

WP8 - Platform for population based registries

Consolidation of the Network of field work experts

Technical report of the task 1
31 October 2016

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This project is funded
by the Health
Programme of the
European Union

Contents

1.	Executive summary.....	3
2.	Key points	3
3.	Introduction.....	4
4.	Wp8-platform for population based registries.....	5
5.	Description of task 1 activities	5
6.	Population based registries.....	6
7.	Aims of this report.....	8
8.	Criteria adopted in the selection of experts.....	8
9.	Experts network first meeting	9
10.	Agreement subscription	9
11.	Web community practice.....	9
12.	List of fieldwork experts of population based registries.....	10
13.	Experts professional profile	13
14.	References.....	29

1. Executive summary

The BRIDGE Health (BRidging Information and Data Generation for Evidence-based Health Policy and Research) aims to create the European Health Information System (EU-HIS) and data generation networks covering major public health policy areas. It works towards a comprehensive integrated and sustainable EU-HIS supporting evidence based health policy and research for the EU and Member States (MS) by providing blueprints and concepts of building blocks for a future Research Infrastructure Consortium on Health Information for Research and Evidence based Policy (HIREP-ERIC). The BRIDGE Health gathers key EU projects previously supported by Health Monitoring Program and is organized in twelve Work Packages (WP) and seven Horizontal Activities (HA).

The strategic objective of the WP8 - Platform for population based registries - is to improve and guarantee the quality of data collected by population-based registries of chronic diseases, facilitate their implementation, sustainability and maintenance, including the provision of specialized software for the statistical analysis, data exchange, and automated calculation of indicators, both at local and EU level; the work is realized in collaboration with an expert group of medical doctors, statisticians, public health researchers and epidemiologists involved in population based registries and/or experts in integrated health information systems; their work includes the gathering, harmonization and dissemination of procedures/methods and best practices for population-based registries in order to build a common platform for the provision of community health indicators of occurrence, quality of care and outcomes of chronic diseases in Europe.

The consolidation of the network of field work experts is the first delivery of this work package.

The aim of this report is to describe the procedure followed for the selection of field work experts of population based registries, the meetings, the agreement and the delivered list of experts.

2. Key points

Population based registries, field work expert networks, health information system

3. Introduction

Chronic non communicable diseases represent a substantial public health problem in Europe; there is a pressing need to implement comprehensive strategies to address this growing epidemic [1]. To this purpose, surveillance remains the primary tool to evaluate the burden of diseases to support research, to plan preventive actions at both population and individual levels, to assess individual and public health outcomes and to influence policy and decision making.

Public health surveillance has been defined as '*the ongoing, systematic collection, analysis, interpretation and dissemination of data regarding health-related events for use in public health action to reduce mortality and morbidity and to improve health*' [2-3].

In recent years, thanks to the information technology, a substantial volume of data are recorded on hospital admissions and discharges, medication use, in-patient care utilization, surgical operations, drug dispensations, ticket exemption and invasive procedures. Population based registries are based on properly linked and validated data and represent an important sources of information for achieving better knowledge and more effective interventions, studying disease trends, producing annual reports, orientating preventive actions and making comparisons among countries.

The BRIDGE Health (BRIdging Information and Data Generation for Evidence-based Health Policy and Research) [4] aims to gathers key EU projects (4) previously supported by Health Monitoring Program and to use experience and knowledge of the networks from past health and research frameworks. These EU-projects have developed indicators and methods to process data, manuals for health examination surveys, establish protocol for human bio-monitoring, injury and disease population based registries, clinical and administrative health data collection systems and methods of health system monitoring and evaluation. The aim of the BRIDGE Health is therefore to ensure sustainability of key health information activities that have been run under the past EU-health and research framework programmers, enhance synergy among these activities and to work towards a comprehensive integrated and sustainable EU-HIS supporting evidence based health policy and research for the EU and MSs for a future HIREP-ERIC.

The project was launched in May 2015 and will be running for 30 months. It includes 31 partners in 16 countries and includes twelve WP and seven HA [4]

Work Package (WP)	Horizontal Activity (HA)
WP 1 Coordination	HA 1 Transferability of health information and data for policy
WP 2 Dissemination	HA 2 Health information inequality within the EU and within MS
WP 3 Evaluation	HA 3 Information at regional level (ECHI indicators, health inequalities) and for specific population groups
WP 4 European Core Health Indicators Monitoring (ECHIM)	HA 4 Standardization methods of the collection and exchange of health information
WP 5 Harmonized population based health examination surveys	HA 5 Data quality methods including internal and external validation of indicators
WP 6 Impacts of environmental chemicals on health	HA 6 Priority setting methods in health information
WP 7 Reproductive, maternal, newborn, child and adolescent health (RMNCAH)	HA 7 Ethical and legal issues in health information
WP 8 Platform for population based registries	
WP 9 Platform for Injury Surveillance	
WP 10 Building a platform for administrative data on Health Care	
WP 11 Integration of approaches in EU information system for health monitoring and reporting	
WP 12 Evaluation of health care systems	

4. WP8-Platform for population based registries

The WP8-Platform for population based registries aims at improving and guaranteeing the quality of data collected by population-based registries of chronic diseases, facilitating their implementation, sustainability and maintenance, including the provision of specific software for the statistical analysis, data linkage, and calculation of indicators.

The objectives of the WP8 are to gather, harmonize and disseminate procedures/methods and best practices in population based registries as a common platform for the provision of community health indicators of occurrence, quality of care and outcomes of chronic diseases in Europe.

The activities of WP8 consist of two tasks; the first one is focusing on chronic disease occurrence and the second on quality of health care.

5. Description of Task 1 activities

The experience carried out in EUROCISS project (5-6), allows to identify standardized definitions of non-communicable chronic diseases of interest in public

health and to identify common procedures and methods for establishing population based registries.

These activities consist in: identification of the main sources of information and population size criteria; identification of events; definition of diagnostic criteria for events validation; identification of internal and external validation procedures, description of ethical issues; delivery of the processed core indicators of disease occurrence recommended by ECHIM (7-8); drafting of a manual of operations with a stepwise procedure for setting up population based registries, the development of guidelines for the training of epidemiological team involved in population based registries.

Synergies with other groups involved in health information/health examination surveys (EHIS/EHES) and in morbidity/mortality surveillance (EUROSTAT) are explored.

The activities carried out in Task 1 are reported in three technical reports:

1. Consolidation of the collaborative network of fieldwork experts involved in surveillance of chronic diseases and interested in building a platform for population based registries;
2. Manual of operations with stepwise procedures for population based registries implementation, sharing sources of information and including population size, sources of information, standardized diagnostic criteria, internal and external validation, elaboration of disease occurrence indicators.
3. Guidelines for training personnel involved in the implementation of population based registers of chronic diseases at local level including definitions, procedures for record linkage, validation, assessment of disease.

6. Population based registries

A short description of the characteristics of a population based registry is fundamental to understand the procedures to build the platform.

The terms register and registry are often used as synonym, but the registry is the organization and process that supports many registers.

A population based registry is intended for researchers, health professionals and policy makers.

The objectives of a population based registry are: to evaluate the frequency and distribution of a disease in the population providing indicators, such as attack rate,

incidence rate, and case-fatality rate; to evaluate trends and changing pattern, outcomes and treatment effectiveness; to monitor prevention programs. Being focused on general population, it provides a comprehensive picture of a disease in the community, highlights problems, and suggests where treatment facilities are most in need of improvement. Therefore, it includes all cases in a defined population, treated either at home or in hospital, in each season of the year or time of the day they may occur, also fatal cases, which occur suddenly, then unable to reach the medical service. The collection of information on suspected events and application of diagnostic criteria should follow standardized methodologies in case definition and control quality checks in order to assess comparable indicators (between and within countries and over time periods). The collection of information is crucial to develop essential knowledge for research; to develop health strategies and policies; to plan health services and health expenditures; to improve appropriate allocation of resources; to evaluate the effectiveness of interventions.

A population based registry is implemented starting from record linkage of various sources of information: administrative and demographic data (age or date of birth, gender, race and ethnic origin, marital status, address of residence), compulsory data (mortality, hospital discharge, GP's clinical records) and supplementary information data (commissions for the authorization of the reimbursement of treatment, analytical laboratory services, ticket exemption archives). The registry covers defined population (entire municipalities, regions or whole country) and/or specific target of population (children, adults, elderly). The registry is not only an integration of different sources of information; it must be validated. Validation provides the means to take into account bias from diagnostic practices and changes in coding systems; it traces the impact of new diagnostic tools and new definition of events; it ensures data comparability within the registry; it ensures data comparability with other registries within and between countries and over time periods.

Due to the different characteristics of population based registries, experts of different aspects which characterize the setting up and the implementation of a population based registry have been invited: epidemiologists, statisticians, general practitioners, public health professionals and ethical issues experts. Their expertise covers various topics, such as definition of cases, record linkage of different sources of information, validation procedures, and assessment of ECHI indicators. The goal is to promote a fruitful discussion for the preparation of the manual of operations of population based registries and guidelines for training personnel involved in population based registries.

7. Aims of this report

This report represents the first delivery of the task 1 of WP 8; it aims at describing the procedures adopted to deliver the list of fieldwork experts of population based registries and it describes the meetings and the work carried out by the experts during the first year of the BRIDGE Health to consolidate the network.

8. Criteria adopted in the selection of experts

The first step to build the network of experts was to propose to professionals involved in the fieldwork of population based registries to collaborate in the work of WP8. The manual of operations of population based registries is intended as a practical manual for those who are willing to set up or implement a population based registry, therefore the manual should include all practical information to guide the building up and the management of a population based registry. Several manuals of operations concerning registries of different diseases are available; nevertheless the procedures indicated to implement registries rarely take into account recommendations reported in the European Commission (EC) or World Health Organization (WHO) documents, or are based on results of the projects of the Health Monitoring Programme. Consequently, the first selection of experts interested to collaborate was based on the experience in the fieldwork of population based registry organization (use of routine data of mortality and hospital discharge diagnoses, experience in record linkage of different sources of information, in adopting epidemiological definitions of disease, in standardized diagnostic criteria, in validation of cases, in the assessment of diseases occurrence indicators, in quality control methods, etc.).

Since the present project is a European project aiming to provide blueprints and concepts of building blocks for a future EU-HIS research infrastructure consortium, the second criterium of selection was based on previous participation in European projects and publications on international journals related to surveillance, population based registries, and public health.

After the first selection, based on the criteria over described, we realized that the close collaboration with national institutions is essential, those institution which usually provide data to the international organizations; that is basic to set up/implement registries. Therefore investigators of the Italian Ministry of Health and investigators of the National Institute of Statistics have been invited together with other investigators of the National Public Health Institute involved in activities of integrated Health Information Systems. Moreover the EUROCISS network was invited formally to take part to the activities of the WP8.

9. Experts Network first meeting

The first meeting of the experts' network was held in 2015 on June the 25th at the Istituto Superiore di Sanità (Rome, Italy). Each participant presented his/her experience within registries and/or European projects.

During the meeting the experts received all the information on the BRIDGE-Health project and in particular on the WP 8 'platform for population based registries'. The participants also received the working plan, the schedule for the realization of the manual of operations for the population based registry of chronic diseases and the guidelines for personnel who need to implement population based registries. The possibility to collaborate with the Ministry of Health to improve utility and use of data in the health information was also suggested. Others meetings were followed in Rome on June, July and September 2016, thanks to the support of the Ministry of Health. Four working groups were consolidated: the first involved in the ECHIM indicators, the second in availability and accessibility of data, the third in the governance and the fourth in interconnection of datasets. The working groups should encourage and support the field work group of experts and collaborate in the delivery of the manual of operations of platform for population based registries; due to their experience they collaborate also in the delivery of the report of guidelines for training personnel involved in population-based registries.

10. Agreement subscription

Experts have signed the agreement to participate in the BRIDGE Health project. In the form a specific request on the possibility to share experience with other researchers involved in the BRIDGE-Health was reported.

11. Web community practice

In order to encourage intense long-distance exchange, a web based platform of virtual interaction and communication, called the WP8 Community of Practice (CoP), has been created; the CoP encourages the transfer of knowledge, the development of new ideas, the re-framing of problems and the finding of original solutions. (<http://wp8community.bridgehealth.eu/login/index.php>).

The CoP is based on a open-source software, developed with the learning platform MOODLE, which powers internet platforms for proposition development and decision making. The Web Platform is an online system with several services tailored on the WP8-task1 needs and there is an open forum for discussing proposals about each issue. The activity leading to the expected deliverables is enriched by each forum discussion that contributes to the work in progress. A repository of deliverables is also included as well as a common events calendar and a resource space.

One of the strengths of the CoP is the availability of automatic functions to be tailored to individual partner needs; for example the possibility of filtering messages, the opportunity to activate calendar functions, and to download materials.

To encourage the use of the CoP platform and exchange between partners, the Zadig s.r.l. (subcontractor) management has designated a platform “tutor” for clarifications or problems solving. The tutor also acts in a proactive manner, soliciting the participation of partners when necessary, and proposing eventual activation of new functions with regard to the requests and needs that rise during the project life span.

The CoP combines the best automatic functions imagined by MOODLE with a human touch. Everything is finalized to create a true group of work capable of sharing activities, materials as well as exchanging various ideas, experiences, and points of view.

All the documents are filed in the web-community (minutes of the meetings, letters of invitation, agreements of experts, articles manuals, etc).

12. List of fieldwork experts of population based registries

The table below shows the list of experts with affiliations, contact addresses and the European Projects in which they collaborate/have collaborated.

EXPERT	AFFILIATION	CONTACT ADDRESS	EU PROJECT
Bonfigli Sandro	Ministry of Health	s.bonfigli@sanita.it	
Brignoli Ovidio	Italian College of General Practitioners	docbri@fastwebnet.it	
Burgio Alessandra	National Institute of Statistics	burgio@istat.it	
Carle Flavia	Ministry of Health	f.carle@sanita.it	EGHI Group
Carraturo Antonio	AUSL RECC Latina	a.carraturo@ausl.latina.it	
Conti Susanna	Istituto Superiore di Sanità	susanna.conti@iss.it	EuroMOMO
Corrao Giovanni		giovanni.corrao@unimib.it	
De Angelis Roberta	Istituto Superiore di Sanità	roberta.deangelis@iss.it	EUROCARE 5, CONCORD STUDY
Di Minco Lidia	Ministry of Health	l.diminco@sanita.it	
Ferrario Marco	University of Insubria, Varese	marco.ferrario@uninsubria.it	EU-BIOMARCARE
Galeone Daniela	Ministry of Health	d.galeone@sanita.it	
Gargiulo Lidia	National Institute of Statistics	lidia.gargiulo@istat.it	
Ghirini Silvia	Istituto Superiore di Sanità	silvia.ghirini@iss.it	ECHIM Project, JOINT ACTION FOR ECHIM
Giampaoli Simona	Istituto Superiore di Sanità	simona.giampaoli@iss.it	EUROCISS Project
Iannucci Laura	National Institute of Statistics	iannucci@istat.it	
Maggini Marina	Istituto Superiore di Sanità	marina.maggini@iss.it	JA-CHRODIS
Maggioni Aldo Pietro	European Society of Cardiology	maggioni@anmco.it	EURObservational Research Programme (ESC)
Nicoletti Giovanni	Ministry of Health	g.nicoletti@sanita.it	EGHI Group
Olivieri Antonella	Istituto Superiore di Sanità	antonella.olivieri@iss.it	

Pace Monica	National Institute of Statistics	mopace@istat.it	ISTAT; EUROSTAT
Palmieri Luigi	Istituto Superiore di Sanità	luigi.palmieri@iss.it	EUROCISS Project
Pannozzo Fabio	AUSL RECC Latina	fpannozzo@ausl.latina.it	Eurocare-5; Concord Study; European High Resolution Study; International Incidence of Childhood Cancer, volume 3 (IICC-3 of IARC)
Pitidis Alessio	Istituto Superiore di Sanità	alessio.pitidis@iss.it	JA on Monitoring Injuries in Europe
Scafato Emanuele	Istituto Superiore di Sanità	emanuele.scafato@iss.it	ECHIM Project
Solipaca Alessandro	National Institute of Statistics	solipaca@istat.it	
Spizzichino Lorenzo	Ministry of Health	l.spizzichino@sanita.it	
Stazi Antonia	Istituto Superiore di Sanità	antonia.stazi@iss.it	GEHA, HEALS, GENOMEUTWIN
Taruscio Domenica	Istituto Superiore di Sanità	domenica.taruscio@iss.it	EPIRARE; RD-Connect; EUROPLAN
Tavazzi Luigi	European Society of Cardiology	ltavazzi@gvmnet.it	EURObservational Research Programme (ESC)
Toccaceli Virgilia	Istituto Superiore di Sanità	virgilia.toccaceli@iss.it	GEHA; HEALS; GENOMEUTWIN
Torre Marina	Istituto Superiore di Sanità	marina.torre@iss.it	EUPHORIC; EURHOBOP; EUROTRACS
Traversa Giuseppe	Istituto Superiore di Sanità	giuseppe.traversa@iss.it	
Uccioli Luigi	University of Tor Vergata, Rome	luccioli@yahoo.com	EURODIALE
Vanuzzo Diego		diego50rdc@gmail.com	EUROCISS Project
Vittozzi Luciano	Istituto Superiore di Sanità	cnmr.eu@iss.it	EPIRARE; RD-Connect; EUROPLAN

13. Experts professional profile



Ovidio BRIGNOLI, MD

Italian College of General Practitioners SIMG

Florence, Italy

Ovidio Brignoli, MD, GP, Vice President of the Italian College of General Practitioners (SIMG). Member of the CRONOS Project - observational study of Alzheimer's Disease- of the Ministry of Health; Member of the Commission of Rheumatic Diseases, of the Commission of Pharmacovigilance of the Agenzia Italiana del Farmaco, of the Medicine Utilization Monitoring Centre (OsMED); Member of the Project Antares (ISS-Ministry of Health) on rheumatoid arthritis treatment; Co- founder of the Network of GPs for data collection on chronic diseases (Health Search). Tutor at the European School of General Practitioners.



Alessandra BURGIO,

National Institute of Statistics, Rome

Senior researcher at the National Institute of Statistics in Italy, she carries out research in the field of health, health care, morbidity and mortality. Expert in the management of statistical surveys from the design phase to the phase of analysis and dissemination of results. Recently responsible for the European Health Interview Survey (EHIS2). At international level she is the Focal Point for Eurostat for the Joint Questionnaire on non-monetary health data. She participated to several European projects and working groups set up by Eurostat as part of the activities related to the implementation of EU regulations.



Flavia CARLE, MSc

Unit of health indicator and hospital data

Healthcare Department

Italian Ministry of Health, Rome

Prof. Flavia Carle, MSc in Biology, Full Professor in Medical Statistics. Head of Department of Epidemiology, Biostatistics and Medical Information Technology at Università Politecnica delle Marche, Italy (years 1996-2011). Head of the Unit of health indicator and hospital data at the Healthcare Department of the Italian Ministry of health. Executive Editor of: BioMedical Statistics and Clinical Epidemiology (BMSCEJ) (years 2007-2012), Epidemiology, Biostatistics and Public Health (EBPH). Chairperson of the Registry for Type 1 Diabetes Mellitus in Italy (RID1); member of European Diabetes Epidemiology Group; member of International Diabetes Epidemiology Group.

National referent for OECD projects “*Geographic Variations in Health Care: What do we know and what can be done to improve health system performance?*” . International Coordinator of *OECD Rapid R&D Study on Amputation Rates in Diabetes*. Italian delegate at Experts Group on Health Information of Health & Consumer Directorate-General of European Commission. Her research work is based on the application of statistical and epidemiologic procedures of analysis to the study of health status of population.



Antonio CARRATURO, MSc, PgD

Unit of Epidemiology

Register for acute cardiovascular and cerebrovascular events

Azienda Unità Sanitaria Locale di Latina, Latina, Italy

Prof. Antonio Carraturo, MSc in Biological Sciences, PgD, epidemiologist, deputy Director of the “Register for acute cardiovascular and cerebrovascular events of the Province of Latina” (REACaCeV). He currently works at the Azienda Unità Sanitaria Locale di Latina collaborating with the Cancer Registry and is professor of Epidemiology in the Faculty of Pharmacy and Medicine at the University of Rome “Sapienza”, Latina site. Previously, he worked at the National Research Council and has participated as a researcher and expert in several research projects. His expertise is in the field of epidemiology and population-based registers for public health.



Susanna CONTI, MSc

Unit of Statistics

Istituto Superiore di Sanità, Rome

Susanna CONTI, MSc in Mathematics, Director of Research in Epidemiology and Biostatistics, Head of the Unit of Statistics of the Istituto Superiore di Sanità. Her expertise focuses on the areas of Data Analysis, Biostatistics and Epidemiology. Main activities have included: Studies on the health status of the population; Mortality studies: systematic analysis on the mortality distribution over time and space, premature mortality, evaluation of the impact of the different causes, avoidable mortality; Studies regarding environment and health: mortality and hospitalization as observed in polluted areas, participation in several study groups regarding Italian polluted sites and in studies regarding pathologies associated with exposure to asbestos. Involved, as WP leader, in EUROSTAT Morbidity Data Sources Project, Feasibility of a European Health Examination Survey (FEHES); European monitoring of excess mortality for public health action (EuroMOMO); European Tender Development and planning of a pilot EHES (European Health Examination Survey) in EU and EFTA Members (EHES); Syndromic Surveillance Survey: Assessment towards Guidelines for Europe (Triple-S-AGE).



Giovanni CORRAO, MD

University of Milano-Bicocca, Milan

Full Professor in Medical Statistics, University of Milano-Bicocca since 1993. Director of the Healthcare Research & Pharmacoepidemiology Interuniversity Center, Chairman of the Italian College of Medical Statistics Professors, President of the Ethical Committee of the Southern Lombardy, Italy, Coordinator of the master program in Biostatistics, University of Milano-Bicocca, Founding Editor of the Journal Epidemiology, Biostatistics and Public Health. He is involved in several project supported by public agencies (European Community, European and Italian Medicines Agencies, and Italian Health Ministry) focused on the use of health electronic archives for generating evidence in the fields of healthcare research and pharmacoepidemiology.



Roberta DE ANGELIS, MSc

Unit of Cancer Epidemiology

National Centre of Epidemiology, Surveillance and Health Promotion

Istituto Superiore di Sanità, Rome

Roberta De Angelis, MSc in physics, Senior Researcher, Head of the Cancer Epidemiology Unit of the National Centre of Epidemiology, Surveillance and Health Promotion of the Istituto Superiore di Sanità. Work experience in descriptive cancer epidemiology since 1993. Member of the Scientific Board of the EURO CARE project aimed at monitoring the survival of cancer patients in Europe based on registries data. Work Package leader in EU-funded projects to estimate health indicators for haematological neoplasms (HAEMACARE) and for rare tumours (RARECARE and RARECARE-net) in Europe.



Lidia DI MINCO, MSc
Italian Ministry of Health, Rome

Director of the Health Information System of the Ministry of Health (NSIS)



Marco M FERRARIO, MD, PgD
Department of Clinical and Experimental Medicine
University of Insubria, Varese, Italy

Prof. Marco M Ferrario, MD, PgD in Occupational Health and Biostatistics. Director of post-graduated School in Occupational Medicine. Principal investigator (PI) of the WHO MONICA (*MONItoring trends and determinants of CARDiovascular diseases*) Project in the Brianza (Northern Italy). Member of the WHO MONICA Steering Committee from 1994 to 2000. PI of the JACE (Job stress, Absenteism and Coronary Diseases) Study, EU Concerted Action in BIOMED-I. PI and member of the Management Group of the MORGAM (*MOnica Risk, Genetics, Archiving and Monograph*) Project. PI of Regional Registers of Cardiovascular Diseases in Lombardia Region - Progetti CAMUNI I, II and III (CARDiovascular Monitoring Unit in Northern Italy). PI of the ongoing BIOMARCARE Study co-funded under the European Unions' Seventh Framework Programme.



Daniela GALEONE, MD

Senior Medical Officer

Italian Ministry of Health, Rome

Head of the health promotion, and prevention and control of chronic diseases office. She is an expert in primary prevention and education of non communicable diseases. Italian delegate at the EU-WHO Tobacco control-FCTC Geneva, 1999-2003. National Focal Point for Tabagism in European Region of WHO. Italian delegate of the drafting committee. Italian delegate at the meeting of South Expert - High level group on nutrition and physical activity. Coordinator of the Programme Gaining in Health - Strategy to make healthy choices easier. Responsible of the realization Preventive Programme.



Lidia GARGIULO, MSc

National Institute of Statistics, Rome

Senior Researcher at the Italian National Institute of Statistics (Istat). Since 2001 responsible for the National Health Interview Survey (HIS), member of the Scientific Commission for Italian BES (Benessere Equo e Sostenibile - Equitable and Sustainable Well-being) (2011-2015). She was involved in projects finalized to the harmonization of Health Interview Survey among European countries (Eurohis-WHO-Europe, "Health and Health related Health Interview Survey and morbidity" - TF-Eurostat, Steering Committee on European Survey System (EHSS) (2000-2007). At international level she was involved for a proposal of implementing a common health status module (Task Force UNECE/WHO/Eurostat for Measurement of Health Status (2004-2007, 2010). She took part as expert in projects such as Core group of HIS/HES, ECHIM, Joint Action on ECHIM. She was involved in the different phases for the definition of European Health Interview Survey (EHIS) from the pilot EHIS modules in 2006 to the Implementing Regulation of EHIS wave2, that was carried out in Italy in 2015. Member of the Technical Group His of Eurostat since 2005, at the present she is involved in the Eurostat TF for Implementing the next Ehis wave3 in 2019.



Silvia GHIRINI, MSc

Unit of Population's Health and Health Determinants

National Centre of Epidemiology, Surveillance and Health Promotion

Istituto Superiore di Sanità, Rome

Silvia Ghirini, MSc in Statistics, Researcher at the Istituto Superiore di Sanità, National Centre of Epidemiology, Surveillance and Health Promotion, Population's Health and Health Determinants Unit from 2003. She is involved in the research programmes on alcohol, ageing, cognitive impairment, health monitoring, and in epidemiology of ageing. She was involved as expert in EU Projects on alcohol and health monitoring (PHEPA, ALICE RAP, ECHIM, Joint Action on ECHIM, VINTAGE, ODHIN AMPHORA). At present, she is responsible for the activity of the WP4 of the RARHA JA. At the national level she is involved in the activity of the two main longitudinal studies on ageing: ILSA and IPREA. She is a member of the WHO Collaborating Centre for Research & Health Promotion on Alcohol & Alcohol-related Health Problems.



Simona GIAMPAOLI, MD, FESC, FAHA

Unit of Cerebro and Cardiovascular Diseases

National Centre of Epidemiology Surveillance and Health Promotion

Istituto Superiore di Sanità, Rome

Simona Giampaoli, MD, PgD in Hygiene and Preventive Medicine. Head of the Unit of Cerebro and Cardiovascular Diseases of the National Centre of Epidemiology, Surveillance and Health Promotion at the Istituto Superiore di Sanità. Since 1982 she is involved within the Cuore Project in epidemiology and prevention of cardiovascular disease (CVD) through the following main activities: longitudinal studies to assess the 10-year CVD risk prediction of the Italian adult population; role of CVD risk factors and chronic diseases in the development of ageing-related diseases; management of cross-sectional studies to assess the distribution of risk factors, high risk conditions, and prevalence of CVD in the Italian adult population; implementation of population-based registers for surveillance of coronary and cerebrovascular events. She is the Italian representative of the multicentre CASCADE project (Cardiovascular Determinants of Dementia), the EURALIM (Europe Alimentation), the FINE (Finland Italy, Netherlands Elderly Study), the EHES (European Health Examination Survey) JA. From 2000 to 2008 she was the coordinator of the EUROCIS - European Cardiovascular Indicators Surveillance Set - Project within the Health Monitoring Programme of the DG SANCO.



Laura IANNUCCI, MSc
National Institute of Statistics, Rome

She has been a researcher at the Italian National Institute of Statistics since 2000. Her expertise areas cover the HIS (Health Interview Surveys). Her activity has dealt with methods to improve quality during data collection, data editing and imputation. She has analyzed health status and life styles among population focusing on trends and social inequities. She has participated in the following European projects: “European Module on disability and social integration” (2008-2009); “Phare - Statistics Programme Romania” (2000), “Core group of HIS/HES, ECHIM, Joint Action on ECHIM”.



Marina MAGGINI, MSc
Unit of Pharmacoepidemiology
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Marina Maggini, MSc in Biology, Senior epidemiologist, Coordinator of the Pharmacoepidemiology Unit of the National Centre of Epidemiology, Surveillance and Health Promotion at Istituto Superiore di Sanità. Responsible of the National diabetes disease management project IGEA (Diabetes integration, management and assistance), and of the National project on chronic disease management. Leader of the Work Package7 of the Joint Action CHRODIS (Chronic Diseases and Promoting Healthy Ageing across the Life Cycle).



Aldo P. MAGGIONI, MD, PgD, FESC
Research Center
Italian Association of Hospital Cardiologists, Florence, Italy

Aldo Maggioni MD, PgD in clinical cardiology. Member of the Steering Committee of the GISSI studies and Director of the Research Center of the Italian Association of Hospital Cardiologists. Since 2010, Scientific Coordinator of the EURObservational Research program of the European Society of Cardiology. He served as a member of the Steering Committee, Event Evaluation Committee, Data and Safety Monitoring Board of more than 50 clinical studies in areas including myocardial infarction, secondary prevention, diabetes, stroke, and acute and heart failure.



Giovanni NICOLETTI, MD, PgD

Department for prevention

Ministry of Health, Rome

Giovanni Nicoletti, MD, PgD in Haematology and Medical Oncology, Director of the Unit III of the Department for prevention of Ministry of Health. He worked for several years as a research in Oncology at the Catholic University of Rome, since 1994 he has been serving as Medical officer at the Ministry of Health. In 2003 he was appointed as Director of the Unit III of the Department for prevention at Ministry of Health, whose commitments involve general strategic coordination of several Ministerial Directorate and International Relationships, in particular with Europe.

His on-going main duties include Heading of the Italian Focal point of the EU Health programme 2014-2020 and scientific coordination of several projects of the National Fund for Health of the Ministry (CCM), in particular those involving Regions, with main focus on chronic diseases and prevention.



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Antonella Olivieri, MSc in Biology, Senior researcher in the Department of Cell Biology and Neuroscience at the Istituto Superiore di Sanità. Her scientific activities are focused on research, prevention and surveillance of congenital and acquired thyroid hypofunction. She is responsible for the Italian National Registry of Infants with Congenital Hypothyroidism (INRICH), a population-based registry that performs the nationwide surveillance of permanent forms of congenital hypothyroidism in Italy. She is also responsible for the Italian National Observatory for Monitoring Iodine Prophylaxis (OSNAMI), a nationwide monitoring program of universal salt iodization in Italy.



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Monica Pace, MD, PgD in Allergology and Immunology, holds also a degree in Population Biology. Senior Researcher at the Italian National Institute of Statistics from 2000, Seconded National Expert at the European Commission, DG Eurostat on 2012-2014. Her expertise areas cover mortality by cause statistics, International Classification of Disease and diagnose-based morbidity statistics. She is currently member of the Coordination Group of the EU project “inventories activities and methodologies for morbidity statistics in Member States” (2015-2017). She has participated to two “Partnership Health” Eurostat Projects as Leader of the Core Group on Causes of Death statistics (2007-2011). She worked as researcher at the Istituto Superiore di Sanità at the Ecotoxicology and Virology Laboratories (1989-2000).



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Luigi Palmieri, MSc in Statistics, PhD, Senior Researcher in the Unit of Cerebro and Cardiovascular Diseases Centre for Epidemiology, Surveillance and Health Promotion of the Istituto Superiore di Sanità, Responsible of the Italian National Register of Major Coronary and Cerebrovascular Events; Member of the Coordination Group of the EUROCISS I and II (Cardiovascular Indicators Surveillance Set) Projects; PI of the Project CUORE-ISS-Epidemiology and prevention of ischaemic heart disease; PI of CUORE Italian cohorts in ERFC-Emerging Risk Factors Collaboration; PI of Italian cohort ROMA in ‘multinational collaborative study MORGAM-Monica Risk Genetics Archiving and Monograph’; Leader of WP-3 ‘Evaluation of the ‘European Health Examination Survey (EHES)-Joint Action’.



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Fabio PannoZZo, MD, is an epidemiologist, Director of the Cancer Registry of Latina province and of the Register for acute cardiovascular and cerebrovascular events of the Province of Latina. He currently works at Azienda Unità Sanitaria Locale di Latina. He has participated in the following European projects: European Cancer Registry5-6 (EUROCARE5-6), CONCORD (Global surveillance study of cancer survival), International Incidence of Childhood Cancer 3 (IICC3), Translational Cancer Research - High resolution project on prognosis and Care of cancer patients (TRANSCAN-HIGHCARE), Europe Alimentation (EURALIM), Countrywide Integrated Non-communicable Diseases Intervention (CINDI). His expertise is in the field of epidemiology of chronic disease and population-based registers for public health.



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Alessio Pitidis, MSc in Economics. Many professional training courses in information technology and statistical applications. Certified coder by the Association for the Advancement of Automotive Medicine with concern to Injury Scaling Uses and Techniques. Senior Researcher in biostatistics and health economics. Director of the Environment and Trauma Unit of the Istituto Superiore di Sanità. His expertise is in epidemiology of trauma, injury prevention, health economics. Responsible of the National Information System on Home Injuries (SINIACA). National Database Administrator for Italy of the European Injury Database (EU-IDB) of the EC DG-SANCO. Member of the scientific committee "Health and Home Accidents" of the Prevention Department of the Ministry of Health. Member of the advisory board of the Department of Road Traffic Safety of the University of Parma. Project leader of many National and European projects concerning surveillance, prevention, severity and economic evaluation of injuries.



Emanuele SCAFATO, MD, PgD

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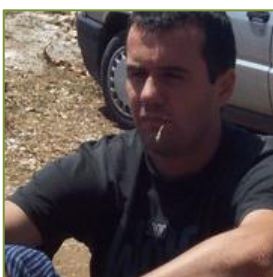
Prof. Emanuele Scafato MD, PgD in epidemiology and gastroenterology, Head of Population's Health and Health Determinants Unit (PHU) of the National Centre of Epidemiology, Surveillance and Health Promotion at the Istituto Superiore di Sanità, dealing with four main fields of research: Alcohol, Ageing, Alzheimer and Assessment. Director at the WHO Centre for Research on Alcohol and of the National Observatory on Alcohol deserving its activities to research, assessment, prevention and training in Epidemiology and Public Health particularly on surveys on alcohol assessment of alcohol-related harm, assessment and analysis of population health status consumption/abuse, evaluation and assessment of alcohol-related harm, assessment and analysis of population health status trends. PHU acts as Sub-secretariat of the European Commission Working Party on Health Indicators - European Community Health Indicators and Monitoring, via the ECHIM group. He is partner of almost all the past and current EU Projects on alcohol and health monitoring such as PHEPA, PHEPA2, AMPHORA, ECAT, Building Capacity, ELSA, Alcohol Policy Network, MEGAPOLE, ALICE RAP, EWA, ECHI, ECHI2, ECHIM. He has been partner in several EU FP7 Projects on ageing such as ERA-AGE, ERA-AGE II, FUTURAGE and coordinator of the VINTAGE Public Health Programme project.



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Maria Antonietta Stazi, Msc in Biology, Head of the Genetic Epidemiology Unit at the National Centre of Epidemiology, Surveillance and Health Promotion of the Istituto Superiore di Sanità. She has been the Principal Investigator of several projects within multicentre national and international collaborations. Founder and actual coordinator of the Italian Twin Registry which, with its 25.000 twins actively participating to medical and social research, is a major biomedical research resource in Italy. She has a long experience on population studies, sample surveys and twin studies.



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Domenica Taruscio MD, PgD in histopathology and in human genetics, II level Master Degree in Bioethics. Director of the National Centre for Rare Diseases at the Istituto Superiore di Sanità. Member of: Committee for Orphan Medicinal Products of European Medicine Agency (EMA), European Rare Diseases Task Force, European Commission of Expert Group on Rare Diseases (EUCERD), Health Research Advisory Group (DG-Research), Management Board of the European Molecular Genetics Quality Network; Interdisciplinary Scientific Committee of International Rare Diseases Research Consortium (IRDIRC). Scientific leader of the bilateral agreement on rare diseases between ISS-Italy and NIH-USA. Coordinator of the following European projects: RARE-Bestpractices, European Project for Rare Diseases National Plans Development (EUROPLAN), European Platform for Rare Disease Registries(EPIRARE). WP leader in the following EU projects: RD-Connect, Advance Health Technology Assessment (Advance-HTA), Social Economic Burden and Health-Related Quality of Life of Patients with Rare Diseases in Europe (BURQ-OL) , European research Projects on Rare Diseases-(E-RARE) , European Joint Action for Surveillance of congenital anomalies (EUROCAT), EUCERD Joint Action, Co-leader for the Work Package 2 in the Rare Disease-Action (RD-Action). Past President of International Conferences on Rare Diseases and Orphan Drugs (ICORD). Her efforts are directed mainly to tackle rare diseases from science to society.



Luigi TAVAZZI MD, PgD, FESC, FACC

GVM Care&Research

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Prof. Luigi Tavazzi, MD, PgD in Clinical Cardiology, former director of the Cardiology Department at the University Hospital of Pavia (Italy), at present Scientific Director of a network of European cardiovascular hospitals. Involved in coordinating Committees of numerous cardiovascular international randomized clinical trials and observational studies. Committed in several roles by the European Society of Cardiology, including the Board, WGs and Associations. Presently past-chairman of the ESC Eurobservational Research Programme. Also involved in Italian governmental committees and former President of the Italian Association of hospital cardiologists (ANMCO) and of the Italian Federation of Cardiology.



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Virgilia Toccaceli, MSc in Social science, II level Master Degree in Bioethics. Collaborator of Research at the Centre of Epidemiology, Surveillance and Health Promotion of the Istituto Superiore di Sanità since 1995. Field of expertise: Research ethics, biobanking for research ethical and legal procedures, Disease Registers (establishment, analysis of the data flow and anonymization, ethical and legal requirements according to international guidelines and national law - "privacy by design"). Member of the Ethics Advisory Board for the following European Projects: PROPAG -AGEING, Horizon 2020; HEALS (Health and Environment-wide Associations based on Large population Surveys), 7th Framework Programme; CHANCES (Consortium on Health and Ageing: Network of Cohorts in Europe and the United States), 7th Framework Programme; GEHA (Genetic of Healthy Aging), 7th Framework Programme. Expert for Italy in the Projects hSERN (Human sample exchange regulation navigator) and BBMRI (Biobank and biomolecular research infrastructure).



Marina TORRE, MSc

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Marina Torre, MSc in Mechanical Engineer, Senior researcher at Unit of Statistics of the National Centre of Epidemiology, Surveillance and Health Promotion at the Istituto Superiore di Sanità. She worked as researcher at the Biomedical Engineering Laboratory of the Istituto Superiore di Sanità in studies relevant to the development of instrumentation and specific devices for human movement measurement, the rehabilitation, and the ankle joint biomechanics and she was responsible of the CE certification of hip prostheses. In 2002 she became responsible of studies aimed at defining the organization of a national hip replacement registry and since 2006 she is the project leader of the Italian Arthroplasty Registry. Leader in the following European Projects: EUPHORIC (European Public Health Outcome Research and Indicators Collection), WP2 Dissemination in EURHOBOP (European Hospital Benchmarking by Outcomes in acute coronary syndrome Processes) and EUROTRACS (European Treatment and Reduction of Acute Coronary Syndromes cost analysis).



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Senior researcher at the Istituto Superiore di Sanità (ISS), scientific body of the Italian National Health Service; involved in research activities aimed at acquiring a better understanding of the benefit-risk profile of drugs, describing and promoting a more appropriate drug use within the National Health Service, and organizing educational activity and scientific events. Specifically, he took part and/or coordinated epidemiological studies, mostly observational designs, in different areas of safety and effectiveness such as: neuropathies associated with gangliosides use; comparison of the gastrotoxicity and hepatotoxicity of NSAIDs; events associated with drugs and vaccines use in pediatrics; assessment of the effectiveness of the Di Bella treatment. Between December 2005 and May 2009 he was in charge of the Research and Development Unit which coordinated the program on independent research on drugs of the Italian Medicines Agency (AIFA).



Luigi UCCIOLI, MD, PgD

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Prof. Luigi Uccioli, MD, PgD in diabetes and in endocrinology, Professor of Endocrinology and Geriatric Medicine at the University of Rome Tor Vergata. He has a long research experience on diabetic late complications as neuropathy and diabetic foot. A recent field of interest is the treatment of diabetic patients with peripheral vascular disease and critical limb ischemia at risk of major amputation. Chairman of the Study Group on Diabetic Foot for the Italian Society of Diabetes and Treasurer of the Diabetic Foot Study Group for the European Association for the Studies on Diabetes (EASD). Chairman of the regional section of the Italian Society of Diabetes (SID). Member of the working group for the International Guidelines on Diabetic Foot (IWGDF). Participant in the European Study Group on Diabetes and the Lower Extremity (EURODIALE) network.



Diego VANUZZO, MD, PgD, FESC

Italian Association of Hospital Cardiologists

Fondazione “per il Tuo Cuore” HCF, Florence, Italy

Diego Vanuzzo, MD, PgD in Cardiology, Preventive Medicine, and Sports Medicine. From 1981 to August 2015, he was Director at the Cardiovascular Prevention Centre Udine, Italy. His research activity has always been devoted to cardiovascular epidemiology and prevention. He was involved in four WHO Projects: Community Control of Hypertension - Italian section: Progetto di Camposampiero, Comprehensive Cardiovascular Community Control Programmes - Italian section: Progetto Martignacco, European Risk Factor and Incidence Coordinated Analysis ERICA Project, Monitoring of Trends and Determinants of Cardiovascular Diseases MONICA : (MONICA-Friuli). Since 1996, PI of the Martignacco and MONICA-Friuli Projects. He participated in the following European Union Projects: Community Learning Action to Reduce cardiovascular risk (CLARA), European Health Risk Monitoring (EHRM), Cardiovascular Indicators Surveillance Set Projects I and II (EUROCISS). He took part also in the EuroASPIRE I and III Studies (European Action on Secondary and Primary Prevention through Intervention to Reduce Events) of the European Society of Cardiology (ESC).



Luciano VITTOZZI, MSc

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Luciano Vittozzi, MSc in Chemistry, consultant for the National Centre for Rare Disease at Istituto Superiore di Sanità, Rome. From 1977 to 2000 he spent his research career at Istituto Superiore di Sanità becoming Director of the Biochemical Toxicology Unit in 1982. After a period of service as Seconded National Expert in the European Commission, Unit of Emerging, Rare and Communicable Diseases, in 2005 he became consultant at the Italian Ministry of Health. In 2008, he joined the National Centre for Rare Diseases becoming Director of the Unit dealing with public health aspects and EU relations. In his career, he served as expert in several National and EU, WHO and Organisation for Economic Co-operation and Development (OECD) committees, managed several European Commission activities networking experts from the national health authorities, including the EU Early Warning and Response System and the EC Working Group on Chemical Threats. He also coordinated operatively several EU public health projects, such as Report on the status of health in the EU (EUGLOREH), Rare Diseases National Plans Development (EUROPLAN), the EU Tender on Neonatal Screening Practices in Europe and European Platform for Rare Disease Registries. (EPIRARE).

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