

HA3 - Adding the multiple level / multiple strata approach to the HIREP-ERIC

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EXECUTIVE SUMMARY

The BRIDGE Health project aims at preparing the transition towards a comprehensive, integrated and sustainable EU health information system structure, supporting research oriented to underpin policy making in Europe.

To achieve this aim, developing a Health Information for Research and Evidence-based Policy-ERIC (HIREP-ERIC) seems the most suitable option. This platform/infrastructure would be expected to carry out research, and provide scientific and technical and legal services to researchers.

HA3 recommends the design, development and maintenance of a distributed data infrastructure that allow getting the previous objectives. Operationally, the development of such an infrastructure should accomplish the following steps: 1) Entitlement of datasets according to HIREP-ERIC criteria; 2) Data model design and data sources linkage; 3) Harmonization and standardization of data; 4) Infrastructure design and data sources integration; 5) Definition of the Governance principles of the data infrastructure.

To be informative and actionable, research and reporting should be conducted using the units of analysis that are more relevant for health and health care decision- making. Conducting research considering multiple levels and multiple strata of analysis enhances research meaningfulness. The HIREP-ERIC should foster the use of multilevel and multi-strata approach in different ways: 1) Increasing awareness on the importance of collecting data at meaningful levels of interest; 2) Helping to develop a wider EU legal framework that could facilitate this approach; and 3) Developing a data infrastructure that enables the linkage, curation, management analyses and reporting of data at multiple levels (e.g., census areas, health care areas, health care providers, smaller NUTS) and population subgroup analyses (e.g., gender, age groups, socioeconomic groups).

Key points

1. The Health Information for Research and Evidence-based Policy-ERIC (HIREP-ERIC) is expected to carry out research, and provide scientific and technical and legal services to researchers.
2. Most of the European health research projects and institutional initiatives yield country level results, which may not result useful to health decision-making.
3. To be informative and actionable, research and reporting should be conducted using the units of analysis that are more relevant for health and health care decision- making.
4. Conducting research considering multiple levels and multiple strata of analysis enhances research meaningfulness.
5. The HIREP-ERIC should foster the use of multilevel and multi-strata approach in different ways: 1) Increasing awareness on the importance of collecting data at meaningful levels of interest; 2) Helping to develop a wider EU legal framework that could facilitate this approach; and 3) Developing a data infrastructure that enables the linkage, curation, management analyses and reporting of data at multiple levels (e.g., census areas, health care areas, health care providers, smaller NUTS) and population subgroup analyses (e.g., gender, age groups, socioeconomic groups).
6. HA3 recommends the design, development and maintenance of a distributed data infrastructure that fosters this kind of analyses.

Keywords: Multiple levels, Population subgroups, Distributed data infrastructure, and Translation into decision-making.

I. INTRODUCTION

What the ERIC is supposed to do?

The BRIDGE Health project aims at preparing the transition towards a comprehensive, integrated and sustainable EU health information system structure, supporting research oriented to underpin policy making in Europe. Considering the different structural and institutional options as well as funding schemas, a comprehensive European Research Infrastructure Consortium (ERIC) in health information seems the most suitable option to achieve that goal^{1,2}.

As in any ERIC, this Health Information for Research and Evidence-based Policy-ERIC (HIREP-ERIC) is expected to carry out research, and provide scientific and technical and legal services to researchers in the domains of health, health determinants and health services and policy research. In the particular case of HIREP-ERIC, the research agenda is expected to cover the health and health care priorities in Europe and support policy makers' decisions.

What are the services that the HIREP-ERIC is expected to provide?

- The HIREP-ERIC will facilitate and **support the development and hosting of health data** (individual or aggregated) **and metadata repositories** using state-of-the-art distributed systems respectful with data protection and privacy issues.
- The HIREP-ERIC will provide researchers with **methodological support**, including: data collection, quality assessment, standardization, analysis and reporting and knowledge translation.
- The HIREP-ERIC will provide **legal advice** to researchers with regard to the data access and treatment, and research outputs reporting.
- The HIREP-ERIC will provide technical and expert support to **create and maintain a set of comparable and accessible indicators** for health status, health determinants, health services and health systems.
- The HIREP-ERIC will enhance **knowledge translation** of health research outcomes into decision making for both, policy makers and general public.
- The HIREP-ERIC will carry out **capacity building** activities -training programmes enhancing researchers' mobility.

Why should we privilege a multiple level / multiple strata approach?

Cross-country research in health status, health determinants and health systems performance reveals that the observed differences within country are systematically larger than those found across countries, suggesting that the

underlying causes of such differences (and any eventual policy corrective decision) operate at local level.

Research on small area analysis or hospitals performance is plenty of examples. Along the same lines, frequently the only sub-strata analyses addressed in international research are age and sex sub-analyses, although other subgroup analyses as socio-economic or high-risk populations' subgroup analyses are of major relevance.

The use and impact of health research results in policy making will depend on how informative and actionable are its results. As a key element to be informative and actionable research and reporting should be conducted using the units of analysis that are more meaningful for decision making. Multiple level / Multiple Strata Approach should be implemented by default in the HIREP_ERIC.

Concepts in this chapter

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.

II. AIM AND OBJECTIVES

The main objective of this horizontal activity (HA3) is to incorporate multiple level/multiple strata (ML/MS) approach and the use of meaningful units of analysis in the HIREP-ERIC, to get tailored research results for better decision-making.

The key questions that HA3 addresses are the following:

1. Whether EU projects and international organisations use ML/MS approaches.
2. What are the reasons for the use/not use of ML/MS?
3. How the HIREP-ERIC could integrate a ML/MS approach.

III. APPROACH

To respond to the first question, HA3 conducted a non-systematic ad-hoc review of the BRIDGE HEALTH projects^{3,4,5,6,7,8,9,10,11,12,13}, and projects listed in the Health Data Navigator developed by the EuroREACH project,^{14,15,16,17,18} as well as some institutional initiatives using routinely collected data.^{19,20,21} We assessed 19 initiatives or projects that analysed health status, health determinants or health systems. For each of these projects we determined: origin of data (primary collection, survey, administrative data), level of data disaggregation (individual/aggregated), units of analysis (country level, region, small areas, hospitals), domain(s) (health determinants, health status or health system), scope (monitoring/research) and we also provided a brief description of the project. Finally, among those projects, we extracted examples illustrating ML/MS.

To respond to question 2, we used the *ad hoc* scoping survey sent to BRIDGE Health partners. The survey included three questions: (a) How did your project approach population subgroup and/or regional analysis in your project?; (b) Which were the limitations for your project to dig into those levels of analysis? And (c) What should be the way forward to include population subgroups' and/or regional analyses in a future EU-HIS? A total of eighteen surveys were sent to Bridge partners and 16 were sent back fully answered providing information about 14 projects

At a second stage, we also reviewed some research papers describing the initiatives and projects analysed in the previous point.^{22,23,24,25}

IV. RESULTS

Case studies in multiple level / multiple strata approach

The different case studies analysed are described in table 1. Interestingly, 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 (e.g. ECHI, EHES or EHLEIS) or, at most, at regional level (e.g. ISARE2). Exceptions to this statement are those projects whose analyses focus on hospital performance as EuroHOPE, ECHO or EuroDRG, or those focusing on regions as EURObirod or districts/neighbourhoods as iNEQCities.

When it comes to **monitoring exercises conducted by international institutions** [i.e., EC EUROSTAT, OECD, WHO], the countrywide approach is the most prevalent, in general, the only one. Just EUROSTAT²⁶, for a limited number of indicators, digs into the statistical areas (i.e., NUTS) although, frequently, those areas are not meaningful from the point of view of health. In turn, the OECD has used in-country units in some specific report²⁷ and is piloting some research on hospital performance.

Finally, among those analysed project, several examples of the ML/MS approach were found, stressing the need of the multiple level/multiple strata perspective. Thus, figures 1 to 4 exhibited the higher variation relative to health care utilisation or health status that can be found when digging into smaller levels of analysis [healthcare area (figures 1b), hospital (figures 2b or 4b)] or strata (sex group in figure 3b).

Table 1. Main characteristics of European projects based on health data

PROJECT	Origin of data	Level of data disaggregation	Units of analysis	Domain	Scope	About the project
COPHES (Consortium to Perform Human Bio-monitoring on a European Scale)	Primary data	Individual	Country level and regional comparison within countries.	Health determinants. Environmental factors	Monitoring	First European wide protocol for human bio-monitoring. Biomarkers for mercury, cadmium, phthalates, bisphenol A, environmental tobacco smoke in human hair and urine from around 120 mother-child pairs in the 17 participating countries, in total almost 4000 samples. COPHES used a pilot stratification approach with predefined strata of gender, age and sampling area (urban/rural) in each country. The sample size allowed us to estimate preliminary country specific reference values and a minimally important difference in mean biomarker values of 30% between countries. Multiple regression models were used for comparison between countries Data were adjusted for specific exposures, educational level, life-style and socio-economic status as well as for age, gender and weighed for equal group sizes.
CHICOS (Developing a Child Cohort Research Strategy for Europe)	Previous cohorts studies	Individual	Pooled data from cohorts (individual level)	Health status and health determinants	Research	Promote an inventory of all mother-child cohorts in Europe , to evaluate existing information on outcomes and determinants from these cohorts, to identify gaps in knowledge, and to develop recommendations for research action at a European level for the next 15 years, focusing on key areas of policy concern. 21 countries, 77 cohorts
Euro-Peristat (Better statistics for better health for mothers and babies in Europe).	Administrative data, medical birth registers, surveys	Aggregated	Country level (when national data is not available, the region data is accepted)	Health, health determinants and health system (services)	Monitoring/ Research	Covers perinatal health , defined as maternal and child health during pregnancy, delivery and the postpartum. Indicators cover health determinants, health care services and interventions and maternal and child health outcomes. Data for some population sub-groups based on SES (education and profession) and country of birth.
ENRIECO (Environmental Health Risk in European Birth Cohorts)	Previous cohorts studies	Individual	Pooled data from cohorts	Health determinants. Environmental factors	Research/ Monitoring	The aim is to advance knowledge on specific environment and health causal relationships in Pregnancy and birth cohorts by providing support to exploitation data generated by past or ongoing studies funded by the EC and national programmes. Exposures in 37 European birth cohort studies, with data available for smoking and SHS (N=37 cohorts), occupational exposures (N=33), outdoor air pollution, and allergens and microbial agents (N=27). The structuring and consolidation of data from various studies will improve the knowledge base for environment and health linkages. Data regarding environment-health causal relationships will be more readily available in a form useful for policy makers.

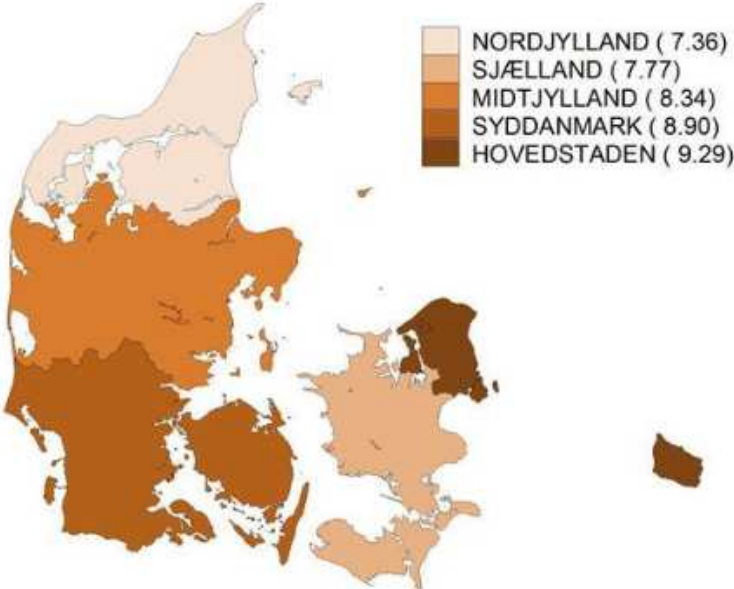
PROJECT	Origin of data	Level of data disaggregation	Units of analysis	Domain	Scope	About the project
ECHI (European Core Health Indicators)	Mainly Eurostat, but also: WHO, OECD, specific programmes, databases and surveys (i.e. EHES).	Aggregated	Country level (but a set of regional health indicators was developed)	Health status and health determinants	Monitoring	Health indicators are sets of data on health status, determinants and care in EU member countries and other European countries. They allow for monitoring and comparison, and serve as a basis for policy-making. Operational indicators reflect the precise definitions of the breakdowns required for the indicators according to sex, age, socio-economic status, and other possible dimensions. For some indicators a breakdown by region is required.
EHES (European Health Examination Survey)	Survey	Individual	Country level (some countries have extended the sample size to allow regional analysis)	Health status and health determinants	Monitoring	Initiative to set up a system of standardized, representative health examination surveys (HES) of the adult population of the European countries. Health examination surveys include questionnaire(s) as well as physical measurements, (anthropometry, blood pressure), and collection of biological samples (e.g. blood, urine). National sample should allow age and sex stratification at least, but it is also recommended reporting results by one additional strata, for example education, employment status, etc.
EHLEIS (The European Life and Health Expectancy Information System)	Data from existing surveys: SILC, SHARE, ESS, ECHP	Individual	Country	Health status and health determinants	Monitoring	Monitors several health expectancies based on 3 questions (Life expectancy in good perceived health, life expectancy without chronic morbidity and life expectancy without activity limitation) composing the Minimum European Health Module (MEHM) that was included in the Statistics on Income and Living Conditions (SILC). Population and health data databases access in its website
IDB (European Injury Data Base)	Patient based administrative data collected in representative sample of hospitals, nationwide or in one regions or provinces.	Individual	Country estimation. In countries where population based data is collected it is possible to undertake regional and small area analyses.	Health status and health determinants	Monitoring	To facilitate targeted injury prevention policies and programs at EU and national level. It provides information on frequency, main causes, circumstances and consequences of non-fatal injuries in the EU and the EU member states. Standardized cross-national information on the external causes of non-fatal unintentional injuries treated in emergency departments in the EU (home injuries, sports and leisure, workplace and road injuries, intentional injuries resulting from violence and self-harm). Work is being done in analysing injury data related to specific risk groups such as children and older people.
EuroHOPE European Health Care Outcomes, Performance and Efficiency.	Patient level linkable registers and administrative data	Individual	Regional and hospital level analysis	Health status and health system	Research	Evaluates the performance of European health care systems in terms of outcomes, quality, use of resources and costs.

PROJECT	Origin of data	Level of data disaggregation	Units of analysis	Domain	Scope	About the project
ECHO (European Collaborative for Healthcare Optimization)	Patient-based administrative data	Individual	Small area, health authority, region, country	Health status and health system	Research	Provide insight on how to build a data infrastructure based on individual patient-level data and exploring the integration of routinely collected administrative data from different European experiences
EUBIROD (European Best Information through Regional Outcomes in Diabetes)	Patient-based administrative data. Regional registries already implemented	Individual/Aggregated	Region (but only some regions in a few countries)	Health status and health system	Monitoring	Implement a sustainable European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO technology. Participants are connected through a system that automatically generates local statistical reports and safely collects aggregate data to produce international reports of diabetes indicators . Compendium of existing databases. The completeness and range of indicators varied among regions.
INEQ-cities	Census, census based sample, register	Individual	Census tract, neighbourhood, district, parish	Health status (mortality) and health determinants	Research	Identify socioeconomic inequalities in health and mortality and to examine urban health policies developed to tackled such inequalities in health in 16 European cities. Cross sectional ecological mortality study using data from census or register
I2SARE	Eurostat	Aggregated (Eurostat)	NUTS2.basic regions for the application of regional policies	Health status and health determinants	Monitoring/ Research	The main objective of the I2sare project is to assist European, regional and local decision makers in developing their health policy, by informing them of the state of health of the populations in the regions of Europe.
SHARE Survey of Health, Ageing and Retirement in Europe	Survey	Individual	Country level (You can ask for data individual¿?)	Health status and health determinants	Monitoring/ Research	The Survey of Health, Ageing and Retirement in Europe (SHARE) is a multidisciplinary and cross-national panel database of micro data on health, socio-economic status and social and family networks of approximately 123,000 individuals (more than 293,000 interviews) from 20 European countries (+Israel) aged 50 or older.
EuroDRG	Patient-based administrative data	Individual	Hospital	Health system	Research	Analyse national DRG based hospital payment system in 12 countries. Comparison of hospital costs and resources (los) for common treatments and relation ship between DRG and quality of care

Shaded rows projects not participating in BRIDGE

Figure 1. Age and sex-standardised coronary artery bypass grafting utilisation rate per 10,000 inhabitants by health regions (a) and *kommuner*, in Denmark 2009. Source: http://echo-health.eu/wp-content/uploads/2014/12/report_CV_DNK.pdf

(a)



(b)

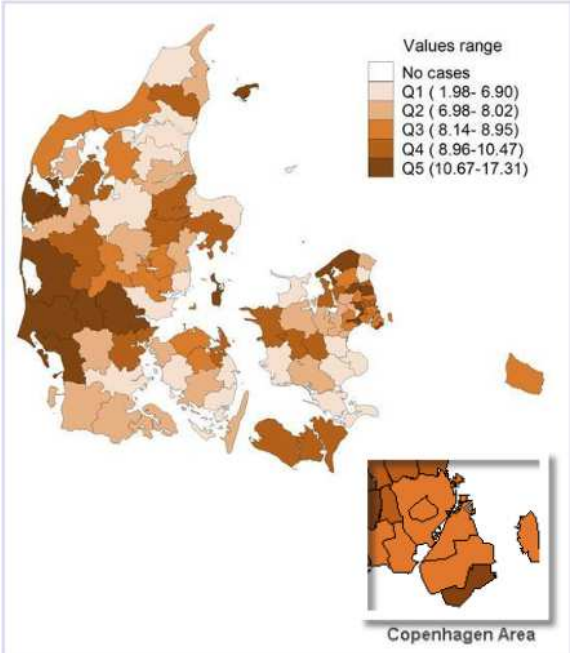
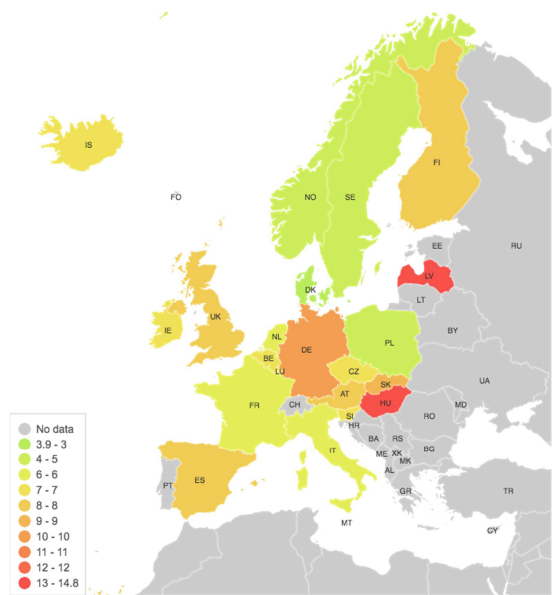


Figure 2. (a) Proportion of in-patients with primary diagnosis of acute myocardial infarction (AMI) who died within 30 days after admission in 2009 (ECHI Indicator) (b) In-hospital mortality after AMI admission at English hospitals, 2009 (ECHO project). Sources: (a) http://ec.europa.eu/health/indicators/indicators/index_en.htm; (b) http://echo-health.eu/wp-content/uploads/2014/12/report_CV_ENG.pdf

(a)



(b)

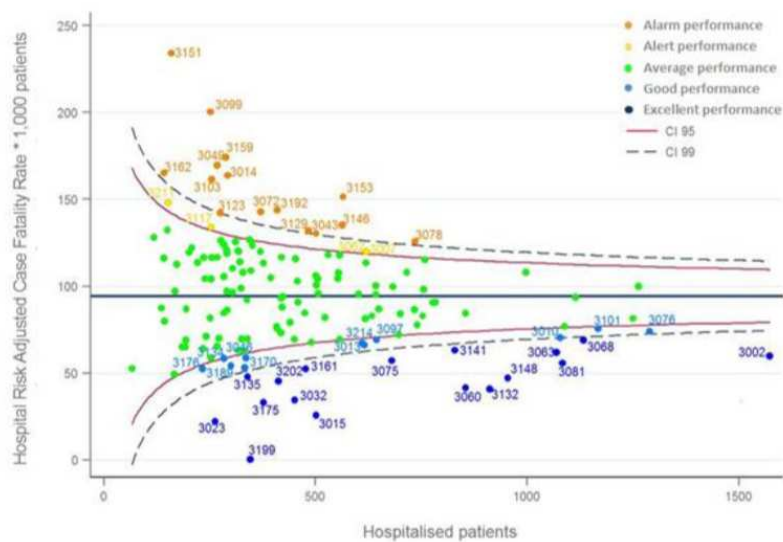
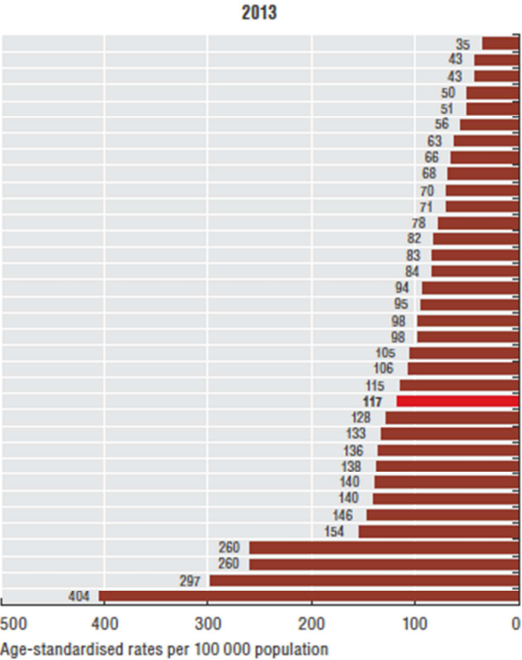


Figure 3. Ischaemic Heart Disease Mortality (a) in OECD countries 2013, and (b) in Barcelona over the period 2000-2008. Sources: (a) <http://www.oecd.org/health/health-systems/health-at-a-glance-19991312.htm>.(b) <https://www.ucl.ac.uk/ineqcities/atlas/cities/barcelona/disease-specific-mortality/ischaemic-heart-disease>

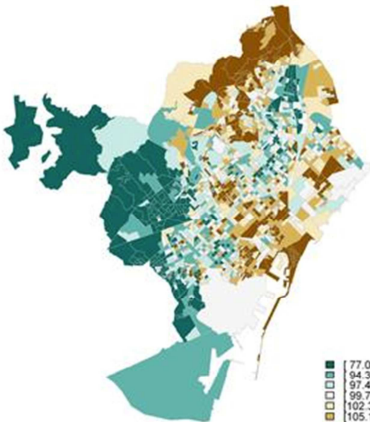
(a)

(b)



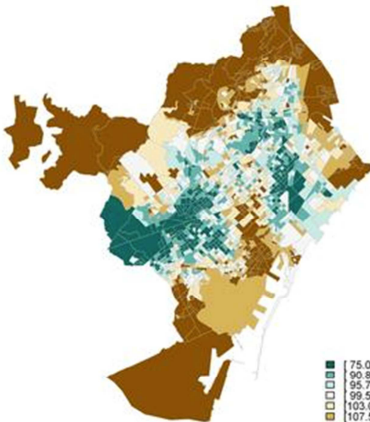
Men

Smoothed Standardised Mortality Ratio (sSMR)



Women

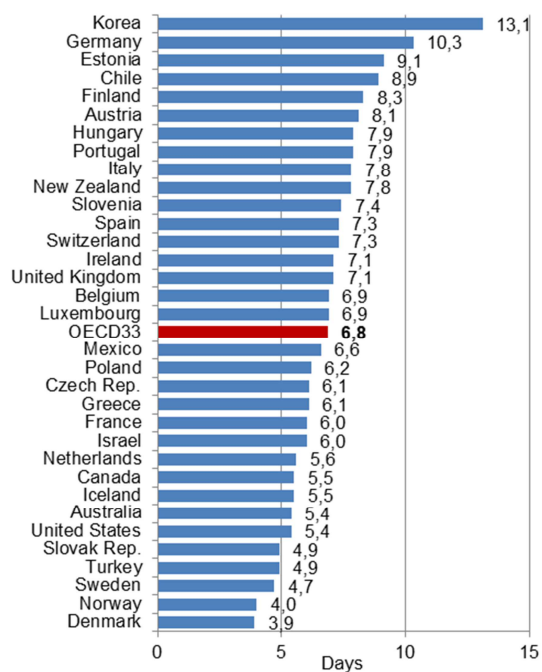
Smoothed Standardised Mortality Ratio (sSMR)



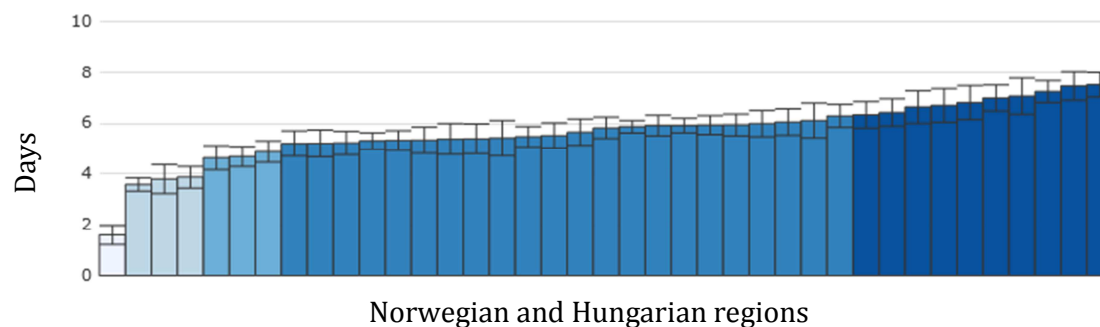
Source: OECD Health Statistics 2015, <http://dx.doi.org/10.1787/health-data-en>.

Figure 4. Average length of stay for acute myocardial infarction (AMI) (a) in OECD countries 2013, and (b) age and sex standardized acute hospital days for first hospital AMI episode in Norwegian and Hungarian regions 2014. Sources a) OECD Health Statistics 2015, <http://dx.doi.org/10.1787/health-data-en> (b) <http://www.eurohope.info/map/atlas.html>

(a)



(b)



Reasons for the paucity of ML / MS approach

Out of the questionnaire responses from the different BRIDGEHealth partners and a more extensive review of those projects and expanded literature review on the topic, there are six overarching reasons that, could be argued to understand the scarcity of the multiple level / multiple strata approach. Thus,

1. Lack of data disaggregated at the units of interest^{22,23,24}
2. Lack of interest in the secondary use of routinely collected data²⁵
3. Limited access to data, in particular to individual data^{22,23,24}
4. Limits to the reporting at smaller units due to privacy and legal issues
5. Methodological gaps on how to adequate the research design to a multiple level /multiple strata approach, how to manage data, primary or secondary, from many sources, and how to conduct relevant analyses;
6. Lack of logistic capacity to manage and analyse big amounts of data.

Ideally all these arguments should be tackled in an eventual HIREP-ERIC. A reflection on the way forward is provided in the next paragraphs.

V. RECOMMENDATIONS ON HOW THE HIREP-ERIC COULD INTEGRATE A ML/MS APPROACH

- With regard to the lack of data or the poor interest in the secondary use of routine data, although both pretty much depend on country specific idiosyncrasy and different political priorities, the HIREP ERIC could play a role in increasing awareness on the importance of collecting data at meaningful levels of interest, or 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 arguments behind lay mostly on the legal boundaries; in this case, the HIREP-ERIC must assure the strict accomplishment of the legal provisions in each country in any task developed within its mission, while working on developing a wider EU legal framework which could facilitate this kind of research.
- The HIREP-ERIC should privilege and promote the use of those existing European databases suitable for a ML/MS approach.
- With regard to methodological gaps, the HIREP-ERIC could play an important role increasing the EU research capacity via training and mobility programs, on the other hand, one of the classical services that an ERIC is expected to provide.
- Finally, to deal with the lack of logistic capacity to manage and analyse big amounts of data, the HIREP-ERIC should develop the data infrastructure and associated services that would support the previously illustrated multiple level / multiple strata perspective. This element is detailed in the next section.

Developing a distributed data infrastructure enabling a ML / MS approach

To enable ML/MS approach a research infrastructure should be built upon four cornerstones.

1) The HIREP-ERIC should be designed to support any kind of research in health status, health determinants and health systems performance. In the achievement of this aim the HIREP-ERIC should provide added value services upon the development and hosting of health data and metadata.

2) Unlike the usual development of project-specific ad hoc data sets, the infrastructure should first host a common set of data (i.e., useful for any kind of research) and then any specific data sets that, linked to the common set, would enable further research in specific domains.

3) Not all data sets will be suitable for this data infrastructure. Beyond the basic elements (i.e., data are relevant to the mission of the HIREP-ERIC, data allow research, and data origins are available electronically), three requirements should be considered to entitle each data set as potentially contributing to the infrastructure.

- The dataset should allow linkage to other data sets, once personal data are de-identified and / or pseudo-anonymized.
- The dataset should enable multiple level analysis (e.g., census areas, health care areas, health care providers, NUTS 2 and 3) and strata analyses (e.g., gender, age group, socioeconomic group).
- The dataset should accomplish international standards (e.g., standard taxonomies) and be built and maintained according to *data quality assurance* standards (i.e., coverage, reliability and accuracy)²⁸

4) Finally, to provide support to policy makers, the HIREP-ERIC should be able to produce policy oriented outputs, easily accessible, and user friendly. Example of this kind of outlets can be found in the English NHS Atlas,²⁹ in the INEQcities project,³⁰ in the Spanish AtlasVPM³¹ or in the Epidemiology Department in Lazio in Italy website.³²

Steps to get the data infrastructure implemented

Operationally, the development of such an infrastructure should accomplish the following steps: 1) Entitlement of datasets according to HIREP-ERIC criteria; 2) Data model design and data sources linkage; 3) Harmonization and standardization of data; 4) Infrastructure design and data sources integration; 5) Definition of the Governance principles of the data infrastructure.

1) Entitlement of datasets according to HIREP-ERIC criteria

Country partners participating in the HIREP-ERIC should map out the information sources with a potential in ML/MS analysis; for example, administrative, other non-administrative routinely collected info (i.e., registers, surveys), and also project-specific datasets. (In an ulterior step electronic health records should be considered, as well).

To get the data sources entitled the HIREP-ERIC would qualify the datasets, in terms of a) Linkage capacity, b) Type of multiple level /strata analysis that could be performed; and, c) Quality of the original sources.

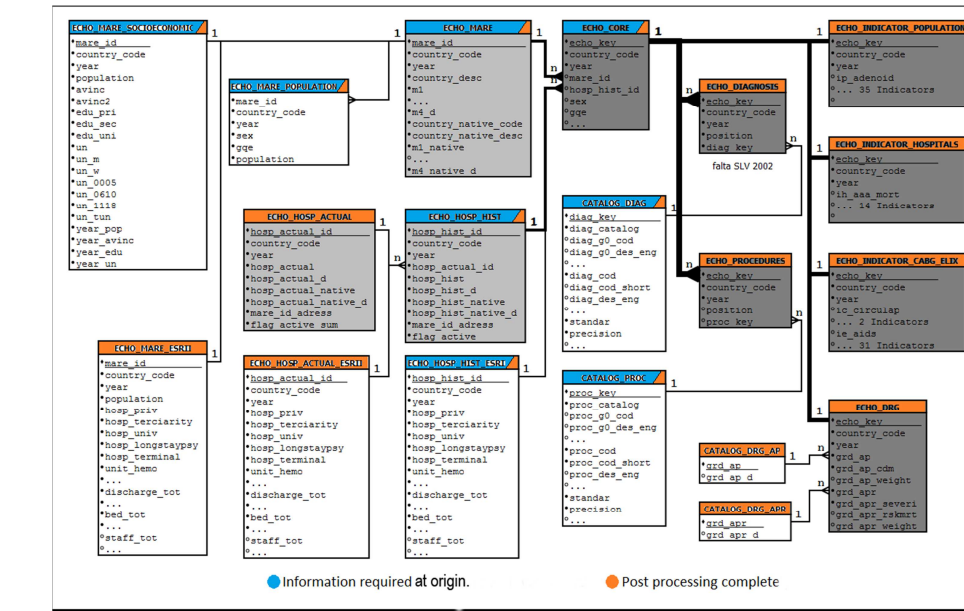
[NB. The corresponding governing body in the ERIC should decide in advance on the qualification and entitlement methodologies a,b]

2) Data model design and data sources linkage

Data model design entails decisions on whether the data infrastructure is allowed to manage individual data, to perform 1 to 1 linkage and 1 to N linkage and on how to manage big data processes efficiently.

Figure 5 shows the data model used in the ECHO project, as an illustration of a relational model that allows 1 to 1 and 1 to N linkage, designed to manage millions of registers (200 million).³³

Figure 5. ECHO data warehouse relational model scheme



^a Several methodologies have been proposed, as a matter of examples: Quality Assurance Framework of EUROSTAT [<http://ec.europa.eu/eurostat/documents/64157/4392716/ESS-QAF-V1-2final.pdf/bbf5970c-1adf-46c8-afc3-58ce177a0646>] or Harrison et al Critical Care 2004 [https://openi.nlm.nih.gov/detailedresult.php?img=PMC420043_cc2834-1&req=4]

^b An algorithm as the one presented in could be used to make the decision Black C, McGrail K, Fooks C, Baranek P, Maslove L. Data, data, everywhere: Improving access to population health and health services research data in Canada. Final Report. Canadian Policy Research Networks Centre for Health Services and Policy Research April 2005 (pg 77)

3) Harmonization and standardization of data.

Once the data sources are mapped out and entitled to be part of the HIREP-ERIC, harmonization/standardization processes should be put in place to increase data reliability and accuracy, either on original sources or over the consolidated dataset. Moreover, a specific effort should be made to get the units of interest comparable. Some of these tasks are common to the any data set, and some are project specific.

[N.B. details of this task are presented in horizontal activity 4 -Standardisation methods of the collection and exchange of health information- and 5 -Data quality methods including internal and external validation of indicators-].

4) Infrastructure design and data sources integration

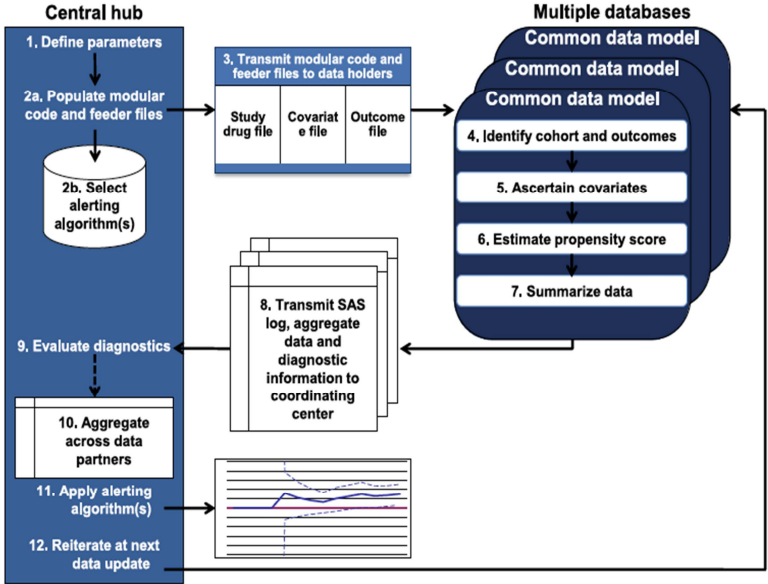
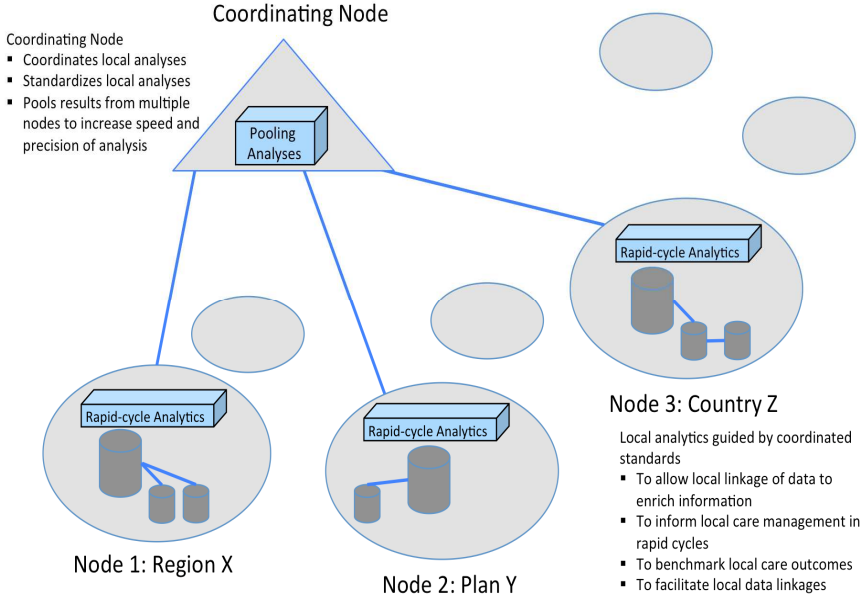
Given the data transfer restrictions, limitations, or merely administrative barriers, as well as the legal implications associated to data protection, a growingly accepted solution is **the design and development of a distributed infrastructure**. This approach has been used in some initiatives as Mini Sentinel, a surveillance system to monitor safety of medical products developed in the context of the FDA³⁴, the demo of European Remote Access Network developed by Data without Boundaries project,³⁵ or in EuroBIROD project to safely collect aggregated data about diabetes from the existing national/regional frameworks³⁶. Figure 6 exhibits the example of Mini Sentinel.

Main characteristics of this kind of system are: data remain in the country, de-identification and pseudo-anonymization of original personal data are implemented in origin, data are linked in the country following the common data model design, standardization and quality processes are implemented in the country following the HIREP-ERIC prescriptions, and data extraction and analyses are implemented in the country following a common methodology developed in a specific hub, while enabling data transfer if necessary (and legally possible). Among the cons of such a distributed system, contributing to a distributed system a minimum amount of resources (equipment, network and personnel) is required.

5) Definition of the Governance principles of the data infrastructure

HIREP ERIC governance body should include in the governance rules of the ERIC specific elements to rule this distributed infrastructure. Aspects to make decisions on will be: a) the requirements for partners to be part of the distributed infrastructure; b) how to access and use the infrastructure; c) how to prioritize the research initiatives; d) how to approve research initiatives; e) what support services should be implemented and how should be provided; and f) how to curate, maintain and upgrade the infrastructure.

Figure 6. Mini sentinel distributed system



VI. CONCLUSIONS

The Health Information for Research and Evidence-based Policy-ERIC (HIREP-ERIC) is expected to carry out research, and provide scientific and technical and legal services to researchers in the domains of health, health determinants and health services and policy research.

For research to be relevant, the units of analysis (i.e., the disaggregation at which research results are study and represented) should be meaningful in decision-making.

HIREP ERIC should actively be involved in developing a data infrastructure that enables multiple levels (e.g., census areas, health care areas, health care providers, NUTS 2 and 3) and population subgroup analyses (e.g., gender, age group, socioeconomic group).

HA3 recommends the design, development and maintenance of a distributed data infrastructure that fosters this kind of analyses. Operationally, the development of such an infrastructure should accomplish the following steps: 1) Entitlement of datasets according to HIREP-ERIC criteria; 2) Data model design and data sources linkage; 3) Harmonization and standardization of data; 4) Infrastructure design and data sources integration; and 5) Definition of the Governance principles of the data infrastructure.

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