

EBPH Monography

'The Italian Hub of the European Health Information System

BRIDGE - BRIdging Information and Data Generation for Evidence-based Health Policy and Research'

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Europe is now facing the challenge to implement preventive actions, identify persons in need of treatment, apply the European Guidelines for Cardiovascular Diseases (CVD) Prevention in Clinical Practice and verify improving effectiveness. The development, testing and implementation of effective surveillance systems for CVD and Non Communicable Diseases will produce reliable and comparable indicators, thus enabling policy makers to trace differences within and between countries and to make better decisions on planning and evaluation of prevention programs, healthcare delivery, resource allocation, and research.

Information about the population health, high-risk conditions, diseases and healthcare interventions are the corner-stones to support evidence based prevention and to plan and address health policy activities.

Mortality, population-based registries, and longitudinal studies provide health information on occurrence of disease, in particular CVD, cancer, diabetes, chronic obstructive pulmonary disease; Health Examination Surveys (HESs) provide information on risk factors, high-risk conditions, lifestyles, and on prevalence of those diseases which do not need hospitalisation. However, the pathway of medical care, as well as the diagnosis of acute and chronic illnesses and conditions, cannot be traced at the current time.

Healthcare utilization (HCU) databases store data on patients' demography, healthcare procedures and services (drug dispensations, hospital admissions and diagnoses, surgical and other interventions in and outside hospitals, outpatients visits by general practitioners and specialists, laboratory examinations, vaccinations). HCU databases are designed for managing National Health System (NHS) rather than for clinical and epidemiological research, and lifestyle information and clinical characteristics are completely missing.

At European level, the increasing need of using, exploiting, and integrating available health data to obtain a complete and comparable information on health status, health care, and health system performance is increasingly strong for 1) generating reliable evidence addressing healthcare policy or 2) guiding the decision making process, and 3) for research. This is leading European Commission to support projects aiming at defining, designing, planning and organizing an integrated and sustainable European Health Information System.

The BRIDGE Health-bridging information and data generation for evidence-based health policy and research, funded by the European Commission, started in 2015 involving 31 partners from 16 Countries with the following aims:

1. To enhance the transferability of Health Information (HI) and data for policy making and improve the utility and use of data and indicators for stakeholders in policy making, public health surveillance and healthcare;
2. To reduce HI inequality within the EU and within member states (MS);
3. To develop a blueprint for a sustainable and integrated EU HI system by developing common methods for: (a) standardising the collection and exchange of HI within and between domains, between MS, including e-health platforms; (b) ensuring data quality, including procedures for internal and external validation of health indicators; (c) undertaking priority setting exercises for HI; (d) addressing ethical and legal issues associated with the collection and use of health data within MS and the EU.

The Italian project "Creation and development of the Italian network supporting the European BRIDGE Health project

aimed at structuring and providing sustainability to European activities in the field of Health Information (HI)", funded by the Centre for Disease Control of the Ministry of Health, developed and implemented by the Istituto Superiore di Sanità (ISS) between April 2016 and October 2017, was approved with the aim of supporting the activities envisaged under the European BRIDGE Health project, for the development of a national HI infrastructure.

The Italian involvement in these projects took advantage of the experience in the European Cardiovascular Indicators Surveillance Set-EUROCISS I and II projects, coordinated by the ISS from 2000 to 2007 and producing Manuals of Operations for Population-based registries of acute myocardial infarction and stroke, and for Cardiovascular surveys; then followed by the experience in the Joint Action-European Health Examination Survey conducted between 2010 and 2012, which aimed at planning and preparing national HESs in 14 European countries and at piloting the fieldwork, data collection, assessment and reporting. The EHES Project was an important step in paving the way for a sustainable system of national health examination surveys, covering all EU and EFTA/EEA countries in order to provide nationally representative, high quality, comparable information on major chronic disease risk factors and disease prevalence to support the planning and evaluation of health policies and preventive activities.

In the path forward the creation of the Italian Hub of the European Health Information System providing reliable and comparable health information and indicators on major chronic disease, this monography reports main Italian experiences in

- conducting Health Examination Survey, facing organizational issues (examination sites and selection of analytic laboratories, coordination and involved personnel, sampling and recruitment, information notice and informed consent, participation rate and non-participation bias, quality assurance and quality control, survey data, long term storage of the samples, data transfer and storage, statistical analyses, interpretation and dissemination of results);
- describing and suggesting the different aspects and dimensions of quality to be controlled, in the field of HIS or HES surveys, to generate useful and reliable results that can help monitoring health policies in Europe;
- coordinating and implementing population-based registries for coronary and cerebrovascular events adopting common and standardised procedures and validating events according to standardised diagnostic criteria, which derive from the historical participation to the international MONICA project and the EUROCISS;
- elaborating and producing a web-based research platform for interconnecting, processing, and analysing regional healthcare data from the National Health System (NHS) (healthcare utilization (HCU) databases, drug and disease registries, electronic medical records, etc.) with health data collected from research epidemiological studies conducted for example by the ISS (health examination surveys, longitudinal cohorts, population-based registries) in order to provide 'real-world evidence' in terms of appropriateness with respect to evidence-based guidelines; post-marketing drugs' safety, particularly in special populations (e.g., pregnant women, children, elderly); and comparative effectiveness and cost-effectiveness profiles of drug therapies and healthcare pathways.
- considering strategies and tools for assessing quality of healthcare databases and other secondary data sources. These data are increasingly used to support research on patient outcomes, comparative effectiveness, and health systems research, as well as to support individual studies, or more generally to support aggregation of large volumes of data in disease specific registries or clinical data repositories, facilitating rapid translation of findings back into practice.

All these experiences provide simple and practical tool to implement epidemiological studies which contribute to provide reliable and comparable indicators which can contribute to feed, as the Italian Hub, the European Health Information System.

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