WP-8 ‘Platform for population based Registries’

REPORT

NETWORK OF FIELD WORK EXPERTS

30 September 2015

Prepared by:

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CONTENTS:

Objectives of the Work Package 8 “Platform for population based registries”

The objectives of the WP8-Platform for population based registries 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 strategic objective is to improve and guarantee the quality of data collected by population based registries of chronic diseases, facilitate their implementation, sustainability, maintenance, including the provision of specific software for the linkage of different sources of information, statistical analysis, data exchange and automated calculation of indicators. The compliance of the process with strict privacy and data protection requirements will be assessed.

Two tasks will contribute to the realization of the work, task 1 focusing in particular on chronic disease occurrence and task 2 focusing in particular on quality of health care.

Description of the work of the Task 1

Task 1 will identify standardized definitions of non-communicable chronic diseases of interest in public health; identify common procedures and methods for establishing population based registries, including sources of information, population size criteria, identification of events, diagnostic criteria for events validation, internal and external validation procedures, ethical issues, to deliver the processed core indicators of disease occurrence recommended by ECHIM, to prepare a manual of operations with a stepwise procedure for the setting up and/or implementation of the population based registries, to prepare guidelines for the training of epidemiological team involved in the setting up/implementation of the population based registers.

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

The first deliverable of the Task 1 is the technical report on the network of fieldwork experts involved in surveillance of chronic diseases by using population based registry and interested in building up a platform of population based registries.

Background of registries

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

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 the 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 programmes. If survival rates are assumed to be known, prevalence can also be estimated. Being focused on general population, it provides a comprehensive picture of a disease in the community, highlights problem areas, and suggests where treatment facilities are most in need of improvement. Therefore, it includes all cases in a defined population, treated both 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. For these reasons, collection of information on suspected events and application of diagnostic criteria should follow standardized methodologies in order to assess comparable indicators (between and within countries and over time periods).

This 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 (mortality data, hospital discharge and GP’s records) and covers defined population (entire municipalities, regions or whole country) and specific age groups (children, adults, elderly).
A registry 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.

Differently, a hospital based registry provides the number of hospitalisations but does not provide data on less severe events and out-of-hospital mortality. Hence, it cannot be directly used to estimate incidence or prevalence of the disease in the population. Nevertheless, case series from hospital based registry provide important clinical information. A hospital based registry collects information about hospital patients through surveillance of admission and discharge records. In particular, it provides detailed information on diagnostic and therapeutic procedures. A primary objective of this type of registry is to assess length of stay, in-hospital treatment, and outcome.

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. 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 operation of population based registries and guidelines for training personnel involved in population based registries.

Procedures followed for the selection of fieldwork experts of population based registries

The first step to build a network of experts was to propose to professionals involved in the fieldwork of population based registers/registries to collaborate in the WP focused on population based registries within the European Project BRIDGE-Health (see letter attached in appendix 1).

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 EC or 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 etc.).

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

Experts Network first meeting

The first meeting of the experts network was held 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, on the WP-8 'platform of population based registries', on the working plan, and on the schedule for the realization of the manual of operations for the population based registry of chronic diseases and the guidelines for personnel who needs to implement population based registries. The possibility to collaborate with the Ministry of Health to improve utility and use of data in the heath information was also suggested. Minutes of the meeting are attached (appendix 2).

Agreement subscription

Experts have signed the agreement to participate in the project (appendix 3). In the form a specific question on the possibility to share experience with other researchers involved in the BRIDGE-Health was included. The experts who presented their data during the meeting signed a specific form to authorize data sharing (appendix 4). Experts included also a short professional profile evidencing their experience in the field of registries and European project/s (appendix 5).

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 an open-source software, 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: for each issue there is an open forum for discussing proposals about the topics. 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” to whom all partners may address for clarifications or to solve functional problems. 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.

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.

Table: BRIDGE Health, WP 8 - TASK 1, List of Experts

NAME	SURNAME	AFFILIATION	E-MAIL	Registers involvement	European Projects involvement
OVIDIO	BRIGNOLI	Italian College of General Practitioners	docbri@fastwebnet.it		
FLAVIA	CARLE	Ministry of Health	f.carle@sanita.it		EGHI Group
ANTONIO	CARRATURO	AUSL RECC Latina	a.carraturo@ausl.latina.it	Cancer Register in Latina Province, Italy	
SUSANNA	CONTI	Istituto Superiore di Sanità	susanna.conti@iss.it		EuroMOMO
ROBERTA	DE ANGELIS	Istituto Superiore di Sanità	roberta.deangelis@iss.it		EUROCARE 5, CONCORD STUDY
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ANTONELLA	OLIVIERI	Istituto Superiore di Sanità	antonella.olivieri@iss.it	Responsible of the Italian National Registry of Infants with Congenital Hypothyroidism-INRICH	
MONICA	PACE	National Institute of Statistics	mopace@istat.it		ISTAT; EUROSTAT
LUIGI	PALMIERI	Istituto Superiore di Sanità	luigi.palmieri@iss.it	Responsible of the National Registry of Coronary and Cerebrovascular Events, Italy	EUROCISS Project
FABIO	PANNOZZO	AUSL RECC Latina	fpannozzo@ausl.latina.it	Responsible of the Cancer Register in Latina Province, Italy	Eurocare-5; Concord Study; European High Resolution Study; International Incidence of Childhood Cancer, volume 3 (IICC-3 of IARC)
ALESSIO	PITIDIS	Istituto Superiore di Sanità	alessio.pitidis@iss.it		JA on Monitoring Injuries in Europe
EMANUELE	SCAFATO	Istituto Superiore di Sanità	emanuele.scafato@iss.it		ECHIM Project
ANTONIA	STAZI	Istituto Superiore di Sanità	antonia.stazi@iss.it	Responsible of the National Registry of Twins	GEHA, HEALS, GENOMEUTWIN
DOMENICA	TARUSCIO	Istituto Superiore di Sanità	domenica.taruscio@iss.it	Responsible of the National Registry of Rare Diseases	EPIRARE; RD-Connect; EUROPLAN
LUIGI	TAVAZZI	European Society of Cardiology	ltavazzi@gvmnet.it	Responsible of the Registries of the European Society of Cardiology	EURObservational Research Programme (ESC)
VIRGILIA	TOCCACELI	Istituto Superiore di Sanità	virgilia.toccaceli@iss.it		GEHA; HEALS; GENOMEUTWIN
MARINA	TORRE	Istituto Superiore di Sanità	marina.torre@iss.it	Italian Arthroplasty Registry Project (RIAP)	EUPHORIC; EURHOBOP; EUROTRACS
LUIGI	UCCIOLI	University of Tor Vergata, Rome	luccioli@yahoo.com		EURODIALE
DIEGO	VANUZZO		diego50rdc@gmail.com	Register of Coronary and Stroke Events of Friuli Venezia Giulia Region	EUROCISS Project
LUCIANO	VITTOZZI	Istituto Superiore di Sanità	cnmr.eu@iss.it	National Registry of Rare Diseases	EPIRARE; RD-Connect; EUROPLAN

APPENDIX 1

Invitation letter to join network of Experts

ISTITVTO SVPERIORE DI SANITÀ

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

Dear Colleagues,

On May the 1st 2015 the project BRIDGE Health (BRidging Information and Data Generation for Evidence-based Health Policy and Research) started, funded by the DG SANTE'.

The project aims to create European health information (EU-HI) and data generation networks covering major EU health policy areas; the network uses comprehensive experience and assures a knowledge transfer from past health and research frameworks. The aim is to work towards a comprehensive, integrated, and sustainable EU-HI supporting evidence-based health policy and research for the EU and Member States by providing blueprints and concepts of building blocks for a future EU-HI research infrastructure consortium (ERIC).

The Project is coordinated by Prof. Herman Van Oyen of the Institut Scientific de Santè Publique, Bruxelles. Coordination, dialogue and interaction between BRIDGE Health and DG-SANCO, the Expert Group on Health Information, Eurostat, DG Research and other DGs ensure the sustainability of the work and bridge to a future ERIC-HI. Thirty institutions take part in the project including Robert Kock Institute, RIVM, THL, Istituto de Salud Carlos III; Italy participates with the ISS and Bocconi and Tor Vergata Universities.

Thanks to our past experience with the EUROCISS Project, which produced manuals of operations for population based registries of stroke and acute myocardial infarction and recommendations of frequency indicators, we lead the Working Package 8 "Platform for population based registries". The objectives 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 strategic objective 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 a suite of open source software for statistical analysis, data exchange, and automated calculation of indicators, both locally and at EU level. The compliance of the process with strict privacy and data protection requirements will be systematically assessed.
Two tasks will contribute in the realization of the work, task 1 focusing in particular on chronic disease occurrence and task 2 focusing in particular on quality of health care.

We are involved in the task 1 with the aim to: identify standardized definitions of non-communicable chronic diseases of interest in public health; identify common procedures and methods for establishing population based registries, including sources of information, population size criteria, identification of events, diagnostic criteria for events validation, internal and external validation procedures, ethical issues, to deliver the processed core indicators of disease occurrence recommended by ECHIM; prepare a manual of operations with a stepwise procedure for the setting up and/or implementation of the population based registries of the chronic non-communicable diseases; prepare guidelines for the training of epidemiological team involved in the setting up/implementation of the population based registries.

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

Task 2 is led by the Tor Vergata University group (Prof. Luigi Uccioli) and the University of Surrey (Prof. Fabrizio Carinci).

The first deliverable of our task is the technical report on the network of fieldwork experts involved in the surveillance of chronic diseases by using population based registries and interested in building up a platform for population based registries. In order to constitute the experts network, we would like to ask your agreement to participate as expert to the WP8-task1 activities. Whether you are willing to participate, please fill and return the attached form ‘ISS-BRIDGE-disclosure’.

The first meeting of experts will be held in a short time at the Istituto Superiore di Sanità.

Do not hesitate to contact us for more information.

Best regards,

Simona Giampaoli

Simona Giampaoli

Leader of

BRIDGE Health WP8 “Platform for population based registries”

May 2015

APPENDIX 2

Minutes of the Experts meeting in Rome

25.06.2015

First meeting of the WP8-Task 1

Rome, Istituto Superiore di Sanità

Room Zampieri

25 June 2015

MINUTES of WP8 Meeting

Participant Experts:
Simona Giampaoli (Istituto Superiore di Sanità-ISS) (*SG*)
Flavia Carle (Ministry of Health) (*FC*)
Antonio Carraturo (Latina Health Local Unit) (*AC*)
Susanna Conti (ISS) (*SC*)
Roberta De Angelis (ISS) (*RDE*)
Silvia Ghirini (ISS) (*SGh*)
Giovanni Nicoletti (Ministry of Health) (*GN*)
Antonella Olivieri (ISS) (*AL*)
Monica Pace (National Institute of Statistics-ISTAT) (*MP*)
Luigi Palmieri (ISS) (*LP*)
Fabio Pannozzo (Latina Health Local Unit) (*FP*)
Alessio Pitidis (ISS) (*AP*)
Emanuele Scafato (ISS) (*ES*)
Antonia Stazi (ISS) (*AS*)
Luigi Tavazzi (responsible of the Register of the European Society of Cardiology) (*LT*)
Virgilia Toccaceli (ISS) (*VT*)
Luigi Uccioli (University of Tor Vergata) (*LU*)
Diego Vanuzzo (National Association of Hospital Cardiologists-ANMCO) (*DV*)
Luciano Vittozzi (ISS) (*LV*)

Auditors:
Eva Benelli (Zadig) (*EV*)
Anna Di Lonardo (ISS) (*ADL*)
Paola Franzese (Latina Health Local Unit) (*PF*)
Cinzia Lo Noce (ISS) (*CLN*)
Ilaria Luzi (ISS) (*IL*)
Claudia Meduri (ISS) (*CM*)
Paolo Salerno (ISS) (*PS*)
Serena Vannucchi (ISS) (*SV*)

Aplogises:
Ovidio Brignoli (Italian Society of General Medicine-SIMG) (*OV*)
Marco Ferrario (University of Insubria) (*MF*)

Marina Maggini (ISS) (*MM*)
Aldo Maggioni (ANMCO) (*AM*)
Domenica Taruscio (ISS) (*DT*)
Marina Torre (ISS) (*MT*)

AGENDA

10.00 - Registration of participants
10.30 - Introduction of participants
10.45 - Presentation of the BRIDGE project
11.00 - Presentation of WP8: objectives and working plan
11.30 - Short presentation of population based registers, in particular on methods, indicators and main difficulties in implementation
12.30 - Morbidity statistics in Europe
12.45 - ECHIM indicators
13.00 - General discussion
13.30 - Light lunch
14.15- Organization of the work for the preparation of the manual of operation of population based registers
15.30 - Presentation of the web community platform
15.45 - Expression of interest to participate in the WP8
16.00 - Miscellaneous
16.30 - End of the meeting

Welcome of *GN* from the Ministry of Health: greetings and thanks to all present experts for participating to the WP8 of the project. The BRIDGE project develops key results of previous EU projects in domains of population and Health System monitoring in order to build a network and an infrastructure of Health Information (HI) towards an ERIC-HI (European Research Infrastructure Consortium for Health Information).
GN: The EU Commission has now the willing of building and Health Information System and is intentioned to organize a law framework for 1) selected ECHIM indicators, 2) standardization of collection procedures and methods for producing indicators, 3) making provision of indicators mandatory for EU Member States.

Introduction of participants: participants presented themselves as experts involved in population-based registers and European projects or as experts involved in statistical analyses at national and European level. Some of them participate in the networks of WP4, WP5, WP6, WP9, WP10, and WP11.

Presentation of the BRIDGE project: *SG* presented the overall BRIDGE Project including aims, organization, dissemination and the 12 WPs with the slides presented by Herman Van Oyen at the pre-kick-off meeting in Luxembourg on January 2015. The project aims to enhance transferability of HI, to reduce inequality, and to develop blue print of sustainable HI system by standardization of data collection, ensuring data quality, including procedure of validation, and addressing ethical issues.
The project started on May 1st 2015 and will last 30 months.

Presentation of WP8, objectives and working plan: *SG* presented specific aims, organization, deliverables, and time table of the WP8. Activities are organized in two tasks: task-1 mainly focuses on HI for measuring occurrence of the disease, while task-2 mainly focuses on health care.

Population based registers, focusing on different chronic diseases, are often implemented in different geographical areas, even though such registers are based on record linkage of the same sources of information: to succeed in integrating such registers could save efforts and be extremely efficient and cost sustainable.

The challenge of task 1 and task 2 of WP8 will be to use population-based and hospital registers to integrate and create strict connections between HI on occurrence of the disease in the population, and HI on health care.

Test cases for some specific pathologies will be considered in relation to population health and health care.

Cancer, infection diseases, and drugs registers are not included in the BRIDGE project since already covered in other agencies or bodies; nevertheless experts of these fields have been invited for their expertise in conducting population-based registers; their contribution to build a manual of operation as a platform for population-based registers is fruitful.

Short presentation of population based registers, in particular on methods, indicators and main difficulties in implementation: the following population based registers were presented:

- Cancer Register in Latina area (*FP*); Criticisms: Migration Health (persons recovered out of the surveillance area); quality assessment (prevalence of death certificates with cancer as cause of death without previous recoveries in the area under surveillance); privacy law; timeliness; quality of information flows; completeness and reliability.
- Arthroplasty Registry (*IL*): it is based on registration at regional level; the aim is to evaluate the performance of prostheses based on Hospital Discharge Records and data from device producers. If widened at national level it could become an important instrument of surveillance of arthrosis and arthritis. Criticisms: Coverage and lack of Unique Personal Identification Number for data linkage.
- Rare Diseases (*LV*): It is a national register based on data available at specialized centers designated to ensure Rare Diseases care and assess the right to special rules of cost exemption. Criticisms: high quality of diagnosis (centralized diagnosis) but not total completeness for complexity of diagnoses; absence of linkage with mortality; lack of ICD codes for recent specific rare diseases; few variables regularly collected.
- Hospital registers of Cardiovascular Diseases (*LT*): registers from the ESC-European Society of Cardiology's EURObservational Research Programme (EORP) were presented describing the European experience in building cardiovascular registers, the Italian experience on the register of Heart Failure, and what is changing in Europe for CVD registers. EORP includes general (e.g. Acute Coronary Syndromes), special (e.g. Cardiomyopathies), and sentinel (e.g. Atrial Fibrillation Ablation for monitoring safety aspects) registers. Criticism: they are not representative at EU level (large heterogeneity for geography, culture, economy, technology level, health facilities' availability). Such registers are conducted by ESC Constituent Bodies (ESC sub-specialty Associations and National Cardiac Societies (NCS)); they are managed centrally by a Research Centre; these registers usually cooperate with, but independently from Industry. These registers give a less expensive opportunity for implementing randomized clinical trials.
- Cardiovascular Diseases population-based registers (*LP*) was skipped for lack of time.

Morbidity statistics in Europe: Diagnosis-specific morbidity statistics in Europe (*MP*): The aim of diagnosis-specific morbidity statistics is to have a comprehensive overview and an adequate summary on the occurrence of diseases at population level. Criticisms: “European paradox”: many sources exist, but each country operates in own Institutional environment; differences in the available sources and health systems persist; restrictive interpretation of laws and regulations, and sense of “data ownership”, lack or unavailability of patient Unique Identification Number pose barriers to data linkage for statistical purposes; poor integration between health and statistical fields. Pilot studies in 16 Member States showed the feasibility of a common methodology for many of the 103 indicators (both for incidence and prevalence) that are included in the Eurostat Morbidity Short List (SL MORB).

ECHIM indicators: Joint Action for ECHIM-European Community Health Indicators and Monitoring (*SG*): it was shown and described the identification and selection path starting from 1998 to 2012 of a short list of common Health Indicators for monitoring health in the EU Countries. The 2012 version of the ECHI shortlist contains 94 indicators. These are the same 88 indicators as in the 2008 version of the shortlist, but for six of these both a self-reported and a register-based indicator variant have been defined. Criticisms: Register data on diseases are largely not available or of little use (except AMI and Stroke from 11 countries but with a lot of differences in definitions); ECHIM indicators are recommended to be provided by countries, but they are not mandatory.

General Comments:

Some diseases need register at national level, especially when the aim is to recall individuals for specific issues, such as the Arthroplasty Registry settled for assessing advice performance and substitution of failing prostheses; while, for other diseases it is sufficient to implement registers in different areas of the country, that would be representative of the population such as injuries, cardiovascular, and cancer population based register.

Powerful technology and tools have made a huge amount of information available to build an HI system, but it’s crucial to manage the process to ensure high quality, standardization and validation of data, but overall interpretation of population HI.

In every reported experience of register implementation, ethical issue raised as one of the main problem to be faced and consequently as one of the main topic to be addressed in the manual of operation of the platform for population based registers.

Organization of the work for the preparation of the manual of operation of population based registers: *SG* presents the organization of the work of the WP8-task 1 including following activities and time table:

- Collection of specific literature and manuals on population based registers provided by experts
- Revision and summarizing of collected material
- Elaboration of draft of deliverable on the manual of operation of the platform for population based registers
- Revision of the first draft of the manual of operation (expert group of task 1)
- Test cases on selected diseases to be included in the manual of operation as examples
- External revision of the manual of operation (external experts)

Presentation of the web community platform: *EB* presents the proposal for building a web community moodle based interactive platform for dialogue, dedicated to the WP8 of the BRIDGE project where sharing documents, information, comments related to the activities of the WP in order to encourage transfer of knowledge, to develop new ideas, to reframe problems, and to find original solutions.

Miscellaneous: *SG* asked to all participants to fill in and sign the form for the agreement in sharing contact information with other WPs of the BRIDGE Health Project, and the form for the agreement in using slides presented at the meeting for the purposes strictly related to the BRIDGE Project activities.

SG asked to all participants to manifest own willing to have access to the drop box of the BRIDGE Project, taking into accounts that, according to the project coordinator rules, the access was allowed to project partners only.
MP asks to have contacts with WP10, WP11, and WP12; for this reason she asks to have access to the drop box;
FC asks to have access to the drop box;
LU asks for Massimo Massi Benedetti (Task 2 of WP8) to have access to the drop box

SG, as coordinator of WP8, assures to give circulation of all material of interest as much as possible.

At 17,30 p.m. the meeting was closed.

NOTE: Minutes are integrated with slide presentations (http://wp8community.bridgehealth.eu/login/).

APPENDIX 3

Project participation Experts agreement

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME	OVIDIO
SURNAME	BRIGNOLI
INSTITUTION	SIMG SOCIETÀ ITALIANA DI MEDICINA GENERALE (ITALIAN COLLEGE OF GENERAL PRACTITIONERS)
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I AGREE	☒ YES ☐ NO
SIGNATURE	Ovidio Brignoli

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME FLAVIA

SURNAME CARLE

INSTITUTION MINISTERO DELLA SALUTE

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I AGREE ☒ YES ☐ NO

SIGNATURE Flavia Carle

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME ANTONIO

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I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

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I AGREE ☒ YES ☐ NO

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BRIDGE – Health Project – WP8

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I AGREE ☒ YES ☐ NO

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BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

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I AGREE [✓ YES] NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

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I AGREE ☒ YES ☐ NO

SIGNATURE

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

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

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I AGREE ☒ YES ☐ NO

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BRIDGE – Health Project – WP8

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I AGREE ☒ YES ☐ NO

SIGNATURE Marina Maggini

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

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E-MAIL ADDRESS __maggioni@anmco.it_____________

I AGREE YES

SIGNATURE _____ Aldo Maggioni ____________________

ISTITVTO SVPERIORE DI SANITÀ

BRIDGEHEALTH
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BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME GIOVANNI

SURNAME NICOLETTI

INSTITUTION MINISTERO DELLA SALUTE

E-MAIL ADDRESS g.nicoletti@sanita.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME ANTONELLA

SURNAME OLIVIERI

INSTITUTION ISTITUTO SUPERIORE DI SANITÀ

E-MAIL ADDRESS antonella.olivieri@iss.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME PACE

SURNAME MONICA

INSTITUTION ISTAT

E-MAIL ADDRESS mopace@istat.it

I AGREE ☒ YES ☐ NO

SIGNATURE Monica Pace

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME LUIGI

SURNAME PALMIERI

INSTITUTION ISTITUTO SUPERIORE DI SANITA'

E-MAIL ADDRESS LUIGI.PALMIERI@ISS.IT

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME Fabio

SURNAME Pannozzo

INSTITUTION AUSL LATINA
Registro Tumori – Reg. Eventi CV

E-MAIL ADDRESS fpannozzo@ausl.latina.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME ALESSIO

SURNAME PITIDIS

INSTITUTION ISTITUTO SUPERIORE DI SANITÀ

E-MAIL ADDRESS ALESSIO.PITIDIS@ISS.IT

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGEHEALTH
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BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME EMANUELE

SURNAME SCAFATO

INSTITUTION ISTITUTO SUPERIORE DI SANITA'

E-MAIL ADDRESS emanuele.scafato@iss.it

I AGREE [✓ YES] NO

SIGNATURE

BRIDGE – Health Project – WP8

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NAME ANTONIA

SURNAME STAZI

INSTITUTION ISTITUTO SUPERIORE di SANITA'

E-MAIL ADDRESS STAZI@ISS.IT

I AGREE [✓ YES] NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME DOMENICA

SURNAME TARUSCIO

INSTITUTION ISTITUTO SUPERIORE SANITÀ
CENTRO NAZIONALE MALATTIE RARE

E-MAIL ADDRESS DOMENICA.TARUSCIO@ISS.IT

I AGREE ☒ YES ☐ NO

SIGNATURE

ISTITVTO SVPERIORE DI SANITÀ

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

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME _Luigi ____________________

SURNAME _ Tavazzi ____________________

INSTITUTION GVM Care&Research – E.S. Health Science Foundation____

Via Corriera, 1 Cotignola (RA)

____

E-MAIL ADDRESS _ltavazzi@gvmnet.it__________

I AGREE ☒ YES ☐ NO

SIGNATURE ____________________

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME VIRGILIA

SURNAME TOCCACELI

INSTITUTION ISTITUTO SUPERIORE DI SANITÀ

E-MAIL ADDRESS virgilia.toccaceli@iss.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME MARINA

SURNAME TORRE

INSTITUTION ITALIAN NATIONAL INSTITUTE OF HEALTH

E-MAIL ADDRESS marina.torre@iss.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME Luigi

SURNAME Uccioli

INSTITUTION Universita' di Roma Tor Vergata

E-MAIL ADDRESS luccioli@yahoo.com

I AGREE [✓ YES] NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME DIEGO

SURNAME VANUZZO

INSTITUTION ANMCO – ASSOCIAZIONE NAZIONALE MEDICI CARDIOLOGI OSPEDALIERI FIRENZE

E-MAIL ADDRESS diego.vanuzzo@aas4.sanita.fvg.it

I AGREE ☒ YES ☐ NO

SIGNATURE

BRIDGE – Health Project – WP8

Can we share your contact information with other Work Packages of BRIDGE health Project?

NAME LUCIANO

SURNAME VITTOZZI

INSTITUTION ISS

E-MAIL ADDRESS cnmr.eu@iss.it

I AGREE [✓ YES] NO

SIGNATURE Luciano

APPENDIX 4

Authorization of data sharing

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Full Name SILVIA GHIRINI

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Email Address silvia.ghirini@iss.it

Date 25/6/2015 Signature

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Full Name SIMONA GIAMPAOLI

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Phone +390649904231 Fax +390649904227

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Date ______________ Signature Simona Giampaoli

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Full Name MONICA PACE

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Phone Fax

Email Address mopace@istat.it

Date 25/6/2015 Signature Monica Pace

PHOTOGRAPH AND PRESENTATIONS RELEASE

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Full Name LUIGI PALMIERI

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PHOTOGRAPH AND PRESENTATIONS RELEASE

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Date 25/6/2015 Signature

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Email Address emanuele.scafato@iss.it

Date ______ Signature ______

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BRidging Information and Data Generation
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PHOTOGRAPH AND PRESENTATIONS RELEASE

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Full Name Luigi Tavazzi

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Email Address ltavazzi@gvmnet.it

Date 28/09/2015 Signature

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Full Name MARINA TORRE

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Email Address marina.torre@iss.it

Date 1/07/2015 Signature

PHOTOGRAPH AND PRESENTATIONS RELEASE

With reference to my participation to Project BRIDGE-Health – Bridging Information and Data generation for Evidence based Health Policy and Research, WP8 – Task 1, I grant to the Istituto Superiore di Sanità the use of the slides of my presentation.

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Phone 348 2621525 Fax

Email Address cnmr.eu@iss.it

Date 25/06/2015 Signature Luciano

APPENDIX 5

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.

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 (RIDI); 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

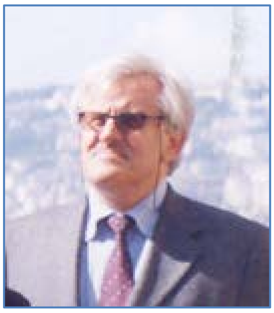
Prof. Antonio Carraturo, MSc in Biological Sciences, PgD, epidemiologist, deputy Director of the "Register for acute cardiovascular and cerebrovascular events of the Province of Latina" (REACaCeV). He currently works at the Azienda Unità Sanitaria Locale di Latina collaborating with the Cancer Registry 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 Biostatics, 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).

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 EUROCARE 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.



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, Absenteeism 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.

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, PgD, 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 EUROCISS - European Cardiovascular Indicators Surveillance Set - Project within the Health Monitoring Programme of the DG SANCO.

Marina MAGGINI, MSc
Unit of Pharmacoepidemiology
National Centre of Epidemiology, Surveillance and Health Promotion
Istituto Superiore di Sanità, Rome

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.

Antonella OLIVIERI, MSc
Department of Cell Biology and Neuroscience
Istituto Superiore di Sanità, Rome

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.

Monica PACE, MD, PgD
Italian National Institute of Statistics, Rome

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).

Luigi PALMIERI, MSc, PhD
Unit of Cerebro and Cardiovascular Diseases
Centre for Epidemiology, Surveillance and Health Promotion
Istituto Superiore di Sanità, Rome

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'.

PANNOZZO Fabio, MD
Cancer Registry of Latina province
Azienda Unità Sanitaria Locale di Latina, Latina,Italy

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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