BRIDGEHEALTH

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

WP8 Platform for population based registries

EUBIROD Network meeting
ROME, 23-24 November 2015

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www.bridge-health.eu

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

BRIDGE-Health

The BRIDGE-Health project aims to work towards a European health information and data generation network covering major health policy areas by promoting the coordination and covergence of existing projects in health information

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BRIDGE-Health mission

- To develop a framework for a comprehensive, integrated and sustainable health information structure which incorporates know-how and technical tools to coordinate and harmonise research and surveillance for Member States

- To develop blueprints for specific actions (tasks) of a EU-HIS

- To propose possibilities to develop the health information structure in a sustainable manner

- To evaluate different structural and istitutional options including a comprehensive European Research Infrastructure Consortium (ERIC) in health information

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WP	Title
WP1	Coordination of the project
WP2	Dissemination of the project
WP3	Evaluation of the project
WP4	European Core Health Indicators Monitoring
WP5	Harmonized population based health examination survey
WP6	Impacts of environmental chemicals on health
WP7	Reproductive, maternal, newborn, child, adolescents
WP8	Platform for population based registers
WP9	Platform for Injury Surveillance
WP10	Building a Platform for administrative data on health care
WP11	Integration of approaches into a comprehensive EU information system for health and health care monitoring and reporting
WP12	Evaluation of health care system

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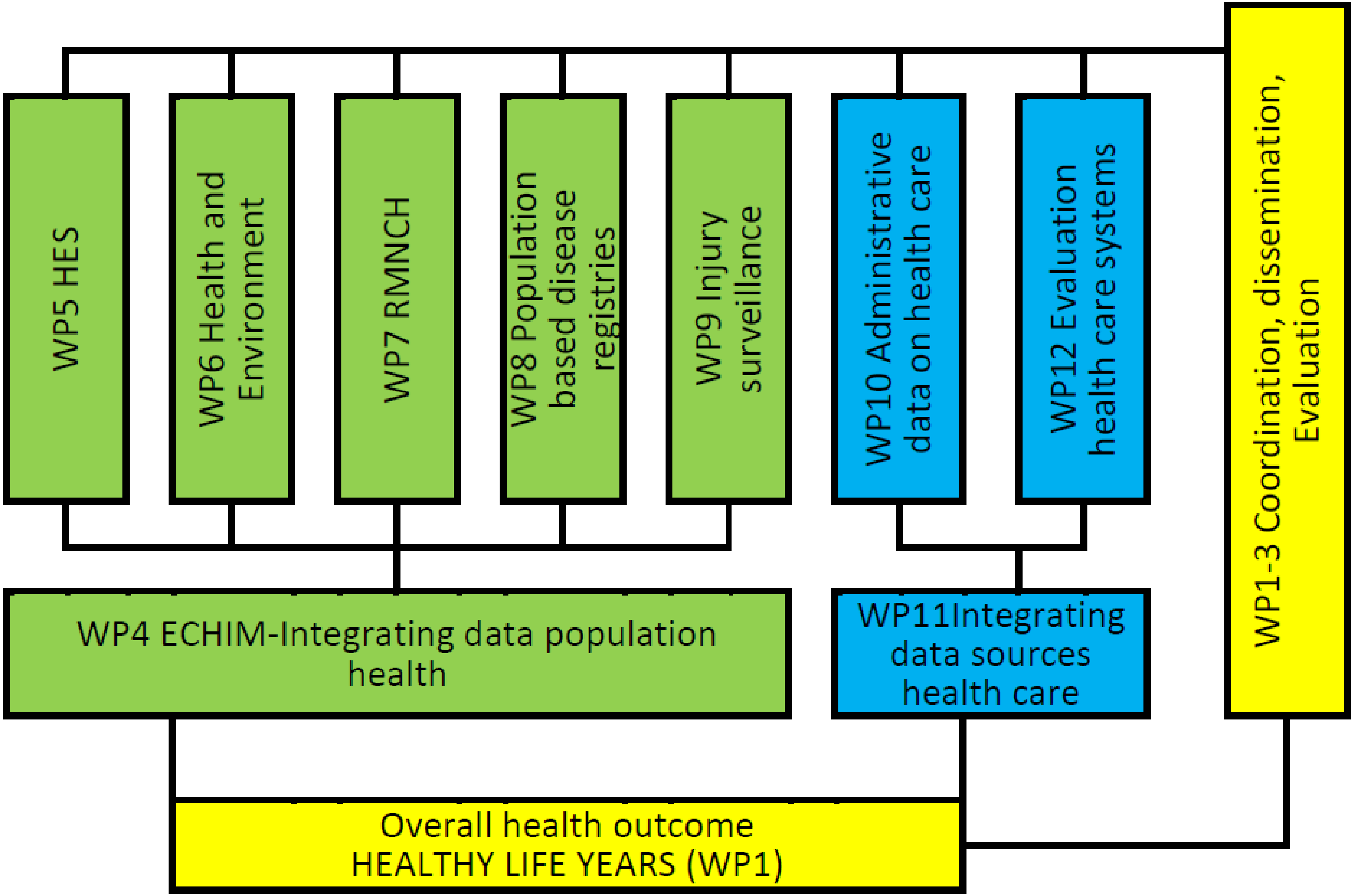
Structure BRIDGE Health



Aims

- To gather and harmonise procedures/methods and best practices of population-based registries
- To improve standardisation and quality of data collection
- To facilitates implementation, sustainability, and maintainance
- To provide community health indicators occurrence, quality of care and outcomes

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A population based registers is intended to cover all residents in a given geographic area within a time period and includes all events of a specific disease for

- *monitoring the occurrence of the disease*
- *understanding the differences and changes in the natural disease dynamics*
- *identifying vulnerable groups*
- *monitoring in and out of hospital case fatality*
- *monitoring the consequence of disease in the community in terms of medication and rehabilitation*
- *monitoring the utilization of new diagnostic tools, treatment and their impact*

EJCPR - 2008

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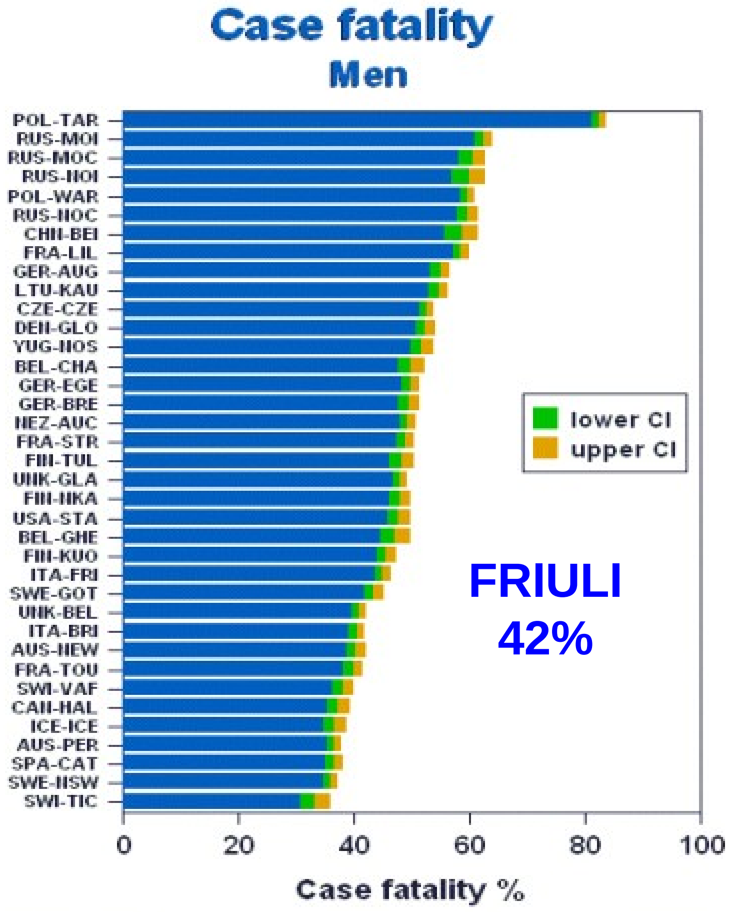
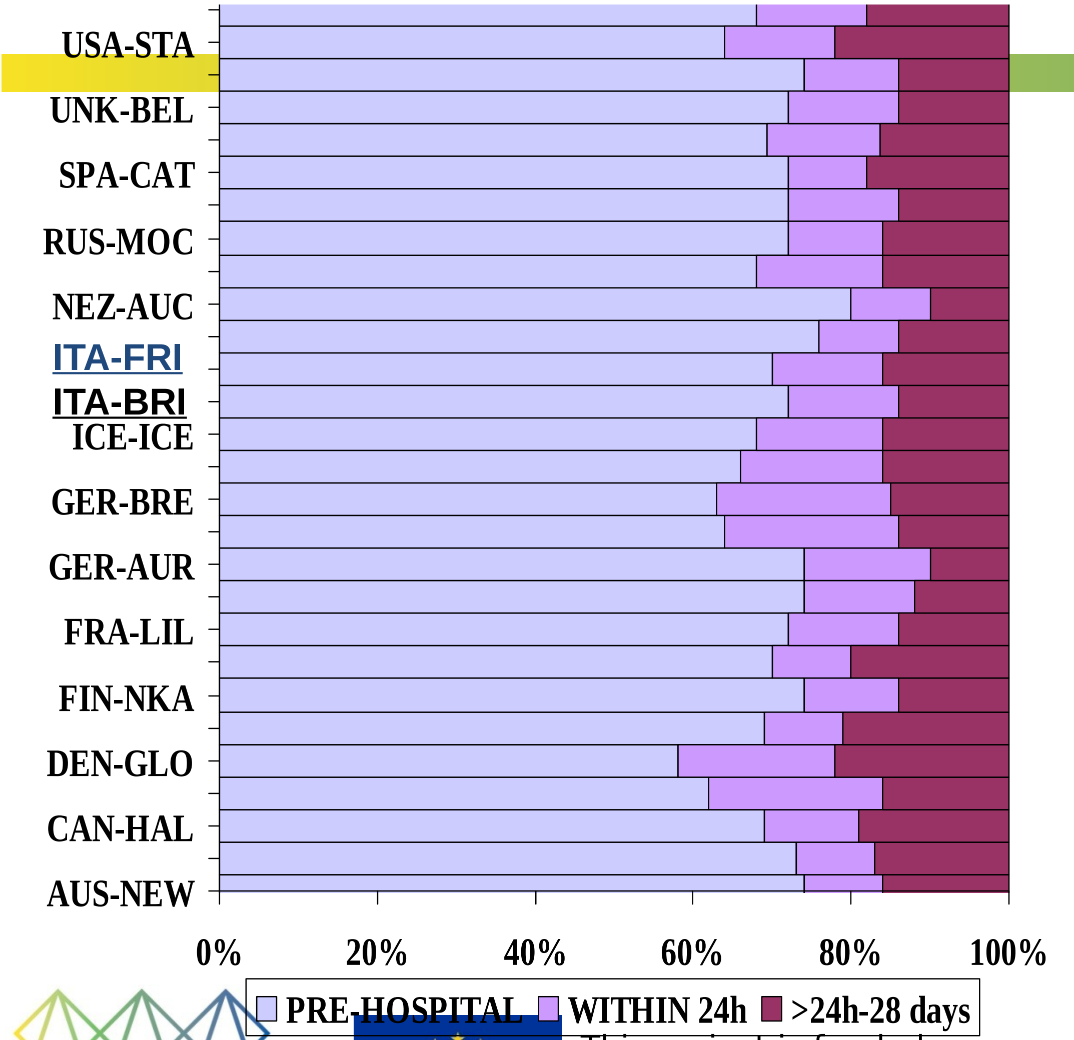
WHO MONICA Project

CHD CASE FATALITY - Men 35-64 yrs



FRIULI 42%

WHO MONICA Project Lancet, 1999; 353: 1547-1557 CORMORANT



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AMI/ACS Population-based Registers in Europe:

population characteristics

Country	Years	Age range	Population x 1000	Accessibility
Charleroi Ghent	1983-2003	25-69 25-74 (Ghent)	100 142 (Ghent)	School of Public Health/Univ Ghent
Belgium Bruges	1999-2003	25-74	151	University of Ghent
Northern Denmark	1978-2001	All	494	Aarhus University
Finland	1993-2002	35-85	193	NIPH
France	1985-2004	35-74	1,519	INSERM U780
Germany	1985-2002	25-74	407	National Institute of Statistics
Italy	1998-2003	35-74	2,600	Institute of Health
Norway	1972-2002	All	1,000	National Institute of Statistics
Spain	1985-1998	25-74	480	Institute of Health Studies
Northern Sweden	1985-2005	35-74	322	MONICA

EUROCISS

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AMI/ACS Population–based Registers in Europe:
case definition

Country	ICD version	Mortality ICD codes(*)	HDR ICD codes(*)	Linkage Mortality / HDR	Validation
Belgium	IX, X	410-414, 428, 799	410-414, 428 PTCA, CABG	Name, date of birth	ECG, enzymes, symptoms, MONICA
Northern Denmark	VIII, X	410	410	PIN	No validation
Finland	X	410, 411, 428,798, 799	410, 411 PTCA, CABG	PIN	MONICA, ESC/ACC
France	IX, X	410-414, 428, 798, 799, others	410-414, 428	Name, date of birth	MONICA
Germany	X	410-414, 798,799	410, 411 PTCA, CABG	Name, date of birth	MONICA, ESC/ACC
Italy	IX	410-414, 798,799, others	410-414	Name, date of birth	MONICA
Norway	X	410	410 PTCA, CABG	PIN	No validation
Spain	IX	410-414, 428, 798, 799, others	410-414	Name, date of birth	MONICA
Northern Sweden – MONICA	X	410, 411	410, 411	PIN	MONICA

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Platform for population based registries
Task 1 deliveries

- Create a network of experts of population based registries

- Identify standardised definitions for diseases, common procedures and methods to establish population based registries (including sources of information, population size, identification and validation of events, quality control, ethical issues) to deliver estimates of ECHIM indicators of disease occurence

- Set up a stepwise procedure to implement population based registries

- Prepare guideline for training personnel involved in population based registries

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BRIDGE –Health Steering Committee 6-7 October 2015

- Consortium agreement: in October, 7 institutions had not replayed yet; Tor Vergata was one of those
- Timeline of deliveries was presented
- Discussion on conceptual framework of EU-HIS, finalising definitions of mission, vision, goals and tasks
- Presentation of Horizontal Activities, rationale and questions for each HA
- Dissemination: website, leaflet, 2015 EUPHA workshops
- Work of the WPs months 1-6 and plans for 6-12

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Conceptual framework of EU-HIS

- **Vision:** EU-HIS provides the best available knowledge for decision makers to improve EU populations’ health and well-being

- **Mission:** to improve population health of Europe by unnderstanding dynamics of health, identify best practices and comparison on local, regional, national, European and global level

- **Goals:** to support social and health policy:
  - with comparable data (harmonisation and standardisation)
  - of high relevance and utility (priority setting methods)
  - identifying gaps and addressing information needs
  - addressing ethical and legal issues

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BRIDGE –Health Steering Committee 6-7 October 2015

Conceptual framework of EU-HIS

Tasks: (EU, MS)

- identify priority setting methods, data sources and data gaps

- set up a data indicators repository (*collection*-with standardised tools; *compilation* by access, transfer; *integration* by data extraction; *transformation* by harmonisation; *analysis* by data quality output; *inference*)

- identify ethical and legal issues (ownership, sharing, access, transfer, storage, processing)

- linkage and exchange with stakeholders: research policy interaction, transferibility of data, ensure dataset per research purposes, guideline for training, sustainability interpretation

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Work of the WPs months 1-6 and plans for 6-12

WP8 –Platform for population based registries

- Identification of experts (experience in fieldwork of population based registries, participation in European projects), invitation to collaborate, web community
- Meeting of the experts network on June the 25th in Rome and agreement to participate
- Technical report of network experts
- EUPHA workshop in Milan 17 Oct 2015, on standardization and quality
- Questionnaire for interviews to experts on manual of operations

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BRIDGE –Health Steering Committee 6-7 October 2015

Presentation of Horizontal Activities

BRIDGE-Health is working through Horizontal Activities that bring together the experties developed within specific health information domains to tackle the following objectives:

- ensure transferibility of health information and data for policy
- reduce health information inequality
- enhance information at regional level and specific groups
- develop standardisation methods of the collection and exchange health information
- identify data quality methods including internal and external validation of indicators
- determine methods of health information priority settings
- harmonisation of ethic-legal issues

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HA5 - Data quality methods including internal and external validation of indicators

Rationale

- Using administrative data is attractive to outcomes researchers because they are at low costs, the number of people and events is large, and they are «population-based» data

- The quality of sources of information is crucial together with validation process to ensure reliability and comparability of health information among countries, across regions and over time periods

- This process is time and cost consuming

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HA - Data quality methods including internal and external validation of indicators

Completeness of cases in the target population under surveillance (all cases- AMI, stroke, cancer, diabetes, …….)

Completeness of information (date of birth, place of treatment, date of admission, date of discharge, sex, hospital discharge diagnoses, treatment/procedures); **completeness of information sources of information** (hospitals, nursing home and clinics, drug dispensing registry, GPs registry, emergency and ambulance service, autopsy registry)

Internal validity (diagnostic criteria of event, validation of events). Often population based registries are used to validate national routine statistics, consistency of coding with the diagnosis, consistency of comparability among different areas, consistency of comparability over time

External validity representativeness of registry data in relation to mortality rate, risk factor distribution in the general population and health care system of the whole country

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HA - Data quality methods including internal and external validation of indicators

Actions

- to identify adopted methods of **quality assessment in the data sources/data collection** among participating projects included in own protocol/manual of operations

- to identify adopted methods of **quality assessment in the elaboration of health indicators** among participating projects included in own protocol/manual of operations

- to create an overview of health information projects (population-based registries, Health Examination Survey, …..) where quality issues are addressed

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HA - Data quality methods including internal and external validation of indicators

Questions

- What kind of health information do you collect using standardised procedures/methods
- Do you assess ECHIM indicators following the recommended procedures/methods? In case you do not, please specify
- How do you assess completeness of event/information?
- Please describe methods
- How do you perform internal validity
- How do you assess external validity
- Have you received training for standardisation and data quality? How many training sections have you received and what type of training was it?
- What are the major difficulties that you have encountered to assure data quality?

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