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

HA2- Reducing health information inequality in Europe: A scoping paper

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Table of contents

Lists of tables and figures

I. Introduction

A health information (HI) system that involves all of Europe's member states is strongly justified from population health and health system performance perspectives. European countries face common health challenges such as aging populations and increasing multimorbidity, obesity, chronic diseases, geographical and socio-economic health differences and the optimal use of new health technologies. They can benefit from pooling information regarding population-level risk factors, high risk conditions and prevalence of chronic non-communicable diseases. Furthermore, a great diversity in cultural, social, and organizational approaches to prevention and health care exists within Europe. Sharing experiences about the benefits of prevention, the best use of healthcare interventions and the quality of care, as well improving an understanding of how neighbouring countries structure their healthcare systems to manage health risks and challenges will allow for the development and evaluation of national and European policies based on best practices. European countries also face similar economic and demographic pressures and share an interest in monitoring the impact of their policies on all EU citizens. Common care and outcome data are essential benchmarks for identifying possible gains in efficiency and cost and keeping our systems sustainable and accessible.

The availability of high quality, reliable and comparable health information (HI) across all European health systems is necessary for achieving a HI system that provides evidence to meet these challenges. Having full representation of Europe's diversity is essential to maximize added value for planning preventive actions, improving the quality and performance of care and for evaluating and shaping health policies. It is also essential for measuring the impact of policy choices in all countries. To create such a system, it is first necessary to assess ***health information inequality***, which we define 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 and other national/representative data collected by ad-hoc surveys/registries.** HI inequalities ultimately limit the ability to conduct comparative analysis, benchmark against targets or other countries and to even observe changes over time, leading to inaccurate estimations of progress in health outcomes and hindering the development of evidence based policies (1).

HI inequality in the European context results from limitations at various levels of the heterogeneous national health and information systems of the member states, but can also reflect unequal participation among MS in European collaborations. These obstacles can affect availability of national data for European HI initiatives due to it not being collected at the national level, or collected but in a non-comparable way or collected but not used for surveillance analyses, or while being available but not included in EU projects. Understanding the level at which these inequalities are generated is important for defining solutions. The marginal costs and efforts of overcoming these obstacles are greatest at the bottom tier, as new and comprehensive health information systems need to be created at the country level (Fig 1).

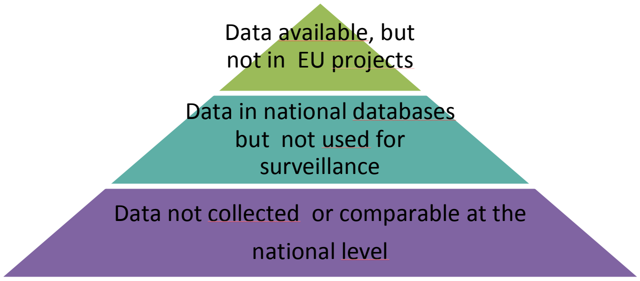

Figure 1: Schematic presentation of levels of HI inequality

This report aims to review existing assessments of HI inequalities between European member states (MS) overall and subsequently assess how they relate to the BRIDGE Health initiative. Our analysis is based on a review of the published literature and on the outcomes of projects participating in the BRIDGE Health initiative. These projects are EU Commission financed HI initiatives set up over the past two decades and constitute the building blocks for a future EU HI infrastructure. Their ability to achieve HI equality as well as the difficulties they have confronted are instructive for identifying the principal obstacles.

This report first maps the countries and institutions participating in the BRIDGE Health HI projects and assesses inequality on the first level of the pyramid represented in Figure 1; it then describes inequality in data availability in the MS and the obstacles and facilitators of high quality data systems based on the published literature and agency reports and assessments by BRIDGE Health project representatives.

II. Methodology

A. Literature Review

In order to review information about differences between health information systems in the member states as well as previously identified determinants of HI inequalities in the European context, we conducted an electronic literature search of Medline and Google Scholar for existing assessments of European health information systems over the last 15 years. The websites of pertinent multilateral agencies (e.g. WHO, OECD, UN, EU) were also queried and the full texts of relevant reports of projects and assessments were abstracted. The reference lists of scientific articles identified from the search were reviewed. Articles citing identified studies and reports were also examined. Table S1 in the appendix provides the search terms and the items returned. A PRISMA diagram was not appropriate for this literature search, as the concept of health information equality is not a term that covers a commonly accepted concept or definition. It therefore does not lend itself to identifying studies that can be included in a systematic review. However, by developing searches based on these terms (*health-information-systems-inequality-Europe)* as shown in the supplementary tables, we were able to identify studies discussing dimensions of health information systems as well as differences across European countries that provided a context for this scoping exercise.

B. Scoping exercise with BRIDGE Health projects

We also carried out a scoping exercise to examine HI data sources and collaborative synergies between countries and institutions among BRIDGE Health partner projects by reviewing project documents and websites. For each project, we identified all the members of the action. In some cases there were several levels of participation (i.e. in the management/coordination team or involvement in data provision or analysis). In these cases, we used the broadest definition of participation. Within participating countries, we identified partner institutions. Several institutions could participate in one action from a single country. We created a classification to describe participating institutions (government, health agencies, university, research institutions, non-governmental organisations, private companies/businesses).

The results were compiled in an excel spreadsheet and circulated to all partners for verification and to fill in missing information. The results of the verified country and institution level HI collaborations allow us to quantify national participation in projects, describe key institutional partners, and assess the links between countries. We used mapping software to describe links between countries overall and for countries separately.

C. Survey of BRIDGE Health Project Leaders

Data also come from a semi-structured survey of BRIDGE Health project leaders which aimed to identify obstacles and the perceived reasons for HI gaps in their project areas. The survey also included questions contributed by other Horizontal Activity leaders on their topic. The survey was completed by 19 respondents from 11 of the BRIDGE Health projects.

The questions asked for the Health Information Inequality Horizontal Activity were:

- In your area, are there countries that have advanced health information systems which could be models for others?
- What are the principal obstacles to developing health information focused on your area in countries with poor health information systems?
- Did your past project implement any specific actions/strategies to improve health information in these countries?
- In your area, is linkage of existing data sources one way to improve available health information.

The responses to this survey were analysed to identify common themes regarding barriers and enablers to attaining comparable and equitable European HI systems.

III. Country and institution participation in BRIDGE Health Projects

Fourteen projects covering a broad range of domains and multiple methodological approaches participate in BRIDGE Health. These projects are described in Table 1 by their acronym and title, coordinating institution, and research field. Coordinators of these projects are from Austria, Belgium, Germany, Ireland, Italy, Finland, France, the Netherlands, Spain and the UK.

Table 1: BRIDGE health Projects

Acronym	Project title/topic area	Coordinating institution	Research field
CHICOS	Developing a Child Cohort Research Strategy for Europe	Centre for Research in Environmental Epidemiology (CREAL) - Spain	Reproductive, maternal, new born, child and adolescent health
COPHES	Consortium to Perform Human Biomonitoring on a European Scale	BiPRO, Germany	Environmental chemicals and health
ECHI/ECHIM	European Core Health Indicators and Monitoring	Robert Koch-Institut (RKI) Rijksinstituut voor Volksgezondheid en Milieu (RIVM) National Institute for Health and Welfare (THL) - Finland	European Core Health Indicators Monitoring
ECHO	European Collaboration for Health Optimization	Aragon Health Sciences Institute - Spain	Platform for administrative data on health care
EHES	European Health Examination Survey	National Institute for Health and Welfare (THL) - Finland	Health examination surveys
EHLEIS	European Health and Life Expectancy Information System	National Institute of Health and Medical Research - France	Healthy Life Years
EUBIROD	European Best Information through Regional Outcomes in diabetes	University of Perugia - Italy	European diabetes register through the coordination of existing national/regional frameworks and systematic use of technology BIRO
EUROCISS	European Cardiovascular Indicators Surveillance Set	National Institute of Public Health - Italy	Manuals of operations for coronary and cerebrovascular population based registries and cardiovascular surveys on the general population
EuroHOPE	European Health Care Outcomes, Performance and Efficiency	National Institute for Health and Welfare (THL) - Finland	Integrate health information systems
EUROPERISTAT	Surveillance of	National Institute of	Reproductive,

	maternal and new born health in Europe	Health and Medical Research - France	maternal, new born, child and adolescent health
EuroREACH	n/a	European Centre for Social Welfare Policy and Research – Austria	Evaluation of health care systems
EU-IDB/Eurosafe	European Injury Database	Eurosafe/ Secretariat: United Kingdom	Integrate information on injuries
OBELIX/ENRIECO	Environmental Health Risk in European Birth Cohorts	University of Amsterdam/ Centre for Research in Environmental Epidemiology (CREAL) - Spain	Environmental chemicals and health
RICHE	Research Inventory for Child Health in Europe	Dublin City University - Ireland	Reproductive, maternal, new born, child and adolescent health

Table 2 illustrates the broad diversity in the data sources used by the BRIDGE Health projects, including data from national registers and databases, GP networks, hospital data, and routine surveys. The most common data sources were hospital data (6 projects), national health registers (5 projects) and routine national surveys (5 projects). Most use sources that are available in routine, whereas several projects incorporate data from research studies as well as population cohorts - the case of CHICOS and ENRIECO which rely on birth cohorts established across Europe.

Table 2: Data sources utilized by BRIDGE health projects

	National registers	GP net-works	Hospital data	Specialized national databases	Other admin databases	Routine National surveys	European databases	Internat. Data-bases	Bio-data	Research study	Population cohorts
CHICOS	X										X
COPHES									X		
ECHIM JA							X				
ECHO			X								
EHES						X					
EHLEIS						X					
EUBIROD		X		X							
EUROCISS	X		X		X	X					X
EuroHOPE	X		X	X							
EUROPERISTAT	X		X	X		X	X				
EuroREACH	X		X	X			X	X			
EU-IDB			X	X			X	X			
OBELIX/ENRIECO						X				X	X
RICHE							X	X			

Figure 2 provides an illustration of the involvement of MS in the BRIDGE projects. This figure displays the involvement of the EU MS in these initiatives. The UK, Denmark, Finland, Norway, the Netherlands, Spain, Italy, Belgium and Germany are involved in 8 or more projects (about 75% or more of the total) while some countries are involved in only 2 or fewer projects (Latvia, Lithuania, Czech Republic, Croatia, Slovakia, Malta). It is of note that some of the projects started before some of the newer member states joined the EU and therefore they would be expected to have less involvement.

Appendix B displays several examples of the connections that exist between countries (i.e. the number of shared projects with others). These figures provide a more dynamic vision of cross-country connections and illustrate the diversity across countries in these links.

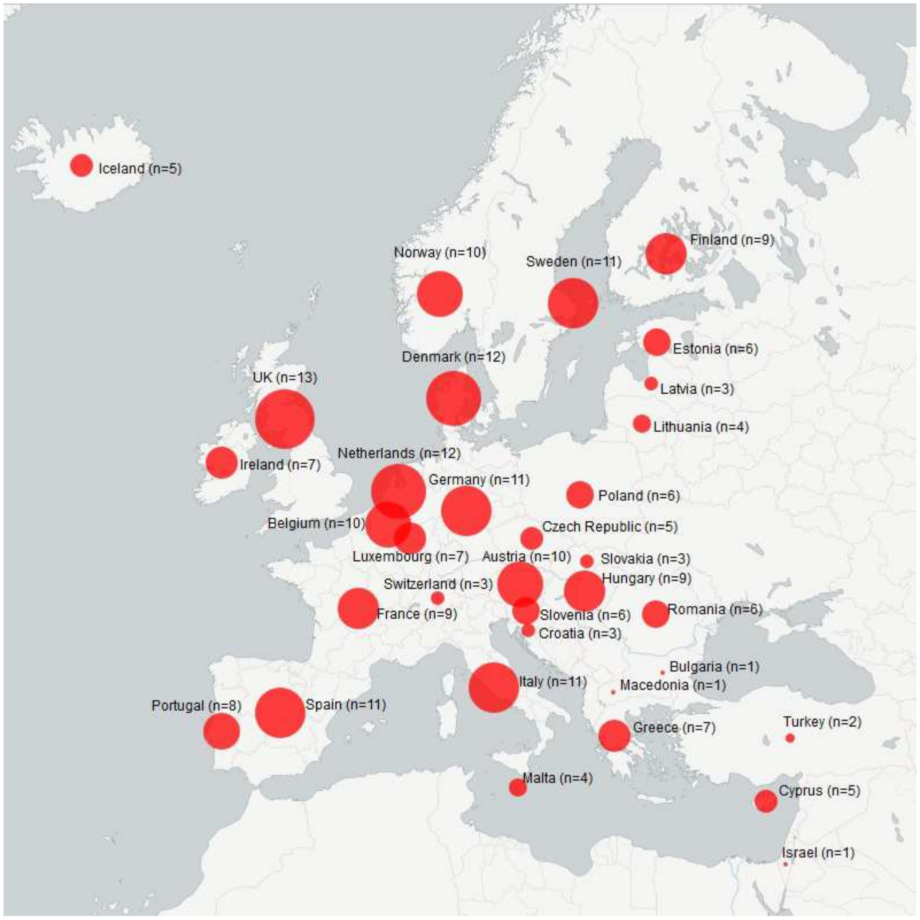

Figure 2 Participation in the 14 BRIDGE Health projects by country

Table 3 provides more data on participation and partners, providing the number of projects (and percent involvement), the number of partners in each project (one project can have several partners from one country) and the number of involved institutions (one institution can be involved in several projects). This table illustrates several different situations which likely reflect the organization of health information systems in each country. One extreme is the UK, which is very well represented in the BRIDGE Health projects by a large number of partners, generally coming from different institutions. In contrast, Finland, while present in 9 of the 14 projects, is represented by 10 partners coming from only 2 institutions. Sweden is also another country where there is involvement of one institution in multiple projects. However, the fact that several partners to the BRIDGE Health projects come from the same institution does not necessarily imply coordination or even information sharing within the institution. But if not, there may be a greater potential, and lower costs, for creating links, reinforcing cooperation, and sharing experiences.

Table 3: Involvement in BRIDGE projects by country

Projects	N of projects	% of projects (N=14)	N of partners	% of total partners (N=274*)	N of institutions	Institutions per project
Austria	10	71.4	11	4.0	11	1.1
Belgium	10	71.4	15	5.5	12	1.2
Bulgaria	1	7.1	1	0.4	1	1.0
Croatia	3	21.4	3	1.1	3	1.0
Cyprus	5	35.7	5	1.8	1	0.2
Czech Republic	5	35.7	5	1.8	4	0.8
Denmark	12	85.7	14	5.1	8	0.7
Estonia	6	42.9	7	2.6	4	0.7
Finland	9	64.3	10	3.6	2	0.2
France	9	64.3	10	3.6	6	0.7
Germany	11	78.6	16	5.8	14	1.3
Greece	7	50.0	8	2.9	6	0.9
Hungary	9	64.3	10	3.6	9	1.0
Iceland	5	35.7	5	1.8	5	1.0
Ireland	7	50.0	9	3.3	9	1.3
Italy	11	78.6	15	5.5	11	1.0
Latvia	3	21.4	3	1.1	1	0.3
Lithuania	4	28.6	4	1.5	3	0.8
Luxembourg	7	50.0	7	2.6	6	0.9
Malta	4	28.6	5	1.8	3	0.8
Netherlands	12	85.7	14	5.1	7	0.6
Norway	10	71.4	14	5.1	7	0.7
Poland	6	42.9	6	2.2	6	1.0
Portugal	8	57.1	10	3.6	9	1.1
Romania	6	42.9	6	2.2	6	1.0
Slovakia	3	21.4	3	1.1	3	1.0
Slovenia	6	42.9	6	2.2	4	0.7
Spain	11	78.6	13	4.7	10	0.9
Sweden	11	78.6	11	4.0	5	0.5
Switzerland	3	21.4	4	1.5	4	1.3
UK	13	92.9	24	8.8	21	1.6
Totals	14 projects	100.0	274* partners	100.0	201 institutions	14.1

Note: *EU partners + Iceland, Norway and Switzerland

As seen in Table 3, 201 institutions participate in BRIDGE Health projects. Table 4 provides information by country about the types of institutions which are involved. The largest group is “public agencies”, which participate in at least one BRIDGE project in almost all countries. However, university departments (in 26 countries) and research institutes (in 14 countries) are also involved. The other types of institutions include hospitals as well as NGOs, private companies, and professional associations, which are grouped together in the table under private organisations.

Table 4: Types of institutions involved in BRIDGE Health projects

Country	University Departments	Public Agencies	Research Institutes	Hospitals	Private organizations*	Multilateral agencies
Austria	X	X	X		X	
Belgium	X	X	X		X	
Bulgaria		X				
Croatia	X	X	X			
Cyprus		X				
Czech Republic	X	X	X			
Denmark	X	X	X		X	
Estonia	X	X				
Finland	X	X				
France	X	X	X	X		
Germany	X	X		X	X	
Greece	X	X				
Hungary	X	X	X		X	
Iceland	X	X			X	
Ireland	X	X	X	X	X	
Italy	X	X		X	X	
Latvia		X				
Lithuania	X					
Luxembourg	X	X	X	X		
Malta	X	X				
Netherlands	X	X	X		X	
Norway	X	X	X		X	X
Poland	X	X	X	X		
Portugal	X	X				
Romania	X	X	X			
Slovakia		X			X	
Slovenia	X	X				
Spain	X	X	X		X	
Sweden	X	X			X	
Switzerland		X			X	
UK	X	X			X	

*includes NGOs, private companies, and professional associations

At the end of this compilation exercise, we investigated whether participation was linked to national income, as there is a broad literature linking health information capacities to economic status and development. Figure 3 illustrates the association between the number of projects and countries' per capita GDP. These two dimensions are associated with lower participation among countries with lower per capita income; this association is statistically significant (Spearman's correlations: rho=.52, p=.003 (N=31)). This likely reflects in part the longer membership of the higher income countries, but illustrates the need to improve participation to avoid creating information systems which are not representative of the diverse economic situations within Europe.

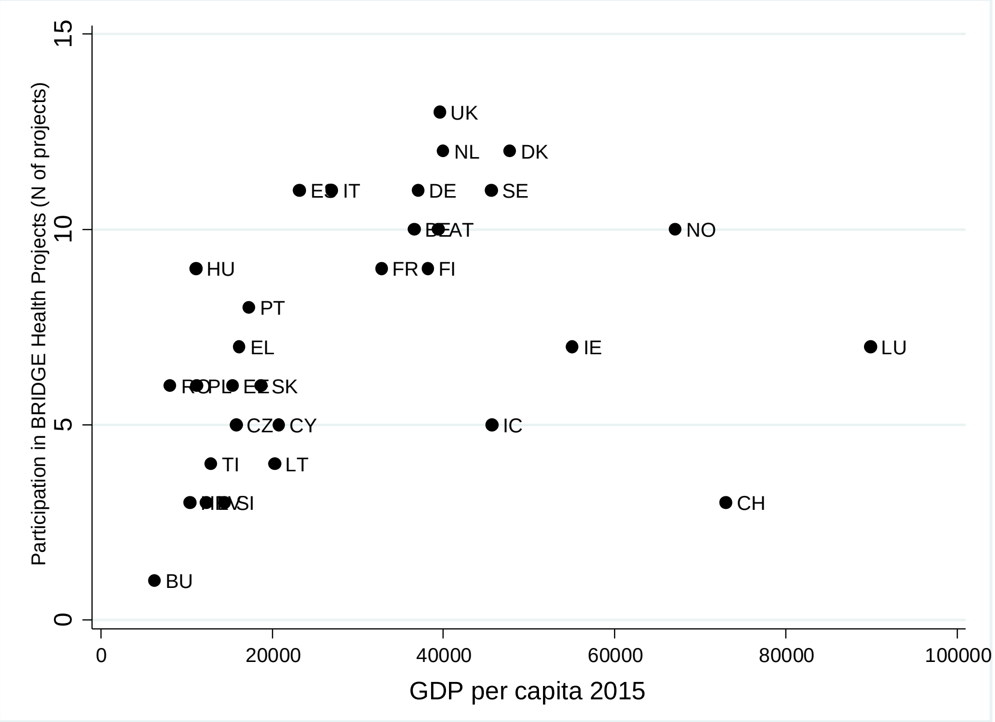

Figure 3 Association between participation in BRIDGE Health projects, as measured by number of projects, and GDP per capita in 2015

IV. Health information inequality in national health information systems

A. Assessment of HI inequality

The literature search revealed a number of studies examining European HI inequality which can broadly be divided into two approaches:

The first investigative approach assessed differences in specific components of the health information systems, such as hospital discharge data/eHealth, information flow between systems, or the capacity to link data. The reports on health information infrastructure highlight a high degree of variability among countries in the availability, management, and linkage of routine data platforms (2, 3). An OECD survey including of 17 out of 28 EU member states concluded only "one-half of countries surveyed have regular programs of health care quality monitoring involving *linked patient data* and one-half of countries are *only beginning to use data from electronic health records* for health and health-care monitoring" (4).

Furthermore, European hospital administrative databases have been found to have significant amounts of missing data which complicate analyses of quality or performance across countries (5). However, given that this is a rapidly evolving field, changes to administrative databases may provide solutions to these problems in the near future. A review on linkage found that countries that linked birth data sources could provide more of the Euro-Peristat perinatal health indicators (6). Such changes could be accelerated by an in-depth comparative analysis of the issues of using administrative data for comparisons of hospital performances in EU countries (5).

Employment of eHealth (i.e. the electronic health record (EHR)) in the acute care setting has been steadily increasing in European hospitals and the gap between high performing (mostly Nordic countries) and less advanced nations has been narrowing (7). eHealth systems remain quite basic in terms of functionality however, and inter-connectivity between facilities and patient access to health records is poor (7). Analyses of differences between specific countries related to use of eHealth has suggested that facilitators and obstacles may differ by context (8). This could also relate to public perceptions: EU funded research on citizen preferences found differences in levels of concern with privacy across the 27 countries of the EU in 2010 (9).

The second approach assessed the availability of information on specific health topics. This approach has been taken primarily by HI projects which provide data on health indicator availability and also reveal varying capacity among the MS. A feasibility study which collected the ECHIM indicators among 25 Member States found that none of the participating countries was able to provide all requested indicators and breakdowns (10). Another investigation showed that the European average availability score for all ECHI indicators was 74%, and ranged from 56% to 84%. In most countries only about half of the indicators could be derived from routinely collected HI. Indicators representing health determinants, the provision and use of health care services, injuries, the quality of health care, and health promotion were typically less readily available (11). These data often come from Health Interview Surveys and are collected by the National Institutes of Statistics or by ad hoc surveys of the Ministries of Health. Data on health system performance are also notoriously scare, variable or difficult to compare and up until now, for instance, ECHI indicators have been lacking in health system performance indicators.

Indicator availability in the Euro-Peristat project on maternal and newborn health was also variable. All 29 countries (26 EU MS + Iceland, Norway and Switzerland) provided information for the project and availability was quite good for the 10 core indicators - 20 out of 29 countries were able to provide data for the core indicators, while 3 countries provided them either partially or using different methods. However, the recommended indicators were less widely available: only 13 out of 29 countries and regions provided data in the form requested and a further 7 were able to produce data either partially or in a different form, while 9 were unable to provide the data. Data on birth characteristics and mortality were more frequently available, whereas socioeconomic factors and indicators related to prevention were less readily available (12).

Since not all EU countries have participated in HI projects, this literature review offers an incomplete understanding of HI inequality in the European context. While the studies highlight areas where there is heterogeneity in health information systems and issues surrounding the availability of data, they do not make it possible to establish an inventory of health systems and associated challenges in all countries. As information about health system structures and capacity constitute one important output of the HI projects, the importance of having complete participation from all MS is underscored.

WHO's European reports and EU reports are an exception as they often included all countries, but we did not find a comprehensive report from either of these organisations assessing the state of health information in Europe. For example, the WHO Health Systems in Transition (HiT) reports are a valuable source of information on European health information systems. These reports all include a sub-section on HI, however they are country-specific and there is no cross-country analysis (http://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits/full-list-of-country-hits). Furthermore they do not follow a systematic format and although some countries provide a high level of detail on all aspects of their health information systems (such as hospital data availability, surveys, and registers), others provide a more succinct description. This information is therefore difficult to use to identify information gaps. However, there is potential for these reports to be further developed for future analyses. The question of whether some types of systems produce more and better quality data is also a question for future research.

B. Obstacles and facilitators

The first question in the survey carried out for this scoping exercise with BRIDGE Health project representatives was about countries with advanced health information systems. Countries which were cited as examples of high-quality health information systems were the Nordic countries and the UK, commended for the comprehensiveness of their data and the capacity to link data sources. It was also noted that in some cases better health information systems for decision making are found at the local or regional levels as opposed to national levels. Therefore, focusing only the national level may not reveal all the resources available for health monitoring. For instance, in some Italian regions, high quality health information systems have been implemented: e.g., the regional program P.Re.Val.E.-Programma Regionale di Valutazione degli Esiti degli interventi sanitari settled in the Lazio region on outcome assessment of health care in the framework of the National Programme on Outcome Assessment (PNE); the program CReG-Chronic Related Group in the Lombardia Region, an innovative model of charging a chronic diseases patient, aiming at assuring an integrated continuity of care between hospital and territory.

When asked to identify barriers to developing HI in countries with poor health information systems, similar barriers were mentioned by many of the respondents. The reported barriers were grouped into 4 principal categories, as illustrated in Figure 3: related to (1) the absence of a political will or priority setting (2) ethics, (3) the absence of knowledge about protocols and lack of harmonized data and (4) infrastructure, governance and communication. Three of these categories (1 to 3) correspond to other horizontal activities identified in BRIDGE Health and are the focus of other reports. This finding shows the necessity of developing these horizontal themes for achieving progress. These categories are slightly broader conceptualizations of those proposed by others assessing obstacles and factors, as for instance in the field of eHealth (political factors/regulatory factors/technological factors and institutional factors). (8)

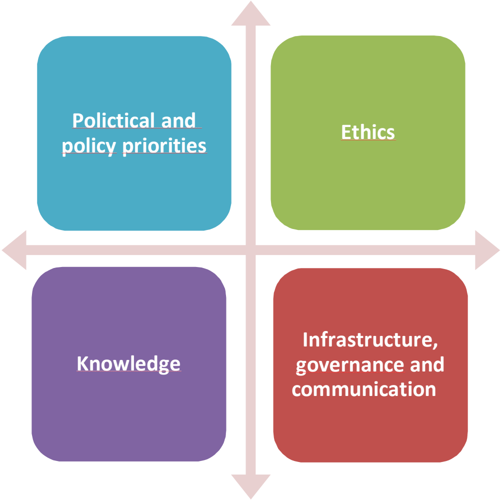

Figure 4 Four categories of obstacles to attaining health information equality across Europe

Political and policy priorities

The lack of political will to base decisions on evidence was cited by many respondents as an obstacle in countries with weak health information systems. Lack of funding and investment in the field of health information is a reflection of this and constitutes a major obstacle. HESs, for instance, are expensive to conduct and require special skills. As health information systems are not a priority in periods of austerity, these concerns become more acute during economic downturns.

The lack of policies related to use of routinely collected data leads to minimal translation of these data into long-term investments. It was noted that countries with a clear commitment to public accountability and evaluation for improvement are better equipped.

Some examples of how an understanding of the policy relevance of data can help were given, such as the development of good quality injury surveillance data which came about "because national authorities in those countries understood the importance of precise injury data and monitoring systems for producing effective policies." In Germany, it was also noted that the perinatal health information systems are directly related to the implementation of quality initiatives within the Lander. Political and policy priorities can relate to government, but also be piloted by health professionals or other groups.

Ethics

Ethics and privacy regulations were seen by many as a major obstacle to developing health information systems. One respondent noted that "Current laws on privacy deeply limits collection of health data and information necessary to implement an integrated information system at national level, in particular for the identification of clinical records important for data validation; this validation is only possible at regional level where different sources of information can be linked by personal data." These comments were also echoed in the OECD report, mentioned above (4), which attributed the disparity between countries primarily to differing approaches to risk management policy and decision-making regarding privacy and informed consent. Other reports highlighted a wide range of difficulties related to data sharing arrangements, data protection rules, liability, regulations regarding secondary use, and access capabilities both within and between countries were noted (2, 3). Further contributing to HI inequality in the EU context are the limited resources available to national health systems to comply with complex data regulation policies, inhibiting the use of patient data for monitoring and surveillance even when it is legally possible (2).

Successfully addressing privacy and consent issues were seen as major facilitators for developing HI equality. For instance, the possibility of having remote access for health-related research and evaluation was a key enabler for health information systems in England and Wales (13). Another comment related to "specific national legislation that does not request personal consent and implements an opt-out policy." Having unique personal identifiers for patients and medical practitioners is also a strength, as in Italy. The BIRO (Best Information Through Regional Outcomes) project developed specific methods of privacy impact assessment that could be used in similar situations across Europe; these were applied to European diabetes registries and seen as a way of to improve "the respect of privacy in each data source, reduce overall variability in the implementation of privacy principles and favour a sound and legitimate cross-border exchange of high quality data across Europe" (14, 15).

Knowledge

Many of the projects cite lack of knowledge and usable protocols as an obstacle to high-quality health information systems. For instance, for the HES, one of the main obstacles for development and collection of health information was seen to be lacking knowledge within countries. To overcome this, standardized protocols were prepared and training seminars were organized to facilitate capacity building. EHLEIS was also cited as a good example where the information needed to contribute has been developed and provided – ie SELECTED data (choice of surveys) and SELECTED information (Life expectancy and Health expectancy), KEY METADATA, along with guides for interpretation and policy briefs. ECHIM cited "National Implementation Teams" which could support countries in the implementation of health information projects. Similarly, the ECHO project found that showing that the depth and breadth of information was slightly different across ECHO countries sent out an implicit message about the need to improve data collection nationally. The project built up a minimum common dataset to allow international comparison of health care performance. These comments show how improving involvement in the first level of the pyramid schematised in Figure 1 can impact on national data use (level 2) as well as infrastructure development (level 3).

High performing systems were also seen as those where researchers study and report on population health and health system performance. The knowledge needed to underpin successful systems is therefore not only the availability of protocols and skills for creating data, but also the capacity to use them for comprehensive and high-quality investigations of health and health care. Where data are used for research, they are more likely to be validated and improve in quality; this also provides an impetus for health providers, who are involved in collecting and transmitting the data, to focus on data quality. In the Euro-Peristat report on data linkage, there was a clear link between the countries' linkage of routine data and scientific publication on perinatal health. (6)

Infrastructure, governance and communication

Many barriers related to infrastructures, governance and communication within and between institutions were mentioned as obstacles for building health information systems. They were also seen to interact with the challenges of the 3 domains mentioned above, since lack of political will and policies, the complexity of data protection and privacy regulations and lack of knowledge are particularly detrimental when infrastructure and governance are poor. Further, it was mentioned that in some countries, the parallel development of a national and a private healthcare system also hinders the collection of national and comparable data. The specific barriers raised by respondents included:

- The absence of sustainable infrastructure (and funding).
- Regional and local governance of health databases, thereby making collection of national level data challenging.
- The expense of creating new HI systems or adding items to existing health systems
- An absence of optimal linkage between data sources.

- No established HI administrative structures that provide coordination between institutions or take charge of using data for surveillance.
- Difficulties communicating between different administrations that are responsible for health information and policy.
- Lack of explicit policy on secondary use of data, consequently leading to minimal translation into long-term investment.
- Budgetary constraints heading money to different priorities other than HI.
- Absence of public accountability and evaluation for improvement of existing HI systems. This creates a vacuum in which inefficient and unproductive systems continue to operate.
- The need for multidisciplinary input, as there needs to be necessarily clinical, statistical and technological expertise involved

The questionnaire specifically asked about data linkage, as this is a major focus of recent changes in many health information systems. The linkage capacity across a broad variety of data sources in Nordic countries was suggested as a case-study for others. Attributed to their capacity to link data sources using PIN or similar identifiers, the possibility of linking different sources of information, in particular clinical records, such as drug prescriptions, hospital diagnoses, outpatient visits, exemption, allows for validation of data items. The system also ensures that hospital discharge records and mortality are available without delay and support the implementation of population-based registries.

One respondent commented: Linkage of existing data sources is the natural way to proceed with routinely collected data as one single dataset does not always provide meaningful answers to complex questions. Linkage makes it possible to take into account and integrate contextual data (i.e., population structure, socioeconomic status, institutional factors) with hospital discharge data and this will allow to test questions of interest for policy-makers (e.g., variations in performance across socioeconomic quintiles).

However, linkage of routine data sources does not solve some of the inherent problems in the databases used for health monitoring, such as hospital discharge, vital statistics, medical registries and other administrative databases. In other words, linkage is needed, but it is not sufficient. For instance, much of current routinely collected datasets (e.g., electronic health records) tend to represent health care utilization rather than health status which may be a poor proxy for population health status and fail to depict health outcomes as well. Some information, such as on lifestyle or compliance with drug prescriptions may be available only from surveys. Therefore to obtain comprehensive information, multiple datasets and methods are needed, varying from regular statistics to specific research where for instancenested designs, in which surveys are linked to routine data could be envisaged to amplify the benefits of both approaches. Another issue is that the geographic granularity used for presentation of the data (e.g., EUROSTAT statistics on health) may not represent geographic areas of interest from the point of view of health - LAU and NUTS areas may not be meaningful for health planning or healthcare performance analysis.

V. Conclusions and recommendations

The current BRIDGE health projects provide a solid foundation for reinforcing HI equality within the European Union:

- Projects participating in BRIDGE health cover a wide range of topics and data sources and therefore the opportunity exists to achieve a broad strengthening of HI systems across multiple domains by expanding participation in these projects.
- All countries are represented in at least one project and therefore the possibility exists for a dialogue with HI information institutions in all countries.
- There is high participation from a wide range of public agencies, university departments and research institutions across the member states. These are the key actors for carrying out the research necessary for innovation and proposing practical strategies for achieving change.

However, there is strong HI inequality and heterogeneity in project participation:

- There is unequal participation in BRIDGE Health projects, ranging from participation in only one or two projects in some countries to participation in almost all projects in others.
- The characteristics of participation in the BRIDGE Health projects are also different, as indicated by the numbers and diversity of institutions involved in BRIDGE Health.
- Research institutes and universities still are playing a large role, which is positive, but this may not ensure links for achieving sustainable HI equality, which may depend on political priorities and sustainable investments.
- Questions also exist about the completeness and continuity of links between institutions within each country and between projects. This is an important question for further study.

Knowledge about national health information system is fragmented, but reveals considerable inequality

- Many of the 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, including hospital discharge data, registers, eHealth systems, linkage capacities have all identified significant differences in capacity in the health information systems across EU Member States.
- Studies focusing on countries’ ability to provide indicators to EU projects have also found significant heterogeneity and gaps in data availability across Europe.
- A comprehensive overview of HI systems in Europe which could identify weaknesses in existing systems and models for change could be an important contribution of an ERIC focused on health information. Existing data collected on country health system infrastructure, in the HiT reports, could provide a starting point for such an investigation.

Multiple obstacles were identified and these map onto BRIDGE Health horizontal areas

- The obstacles identified to implementing and sustaining high-quality health information systems were remarkably similar, as reported by representatives of BRIDGE Health projects
- These obstacles were classified into 4 categories: Political priorities and policies, Ethics, Knowledge and Infrastructure, governance and communication. The first three of these 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.
- Although the HI projects did not aim to improve national health infrastructures, projects were seen to have a role in promoting national action in this area by providing benchmarks for health information achievements and by developing protocols that improved skills and reduced the knowledge gap.

These results provide guidance for an action plan 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.
- Whether HI inequality and the ensuing limited capacity to make decisions based on data - actually impacts on health is a key question which requires further investigation. An ERIC on HI would be well placed to gather evidence about how strong information systems translate into effective policy and better health and care.

VI. References

1. WHO. Regional Office for Europe, European Health Information Initiative (EHII). [cited 2016 21 July]; Available from: http://www.euro.who.int/en/data-and-evidence/european-health-information-initiative-ehii.

2. Oderkirk J, Ronchi E, Klazinga N. International comparisons of health system performance among OECD countries: opportunities and data privacy protection challenges. Health Policy. 2013;112(1):9-18.

3. Commission E. Overview of the national laws on electronic health records in the EU Member States. Brussels, Belgium: 2014.

4. OECD. Strengthening Health Information Infrastructure for Health Care Quality Governance: OECD Publishing; 2013.

5. Groene O, Kristensen S, Arah O, Thompson C, Bartels P, Sunol R, et al. Feasibility of using administrative data to compare hospital performance in the EU. International journal for quality in health care. 2014;26(suppl 1):108-15.

6. Delnord M, Szamotulska K, Hindori-Mohangoo A, Blondel B, Macfarlane A, Dattani N, et al. Linking databases on perinatal health: a review of the literature and current practices in Europe. The European Journal of Public Health. 2016:ckv231.

7. European Commission. European Hospital Survey - Benchmarking Deployment of eHealth services (2012-2013). 2014.

8. Stanimirovic D, Vintar M. Development of eHealth at a national level - comparative aspects and mapping of general success factors. Inform Health Soc Care. 2014;39(2):140-60.

9. Patil S, Lu H, Saunders CL, Potoglou D, Robinson N. Public preferences for electronic health data storage, access, and sharing - evidence from a pan-European survey. Journal of the American Medical Informatics Association : JAMIA. 2016. Epub 2016/04/24.

10. Verschuuren M, Gissler M, Kilpelainen K, Tuomi-Nikula A, Sihvonen AP, Thelen J, et al. Public health indicators for the EU: the joint action for ECHIM (European Community Health Indicators & Monitoring). Arch Public Health. 2013;71(1):12.

11. Kilpelainen K, Tuomi-Nikula A, Thelen J, Gissler M, Sihvonen AP, Kramers P, et al. Health indicators in Europe: availability and data needs. Eur J Public Health. 2012;22(5):716-21.

12. Gissler M, Mohangoo AD, Blondel B, Chalmers J, Macfarlane A, Gaizauskiene A, et al. Perinatal health monitoring in Europe: results from the EURO-PERISTAT project. Inform Health Soc Care. 2010;35(2):64-79.

13. Jones KH, Ford DV, Jones C, Dsilva R, Thompson S, Brooks CJ, et al. A case study of the Secure Anonymous Information Linkage (SAIL) Gateway: a privacy-protecting remote access system for health-related research and evaluation. J Biomed Inform. 2014;50:196-204.

14. Di Iorio CT, Carinci F, Azzopardi J, Baglioni V, Beck P, Cunningham S, et al. Privacy impact assessment in the design of transnational public health information systems: the BIRO project. J Med Ethics. 2009;35(12):753-61.

15. Di Iorio CT, Carinci F, Brillante M, Azzopardi J, Beck P, Bratina N, et al. Cross-border flow of health information: is 'privacy by design' enough? Privacy performance assessment in EUBIROD. Eur J Public Health. 2013;23(2):247-53.

VII. Glossary

Health information (HI): All information, data and evidence regarding personal and population health.

Health information system (HIS): All activities and resources related to health information monitoring and reporting. It also includes some less tangible elements necessary for operating a health information system, such as governance mechanisms and legal frameworks, interinstitutional relationships and values (Source: WHO)

Health information technology (HIT): The application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making. (Source: US HHS)

Electronic health record (EHR): An electronic version of a patient's medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that persons medical care, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports The EHR automates access to information and has the potential to streamline the clinician's workflow. The EHR also has the ability to support other care-related activities directly or indirectly through various interfaces, including evidence-based decision support, quality management, and outcomes reporting. (Source: CMS)

Data linkage: A process of pairing records from two health information sources. (Source: Winglee M, Valliant R, Scheuren F: A case study in record linkage. Survey Methodology. 2005, 31 (1): 3-11.)

Data sharing agreement: A legal agreement which indicates the criteria for data access, whether or not there are any conditions for research use, and can incorporate privacy and confidentiality standards to ensure data security at the recipient site and prohibit manipulation of data for the purposes of identifying subjects. (Source: NIH)

Data protection: The legal control over access to and use of data stored in computers.

Protected health information (PHI): Individually identifiable health information that relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to the individual by a covered entity (for example, hospital or doctor); and the past, present, or future payment for the provision of health care to the individual. (Source: HIPAA)

Confidentiality/privacy: The patient's right to prevent sharing any information regarding his/her personal details or medical care outside of the clinical care team without explicit consent from the patient.

Informed consent (in the context of health information sharing): Obtaining explicit consent from an individual to share personal and medical information outside of the clinical care team.

VIII. Appendix

A. Search terms and results

The following search terms were used:

Search term	Medline records found	Google Scholar records found
"health information"	18,730	880,000
"health information system$"	1,771	31,200
"health information" AND "equality"	18	25,500
"health information" AND "inequality"	51	25,400
"health information system$" AND "equality"	2	1,630
"health information system$" AND "inequality"	1	1,860
"health information" AND "Europe$"	564	85,400
"health information system$" AND "Europe$"	58	6,480
"health information" AND "equality" AND "Europe$"	1	10,800
"health information" AND "inequality" AND "Europe$"	3	16,200
"health information system$" AND "equality" AND "Europe$"	0	1,000
"health information system$" AND "inequality" AND "Europe$"	0	1,170

*Google Scholar only lists approximate number of results for queries

Medline records reviewed in detail: 698

Google Scholar records reviewed in detail: 360

B. Mapping involvement in BRIDGE health projects in selected countries

Examples – to be included for all countries (probably as separate accompanying document)

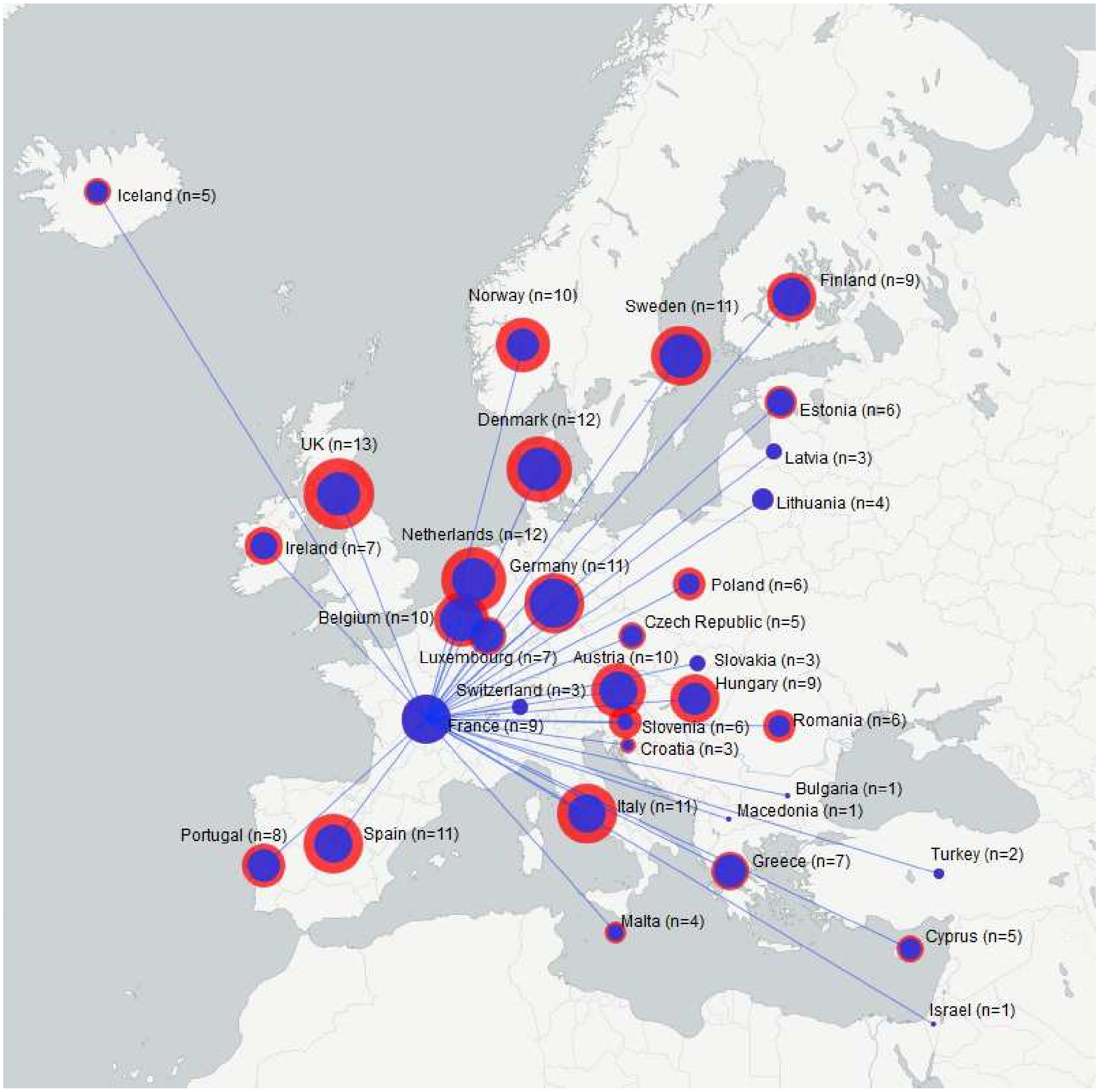

Figure S1_a: Involvement of France in BRIDGE health projects. In blue, projects that involve France; in red (and n provided), all projects.

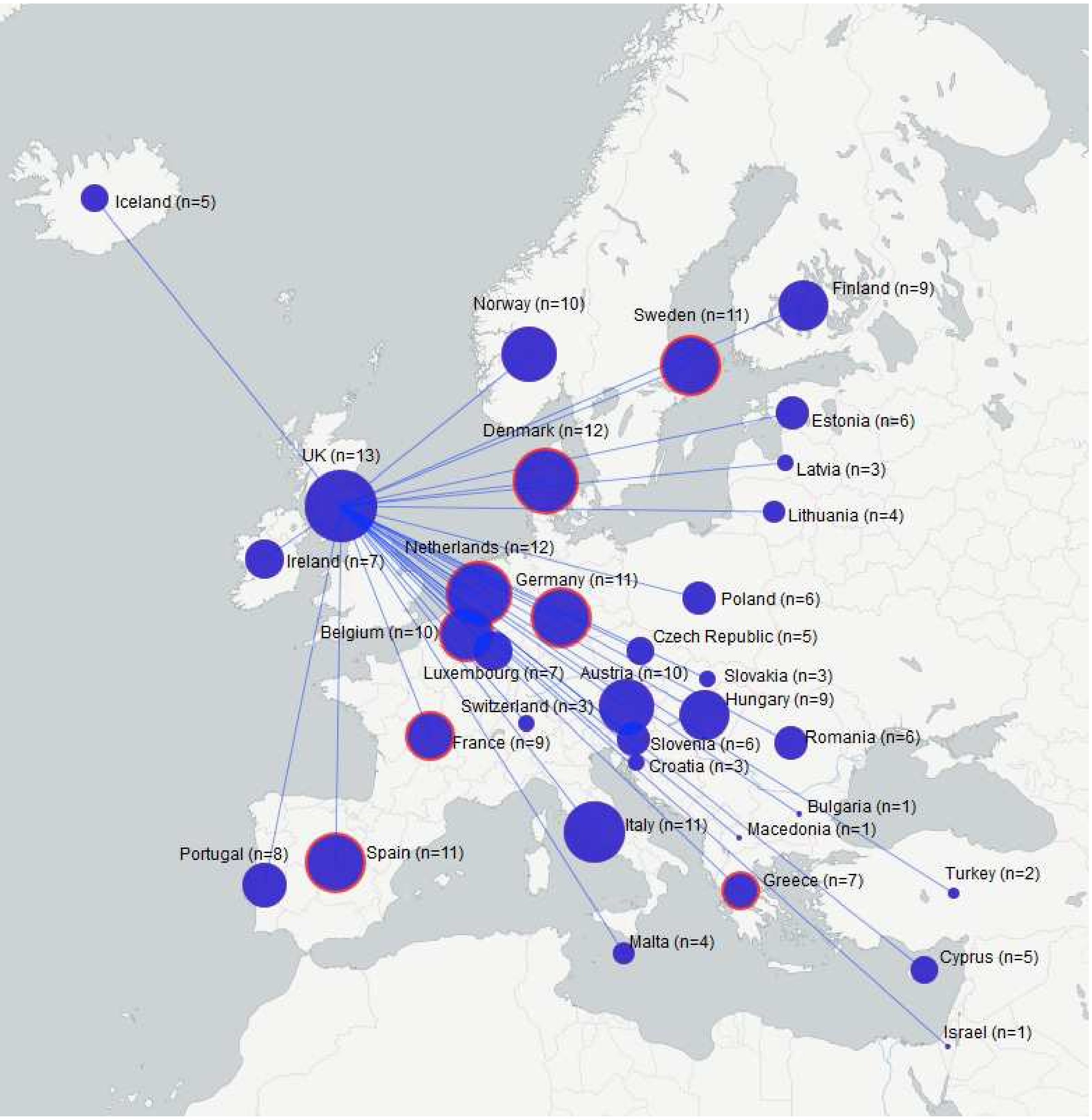

Figure S1_b: Involvement of UK in BRIDGE health projects. In blue, projects that involve UK; in red (and n provided), all projects.

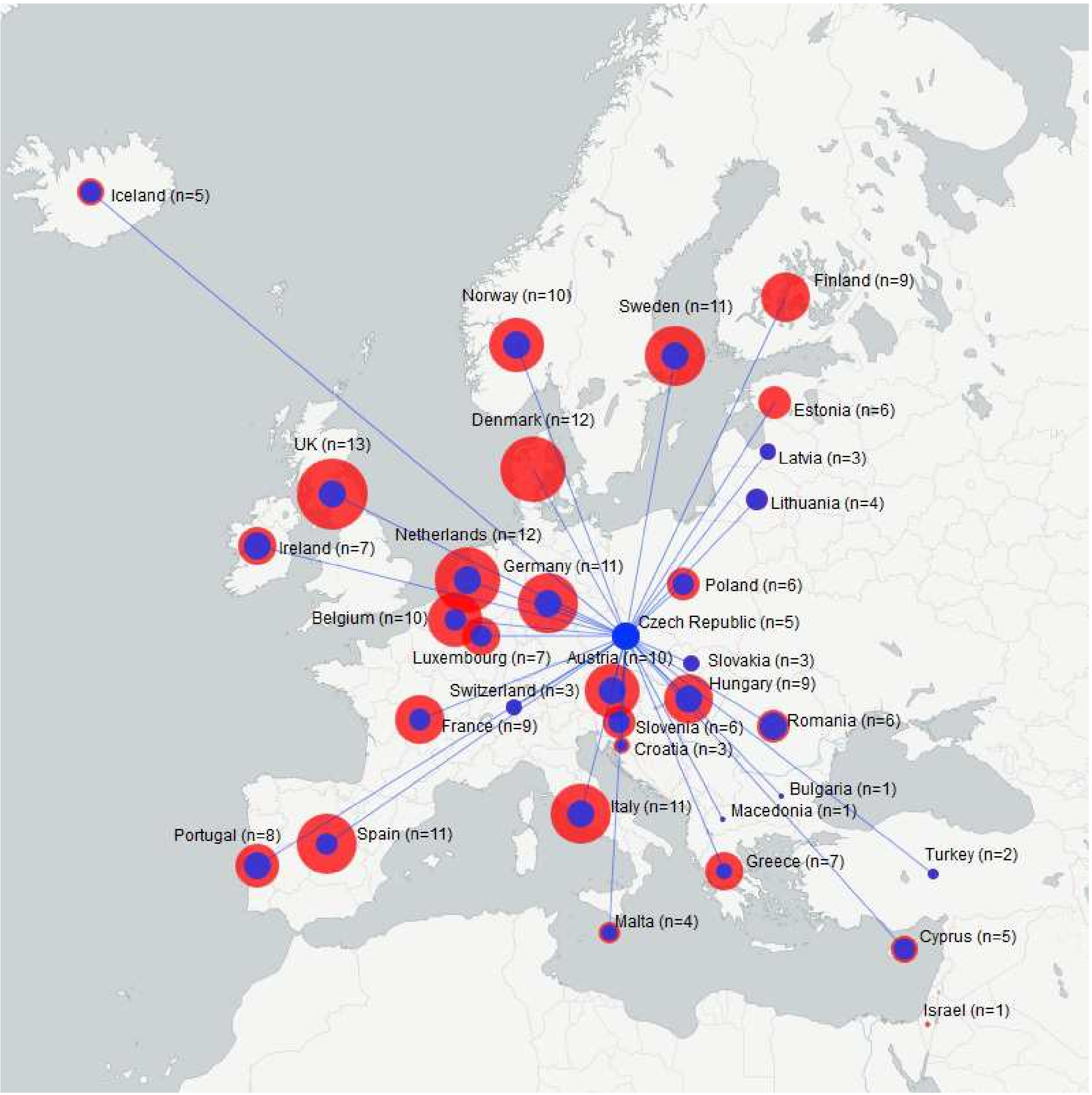

Figure S1_c: Involvement of the Czech Republic in BRIDGE health projects. In blue, projects that involve Czech Republic; in red (and n provided), all projects.