



BRIDGEHEALTH

BRidging Information and Data Generation
for Evidence-based Health Policy and Research

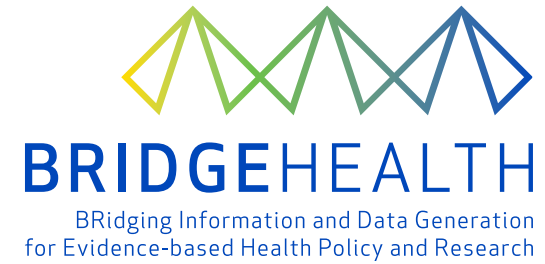
Health Information in the European Union The ERIC as a tool

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“Health Information in the European Union – the ERIC as a tool”

This policy meeting is organised by BRIDGE Health and hosted by the Belgian Scientific Institute of Public Health and the Belgian Federal Public Service Health, Food Chain Safety and Environment.



Health Information in the European Union
The ERIC as a tool

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PROGRAMME

MORNING

9.00-10.00 **Registration and coffee**

10.00-10.30 **Welcome**

Tom Auwers, President, Federal Public Service Health, Food chain safety and Environment

Myriam Sneyers, Managing director, Scientific Institute of Public Health (WIV-ISP)

10.30-11.00 **The current EU health information system**

Introduction of the components of the EU health information system

Philippe Roux, Head of Unit C2, DG SANTE

Challenges and needs

Petronille Bogaert, BRIDGE Health and WIV-ISP

11.30-13.00 **BRIDGE Health Achievements**

Work package and horizontal activities achievements

Ronan Lyons, Professor of Public Health, Swansea University

Enrique Bernal-Delgado, Senior Health Services Researcher, Institute for Health Sciences, IIS Aragón

Maria M. Hofmarcher HS&I HealthSystemIntelligence and Department of Health Economics, Centre of Public Health, Medical University Vienna

Added value for countries: country examples for Germany and Slovenia

Thomas Ziese, Head national health reporting, Robert Koch Institute, Germany

Metka Zaletel, Head of health data department, National Institute of Public Health of Slovenia

Added value for public health research

Nicole Rosenkötter, President of the EUPHA Section on Public Health Monitoring and Reporting

15.30-15.50 **Coffee Break**

15.50-17.00 **The way forward**

Vision of Public Health Institutes

Jean-Claude Desenclos, Secretary General, International Association of National Public Health Institutes (IANPHI)

Political vision of the HIREP-ERIC

Benoit Mores, Ministerial Adviser, Minister of Social Affairs and Health

Xavier Prats Monné, Director General, DG SANTE

Round-up

Herman Van Oyen, Director Public Health and Surveillance, WIV-ISP and BRIDGE Health

AFTERNOON

13.00-14.00 **Lunch Break**

14.00-15.30 **The ERIC on Health Information for Research and Evidence-based Policy (HIREP-ERIC)**

Description of the HIREP-ERIC

Petronille Bogaert, BRIDGE Health and WIV-ISP

Progress of the EGH's drafting group

Giovanni Nicoletti, Ministry of Health, Italy



BRIDGE HEALTH OVERVIEW

BRIdging Information and Data Generation for Evidence-based Health policy and research (BRIDGE Health) is working towards a European health information and data generation network covering major EU health policy areas by promoting the coordination and convergence of existing key projects in health information.

The project was launched in May 2015 and runs until October 2017. It is coordinated by the Scientific Institute of Public Health in Belgium and includes 31 partners in 16 countries. It assures a knowledge transfer from past health and research frameworks in domains of population health and health system monitoring, indicator development, health examination surveys, environment and health, population-based injury and disease registries, maternal and child health, clinical and administrative health data collection systems and methods of health system performance assessment.

The main aim of the BRIDGE Health project is to work towards a comprehensive, integrated and sustainable EU health information system to support evidence-based health policy and research for the EU and Member States. The project reinforces and integrates expert and data provider networks to ensure optimal conditions for the implementation of this system. The BRIDGE Health project work is organised through vertical Work Packages (WP) and Horizontal Activities (HA). In this booklet you can find **fact sheets** on each of the WPs and HAs.

The first overarching outcome of BRIDGE Health is this **concept paper**. This concept paper aims to provide interested Member States, candidate and EEA/EFTA countries with relevant information to make an informed decision on sustainable strengthening of the EU health information system. The concept paper is available on our website.

The analysis concluded that a European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy (HIREP-ERIC) is at this time the most feasible option. This to set important steps in the right direction and fulfil some of the most important criteria for an effective organisation around the scientific underpinning of health policy and research by new and better evidence from more and better comparable data. Read our **policy paper** further on in this booklet and the **technical and scientific description of the HIREP-ERIC** on our website.

Go to our website www.bridge-health.eu or contact the coordination team at bridge.coordination@wiv-isp.be for any additional information.



FACT SHEETS WORK PACKAGES

Overview work packages:

- WP 1-3** Coordination, Dissemination, Evaluation
- WP 4** European Core Health Indicators Monitoring (ECHIM)
- WP 5** Harmonized population based health examination surveys
- WP 6** Impacts of environmental chemicals on health
- WP 7** Reproductive, maternal, newborn, child and adolescent health (RMNCAH)
- WP 8** Platform for population based registries
- WP 9** Platform for Injury Surveillance
- WP 10** Building a platform for administrative data on Health Care
- WP 11** Integration of approaches in EU information system for health monitoring and reporting
- WP 12** Evaluation of health care systems

WP 4

European Core Health Indicators Monitoring (ECHIM)

Background

WP4 implements four tasks:

- Strengthen a network of national and international health indicator experts;
- Map data availability for the ECHI, updating indicators in the light of scientific / methodological developments;
- Assess policy relevance of the ECHI shortlist;
- Design an indicator repository for the future sustainable health information infrastructure.

In part, these activities carry forward work of previous ECHI projects.

Aims/Objectives

WP4 objectives are to assess (changes in) data availability for the ECHI, to keep individual indicators up-to-date with key data sources, such as the EHIS (European Health Interview Survey), to ensure (public health) policy relevance of the ECHI shortlist and to design a repository to enable experts and researchers to retrieve information on indicators, meta-data or publications. As an overarching objective, WP4 re-establishes close ties with national and international health indicator experts to ensure their involvement in the processes of indicator development and health monitoring in Europe¹.

Results

WP4 constituted two expert groups to advise its activities. These are the Expert Group on National Health Indicator Implementation (EG-NHII) and the Advisory Core Group (ACG) of senior public health experts and representatives of international organizations. A meeting and a videoconference were organized in 2016; a joint face-to-face-meeting of both groups will take place on May 16 and 17, 2017 in Berlin. Data availability for the ECHI was mapped among European countries in 2016. Results were submitted as Technical Report in fulfillment of the WP4 deliverable. 23 of 36 countries contacted participated in the mapping survey. Survey outcomes, its consequences for ECHI development and next steps will be discussed at the expert meeting in May 2017. The evaluation of the

policy relevance of the ECHI Shortlist is currently being performed by means of an online survey. Concepts for the content, structure and functionalities of an ECHI indicator repository have been developed. A primary functionality will be to provide access to ECHI-related (meta-) information for researchers, policymakers and the interested public. This would include definitions, operationalizations, quality, availability and purpose of indicators brought together to monitor public health in an EU comparable manner. Results of the ECHI policy evaluation as well as challenges that were identified in the design and governance of the repository will be presented and discussed at the expert meeting in May 2017.

Recommendations

European morbidity statistics and the compulsory EHIS may increase future ECHI data availability. Developments towards potential new data sources and types need to be monitored. The mapping of the policy focus, balance and appropriateness of the ECHI indicator approach will allow improving its use for stakeholders and for comparative EU-wide monitoring and evaluation of population health and health systems performance. In designing and implementing an indicator repository, priority should be attached to creating long term institutional memory in the form of a sustainable web-based repository as a first step, possibly expanded by interactive interfaces. To carry the above activities forward, they need to be embedded in a sustainable European health information structure.

Prepared by: Angela Fehr, Thomas Ziese, Peter Achterberg, Mariken Tijhuis, Sabrina Hense

Harmonized population based health examination surveys

Background

Health examination surveys (HES) are population based surveys with questionnaire(s), physical health measurements such as anthropometric measurement and blood pressure, and collection of biological samples. They provide data for many important health indicators which cannot be obtained reliably through other data sources. Such indicators are useful to support policy decisions, planning and evaluation of prevention programmes and research.

Several European countries have conducted regional or national HES during the past 20 years. However, the results are comparable between surveys only if there is joint standardization of the survey procedures and reporting. The European Health Examination Survey (EHES) Pilot Project (<http://www.ehes.info>) in 2009-2012, prepared standardized protocols for measuring important modifiable risk factors of many chronic diseases (anthropometry, blood pressure, total and HDL cholesterol and glucose/HbA1c), training material and quality assurance procedures to enhance the comparability of data from national HESs.

Aims/Objectives

The work package on Harmonized population based health examination surveys aims to continue work started during the EHES Pilot Project by providing support to countries planning and organizing their national HES, maintaining and further developing standardized protocols and related training materials, and providing external quality assessment for ongoing national HESs through site visits and laboratory quality control. The objective is also to further develop activities and materials to support countries in the process of getting their national HES approved and funded.

Results

The EHES Manuals, which include recommendations for organization of national HES and standardized measurement protocols for key risk factors for many chronic diseases were updated. Protocols for urine collection (overnight, spot and 24 hour) and two physical function tests (chair rise and hand grip strength) were added to this 2nd edition of the Manual. The updated versions of the EHES Manuals were published in December 2016 and are freely available through EHES web site. The related training material is being updated and additional new material is being prepared. These will be available in the EHES web site by October 2017.

In 2016-03/2017, four site visits have been conducted to evaluate ongoing national HESs and a peer-review article about previous experiences has been published (Tolonen et al. Eur J Public Health 2017. doi:10.1093/eurpub/ckw271).

Recommendations

To ensure that the well started European level collaboration on standardization of national HESs continues, central coordination of activities is needed. Countries planning HESs require support in justifying the needs and added value of a relatively expensive new survey, and in planning the measurement procedures and organization of the survey. Availability of European level standards, related training materials and training seminars as well as external quality assurance are important for all organizers of HESs.

National HESs can provide objective information about health and health determinants of the population and population sub-groups, needed for informed policy decision making, prevention of major chronic diseases and health promotion. Together with other sources of health information, such as health interview surveys and register data, HESs form a solid base for health information in Europe.

Prepared by: Hanna Tolonen, Päivi Koponen, Laura Paalanen, Kari Kuulasmaa

Impacts of environmental chemicals on health

Background

Health information (HI) is information that relates to the health of an individual, the general population, or to promotion, preventive or treatment services. HI comprises health status¹, and health determinants, such as life-style, socio-economic conditions, environment, technology, and genetics. HI is commonly based on indicators measured at individual or population level. Target groups comprise besides other citizens, health care providers, policy makers, researchers, media and analysts. To date the European Core Health Indicator list (ECHI) comprise 88 indicators, whilst there are no indicators related to impacts of chemicals on health.

On the other hand, increasing awareness has developed over the past 20 years about impacts of environmental chemicals on health. Political initiatives such as Health 2020 or the Agenda 2030 stress the need to protect citizens from hazardous chemicals. Without data on impacts of environmental chemicals on health a European Health Information system hence may not be considered complete.

Aims

Against this background WP6 aimed at identifying the options to link HBM data with register information, Health examination surveys and to investigate the options to develop an indicator for impacts of environmental chemicals on health, in an intensified exchange between COPHES and ENRIECO networks.

Results

WP6 merges information from horizontal surveys and birth cohorts. It provides an up-to-date inventory of HBM data, a summary of special features and characteristics and information on current use and potential needs for HBM in European health and consumer policies.

WP6 evaluated similarities and differences between HBM data collections, and information in birth and disease as well as administrative data registries. We investigated the differences between environmental health and health examination survey design, and elucidated the options to develop indicators for impacts of environmental chemicals. WP6 evaluated the potential contribution of recent research to use of HBM in HI, and assessed options to link existing data

platforms for HBM and HI.

On this basis WP6 drafts blueprints on how to bridge data collections, develop indicators, link databases, and integrate environmental health and health surveillance systems, and on how to use environmental health surveillance in European HI and in regulatory decision making.

Recommendations

Environmental health surveillance is to be seen as a tool, which is part of the public health and consumer policies and health information systems. To be able to feed environmental health information into a European Health Information system, data from survey should be used.

A HIREP-ERIC could in particular support the adjustment of data collection in birth, disease and administrative registries to enable more efficient use in HBM interpretation, and the development of indicators for measurement of impacts of environmental chemicals on health.

In addition a HIREP-ERIC should coordinate and closely cooperation with HBM4EU to optimise synergies in technical and political developments.

Prepared by: Anke Joas, Madlen David, Gerda Schwedler, Marike Kolossa-Gehring, Gudrun Koppen, Greet Schoeters, Marta Esteban, Argelia Castaño, Maribel Casas, Vrijheid Martine, Lisbeth E. Knudsen

Maternal, Newborn, Adolescent and Child Health

Background

Maternal, newborn, adolescent and child health covers from conception through young adulthood, or 24 years of age. BRIDGE Health brought together experts from perinatal health, health information, child health and birth cohorts to ensure a cohesive and comprehensive consideration of women (pregnancy, childbirth and postpartum), and their children (from newborn through young adulthood) across all the BRIDGE Health work packages. A cohort perspective, linking fetal and early life with health and development across the life course, is needed to inform research and policy.

EURO-Peristat, an EU project on maternal and newborn health, relies on cross-country networks to report on indicators from national routine systems for Europe, while the CHICOS project (Developing a Child Cohort Strategy for Europe) has inventoried birth cohorts and their longitudinal data collection experience and the RICHE project (Research Inventory for Child Health in Europe) has documented and collated the range of health data for children and adolescents across Europe. Team members from the Norwegian Institute of Public Health work in the dual domains of stillbirth and digital health information strategies.

Aims/Objectives

Aims include:

- Optimising the sustainability, timeliness, comprehensiveness, quality and use of perinatal health information from routine systems as specified in the Euro-Peristat roadmap;
- Optimising the synergies of a joint platform and roadmap of the EU funded research initiatives CHICOS and RICHE towards a European observatory of health information for child health research;
- Developing a blueprint to ensure that maternal and child health concerns are visible and sustainably integrated into a European health information system for health care, public health surveillance, research and policy making.

Results

BRIDGE Health has furthered work towards all three aims. EURO-Peristat illustrates the interface between surveillance and research for informing clinical practice and policy. The network added 2 new countries (Bulgaria and Croatia) and now covers all member states, plus Iceland, Norway and

Switzerland. A conference to discuss priorities and sustainability was held with 68 network members and European stakeholders. Successful national experiences with data linkage were shared and countries tested the feasibility of an improved data collection protocol. The network published 9 articles on data linkage, social health inequalities, preterm birth and maternal and neonatal morbidity. A major concern within the network remains sustainability of regular data collection and reporting of indicators.

CHICOS and RICHE have updated the content and dissemination of their inventories, while developing a theoretical infrastructure for a shared research inventory across both the birth cohort and child health domains, aiming to making these disparate sources of information available to critical users of health information. RICHE is assessing the need for and range of possible sources about the lives of children and adolescents in Europe. The overall team consulted with other BRIDGE Health work packages to identify areas for future collaboration to cost-effectively expand maternal and child health data across Europe.

Recommendations

Health information for women and children across Europe is extensive, with governments, researchers and their networks working together to generate methods and priorities for health information. They provide solid building blocks for sustainable use of existing data for improving maternal and child health and health services. However, consolidating, sustaining, and expanding these investments is needed.

Not all maternal and child health domains have achieved equally high priority or quality data across Europe. Collaborations to remedy this situation are possible, but comprehensive reporting requires multiple data sources. The mother-baby relationship, prevention, lifestyle, education and mental health are as key as health services for attaining optimal outcomes. With some important exceptions, other health information projects/sources include unexplored information on maternal and child health and collaborations could reinforce quality and cost-effectiveness in an integrated platform.

Prepared by: Frederik Frøen, Ingrid K. Friberg, Jennifer Zeitlin, Marie Delnord, Martine Vrijheid, Maribel Casas, Anthony Staines, Sara McQuinn

Platform for population based registries

Background

A population-based registry (P-BR) is an organized system that uses observational study methods to collect standardized data and to evaluate outcomes that serve for scientific, clinical and health policy purposes; studies derived from P-BRs may provide a real-world view of occurrence of diseases in the population (attack rate, case fatality, incidence and survival rate) and may be used for evaluating time trends and geographical gradients across countries. P-BRs are designed for coronary and cerebrovascular events, cancers, injuries, rare diseases, diabetes, twins; P-BRs for medical devices provide information on effectiveness and safety.

Aims/Objectives

The Work Package was aimed to gather procedures and methods of different population-based registries, to describe opportunities and weakness, to provide a general guide for the implementation of a population-based registry to be offered to those EU countries where appropriate surveillance systems are insufficient or missing.

Results

Two reports will be produced: the first report, to be delivered on May 2017, focuses on procedures and methods for planning a registry, and provides a standardized model for producing reliable and comparable estimates of indicators following a step-wise procedure; a second report, to be delivered on October 2017, proposes guide lines for training personnel involved in the implementation and management of a P-BR.

Planning a registry involves the following steps: formulating a purpose; determining if the registry is the appropriate tool to achieve the purpose; identifying the stakeholders to whom the research questions are directed; assessing the feasibility of the registry; building, training, and testing the team; establishing a governance; defining the duration, the costs, the clinical data needed; defining the data set, the events, the target population, the appropriate record linkage, the quality and validation methods and the data processing procedures to provide indicators, developing the protocol and the manual of operations; planning the dissemination of results. A pilot study to estimate coverage, validation of sources of information, representativeness of the area under surveillance, completeness of information is of great importance. Data quality should be assessed after the pilot study and periodically during the surveillance period. Subjects who migrate out of the area for health care may limit the accuracy of the P-BR.

Recommendations

The application of a standard methodology results in the availability of reliable and comparable data at the European level and facilitates the transferability of health information for research and evidence-based health policies. Although registries are extremely useful, they require considerable resources to be implemented and maintained, high cost and efforts; then, before starting a registry, formulating the purpose, determining if the registry is the appropriate tool to achieve the purpose, assessing the feasibility are steps of primary importance; it is fundamental to limit the burden of data collection selecting a core data set, the target population by age range and area under surveillance, to define a time period of observation, to disseminate the results.

The added value of the WP8 was to create a network of experts from each country to support the monitoring of non-communicable disease across Europe, to offer a model and a stepwise procedure for the implementation of P-BRs to provide ECHIM indicators; to establish the basis for an improved future regulation in public health policies concerning the surveillance throughout European countries.

Prepared by: Simona Giampaoli in collaboration with the network of fieldwork experts of population based registries

BRIDGE Injury Surveillance

Background

Injury is the leading or second cause of death between ages 1-44 across Europe. Huge numbers of people are injured from preventable causes and there is growing evidence that many do not fully recover from serious and moderate injuries, resulting in disability and inability to participate fully in all aspects of society.

Although various injury data sources exist in Europe; many lack sufficient size, scope, detail or comparability, to support injury prevention research and policy development at regional, national and EU levels. Emergency department (ED) records offer one of the most comprehensive sources of injury data; however, heterogeneous hospital data collection systems often prevent comparative analyses between countries. The European Injury Data Base (IDB), developed as part of the European Commission (EC) co-financed IDB a development and enhancements through JAMIE (Joint Action on Monitoring Injuries in Europe) and the BRIDGE-Health project, to provide Europe with a standardised and sustainable ED based injury surveillance system.

Aims/Objectives

The Injury Surveillance Platform (WP9) of the BRIDGE-Health project, has several aims including:

- Ensuring the IDB remains a comprehensive, standardised, and sustainable ED based injury surveillance system, with the ability to support injury prevention research and policy across Europe;
- Expanding the IDBs coverage, to include further European countries, whilst maintaining current members;
- Ensuring the IDB meets the high-quality standards developed under the IDB and JAMIE projects;
- Developing tools to enable countries to monitor the magnitude and societal impact of injuries, and injury related health inequalities.
- Comparing the IDB to other data sources such as hospital discharge registers and health surveys.

Results

The IDB comprises two datasets: the more detailed Full Data Set (FDS) and the simpler Minimum Data Set (MDS).

To date, 26 European countries have submitted 7,382,143 ED records to the IDB-MDS, and 21 countries have provided sufficient reference population data enabling the calculation of incidence rates. Fifteen of these countries have also provided data in the more detailed FDS format, and a further five new countries have expressed interest in joining the IDB.

An IDB manual provides member states with clear guidelines on inclusion/exclusion criteria, hospital sampling, reference population calculations, and quality assurance procedures. Further, annual training events and rigorous quality checks, ensure consistency across participating countries.

IDB incidence rates for all non-fatal injuries vary from 37 per 1000 population in Finland to 117 in Luxembourg (2012-2014 average). This range in IDB rates suggests that injury morbidity is not the only influencing factor, and it is likely differing health care systems and data quality issues may also exert influence on some IDB estimates.

The simple IDB Minimum Data Set (IDB-MDS) supports the use of relevant injury-related Core Health indicators as ECHI 29b (home, leisure and school injuries), being feasible to be implemented in Member States with wide variation in existing practice. For the period 2012-2014, for 22 countries, national estimates on ECHI 29b could be established. IDB data can be accessed through several channels (e.g. IDB webgate, restricted FDS access, EuroSafe website and the IDB clearing house service). The BRIDGE-Health team are in the process of developing an online interactive burden of injury tool, to enable users to establish the impact of injuries via the Disability Adjusted Life Years (DALY) measure.

Recommendations

Given the scale of the impact of injuries on population health continued and enhanced surveillance on the incidence and burden of injuries is essential in supporting national and EU preventive policies.

The IDB system provides a cost-effective solution for the collection of large scale comparable injury data across Europe. Further, technological developments in medical administration and data linkage, offer new opportunities to expand injury related data in the IDB, including hospital discharge registry data and the development of disability weights for specific groups such as children.

The IDB-MDS contributes data towards two "European Core Health Indicators" (ECHI); ECHI29b (home, school and leisure accidents) and ECHI30b (road traffic accidents). Injuries in the home, school and leisure environment are often a neglected issue; however, most non-fatal injuries occur in this environment, and thus more precedence should be given to this setting.

Prepared by: Samantha Turner, Ronan A Lyons, Wim Rogmans, Rupert Kisser, Bjarne Larsen, Huib Valkenberg, Dritan Bejko, Robert Bauer, Monica Steiner, Gabriele Ellsaesser

Building a platform on administrative data aimed at evaluating health care performance

Background

This piece of work within BRIDGE Health stems from the ECHO project lessons. ECHO aimed at exploring the integration of individual-level routine hospital data from different European countries, and studying unwarranted variations in health care performance (HCPA).

Aims/Objectives

This work package has sought to provide insight on how to build a health data infrastructure (HDI), linking individual and contextual data, routinely collected in different health care systems, with a view to assessing health care performance and reporting meaningful results for policy makers and managers. Specifically,

- a) In different countries, mapping out and describing those information systems that, using patient-level data could be reused for health care performance assessment;
- b) Out of those information systems, eliciting a common meaningful information dataset that would enable cross-national health care performance assessment; and,
- c) Using original datasets from the participant countries, building a pilot data infrastructure, assessing its quality, and exploring its ability to report health care performance.

Results

1. The mapping out exercise elicited the potential of existing datasets to evaluate health care performance; however, international data sharing may be a big hurdle to do international comparison. (table 1)

Table 1. Features that would allow HCPA: insight from different countries

	AUT	DNK	ENG	HUN	PRT	SVN	SPA
Unique Patient's id	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Access to Datasets	Hard	Medium	Hard	Hard	Medium	Medium	Medium
Actual Secondary use	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Linkage Capacity	No	Yes	Yes	Yes	Yes	Yes	Yes
HCPA Reporting	Yes	Yes	Yes	Yes	Yes	Yes	Yes
International Data-sharing	No	Yes	No	No	Yes	Yes	Yes

2. A meaningful minimum common dataset has been identified. Although there are some gaps affecting some of the countries, the information routinely collected may eventually allow cross-national health care performance assessment at meaningful levels of analysis (provider-specific, clusters of providers, geographic units, etc.); and,
3. After harmonizing the original sources, building a final data infrastructure fed with data from Denmark, Portugal, Slovenia and Spain, a set of performance indicators are being produced, covering the following domains: cardiovascular care, orthopaedic care, low-value surgical procedures, potentially avoidable hospitalizations and, quality and safety events.

Recommendations

Routine data in Europe allow cross-national health care performance assessment. In the construction of any data infrastructure aiming this goal:

1. Participants should first map out any information source with a potential to HCPA, and with a view to fit into a meaningful minimum common dataset.
2. The data infrastructure curators should thoroughly address harmonization and standardization procedures assuring comparability both, in the original datasets and in the final infrastructure. This work should be developed to identify exposure and events (i.e., health care performance indicators development) and the proper units of analysis, in an accurate and unbiased manner. A quality analysis of the resulting infrastructure (and subsequent updates) should be designed and implemented.
3. Although our work has been tested using a centralized data infrastructure, given the observed data transfer restrictions, the administrative barriers, as well as the different legal implications associated to data protection, our recommendation would go on the lines of designing and developing a distributed health data infrastructure –original data remain in the country while procedures for extraction, harmonization and standardization and analysis are common and shared among participants.

Prepared by: Enrique Bernal-Delgado, Francisco Estupiñán and Ramón Launa on behalf of WP10 team

Integrating data sources into a comprehensive EU Information System for Health Health Care Monitoring and Reporting

Background

Performance-based governance requires timely and accurate patient data that span the whole care pathway, including health outcomes and costs. Such data are also used to support the re-design and evaluation of new models of health care service delivery and to contribute to the discovery and evaluation of new treatments.

Aims/Objectives

The aim is to develop coherent methodology to integrate health information from existing data sources, covering both population- and disease-based data from administrative, survey and registry sources. First, by making use of available databases, the project will update and further develop the EuroHOPE research infrastructure with the aim of evaluating the performance of health care systems in terms of outcomes, quality, use of resources, and cost. This includes maintaining and updating the protocols of selected diseases/conditions (acute myocardial infarction, stroke, hip fracture).

The protocols include e.g. inclusion/exclusion criteria, definition of cycle of care (when it starts, follow-up etc.), comorbidities (used in risk adjustment), and specification of process, utilization, cost and outcome measures. National, regional and hospital level indicators will be calculated from Finland, Denmark, Hungary, Italy, Norway and Sweden. The episode-based approach will be extended to include primary health care and social services in a pilot study using data from Copenhagen, Helsinki, Madrid, Oslo and Stockholm.

Second, the project will compare the feasibility and quality of performance information calculated from administrative data sets with and without the possibility for register linkages. It will also assess legal issues (e.g. privacy, data transfer, statistical methods) related to the approaches with respect to the feasibility and quality of performance information.

Finally, the project will explore and test the building of a data linkage infrastructure capable of securely and safely managing health information from around the EU, overcoming the fragmentation of health information and data and contributing towards a sustainable and integrated EU health information system for both public health and research purposes.

Results

The updated national and regional indicators (<http://www.eurohope.info/>) are based on data of all new acute hospitalised patients in the five countries and the autonomous region of Friuli-Venezia Giulia in Italy between 2006 and 2014. The indicators are based on information of 461 600 acute myocardial infarction, 347 700 ischaemic stroke and 243 900 hip fracture patients.

The results indicate that within countries, there is vast regional level variation in the outcomes of care in the three analysed conditions. These national and regional differences in performance have sustained over time.

Recommendations

Each country or region taking part in the study, i.e. Denmark, Finland, Hungary, Friuli-Venezia Giulia in Italy, Norway and Sweden, has the potential to identify areas where performance in their health care system can be improved both in terms of quality of care and use of resources. Health care data collected by national registries and other administrative databases, which can be linked with each other at the individual level, are a valuable resource that can be used safely to improve patients' health outcomes and the quality and performance of health care systems.

Prepared by: Unto Häkkinen

Evaluation of health care systems in Europe

Background

Health systems are evaluated against multiple objectives, such as access, efficiency, and quality and equity. The starting point of this project is European research related to conceptualizing health system performance assessment (HSPA) and to providing entry points for finding and accessing data. The Health Data Navigator (HDN) is constructed as a comprehensive repository to enhance standards for cross-country comparison. The creation of such a storehouse is foreseen in a European Health Information infrastructure (ERIC-HIREP). To facilitate this process, the project works towards standards for using and expanding a repository. First, we prepared a list of 2148 health and health system indicators in 46 initiatives at EU, OECD, WHO and Member States level. Out of this list 361 indicators were selected and experts were invited to map these indicators to HSPA domains and to decide whether an indicator has headline importance, is explanatory or operational. This was done through the 1st wave of the European Health System Indicator survey (euHS_I survey). Second, we make recommendation about inclusion criteria of EU health information projects and the mode of up-dates for which a template will need to be developed within the ERIC-HIREP.

Aims/Objectives

- To derive a minimum basic set of broadly agreed robust indicators of HSPA for Europe
- To develop criteria for headline indicators and for EU funded health information projects
- To develop a blueprint to feature a set of headline indicators and relevant meta-information for HSPA across EU Member States.
- To provide recommendation for updating and expanding the HDN

Results

The 1st wave of the euHS_I survey reveals that top headline indicators in the domain Access were 'self-reported unmet need for medical care' and 'share of population covered by health insurance'. Efficiency indicators are implemented rarely. Results show that mostly input or output indicators were selected by respondents. In the domain Quality, 'vaccination coverage in children', 'maternal mortality rate' and 'caesarean section rates' were rated as top headline indicators.

In the area of Equity, 'self-reported unmet need for medical care' and 'Disability-Adjusted Life Year (DALY)' were ranked as the top two headline indicators. In the domain, Health status, 'infant mortality rate' and 'life expectancy' received the highest scores. Results in the domain Health determinants were inconsistent. Enhancements are expected through results from the 2nd wave of the survey.

Recommendations

- ✓ Incorporate findings into "European Core Health Indicators" through providing a widely agreed short list of headline indicators for health and health system performance across Europe.
- ✓ Highlight relevant indicators in respective international databases to ensure standards for cross-country comparisons.
- ✓ Use the Health Data Navigator to facilitate a ERIC-HIREP through a) updating technical standards of the prototype website, b) updating and expanding coverage to all EU MS, c) hosting relevant meta-information of (headline) indicators and d) including and running up-dates of EU funded health information projects.

Prepared by: M. M. Hofmarcher, N. Perić, J. Simon, Z. Or, P. Smith, R. Busse



FACT SHEETS HORIZONTAL ACTIVITIES

Overview horizontal activities:

- HA 1** Transferability of health information and data for policy
- HA 2** Health information inequality within the EU and within MS
- HA 3** Adding the multiple level and multiple strata approach to an ERIC on health information
- HA 4** Standardisation methods of the collection and exchange of health information
- HA 5** Data quality methods including internal and external validation of indicators
- HA 6** Priority setting methods in health information
- HA 7** Ethical and legal issues in health information

Transferability of health information and data for policy

Background

Policy makers need clear messages to take policy measures, whereas science results in uncertainties that need to be interpreted and weighed. Transferability of science to policy requires intensive transfer, to enable understanding and effective implementation of scientific results into policy. To date public health information is reported to remain fragmented and insufficiently used for health policy-making, despite monitoring and reporting of many national and international organizations, and opportunities to overcome the research-policy gap to be weak¹.

Aims/Objectives

HA1 aimed at identifying the major challenges in science to policy transfer in health information, as well as existing approaches to address this, and investigated how a future infrastructural framework could look like on a European scale. The evaluation focussed on the theory of knowledge transfer, on examples of successful science to policy transfer, and summary of regulatory frameworks and requirements for HI to policy transfer as well as current platforms and transfer initiatives, and on proposals for infrastructural frameworks for successful transfer. Other relevant aspects for successful transfer are addressed in separate HAs.

Results

According to the theory of knowledge transfer there are a number of factors for successful science to policy transfer. Health problems that cause substantial damage, can be easily measured and have cost-efficient solutions are likely to gain political support.

There is evidence of success in the health information to policy transfer, and there are regulatory frameworks as well as networks and platforms established for knowledge transfer, but there are a number of major challenges and obstacles in health information and policy transfer.

These are partly due to deficits in data or data quality, restrictions in data transfer, or cultural differences. Mostly however, they are due to highly dispersed data sources and reporting requirements, and to a timing and communication gap between data providers and target user groups. There is lack of policy alignment

and regular exchange about information needs, as well as major shortcomings in guidance on the appropriate framing of the messages to attract interest and generate an impact.

Recommendations

Improved communication between stakeholder groups, strategic planning, tool development and infrastructure are considered key factors for science to policy transfer. HA1 identified the following as priorities:

- Design HI in political context
- Define information needs and adjust level of data quality
- Establish harmonised methods for communication and transfer
- Harmonise data collection and improve high volume data analysis
- Integrate information sources and reporting (one data - multiple use)
- Establish collaborative multi-disciplinary expert network for efficient transfer
- Establish EU wide infrastructure for targeted prioritization and data exchange

A HIREP-ERIC should focus on coordination with relevant Commission services and established networks, as well as with national policy makers, and stakeholder groups. Management of a corresponding “conceptual framework”, identification of best practice, guidance, prioritization, and data management, as well as training, knowledge exchange, tailoring and refinement of tools could be other important tasks.

Prepared by: Anke Joas

Health Information Inequality

Background

A health information (HI) system that involves all of Europe's member states, and captures full representation of its diversity, is strongly justified from population health and health system performance perspectives. Health care and outcome data are essential for tackling common challenges, monitoring population health and benchmarking across health systems.

We sought to review and better understand health information inequality, defined as the unequal capacity among countries to monitor and evaluate population health and health system performance at the national and regional levels using routinely collected data

Methods

We reviewed the published literature, based on an electronic search of Medline and Google Scholar, searched references in relevant articles and queried websites of pertinent multilateral agencies (e.g. WHO, OECD, UN, EU). We also reviewed information from BRIDGE Health partner projects (documents and websites). Finally data on obstacles and perceived reasons for health information gaps were obtained from a semi-structured survey of BRIDGE Health project leaders (19 respondents from 11 projects)

Results

The partners in the 14 BRIDGE Health projects provide a foundation for reinforcing HI equality across Europe. We identified a total of 274 partners involved in health information projects, representing 201 diverse institutions (public agencies (the largest group), university departments, research institutes, NGOs, etc.) However, there was large inequality: EU countries participate in from 1 to 13 projects and have between 1 and 24 partners involved.

Knowledge about national health information systems is fragmented. Many studies on health information inequality come from EU projects and therefore including MS in these initiatives provides essential baseline information. Studies investigating health system infrastructures as well as those identifying ability to report on specific indicators identified significant differences in the capacities of health information systems across MS. Systematic collection of data on country health system infrastructure, in the HiT reports, for instance, could provide a starting point for a standardised baseline description of current capabilities.

Common obstacles to HI equality were identified across health information domains and these map into 4 categories, as shown in Figure 1. The first three categories are topics of other on-going HA reviews. Problems related to infrastructure, governance and communication interact with all three of the other areas, as they can limit capacity to handle complexity and facilitate information flow necessary for the management and development of information infrastructure.

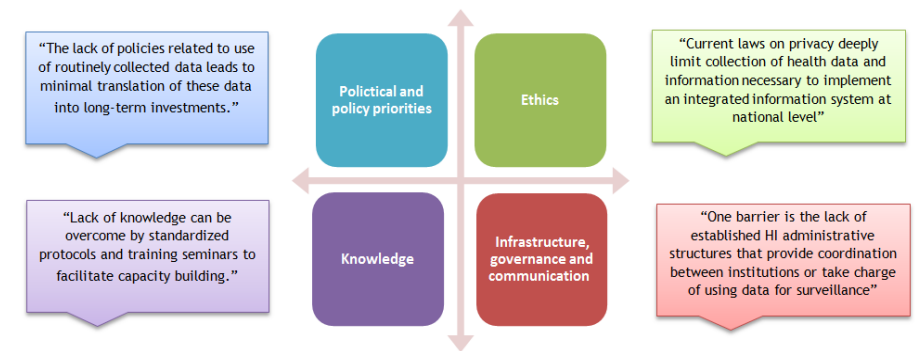


Figure 1. Four categories of obstacles to attaining health information equality across Europe and illustrative comments by respondents.

Suggested action points and next steps:

Knowledge, ethics and political will play an essential role in ensuring HI equality in Europe. These areas are covered by other horizontal activities, but should be linked to the goal of ensuring full coverage among MS. BRIDGE Health can raise visibility of these problems by identifying and publicizing them. Creating a HI inequality benchmarking index could help identify priorities going forward. The HI inequality index could be overall and by data source or domain. Further investigation, based on these initiatives, should focus on generating better evidence about how HI inequality and the ensuing limited capacity to make evidence-based decisions impacts on policy making and health.

Prepared by: Jennifer Zeitlin

Adding the multiple level and multiple strata approach to an ERIC on health information

Background

Cross-country research in health status, health determinants and health systems performance reveals that the observed differences within country (or across population subgroups) are systematically larger than those found across countries (or for the average population), suggesting that the underlying causes of such differences (and any eventual policy corrective decision) operate at specific levels or strata. Moreover, the use and impact of health research results in policy making will depend on how informative and actionable its results are. The multiple levels and multiple strata approach build on that perspective.

Aims/Objectives

The main objective of this horizontal activity has been to figure out how incorporate the multiple level and multiple strata (ML/MS) approach (and the use of meaningful units of analysis) in an eventual ERIC on Health Information for Research and Evidence-based Policy (HIREP-ERIC).

The key questions addressed were: a) Do EU projects and EU institutional initiatives use the ML/MS approach? b) What are the reasons for the use (or not use) of ML/MS analyses? and, c) What would be the way forward to integrate the ML/MS approach in the HIREP-ERIC?

Results

1. With regard to the actual use of ML/MS, although most of the international research initiatives on health depart from individual data, they do tend to develop and report research results at country level or, at most, at regional level. When it comes to monitoring exercises conducted by international institutions the countrywide approach is by far the most prevalent. Notably, the huge variation in health status and healthcare performance observed in those projects using ML/MS underpins the need of implementing this perspective in an eventual HIREP-ERIC.
2. With regard to the reasons for the scarce use of the ML/MS approach, it is worth highlighting: a) the lack of data disaggregated at meaningful units; b) the lack of interest in the secondary use of routinely collected data for health research purposes; c) barriers to access data, in particular individual data; d) limits to reporting due to privacy and legal issues; e) methodological gaps on how to adequate research designs, manage data,

and conduct analyses within a ML/MS approach; and f) lack of logistic capacity to manage and analyse huge amounts of data.

Recommendations

Integrating the ML/MS approach within a HIREP-ERIC should be built upon the following cornerstones.

- With regard to the lack of data or the poor interest in the secondary use of routine data, the HIREP-ERIC could raise awareness on the importance of collecting data at meaningful levels of interest, or on the importance of exploiting existing data to inform policies.
- When it comes to the limited access to individual data and/or barriers to report results at small units, the HIREP-ERIC must assure the strict accomplishment of the legal provisions while working on developing a wider EU legal framework aimed at facilitating this kind of research.
- With regard to methodological gaps, the HIREP-ERIC could play an important role increasing the EU research capacity via training and mobility programs.
- Finally, to deal with the lack of logistic capacity to manage and analyse big amounts of data, the HIREP-ERIC should design, develop and maintain a distributed data infrastructure able to foster the ML/MS approach, as well as provide users with the corresponding IT services.

Prepared by: Enrique Bernal-Delgado, Ester Angulo-Pueyo and Francisco Estupiñán on behalf of BRIDGE Health Consortium

Note of clarification

Strata are the smaller groups into which a defined population may be broken up. Strata are constituted based on members' shared attributes or characteristics, for example, demography, socioeconomic status, or educational level.

Level represents one of the units constituting a hierarchical system where the smaller units (e.g., individuals) are nested into larger units (e.g., neighbourhood). The underlying concept assumes that individuals or populations are influenced by contextual factors (e.g., environment, services to which they are exposed) and those contextual factors are, in turn, influenced by the individuals exposed to them.

Standardization methods of the collection and exchange of health information

Background

Health information is used to monitor health and diseases, health determinants, and cost and quality of health care in the population and population sub-groups, to support policy making, for planning and evaluation of prevention programmes, research and health education. For reliable conclusion and benchmarking between countries or regions, it is essential that the information used is comparable and representative for the target group as well as of high quality and reliable. These can be ensured with proper standardisation and harmonisation of data collection.

To allow benchmarking of national situations with other European countries and for European level health research, exchange of health information between countries is needed. Depending on the use of health information, different levels of information are needed; individual level data, aggregated data on sub-groups or readily defined population level indicators. Since health data is always considered sensitive information, special attention has to be paid for data protection and ethical issues.

Aims/Objectives

The Injury Surveillance Platform (WP9) of the BRIDGE Health project, has several aims including:

- Ensuring the IDB remains a comprehensive, standardised, and sustainable ED based injury surveillance system, with the ability to support injury prevention research and policy across Europe;
- Expanding the IDBs coverage, to include further European countries, whilst maintaining current members;
- Ensuring the IDB meets the high-quality standards developed under the IDB and JAMIE projects;
- Developing tools to enable countries to monitor the magnitude and societal impact of injuries, and injury related health inequalities.
- Comparing the IDB to other data sources such as hospital discharge registers and health surveys.

Results

The IDB comprises two datasets: the more detailed Full Data Set (FDS) and the

simpler Minimum Data Set (MDS).

To date, 26 European countries have submitted 7,382,143 ED records to the IDB-MDS, and 21 countries have provided sufficient reference population data enabling the calculation of incidence rates. Fifteen of these countries have also provided data in the more detailed FDS format, and a further five new countries have expressed interest in joining the IDB.

An IDB manual provides member states with clear guidelines on inclusion/exclusion criteria, hospital sampling, reference population calculations, and quality assurance procedures. Further, annual training events and rigorous quality checks, ensure consistency across participating countries.

IDB incidence rates for all non-fatal injuries vary from 37 per 1000 population in Finland to 117 in Luxembourg (2012-2014 average). This range in IDB rates suggests that injury morbidity is not the only influencing factor, and it is likely differing health care systems and data quality issues may also exert influence on some IDB estimates.

The simple IDB Minimum Data Set (IDB-MDS) supports the use of relevant injury-related Core Health indicators as ECHI 29b (home, leisure and school injuries), being feasible to be implemented in Member States with wide variation in existing practice. For the period 2012-2014, for 22 countries, national estimates on ECHI 29b could be established. IDB data can be accessed through several channels (e.g. IDB webgate, restricted FDS access, EuroSafe website and the IDB clearing house service). The BRIDGE-Health team are in the process of developing an online interactive burden of injury tool, to enable users to establish the impact of injuries via the Disability Adjusted Life Years (DALY) measure.

Recommendations

Given the scale of the impact of injuries on population health continued and enhanced surveillance on the incidence and burden of injuries is essential in supporting national and EU preventive policies.

The IDB system provides a cost-effective solution for the collection of large scale comparable injury data across Europe. Further, technological developments in medical administration and data linkage, offer new opportunities to expand injury related data in the IDB, including hospital discharge registry data and the development of disability weights for specific groups such as children.

The IDB-MDS contributes data towards two “European Core Health Indicators” (ECHI); ECHI29b (home, school and leisure accidents) and ECHI30b (road traffic accidents). Injuries in the home, school and leisure environment are often a neglected issue; however, most non-fatal injuries occur in this environment, and thus more precedence should be given to this setting.

Prepared by: Hanna Tolonen

Data quality methods including internal and external validation

Background

Within an health information system, pursuing and maintaining data quality is crucial to assess population health and health care performance, to monitor time trends of diseases and geographical gradients, to identify gaps and reduce inequalities. Main sources of data which contribute to health information are:

1. administrative datasets (hospital diagnoses, drug prescriptions, outpatient visits, exemptions), systematically collected at national level for management of resources and health services purposes;
2. health examination surveys/health interview surveys which provide standardized data on representative samples of the general population;
3. population-based registries which provide standardized data in definite areas under surveillance. Clear definitions, harmonization and data processing procedures in computing indicators are the key issues to ensure reliability and comparability.

Aims/Objectives

This horizontal activity was aimed at: identifying methods of quality assessment in data collection/data sources among previous and running European Projects, particularly in those participating to BRIDGE Health; identifying methods of quality assessment in data processing from different sources to assess indicators; creating an overview of health information areas where quality issues are faced.

Results

The work is based on experiences and good practices developed by experts in different European Projects; a questionnaire was sent to the leaders; a literature review of quality methods applied in health data, data sources and health indicators was updated. The report is going to be finalised; it includes a detailed description of quality dimensions of data and data sources (relevance, accuracy, timeliness, accessibility, comparability, coherence), a description of systematic and random errors, methods to assess quality and validity of indicators, implications and limitations, including description of major difficulties encountered to ensure data quality in different European projects. Examples of quality checks for data provided by ad hoc surveys, population-based registries and administrative databases are described as well as main steps to improve quality methods.

Recommendations

The first step to plan and organize a quality data collection is to prepare the manual of operations, which includes a detailed description of exams/questions/data, which should follow international standardized procedures and methods in definitions of the diseases under surveillance, in data collection, and in data processing; training and testing of the personnel involved in data collection and data management ensure good quality data and reduce systematic errors; a report with detailed description of quality checks may help the harmonization of different datasets to be included in an health information system. A prompt feedback to the personnel involved in collecting, harmonizing, and processing data may improve data quality.

Without good data, quality of indicators, quality of studies, and therefore decisions on planning and evaluating preventive programs, health care delivery, resource allocation and research, are severely impaired.

Prepared by: Simona Giampaoli in collaboration with the network of the BRIDGE Health WPs Leaders

Good practice priority setting is a must to make progress in EU health research

Background

Priority setting is a challenge at all levels and contexts in health systems because demand for health care usually exceeds available resources. At the same time priority setting differs across countries, within research and across health service areas. Equally, both taxpayers/patients and funders/payers are demanding greater accountability for how resources are spent and how research and health system goals are met. The setting of health targets is another avenue to prioritisation of health research and health care delivery. Currently, about half of all World Health Organisation (WHO) Member States indicated that they have established a national or subnational process. A key function of a useful and manageable HI infrastructure is to set priorities. We frame priority setting in HI as a systematic, explicit and transparent decision-making process to prioritize research in population health, in health services and health systems research. This broad concept of health research should yield societal benefits including reduced research duplication and importantly enhanced collaboration across disciplines.

Aims/Objectives

- To identify methods to inform priority setting at European level which are transferable to the priority setting process in health information
- To inform priority setting to reduce health information inequality

Results

Techniques involving a systematic, interactive forecasting method that relies on a panel of experts and questionnaires (Delphi method) and pre-selected groups identified by managing bodies of organisations through their scientific performance with a view on the health topic of concern (CHNRI Child Health and Nutrition Research Initiative) are most common. Prioritisation is a process where individuals or groups rank identified research priorities in terms of their importance or significance. Specific criteria are normally provided to support this process. At the same time there are no uniform standards to develop priorities for health research. For example, EU research programmes e.g. Horizon 2020, 3rd Health Programme and Member States driven initiatives, e.g. Joint Programming Initiatives have been applying their own approach. Yet some initiatives have established transparent ranking methods, e.g. the European Centre of Disease

prevention and Control (ECDC) or the CHNRI approach. Yet, most priority setting processes lack adequate ex post evaluation. While prioritisation in health research is multi-layered the BRIDGE Health consortium in a recent communication has emphasized the importance of priority setting to take place in an envisioned European Research Infrastructure on Health Information (ERIC-HIREP).

Recommendations

Priority setting processes in an HIREP-ERIC should:

- be inclusive by adopting a comprehensive concept of priority setting of health research,
- be overseen by a well-managed and resourced multi-disciplinary advisory group,
- involve broad representation of stakeholders,
- utilise objective and clearly defined criteria for generating and ranking priorities,
- be systematic and transparently documented, and
- be evaluated.

Prepared by: M. M. Hofmarcher, N. Perić, J. Simon

Ethical and legal issues in health information

Background

Health data is always considered as sensitive information and therefore safeguarding the privacy of individuals has an important role when handling this type of data. If raw, individual level data is used and whenever data is transferred from one entity to the other, it is important to ensure the privacy of the individuals through anonymization.

Aims/Objectives

The aim of this HA was to investigate how BRIDGE Health partners have been hampered in their work by ethical and legal issues. We carried out a semi-structured survey of BRIDGE Health project leaders to look at obstacles that have been experienced regarding ethical and legal issues. Participants were asked 'Have you been hampered in your project by ethical or legal issues?'

Results

The major ethical or legal issues from which the researchers had been hampered in the project were secondary use of data, storage and transport of samples/data, data protection and cross country exchange.

The researchers were asked to elaborate the problem and how it was solved. Often variation in rules made it difficult or impossible to pool data in different countries. Several countries indicate the design of the informed consent was challenging and different rules had to be followed between member states. Some of the countries managed to solve those problems through different methods, which gave them the agreement to complete the study, but in some other countries the problem could not be solved which caused limitations.

Recommendations

Due to the difficulty to get clear information about rules and procedures in different countries it would be extremely helpful to have a resource regarding ethic committees, data protection and providing individual level data at European level.

A new EU Data Protection Regulation could be useful in the development of a structure which systematically brings together information on Member States level in relation to ethical and legal issues, one starting point could be Health

Data Navigator, which is one of the major instruments of EU data protection law and aims at achieving a minimum level of data protection in the Member States.

Prepared by: Lisbeth E. Knudsen

An ERIC on Health Information for Research and Evidence-based Policy for targeted investments in people's health and wealth

Common EU challenges for public health and health systems

A healthy population is a prerequisite for economic productivity and prosperity. EU member states share the ambition of improving citizens' health, providing optimal prevention and universal access to safe, effective and efficient healthcare in a financially sustainable way. Population healthy ageing, technical innovations in health care and growing citizen expectations increase the pressure on health systems. At the same time, EU economies continue to experience low growth rates and find it difficult to afford increases in health expenditure simultaneously with growing demands for health care and health high technology interventions. To make the most of health spending and investments at EU and Member State level, health policy and decision making must be based on robust evidence in the form of high quality and timely data on population health and health systems and thorough research outcomes.

More and better health information is needed throughout the EU

Accordingly, the EU and its Member State¹ need timely, sound, and high-quality health information (such as valid, reliable, comparable and policy-relevant indicators on population health and health system performance) to support policy making, strengthen programme action, including prevention and health care, and improve individual and population health outcomes. However, at present, there are three main challenges to ensure the availability, comparability and use of health information for policy-making and research.

1. Much of the gathered evidence and knowledge is dispersed, incomplete in important areas and difficult to access. A good example is the limited data on non-communicable diseases, even though they are the main cause of death and poor quality of life in the EU². Better health information governance is needed to ensure that the data we collect and knowledge we generate are consistent with our priorities.
2. Large differences can be found in terms of quality and, as a consequence, comparability of health information between and within EU countries. This makes it difficult to learn from each other. Moreover, health information

tends to be poorest in areas where health itself is poorest. This does not even allow to assess the full magnitude of health inequalities across the EU³, let alone to identify appropriate, targeted action. Better support and coordinated action are required to reduce health information inequalities across the EU and improve the quality and comparability of the collected data.

3. Under the lead of Eurostat, the European Statistical System provides a solid working basis for gathering and providing health data⁴. Beside this however, a wide range of health information activities are often funded through ad hoc projects as opposed to more sustainable structures. This lack of research continuity results in lost expertise, data collection mechanisms, research capacity, and networks⁵. Mechanisms are needed to feed the knowledge and know-how generated by these projects into more permanent data collections. Shared and targeted analysis of health data, coordinated research on health indicators and health system performance assessment, as well as comparative models between and within Member States are needed. These actions will translate health statistics and data in health information that supports health policy priorities and steers research.

The solution: creating a European Research Infrastructure Consortium (ERIC) on Health Information for Research and Evidence-based Policy

Both the European Commission and the Council of the European Union already expressed the wish to examine how an improved alignment of health information activities at EU level would function⁶. This gave rise to the BRIDGE Health project which examined the establishment of a "sustainable and integrated EU health information system"⁷, as requested by the Council of the European Union. After thorough analysis, BRIDGE Health concluded that the creation of a European Research Infrastructure Consortium (ERIC) to collect, process, analyse, report, and communicate health information can overcome these obstacles and can facilitate the governance of health information activities in the EU in a way that best supports evidence-based health policies and investments.

The European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy would be able to:

- coordinate health data collection and analysis as informed by health policy priorities,

¹ When referring to Member States in this document all EU Member States and EEA countries are included.

² Elliott H. European Union health information infrastructure and policy. In: Greer SL, Kurzer P, editors. European Union public health policy. New York: Routledge; 2013. p. 36-50.

³ http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf

⁴ <http://ec.europa.eu/eurostat/web/european-statistical-system>

⁵ <http://www.archpublichealth.com/content/pdf/2049-3258-71-12.pdf>

⁶ http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf

http://ec.europa.eu/health/strategy/docs/ev_20090428_rd01_en.pdf

⁷ http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/140004.pdf

- facilitate research on population health indicators and health system performance assessment and provide technical support to Member States,
- effectively support policy and decision-making and strengthen programme action in prevention and health care in a coherent and sustainable way

with the overall aim of improving individual and population health outcomes.

Implementing the European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy at EU level would represent a major step forward in supporting EU Member States and European Economic Area countries in their evidence based policy-making. The outputs of the Consortium in terms of better and more relevant knowledge on population health and health systems could be used to provide benchmarks, define policy ambitions and set realistic targets.

What to expect from a European Research Infrastructure Consortium (ERIC) on Health Information for Research and Evidence-based Policy?

An ERIC serves us in multiple ways:

- An ERIC operates under strict Member State governance, therefore it is tailored to their needs and priorities. It works with, through and for its members. It supports Member States in their actions in health both at national level and at EU level e.g. in the context of the European Semester.
- The ERIC is at the core of health information activities in the EU providing a contact point for Member States, and responding to specific requests by competent national authorities. It builds on existing structures and their knowledge by bringing key players together whilst representing the interest of its members. It will function as a network of networks, linking sets of national and international experts and research facilities and thereby providing clear, valid, reliable, coherent and comparable health information in ways that it is most useful for policy makers. The ERIC will not do what other stakeholders already do, but liaise and guide researchers to available and comparable data and provide information tools for policy-makers. As such, the ERIC:
 - » GENERATES KNOWLEDGE that is valid, reliable, coherent and comparable. It fills the gaps where data collection is lacking and analyses comparable datasets from EU Member States. This will prevent work from being duplicated and reduce both inefficiencies and costs.
 - » MANAGES KNOWLEDGE for better access to data through virtual and integrated platforms and by guiding users to (meta)data and help them in their use,
 - » EXCHANGES KNOWLEDGE by enhancing best practice exchange between Member States and support mutual learning by focussed

capacity building. It will support more and stronger health research networks and communities.

- » TRANSLATES KNOWLEDGE of health research outcomes to the general public and policy makers and enable researchers to optimise their research output to better suit target groups.

- The ERIC has a legal status and available expertise to benefit from relevant EU funding opportunities at a comparatively low cost to its members utilising economies of scale and scope.
- The ERIC carries out horizon scanning activities to detect early signs of important developments including new technology and its effects on the issues at hand. It also explores persistent problems and trends in population health and health systems. This will allow the ERIC to guide Member States in designing work plans and setting priorities in health policy.

The proposed ERIC is the way forward

The ERIC will enable to take up health information issues systematically and sustainably, under strict Member State governance, with the legal status and available expertise to benefit from relevant EU funding opportunities at a comparatively low cost to the Member States. Meanwhile Member States will be improving their data quality, strengthening their national research expertise and reinforcing their national health information systems. All to improve and to innovate our policies and actions that will bring better health and more financially balanced health systems.

Currently, a Joint Action is being established as a supportive step towards the ERIC allowing broad Member State support and selecting the areas where it can add the greatest value.



ACKNOWLEDGEMENTS

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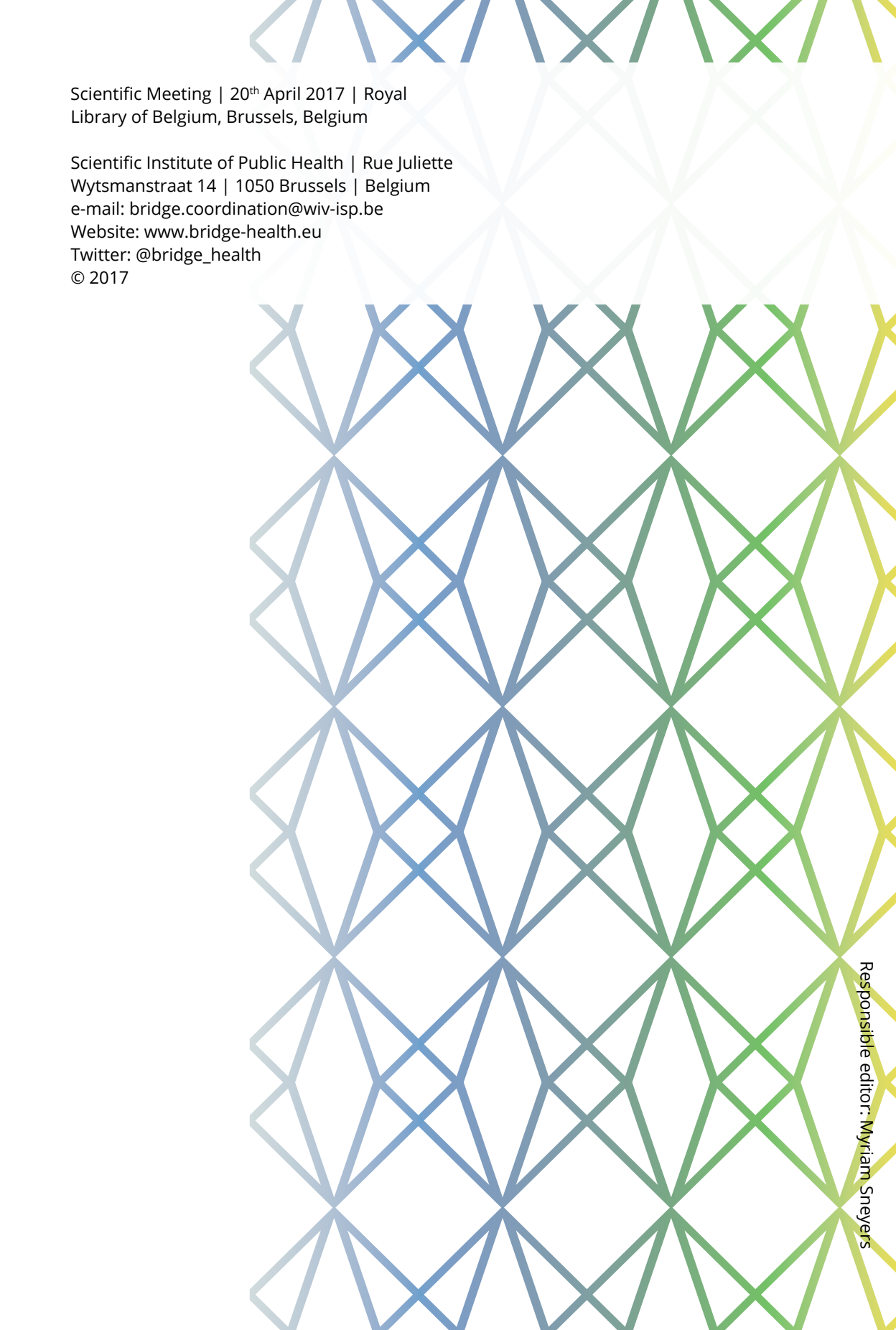
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