

# WP8 - Platform for population-based registers

Simona Giampaoli Rome, 25 June 2015



### **WP8 Objectives**

- ➤ To gather and harmonize procedures/methods and best practices of population based registers
- ➤ To improve standardization and quality of data collection
- ➤ To facilitate implementation, sustainability and maintenance
- To provide community health indicators of occurrence, quality of care and outcomes of chronic diseases

for Evidence-based Health Policy and Research

### **WP8 Applicants**

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# WP8 Population based registers

#### A population based registers is intended 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 diseases in the community in terms of medication and rehabilitation
- monitoring the utilization of new diagnostic tools, treatment and their impact

# **WP8 Organization**

Taking advantage of existing experience from EUROCISS and EUBIROD, two tasks are contributing to the realization of the work on population based registers:

**Task 8.1**. (*ISS*) focusing on chronic disease *occurrence* 

**Task 8.2**. (*UNITOV* and *USURREY*) focusing on chronic disease *health care* 





#### Task -1

- Identify standardized definition of non-communicable disease of interest in public health
- Identifying 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 indicators of disease occurence recommended by ECHIM





- Preparing a manual of operations with a stepwise procedure for the implementation of the population based register for chronic non-communicable diseases
- Preparing guidelines for the training of epidemiological team involved in the implementation of the population based registers





#### **Deliverables**

- Collaborative network of fieldwork experts involved in population based registers
- Manuals of operations of population based register sharing common sources of information and including population size, standardized diagnostic criteria, validation, elaboration of diseases occurrence indicators and health care and outcome indicators





#### **Deliverables**

- Step-wise procedure for the implementation of population-based registers
- Guidelines for training personnel involved in population based registers of chronic diseases including definitions, procedures for record linkage, validation, assessment of disease occurrence, health care and outcome



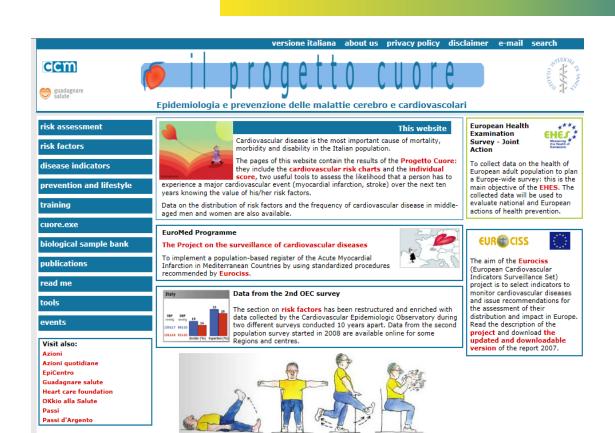


Synergies with other groups involved in population Health Interview / Health Examination Survey (EHIS/EHES) and in mortality/morbidity surveillance (EUROSTAT)





# Web community







# **ACTIVITIES** Organization and preparation of the operative activities Elaboration of the list of fieldwork experts involved in 1 population-based registers: invitation, collection of adhesions, and selection of the final list Participation to BRIDGE-Health Kick-off Meeting in Luxembourg, 20th -21st of May 2015 First meeting with fieldwork experts and collaborators participating to Task 8.1





	ACTIVITIES  Implementation of operative activities
4	Starting elaboration and setting up of the web-based community tool within the www.cuore.iss.it website
5	Preliminary work for: - Selection of specific diseases/population-based registers to be included in WP8 activities; - Selection of main indicators, from the ECHIM list for population-based registers, describing the occurrence/health care of the diseases





	ACTIVITIES  Implementation of operative activities
6	Collection of existing (published) manuals of operations and bibliography on selected diseases/population-based registers
7	Produce the table of contents





	ACTIVITIES  Collaborations with networks and other WPs
8	Network consolidation: collaborative network of fieldwork experts of population-based registers involved in monitoring occurrence of chronic diseases interested in building a platform of population-based registers
9	Exploring possibility of interactions with other WPs of the Project
10	Planning consistent approach to privacy impact assessment in WP 8-10-11



