



Strengths and weaknesses of population-based registries

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... working towards a **European health information and data generation network** covering major European health policy areas

WP8 - Platform for population based registries - task 1 (population health)

Aims at:

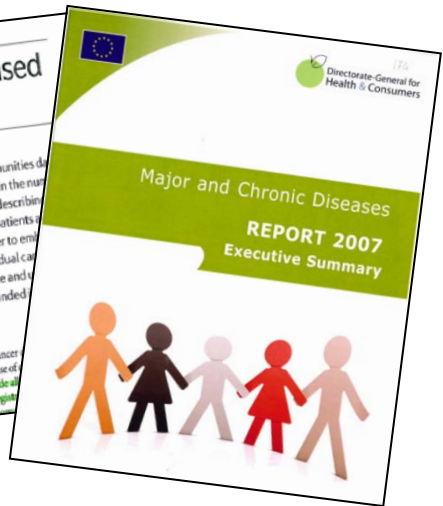
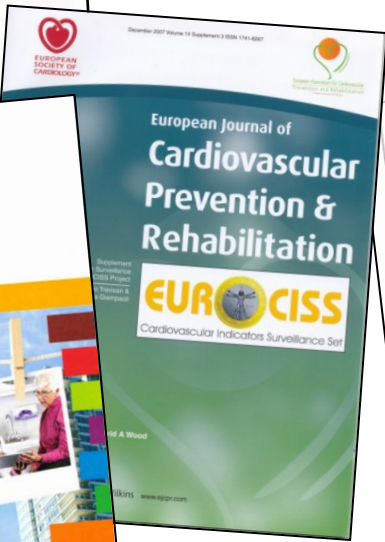
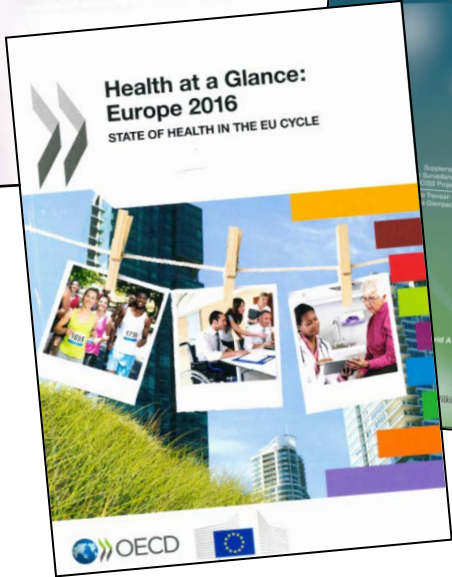
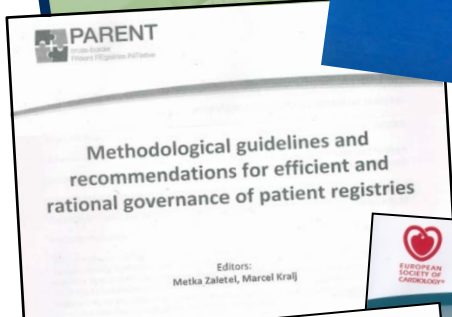
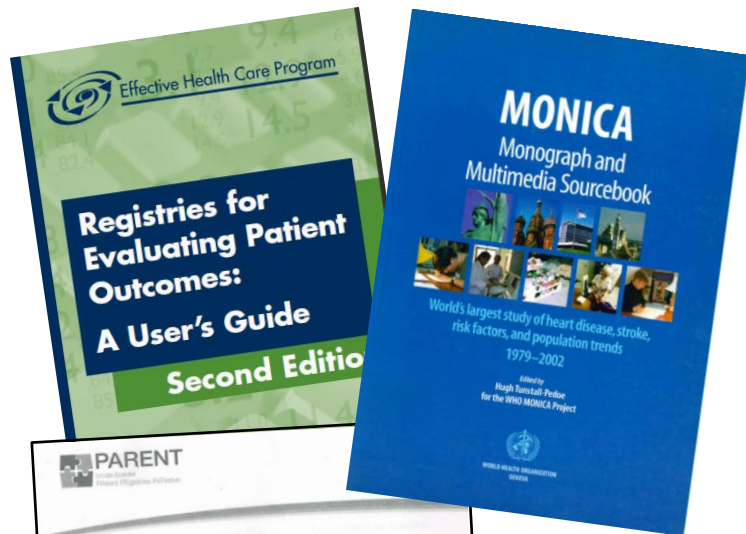
- Gathering and harmonizing procedures/methods and best practices
- Improving standardization and quality of data collection
- Facilitating implementation, sustainability and maintenance (step-wise procedure)
- Providing **community health indicators of disease occurrence**

Deliverables:

- Consolidation of the network of experts
- Manuals of operations
- Guidelines for training

WP8 - task 1 - definition

- A population-based registry is an organised system that records all new cases of a disease in a defined population (most frequently a geographical area)
- The “core” activity is to provide information on incidence and survival



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

Population based registries of high-impact diseases or specific conditions that could provide indications on the methodology applied to favor sustainability and implementation:

**Cardiovascular
Cancer
Injury**

Type 1 diabetes
Maternal mortality

Twins
Implanted prostheses
Congenital hypothyroidism
Italian Transplant Centre

Strength of population based registry

Comprehensive picture of a disease in the community: fatal and non-fatal events occurring in-hospital and out-of-hospital, new cases and recurrent events, in a defined general population, treated at home or in hospital, in whichever season of the year or time of the day, and would also include sudden fatal cases unable to reach the medical service

Burden of the disease: future evolution can be evaluated in terms of incidence and mortality, but other dimensions can be considered as prevalence, person years of life lost, quality or disability-adjusted life years

Clear definition of the sources of information: in terms of case finding

Definition of event: onset, clinical records

Validation of each single event according to standardised diagnostic criteria:



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Strength of population based registry

New events are distinguish from **recurrent events**: with improving survival this is becoming more frequent

Avoid duplicate registration: link with multiple sources - PIN

Avoid selection of single institutions

Great attention is dedicated on **training personnel** (local courses, site visits, audit)

Weakness of population based registry

Area under surveillance: Region, Municipality, population size should be big enough to provide stable estimations

Use of sensitive data

Results are available with a delay of 3-5 years

Cost and time consuming: case finding, validation, training, survival

population based registry - implementation

Simplified model:

- A random sample of current events are validated (day/month/season/year)
- Validated events consent to assess positive predictive value (PPV) for each ICD code of HDD and cause of death
- Estimated number of events is the sum of: current events by the PPV of each specific mortality (or HDD) codes
- Assessment of attack rate: number of events/population at risk

METHODS of registry for coronary events

Positive Predictive Value of an identified ICD code:

PPV_i = proportion of events validated as positive identified by an ICD code, over total events with the same ICD code

In order to estimate the number of events by each specific age group and gender, separately by fatal and non-fatal cases:

$$N_{EC} = N_{OC} * \sum (PPV_i * Pr_i)$$

where:

N_{EC} = Number of estimate cases,

N_{OC} = Number of observed cases,

PPV_i = Positive Predictive Value of a specific ICD code,

Pr_i = Prevalence of a specific ICD code.

Example of estimated events calculation: Men - Non fatal CE

ICD9 code	Number of Events	Preval.	PPV - MONICA		Estimated CE
			CE	Not CE	
410	615	0.20	0.83	0.17	510
411	300	0.10	0.17	0.83	51
412	41	0.01	0.10	0.90	4
413	459	0.15	0.06	0.94	28
414	401	0.13	0.11	0.89	44
420-429	279	0.09	0.05	0.95	14
others	1010	0.32	0.08	0.92	81
Tot(Noc)	3105	1	0.2358		732

CE = Coronary Events

Register of Coronary Events (1998-2003 trends)

Age-standardized estimated attack rates and case fatality, 35-74 years

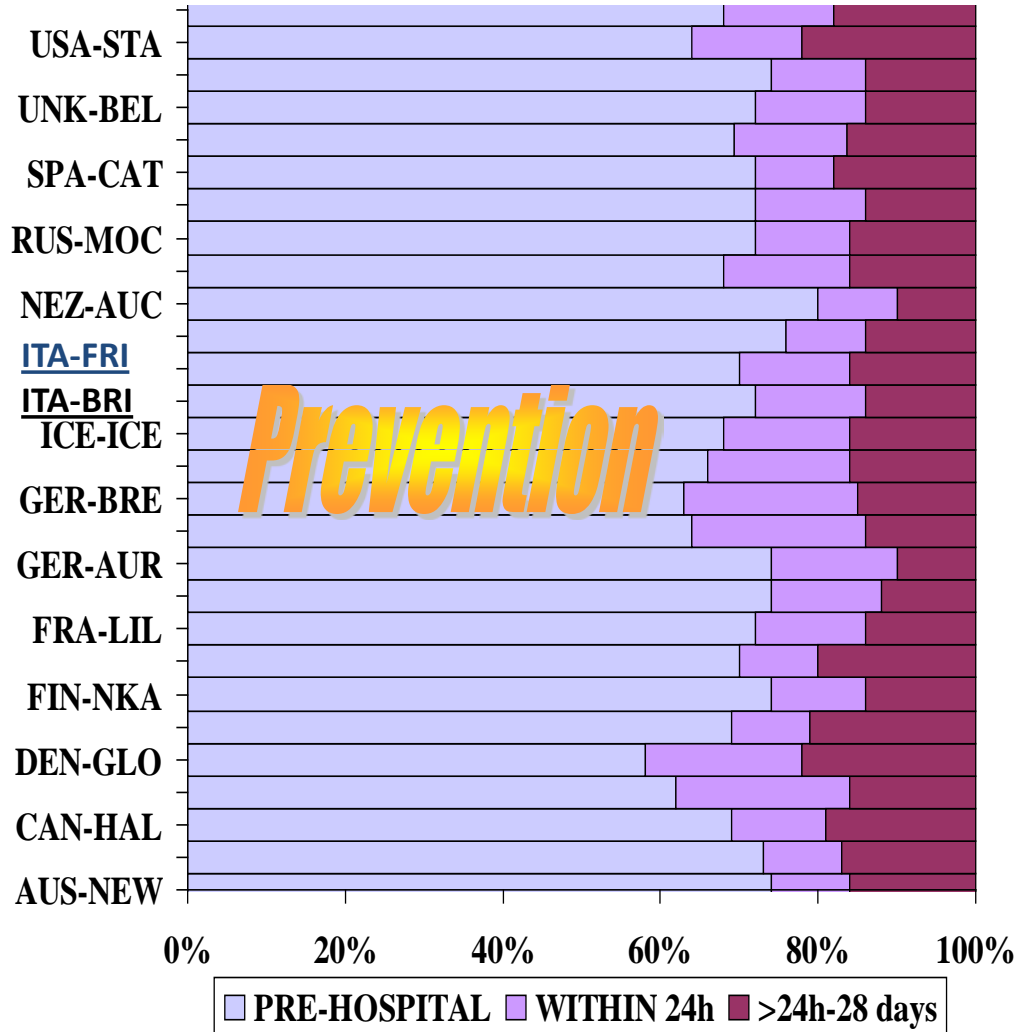
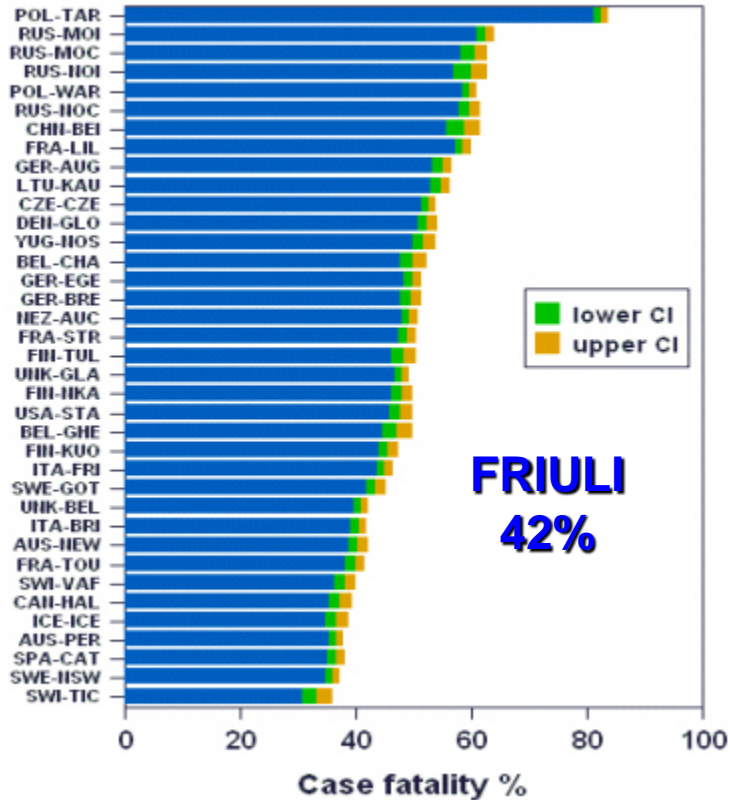
	Men (N= 2,428,541)			Women (N= 2,572,889)		
	Attack Rate (x10,000)	C.I. 95%		C.I. 95%		
1998-99	30.4	29.8	31.1	7.7	7.4	8.0
2003	29.4	28.6	30.1	7.4	7.1	7.8
	Case Fatality, %	C.I. 95%		C.I. 95%		
1998-99	26.0	25.1	27.0	34.6	32.6	36.6
2003	23.4	22.3	24.5	23.4	21.2	25.5



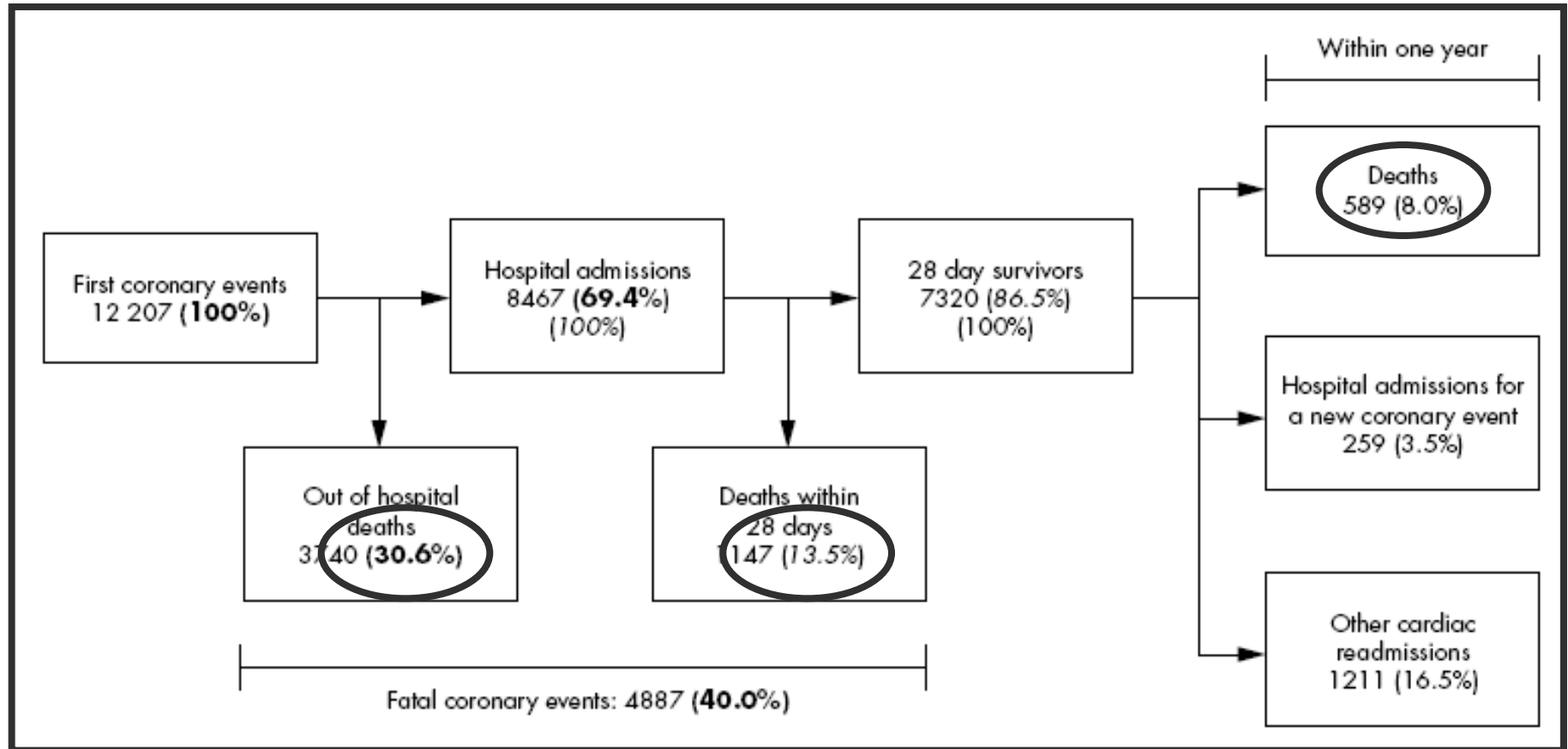
WHO MONICA Project

CHD CASE FATALITY - Men 35-64 yrs

Case fatality Men



Associations of area based deprivation status and individual educational attainment with incidence, treatment, and prognosis of first coronary event in Rome, Italy



population based registry - conclusions

Population-based registries:

- provide incidence, case fatality and survival rate in a definite area*
- are cost and time consuming (finding events, validating events, training personnel)*
- serve for answering one or more scientific, clinic and health policy purposes*
- may be used for data validation of other sources of information*



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