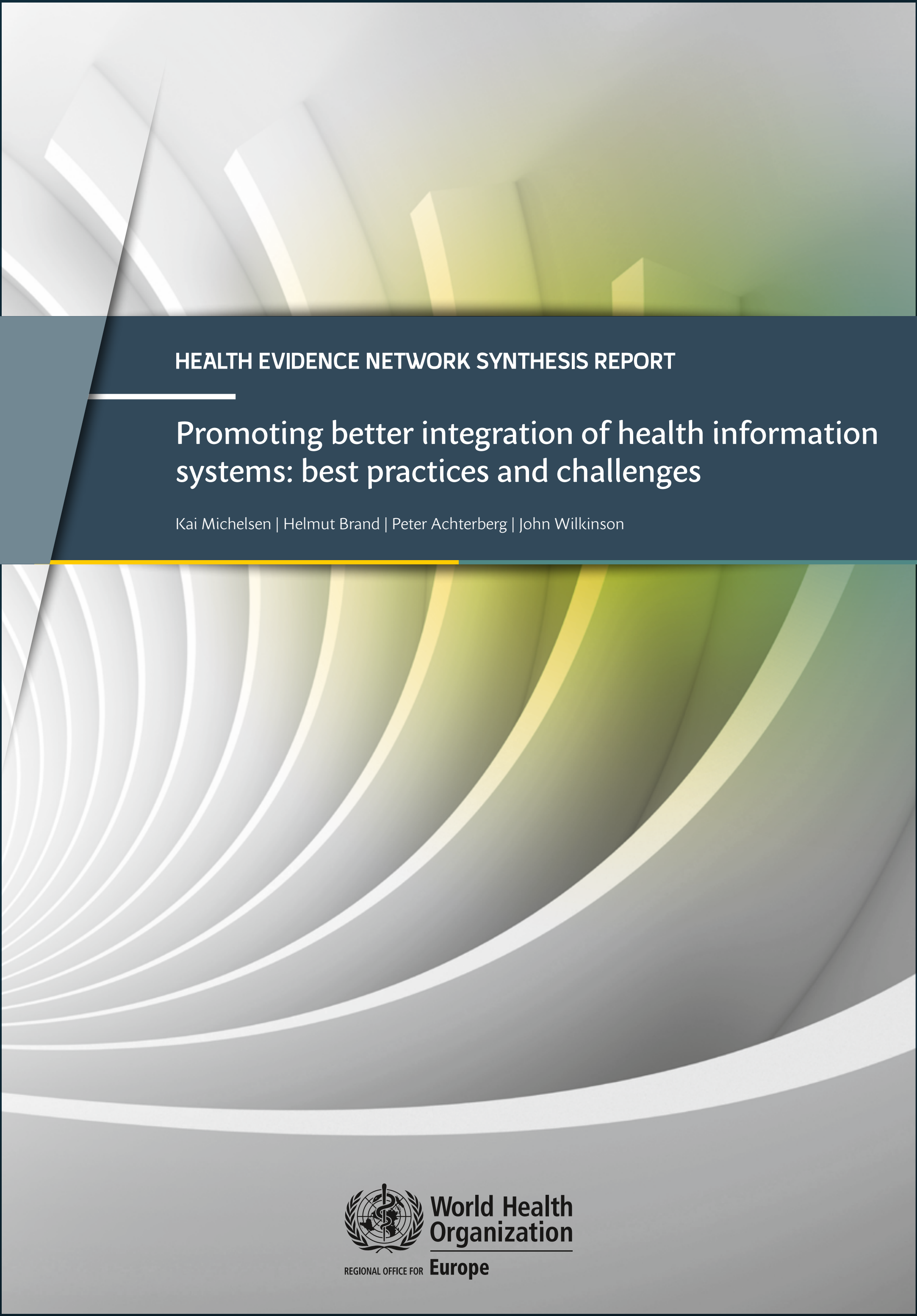

HEALTH EVIDENCE NETWORK SYNTHESIS REPORT

Promoting better integration of health information systems: best practices and challenges

Kai Michelsen | Helmut Brand | Peter Achterberg | John Wilkinson

World Health Organization
REGIONAL OFFICE FOR Europe

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Health Evidence Network synthesis report

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Abstract

This report addresses the current trends in Member States of the European Union (EU) and European Free Trade Association (EFTA) on how to promote better integration of health information systems (HISs). To understand what better integration means from a pragmatic perspective, we conducted interviews with experts from 13 EU Member States, the results of which were combined with the findings from a literature search. The results from the interviews stress the need (i) for ongoing work on some "basics", such as data availability and quality, inventories of data and registries, standardization, legislation, physical infrastructure and workforce capacities; (ii) to continue with the work on more "concept-driven" indicator sets; (iii) to define what better integration means and to demonstrate concrete benefits of integration; (iv) to build leadership for capacity building in further integration of HISs; and (v) for a further international exchange about ongoing activities in this area.

Keywords
COLLABORATION, DATA COLLECTION, eHEALTH, EVIDENCE-BASED HEALTH CARE, HEALTH INFORMATION SYSTEMS

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WHO Regional Office for Europe
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ABBREVIATIONS

DRG	diagnosis-related group
EC	**E**uropean **C**ommission
ECHI	**E**uropean **C**ore **H**ealth **I**ndicators
EFTA	**E**uropean **F**ree **T**rade **A**ssociation
EU	the **E**uropean **U**nion
HEN	**H**ealth **E**vidence **N**etwork
HIE	health information exchange
HIS	health information system
HiT	health systems in transition
HSPA	health systems performance assessment
ICT	information and communication technology
IT	information technology
OECD	**O**rganisation for **E**conomic **C**o-operation and **D**evelopment

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Authors

Kai Michelsen
Department of International Health, Maastricht University
Maastricht, Netherlands

Helmut Brand
Jean Monnet Professor of European Public Health
Head of the Department of International Health, Maastricht University
Maastricht, Netherlands

Peter W. Achterberg
National Institute for Public Health and the Environment (RIVM)
Bilthoven, Netherlands

John R. Wilkinson
Emeritus Professor of Public Health
University of Durham and Independent Consultant
Durham, United Kingdom

External peer reviewers

Pieter G.N. Kramers
Dutch National Institute of Public Health and the Environment (retired) and Independent Consultant
Bilthoven, Netherlands

Richard K. Willmer
Fellow of the Royal Statistical Society
Honorary Member of the Faculty of Public Health
Director of Information and Intelligence, Public Health Action Support Team
London, United Kingdom

HEN editorial team

Claudia Stein, Executive Editor and Director
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SUMMARY

The issue

Evidence-informed health policies require data and information derived from effective health information systems (HISs). Better integration of HISs is widely believed to be a pre-condition for more effective systems and information sharing. This report examines this assumption and addresses current trends in Member States of the European Union (EU) and European Free Trade Association (EFTA) on how better integration of HISs is promoted. Through interviews with experts in the field and the findings from a literature search, this report further provides some lessons learned, opportunities for and challenges to better integration.

Findings

Effective HISs are dependent on an understanding of the aim of integration and its desired benefits. Activities that lead to better integration address the interest in getting more and better information, e.g. on health needs or the outcome of health services. The latter can be measured by assessing the effectiveness of surgical procedures, quality of life, and similar outcomes. Other activities that lead to better integration include better opportunities for linking data between different registries, integration of relevant data sources in a central database or platform, integration of information on health and social care, and opportunities to integrate data at the personal level. These provide better insights into improving the management of care pathways, service delivery and quality, and the impact of social determinants on health.

The work towards better integration is challenged by the need for and lack of availability of better data (e.g. morbidity data, primary care data, integration of data from social health insurance, data on social or community care, economic data) and standards, as well as collection methods. Countries differ in the ways they link data from different sources, often due to differences in the existence or absence of personal identifiers and in their legislative frameworks.

The objectives of national HISs, and integration projects and their challenges differ between decentralized and centralized political structures, systems based on national health services and (social) health insurance, and the size of the population. These structures have an impact on governance, cooperation and coordination, and are of fundamental relevance for the successful development and implementation of integrated HISs.

Optimism has been created for better integration by new technologies, such as information and communication technology (ICT), and secondary use of data from e-health applications, even though there are considerable challenges that need to be overcome before these technologies can be harnessed.

Policy considerations

We identified the following policy options for further consideration. The results from the interviews stress the need for (i) ongoing work to improve basic conditions and structures, including data availability and quality, inventories of data and registries, standardization, legislation, physical infrastructure and workforce capacities; (ii) continuation of the work on more "concept-driven" indicator sets, including the further development of indicator sets that are outcome oriented, for example, for assessing the performance of health systems (HSPA); (iii) the development of a clear understanding of what better integration means and to demonstrate concrete benefits of integration; (iv) establishing good governance across ministries for further integration of HISs; and (v) further international exchange and learning about best practices.

1. INTRODUCTION

1.1. Background

Evidence-informed health policy-making is based on sound data and information (1). National health information systems (HISs), which integrate data and information from different sources and information systems, cater to the information needs of policy-makers and other audiences. (For an overview of the historical development, see (2)).

Currently, national HISs are required to provide information on the following:

- the health status of populations and the impact of the social determinants of health: better integration of primary care data, integration of data from private providers, morbidity data, mental health data, data on social determinants and inequalities, data that inform about the health status from a life-course approach;
- quality of health services: data to address the performance of integrated care, documentation of care pathways, data that allows benchmarking of different outcome parameters of the health services;
- available resources: human resources, facilities, equipment, and information on health status and health services-capacity of and assessments of health system performance.

To meet the above demands, national HISs need (i) to structure an unstructured mass of data (3, 4) in information-rich”environments (5), and (ii) integrate all information. Previous work suggests that the following are required to achieve this (3-5).

- The process from data provision to dissemination of information (from data to information and knowledge) should be integrated.
- Integration has to take place at each step of the process. Data have to be collected and integrated in datasets. Datasets have to be consistent (both operationally and conceptually) and comparable. Different types of data, even across jurisdictions (e.g. as recommended in the health in all policies, and the whole-of-government concepts), have to be collected in a well-coordinated manner to minimize overlaps and allow datasets to be combined in order to compare different populations

or health service providers, to monitor developments over time, or to analyse correlations, and to determine the social determinants of health and the health status of population groups.

- HISs must be a part of the public health action cycle (assessment, policy formulation, implementation, evaluation) and inform decision-makers at each step of the cycle.

Commonly, failure of integration, as outlined above, leads to the use of different definitions and classifications for similar entities, duplication of data collection, lack of consistency, lack of coordination and governance, unclear priorities, ineffective data collection and analysis, among other problems. It often leads to incomplete integration of available information in policy reports, due to not using data, not performing valuable analyses and not providing worthwhile policy inputs. In addition, comparisons are restricted between geographical areas within countries (municipalities, districts, regions) and between countries.

This report addresses the current challenges to, opportunities for and trends in Member States of the European Union (EU) and European Free Trade Association (EFTA) promoting better integration. It summarizes the current discussion on what better integration means from a pragmatic perspective, and what insights have been gained from the ongoing work towards integration of HISs in Member States.

1.2. Methodology

This report combines expert interviews with findings from a literature search of relevant publications (for a more detailed description, see Annex 1). Publications were identified by using the following search terms "(public) health information system", "public health surveillance", "health statistics", "e-health", "health monitoring", "public health reporting" and "implementation" (with different combinations of terms) in PubMed and Web of Science.

For the expert interviews, 31 officially designated national contact points working in their official capacity with the WHO Regional Office for Europe in EU and EFTA Member States were selected as the first points of contact. Fifteen experts from 13 countries participated in the survey. They received background materials with statements, definitions and a synopsis of the interview questions.

Twelve experts from 11 countries took part in the interviews via telephone from June to August 2014, with each interview lasting for 45–60 minutes. Two countries answered the questions in writing.

The information from the interviews was summarized and common themes identified.

2. RESULTS

The interviewees reported interesting positive developments. However, they differed in their perceptions of the current status of good practices for integration. The range of perceptions was highly diverse.

The interviewed experts highlighted different past and current activities and developments that contributed to improving or hindering integration of their (national) HISs. We first present some positive highlights (2.1) and next address problems and challenges (2.2) from the perspective of the interviewees. These include gaps and barriers identified, and matters related to data availability, data standards, data linkage issues, as well as legislation and information technology (IT) infrastructure. Finally, the experts raised the central issue of coordination, collaboration, and governance and leadership, which are needed to optimally integrate national HISs. We present common themes across country respondents, interspersed with individual and anecdotal perspectives.

2.1. Current activities towards better integration: highlights

The experts repeatedly addressed the difficulty of “new information demands from the health system” to serve evidence-informed decision-making. These new information needs were mentioned in relation to the following:

- needs-based resource allocation of health-care services;
- measuring outcomes of health service delivery (e.g. under- and oversupply as well as inappropriate services); or
- assessing the performance of health systems (HSPA) as a whole.

Experts shared examples of current activities for addressing these needs within their HISs.

Other activities mentioned address actions towards improving the **linking of information between registers** (e.g. cancer and mortality registers) by using national identifiers and/or a national geocoding system in order to decrease redundancy and improve consistency.

Some interview partners mentioned the integration of information into one **central database**. An example would be the French National Insurance System Database, a main database for studies on diseases and medical consumption. Other examples would involve the integration of a whole inventory of all subsystems in a **uniform technological (Internet) platform**.

These activities are sometimes linked to a full rebuilding of the national HIS, both content-wise and conceptually. Rebuilding the system would then allow users to collect information in a more timely and consistent manner, offer information in a more "integrated" way to strengthen the opportunities for monitoring, planning, (risk) management and research, and create one platform to meet the information needs of various stakeholders. Some of the country platforms mentioned include geographical information systems that enable the disaggregation of data by different regional levels and mapping of the information. In one country, better integration went hand in hand with a legislative change. In the same country, regional authorities are responsible for contracting health services based on population needs and are therefore in need of regional feedback on the performance of the system and the population's health.

In other countries, there is a need for better integration of information from the **health- and social-care sectors**. The necessary legislative changes have already been implemented or are under development.

While there is progress in identifying opportunities to disaggregate data at different regional levels, which would allow for studies on the impact of the social determinants (e.g. unemployment) on health status, some interview partners were more interested in better opportunities **to integrate data at the individual level** (health/patient records), in order to be able to analyse patient pathways or to study health developments over the life course.

Here, the opportunities differ fundamentally between countries, due to the existence or lack of personalized datasets, personal identifiers and legal restrictions and, of course, data availability.

Opportunities to use **e-health applications for secondary use of data** were also addressed. Such opportunities included e-prescriptions, e-referrals and booking systems, laboratory results, electronic records in primary care, and electronic health record archives. Some countries have already started using data from these sources. One interviewee expressed the future need for national HISs to extract data directly from local digital systems through a provider database.

2.2. Gaps, challenges and barriers

In general, all interviewees, even those with more positive perceptions, pointed out common gaps, challenges and barriers to better integration, which are presented below. These results have been clustered around common themes.

2.2.1. Data availability

From a number of reports from the health systems in transition (HiT) series (Hungary (6), Romania (7), Slovakia (8)), it is apparent that there is a lack of financial investment in data collection as well as ensuring data quality. However, some interviewed experts gave more weight to other problems: the absence of data, non-utilization of existing data, missing possibilities to link data (e.g. by using personal identifiers), legislative regulations (e.g. on privacy), or political will.

Most national experts reported relatively good coverage of hospital data, but poorer availability of data for outpatient services, especially from the private sector.

With regard to data from e-health applications, we found it interesting that two experts reported better coverage for primary care data, and poorer coverage for hospital services data. Some interviewees mentioned that even for hospital data, the availability of clinical data would be limited, because data collection would be organized only around the reimbursement system, which is based on diagnosis-related groups (DRGs).

While there are more data on the incidence of morbidity – more for hospital and less for primary care/outpatient services – there are gaps in the data on the prevalence of morbidity. This information can be drawn from registers in only a few countries and for some diseases.

Health interview surveys are helpful in collecting information on prevalence based on self-declared health and on health events that remain undiagnosed, and also on the social determinants of health, while clinical data are often missing. Health examination surveys could alleviate this but are not conducted in all countries due to funding problems.

The interviewed experts who expressed the need for integrating data on health- and social-care services (such as hospital discharge management, disability, inability to work, financial support of beneficiaries, long-term care) reported limited availability of data on social care. The underlying reasons are the absence of data, gaps in legislation for collecting data, or the allocation of responsibilities to different ministries for data ownership and problems in accessing the data.

Other problems mentioned were data gaps in information on the social determinants of health, expenditure by disease, or out-of-pocket payments and deductibles.

When asked about improving the integration of their national HISs, some of the interview partners answered explicitly that they would like to broaden the number and types of health indicators to get information on the full health spectrum within their HSPA framework, as well as increase data availability from all areas of primary care, both from the public and the private sectors. Some would also like to have more information on socioeconomic status and statistical datasets from other sectors, for example, information about income, taxes, etc.

Some experts discussed the general willingness of health service providers to deliver data in a timely fashion. In all cases, it would be necessary to minimize the burden of data collection as far as possible, for example, by taking data from central registers or by adapting the health provider information systems as much as possible, for instance, by allowing the secondary use of existing data. It could also be possible to work with negative incentives, such as contractual arrangements, or penalizing people if they do not deliver the data and therefore not receive payment. Setting benchmarks for the delivery of high-quality data would be another approach. It would be very important to also think about positive incentives, for instance, providing benefits to data providers such as useful analytical information, coding books, or getting access to information from other providers. This could be backed by projects demonstrating the benefits of data availability. Overall, it was felt that the establishment of national health records would be one way of reducing the reporting burden and enhancing analytical capabilities.

2.2.2. Data standards

Some experts raised the problem of lack of definitions and standards for data collection and description of meta-data.

One expert addressed the need to work on common calculation protocols for complex indicators to prevent differences in numbers between national, or national and international, institutions. These could arise due to different definitions of standard populations and age groups.

When asked about how to improve integration of their national HISs, some experts explicitly mentioned the need for a harmonized approach to unify classifications and codebooks or at least have some code converters when different coding systems are used in parallel, especially at the level where the data are produced. Experts particularly stated the need for better standards for social- and community-care data.

2.2.3. Linking data from different databases

Records that are fairly often linked at the national level include mortality data, inpatient data, cancer registry data, and prescription medicines data. Data linkages with primary care data, population health survey data, mental hospital inpatient data and long-term care data are less common (9).

While in some countries a personal identifier makes it possible to link, for example, data on mortality with those from cancer registers and to follow patients over time, in other countries, such identifiers are not available. (For an overview of the availability of identifiers in countries belonging to the Organisation for Economic Co-operation and Development (OECD) see (9).)

In some countries, health insurance data are important sources of information. Some experts stated that data from health insurance organizations running their own information systems are already integrated into their national HIS. Others are striving for better integration. This is partially motivated by an interest in economic issues and financial data. There is also an interest in exploring opportunities for the secondary use of personalized data, such as for health services research.

The interviewed experts reported some technical and administrative barriers but, in general, there was good cooperation with social health insurance organizations. A memorandum of understanding may help to formalize all activities with regard to interoperability or to decide what data can be exchanged.

Some limitations of social health insurance data were also mentioned, such as missing clinical data and the fact that records from social health insurance schemes are in

some instances not really patient records. Austria and Germany were mentioned as examples of good practice for using data from social health insurance organizations.

For the integration of health- and social-care data, cooperation between different ministries is often necessary. Only two interview partners reported that legislation for full integration of the information systems of the two sectors was already in place or in the final stage of preparation. Some countries can use personal identifiers to follow patients across the health and social sectors. In other countries, access to long-term care data is sometimes problematic, or the mandate to use social-care data is limited to data referring to the interfaces between health and social care.

Some experts were satisfied with the existence of regional identifiers where the data are linked to the zip code/postcode, as well as with the possibility of disaggregating data on different regional levels by municipality, region and district. The possibility of integrating data at the regional level, and conducting ecological analysis, for example, on health information and socioeconomic characteristics, has been mentioned as positive. Others would like to have more opportunities for regional disaggregation of data.

Some experts explicitly mentioned that they would like to see linkages between databases across sectors, e.g. between health and socioeconomic information in order to address inequalities, and reduce restrictions in access to certain data sources, as well as having national identifiers. The availability of data at the patient level was seen as a way towards better integration.

One expert suggested the development of a meta-database. An alternative to the integration of the multitude of data in one database would be the establishment of a central database that does not collect data but merely meta-data, in order to provide central access via a keyword search to as many relevant Internet resources as possible.

2.2.4. Legislation

Countries differ in their legislative frameworks for (i) data collection, (ii) the use of personal data, and (iii) the linkage of data sources (HiT reports) (9). Many experts referred to legal constraints in line with the respective EU regulations on data privacy (10). A number of experts stressed legal restrictions in linking personal data, such as data on health status, social status or mortality statistics. Sometimes identifiers would be in place, but they could not be used due to data protection measures. The status in the interviewed countries was found to differ, even with the EU regulation in place.

Over the past few years, the legal situation for integration of personal data has become more restrictive in some countries and less restrictive in others (9). In some countries, discussion to make linkages easier is ongoing. In others, there is no political will to integrate data, such as those from the mortality database with data from patient records. When experts were asked how the integration of their national HISs could be improved, some answered explicitly that they would like changes in the legislative environment to overcome the limitations of data protection by implementing pseudonyms and finding an answer to how to prevent re-identification. They agreed that this would have to be implemented without compromising the privacy of citizens and patients.

Adapting the legal framework was seen by some as the key step. While data linkage opportunities are highly restricted in some countries, there are more opportunities in other countries.

These include collecting relevant data in one place or registry (however, personal data must not be combined across registries), or by linking data between different registries within the health sector (linking data across sectors is often prohibited). In some countries, it is possible to use all the data regulated or paid for by the government to collect statistics, and to integrate data at the individual level as well. In some countries, there have been negotiations between institutions to meet privacy regulations. In case of doubt, data exchange could be organized by a “trusted” third party, which links data from different sources and deletes personal identifiers.

A number of experts gave the Nordic countries as examples of countries with good practices for linking data through legislation. Some referred particularly to Sweden. Others mentioned good practices in Finland and Denmark, such as the use of anonymous personal identifiers by replacing identification by random numbers.

2.2.5. ICT infrastructure

Some experts linked their reflections on the integration of HISs with comments on the development of ICT infrastructure and e-health They described the challenges involved in shifting from paper formats to electronic formats (digitization). The ICT infrastructure is sometimes limited with regard to connectivity and access, especially in rural areas. One expert stated that IT is better developed in the private sector as compared to the public sector.

Gaps in the ICT infrastructure have been reported in the latest HiT reports for Bulgaria (11), Cyprus (12), the Czech Republic (13), Greece (14) and Slovakia (8).

Denmark (15), England (16), Estonia (17), Finland (18), France (19), Scotland (20) and Sweden (21) have reported well-developed infrastructures. However, all countries are confronted with interoperability challenges. A lack of consistent strategies for ICT infrastructure was addressed in most of the HiT reports.

2.2.6. e-health applications

The use of personalized data was often linked to a discussion about the opportunities offered by e-health tools. Some experts stressed that there were limitations. While efforts are ongoing to create patient records in some countries, others neither have electronic records nor an e-health strategy. Some experts mentioned that electronic records would be developed with the primary aim of supporting communication between health professionals, and not for collecting data for health statistics. Experts also stated that the interoperability of e-health applications would be limited, e.g. between hospitals, and the public and private sectors.

Other experts reported progress in harmonizing their systems. While data providers have different vendors, standards for interoperability are being formulated and integrated in decentralized solutions, based on legislation and contractual requirements, by having the implementation of standards as a requirement for a contract. In one case, a national archive for electronic health records is in development. Until now, this has not matured enough to be used for HIS purposes as data from some providers would be missing. Therefore, it is still necessary to collect data directly from health-care providers. However, the archive could be used for health statistics as soon as enough data are included. For this purpose, at first all data from the public sector need to be integrated, followed by data from the private sector.

Some experts also stated that physicians working in outpatient services would not have the necessary infrastructure at hand, such as access to the Internet in rural areas, or may still prefer to work with paper. Other experts mentioned positive incentives for investing in e-health applications.

Implementation challenges have been described in many publications. This relates to implementing new technologies, for which we found examples in the HiT reports for Bulgaria (11), Denmark (15), England (16) and Ireland (22), or for the implementation of electronic health records in England, Ireland, Scotland and Wales (23), and Switzerland (24). Another challenge is the need for the use and application of new indicators such as the European Community Health Indicators (ECHI) (1).

2.2.7. Cooperation, coordination and governance

In most countries, national HISs are based on cooperation between one or more ministries, departments, national statistics offices, public health institutes and other stakeholders.

Good coordination is important between ministries, institutions or subsystems with responsibilities for databases or the implementation of IT structures and systems. Some experts reported good cooperation, sometimes based on a memorandum of understanding, while others addressed some critical issues, such as the fact that responsibilities for health and social care are divided between two ministries, or unclear ownership of a database. Well-defined competencies and responsibilities of ministries have been mentioned as being beneficial for coordination.

Some experts mentioned the competence of an institution as a prerequisite for effective and integrated HISs. In particular, the centralization of responsibilities for registries and surveys in one place was mentioned as an advantage. Too many institutions with different goals and tasks conducting their own data collection could become a challenge. New laws and extended Eurostat regulations (25) have been mentioned as ways to obtain more direction and coordination.

HiT country reports and the OECD publication *Strengthening health information infrastructure for health care quality governance* (9) highlight structural differences between health, political and health information systems but also similarities between (groups of) countries. The interviewed experts also addressed structural differences between countries. They stated that integration of the national HIS would be less challenging in centralized states than in decentralized structures or federal states such as Austria, Belgium, Germany, Spain and Switzerland. The position of the health ministry would be stronger in a national health system than in a social health insurance system, where social health insurance organizations and other stakeholders would have some level of independence in delivering data or even running their own HISs, and where insurance funds and health service providers might not be interested in investing in a national HIS.

Cooperation, coordination and implementation of change would be easier for smaller EU countries such as Estonia, Latvia and Slovenia. On the other hand, resources would be more limited and a change of even one staff member in coding could have an impact on the national statistics. In other words, the economies-of-scale effects would be unfavourable compared with countries with larger populations.

For further improvement in integration of their HIS, some experts saw the need to define aims and goals, proposals for new institutions, successful negotiations with the main stakeholders regarding collaboration, and providing data from different sectors to the national HIS. In addition, they felt that there was a need to establish horizontal structures and suggested the establishment of an independent body that is able to improve all aspects and raise awareness of interoperability, and convene different subnational administrations and communities to develop the system further.

3. DISCUSSION

3.1. New developments, old and new challenges

An interviewee said, "It seems that information systems need continuous improvement, which goes through a clear identification of information needs; a foretaste in the identification of needs for statistical information, continued investment in information and communication technologies, and necessarily vocational training."

The interview partners illustrated ongoing activities to improve information systems and confirmed that better integration of HISs is still a relevant, but unfinished, issue in their respective EU Member States. They addressed mainly the opportunities for and challenges to integrating data from different sources and certain elements of the process of data collection. They did not discuss much or give detailed examples of integration. The integration of HISs in the policy action cycle, dissemination of data to different audiences (policy-makers, public health professionals, researchers, the general public), transformation of information into knowledge (26), and information and knowledge management systems were seen as relevant, but they played a minor role in the interviews.

The interview partners highlighted interesting developments, such as focus on health outcomes, linking registers, building platforms, integrating information from health and social care, and using data from e-health applications. They addressed similar challenges, which differed in their relevance for countries, such as data availability, opportunities to link data sources, legal restrictions, technical restrictions and institutional issues. However, they mentioned that the work on "basic" problems is ongoing.

3.2. Different perspectives on HISs and integration

Some national HISs, mainly in social health insurance-based health systems, aim to collect all relevant available information on the health status of populations and provision of health services, and to provide the information to all interested audiences. Others are more directly focused on supporting the management of health- and social-care services. In social health insurance-based systems, the respective information systems are run by social health insurance companies and organizations of health service providers.

This raises some questions about the aims, objectives and vision of a national HIS and the way towards better integration. The interviewees agreed broadly on the need for better integration of their national HISs, but had different perspectives on integration. Some interviewees articulated the vision of a full integration of all available relevant data; others stated that a full integration would not be possible, because national HISs would have to target different information needs (e.g. health status, health services, resources) and because the involved institutions would not have the same objectives. Though not explicitly stated by the interview partners, it seems logical to take the different information needs of politicians, managers, public health experts and researchers, and the different functions of HISs into account, and discuss the idea of integrationin the form of developing a national HIS that fulfils all functions and meets all information needs, in comparison with the idea of better information exchange between a couple of HISs, and addressing different functions and needs (e.g. specialized for epidemiological questions, health service research, health economics, monitoring of general developments). One interview partner stated that he would prefer to talk about the secondary use of data and the interoperability between systems, for which the term "integration" would be misleading.

De facto, there are many subsystems within HISs. To what degree can the specific functions and purposes be integrated into one system by taking the respective institutional context of countries into account? What is the aim of the respective national HISs; what kind of data are needed; and what should other, specialized information systems deal with?

These questions are not merely of academic interest. Steps towards better integration have to take the different perspectives and information needs of the respective stakeholders into account, in line with the organization of health systems in the countries. Stakeholders include health service providers, insurance companies, public health services, public administration and various ministries. Countries differ in the centralization of responsibilities and competencies, with consequences for activities that could and should be taken to close gaps in the availability of data, the need for coordination and cooperation between stakeholders and possibility to either work on better integration within systems or organize better operability between systems. It is necessary to take into account that better integration can mean different things for different countries. A clear, general but context-specific understanding is needed of what integration brings and what it looks like, in particular, from an international perspective. Integration can, but does not have to, mean the integration of all available data in a single platform. It can also mean coordinating data collection between HISs and working on the interoperability of these. Interestingly, the interview partners stated that international commitments to deliver data (to Eurostat, OECD, WHO) help in "convincing" stakeholders to provide data. At the same time, they addressed the need to balance the burden of collecting data, such as for health service providers, with benefits.

3.3. Integrating new technological opportunities

The interview partners addressed opportunities and challenges linked with digitization, ICT infrastructure and e-health applications. Health information exchange (HIE) is "centred around direct patient care with the primary goals of improving providers' access to information, thereby improving the safety and quality of care, and reducing costs" (27). Even if public health issues are addressed, the focus is sometimes on surveillance (27) or bidirectional communication to support frontline clinicians (28). The secondary use of data for the national HIS has not found a prominent place in the discussion on the opportunities and challenges of e-health (26, 29). There is "a very large and growing body of evidence of the importance of the collection, analysis, linkage and reporting of results from personal health data assets for health-care quality monitoring and improvement, population health policy, and health system performance measurement and evaluation" (9). It has been stated that the "challenge countries face … is that assessment of the usability of electronic health records for statistical purposes cannot wait until after the implementation of electronic health record systems" (9). A couple of countries have started to use data from electronic health records for public health and health-care monitoring (30). But it has also been stated that "the scope of the effort to implement national electronic health record systems is daunting for governments in all countries" (9). This includes the development of plans, new legislation (protection of privacy of information), development of governance mechanisms, development of standards, engagement of stakeholders from the public and private sectors, certification for software vendors, training efforts, public education and, last but not least, the need for considerable budgetary support. For example, the HiT country reports for Denmark, England, Estonia, Finland, France, Scotland and Sweden report interoperability challenges also for countries with developed ICT infrastructures (15–21) (For further critical issues, see (2), (9), (31–39)).

One interview partner felt that the reason for many of the problems was too much focus on technical issues, technical tools and computer sciences, without thinking about the needs and involvement of the relevant stakeholders. Stakeholders

would have to agree on common goals and discuss the need for changes as a prerequisite for effective implementation. They would have to develop a common understanding of the relevance of the primary and secondary use of data. Sometimes information platforms would be established without clarifying questions like “Who uses the system?” “What are the expectations?” and “What expertise is required?”. This perspective is shared by other publications that give advice on good practices for developing and implementing better integrated HISs (40).

3.4. Leadership and governance

Leadership and governance are prerequisites for developing better integration and interoperability of HISs. At the national level, a health strategy in line with a health information strategy could provide support for framing the further development of HISs. However, many countries do not have such a framework (or a public health research strategy (41)) and, due to differences in the structure of political and health systems in countries, there is the question of who (ministry of health, national public health institute, national statistical office, health service providers, health insurance organizations, etc.) should lead what.

4. CONCLUSION

There was unanimous agreement that improved integration of HISs at the country level is required and desirable; however, there was no unanimous agreement on what integration means or a unified definition of an HIS.

Notwithstanding this, interviewees agreed on many aspects, which were useful for this review. In combination with the literature search of relevant publications, it was possible to develop common themes and suggestions for better integration. While differences between countries have to be taken into account and there is no magic bullet for improved integration, mutual learning for a better integration of HISs, and data and information in the national HISs are possible.

The current situation is characterized by familiar challenges and some new technological opportunities. First, the results from the interviews stress the relevance of continued improvement in some of the basic health information challenges (data availability and quality, inventories of data and registries, standardization, legislation, physical infrastructure and workforce capacities). Second, indicator sets are, for pragmatic reasons, often feasibility driven or availability driven. To enhance work on more concept-driven or purpose-driven indicator sets would be beneficial for the quality of HISs (2). Discussions in this area have not been covered by the interviews and are not well addressed in the publications available at present. This includes the further development of indicator sets for an outcome orientation of HISs, for example, for HSPAs. Third, it is important to develop a clear, context-specific understanding of what better integration means, what it would look like (what should be integrated where, how activities of different systems can be coordinated), what the benefits would be, including the identification of examples of good practice. Fourth, it is important to provide leadership and good governance for the further integration of HIS by improving the architecture and infrastructure of HISs (42). Finally, it would be important to promote international information exchange. Few interviewees had knowledge of the HISs and practices in other countries but such knowledge was highly desirable, as the possibility for exchange of best practices and valuable expertise might be increased by such interaction.

What does this mean for policy-makers and potential policy options? First, countries would benefit from a thorough assessment of their HISs in order to arrive at comprehensive national health information strategies that embrace integration

of data systems and harmonization of indicators. Such national strategies will be important in order to ensure integration, communication and purposeful systems.

In collaboration with 17 European Member States and in consultation with the European Commission (EC) and OECD, WHO Regional Office for Europe has recently developed a tool that guides the assessment of a HIS as well as the development of national health information strategies (43). Second, it would be important to use this tool in countries wishing to enhance their systems and alleviate the challenges outlined in this document, including legislative issues. This would support the development of strategies that are internationally compatible. Third, policy-makers may put in place mechanisms that foster the harmonization of indicators, IT options and HIS infrastructure at the national level. In addition, they may charge international organizations with providing harmonized tools, mechanisms and platforms to achieve higher levels of integration at the European level.

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ANNEX 1. METHODOLOGY

We conducted a literature search of relevant publications followed by expert interviews.

For the literature search, we entered the terms "(public) health information system", "public health surveillance", "health statistics", "e-health", "health monitoring", "public health reporting" and "implementation" (with different combinations of terms) in PubMed and Web of Science. This step delivered some relevant publications; however, only a few of these addressed the integration of **national** HISs. Most of the publications addressed heterogeneous topics for a better integration of different kinds of HIS (e.g. organizational or regional HIS, public health surveillance).

In addition, through a database search of major international organizations (WHO, EU, OECD), hand search of relevant references, and snowballing, further publications for better integration or the architecture of HISs, as well as on data availability and implementation issues was identified (1, 2–7). The Health Systems in Transition (HiT) country reports (8) provide information on health information management and information resources. Other publications address the benchmarking of IT infrastructures (9), the health information infrastructure (10), e-health (11, 12), or health information exchange (HIE) (13).

For the expert interviews, national contact points of the WHO Regional Office for Europe from EU and EFTA Member States were chosen as the first points of contact, to be interviewed themselves or to suggest the names of someone who could. These contacts received background material with statements, definitions and a synopsis of the interview questions to give interviewees the opportunity to consider their responses relating to the their national HIS in advance (see Annexes 2 and 3). The interview questions addressed the understanding of the term "HIS", operation of the HIS in the respective country (including goals, objectives and good practices) and integration (data source feeding into the national HIS, integration of HIS, needs, opportunities and barriers for improvement, and examples of good practices in other countries).

In total, 31 national contact points were contacted. Fifteen experts from 13 countries participated in the survey. Twelve experts from 11 countries answered the questions in telephone interviews of 45–60 minutes from June to August 2014. For two countries, the questions were answered in writing.

The countries participating in the interviews were: Austria, Belgium, Croatia, Czech Republic, England, Finland, France, Germany, Latvia, Malta, Netherlands, Poland, Portugal.

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ANNEX 2. EMAIL TO CONTACT INTERVIEW PARTNERS

Dear ...,

We are writing to you as a key expert in health information systems in Europe and would value **your input** for an international survey on the integration of health information systems (HIS) in Europe, with a focus on monitoring Health 2020 indicators and health inequalities.

This **survey** is a major component of a project carried out by Maastricht University, commissioned by the WHO Regional Office for Europe, at the request of the European Commission (DG SANCO).

Our aim is to collect evidence of good practice from EU and EFTA Member States in making progress towards the integration of national HIS.

We would like to **arrange a telephone interview** with you, but as the integration of national HIS is a wide area we would like to limit the scope and framework of what we would like to discuss with you to some topics of particular interest. In addition, we would like to give you the **opportunity** to send us your response in writing.

We have included a **background document** that outlines the scope and purpose of the work as well as the actual questions (**see attachment**).

We would like you to **reflect on the current status of the HIS in your country** from your personal experience over the past few years. We are not asking you to provide a detailed description of the HISs. We would like to ask you to read the background information before we call you and then collect your reflections and remarks during the interview, generating **concrete examples**, if possible and with the opportunity that you would later provide additional literature, references or other people to contact to allow for a more detailed assessment of the situation in your country. Descriptions of barriers to integration of systems will also be valuable to us.

Please give us the opportunity to contact you by phone. The actual interview will take 45–60 minutes.

For **making an appointment for the interview**, please contact Kai Michelsen at the Department of International Health, Maastricht University.

Phone: +31 43 38 81719

Email: kai.michelsen@maastrichtuniversity.nl

Thank you very much and best regards, and thank you in anticipation of your involvement in this important topic.

ANNEX 3. BACKGROUND MATERIAL AND INTERVIEW QUESTIONS

Effective integration of health information systems (HIS)

Need for better integration

Health policy-makers require reliable information and evidence. There is a plethora of health information in many countries of the European Union and substantial investments are made to strengthen such information systems. However, frequently, the information sought does not originate in the health sector and evidence from other sectors is required to create a holistic picture. Difficulties arise when such information systems are not integrated and cross-sectoral information is not easily obtainable.

In this work we are using the WHO definition of **an HIS**: “An HIS comprises the actions taken to collect, analyse and report information systematically and sustainably and to derive knowledge and evidence in the field of health. This requires a dedicated infrastructure, including human resources, technology, software and databases.” [1]

While the above definition primarily addresses national HISs, we are also interested in developments at subnational (regional, local) levels.

Better integration is a precondition for more effective and efficient HISs. Integration failures lead to the use of different definitions and classifications for similar entities, doubling of data collection, lack of consistency, lack of coordination and overview, unclear priorities, ineffectiveness in data collection and analysis, among other issues. It often leads to incomplete integration of all available information in policy reports, i.e. data not used, valuable analyses not performed and worthwhile policy input not presented. Comparisons between geographical entities within countries (municipalities, districts, regions) and between countries are constrained.

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[1] WHO Regional Office for Europe. Framework of a support tool for national health information strategies for implementation of Health 2020 and beyond. In: Twenty-first Standing Committee of the Regional Committee for Europe. Third session. Copenhagen: WHO Regional Office for Europe: June 2014 (document EUR/SC21(3)/9).

Most improvements in standardization, data collection methods, IT use and governance can be judged to be **improvements in integration**. However, health is a very broad issue and effective health policy-making demands the **integration of information from many sources**, not merely within the system of public health and health care. Besides better integration within the existing structures of a HIS, a better integration of data and information **from other areas and jurisdictions** is of major relevance (e.g. demographics, the social and physical environment).

We are interested in your reflections on the **integration of the HIS in your country** based on your professional experience. We are not asking you to provide a detailed description of the HIS but would be interested to learn more about the opportunities for and barriers to integration of such systems at the national and subnational levels.

National HISs: good practice, relevant aspects and limitations

National HISs serve multiple goals and objectives. The major goals are to collect and analyse health data and information for:

- national (and, if applicable, also regional and local) government(s) to perform health monitoring that will support health policy development;
- the health research community to investigate public health and health (systems);
- fulfilling national obligations to deliver health data to international organizations and agencies.

Health and its determinants (health risks and factors that improve health and well-being) cover a huge area. National HISs therefore have to cover a broad content area and many topics. These are usually measured by a set of different types of health data collections.

Interview questions

- What do you understand by the term “health information system” (HIS)? How does it (or its equivalent) operate in your country?
- What are the goals and objectives of your national HIS?
- Are these goals and objectives formally documented?
- Would you say that there is “good practice” in the HIS in your country? (See explanation below.)

Good practice: adequate availability, quality, consistency, sustainability, reporting

A good national HIS could mean that collection of these types of data is conducted in a well-coordinated way with as little overlap as possible, at appropriate regular intervals, with timely delivery and/or accessibility of high quality and representative datasets that show operational and conceptual consistency and comparability both over time and between data collections, not only within the country but also with data from other countries. The ability to link health data not only to regions but also to socioeconomic characteristics will enhance its policy value. These data should be "digested" adequately and in a timely manner into policy advice, for example, into reports and/or other kinds of outputs.

Good practice: constantly improving methods and standards

An ideal HIS depends not only on the presence or absence of these types of data collection in a country, but also on their quality and timeliness. Improvements in the representativeness of data or collection methods are essential continuous processes. Alignment with international definitions and classifications is important. The ideal situation could be one that reflects optimal integration of relevant data and information from all sectors of the health system, the public as well as private sector and different jurisdictions.

Good practice: good governance, collaboration and coordination

The collection of the various datasets and reporting of the results can be organized within one country between various sectors and organizations, ranging from the ministries of health, justice or interior to a national public health institute, a health observatory, a national statistical office, or university departments. This complex pattern of organization of health data collection and reporting differs between countries.

Integration within and between data sources

Better integration is a precondition for more effective and efficient HISs.

Integration failures lead to the use of different definitions and classifications for similar entities, doubling of data collection, lack of consistency, lack of coordination and overview, unclear priorities, ineffectiveness in data collection and analysis, among other issues.

It often leads to incomplete integration of all available information in policy reports, i.e. data being not used, valuable analyses not performed and worthwhile policy input not presented.

Comparisons between geographical entities within countries (municipalities, districts, regions) and between countries are constrained.

Interview questions

- What are the important data sources feeding into your national HIS?
- Would you consider that your HIS is "integrated"? If not, why not?
- How well are data from different kinds of collections and sectors integrated into your HIS?
- What would improve integration in your country?
- What are the barriers to integration that need to be overcome?
- Do you know of settings/countries where such integration is successful? If so, how has this been achieved?
- If you were charged with enhancing HIS integration in your country, what steps would you take and why?

What are your final reflections?

After discussing the integration of your HIS, we would be grateful for any final comments or reflections that you may wish to share.

World Health Organization
Regional Office for Europe
UN City, Marmorvej 51, DK-2100 Copenhagen Ø, Denmark
Tel.: +45 45 33 70 00
Fax: +45 45 33 70 01
Email: contact@euro.who.int
Website: www.euro.who.int

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