



POPULATION-BASED REGISTRIES

What do we need to produce reliable and comparable indicators?

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Background

- The availability of powerful technology has made possible to build health indicators through linkage of electronic records routinely collected
- Using administrative data is attractive because is at low costs, includes large number of people and events, and is «population-based»
- 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

Population based registry

A population based registry is a registry that intends to cover all residents in a given geographic area within a time period and includes all events of a specific disease (fatal and non fatal, occurring in or out of hospital, in every time of the day and in each season)

Dictionary of Epidemiology - 2008



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BRIDGE Health Project

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

...The project bridges key EU projects in domains of population and health system monitoring and indicator development, health examination surveys, environment and health population injury and disease registries, clinical and administrative health data collection system and methods of health system monitoring and evaluation



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Platform for population based registries

Aims to:

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



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What do we need to produce reliable and comparable indicators?

- Manual of operations with procedure and methods
 - definition of event
 - population size
 - data sources
 - data collection methods
 - quality control
 - ethical issues
 - indicators
- Guidelines for the training of epidemiological team

Acute Myocardial Infarction

Definition: attack rate of AMI (fatal and non fatal) x 100,000 population

Calculation: age-standardized attack rate by sex in the population aged 35-74 years, in a given calendar year based on mortality (ICD-10 I20-I25) and HDD (ICD-10 I21,I22)

Preferred data: population based AMI registries

AMI/ACS Population-based Registers in Europe: population characteristics

Country	Years	Age range	Population × 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

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

Horizontal activities

- Horizontal activities are transversal layers that brings together expertise within each specific health information domain developing common methods for
-
- **data quality including internal and external validation of indicators**
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Quality assessment in population based registries

- **Completeness of cases in the target population** (all cases- AMI, stroke, cancer, diabetes)
- **Completeness of information** (age, place of treatment, date of admission, date of discharge, sex, hospital discharge diagnoses, intervention/procedures, private physicians or hospitals)
- **Internal validity** (diagnostic criteria of event, validation of events)
- **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

Conclusions

- Population-based registries are data source for morbidity and mortality, as they consider both fatal and non fatal events, occurring in and out of hospital, in every time of day and each season; they provide estimates of key occurrence indicators such as attack rate, case fatality, health care performance
- 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



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Conclusions

A surveillance system based on the collection of comparable and valid data at European level is essential for evaluating the burden of diseases, time trends and geographical distribution and for planning and implementing appropriate preventive actions as recommended by the WHO NCD Global Action Plan 2013-2020



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Thank you for your attention



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