Interoperability of data from research and surveillance: a pilot project for cardiovascular diseases

A prospective tool for an European Health Information System

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Background

• current health data are routinely collected for administrative purposes (deaths, HDR, treatment prescriptions, exemptions, laboratory analyses, etc.)

• information on risk factors and lifestyles are there missing

• health data from population studies are available and provide most of such information: HES, longitudinal cohorts

• starting from population studies, integration among sources of health information is crucial
General objective of the pilot

• to build a web-based system to make available and disseminate data from the Istituto Superiore di Sanità-ISS epidemiological studies

• to integrate, process and elaborate ISS data with current data flows from the National Health Service-NHS

• Regions involved are Lombardy, Marche and Sicily

This project is funded by the Health Programme of the European Union
Specific objectives of the pilot

- to verify feasibility of interconnection and processing of epidemiological studies and current health data
- to evaluate different ways of accessibility, availability and use of interconnected data for different stakeholders
- to identify, evaluate and propose solutions to privacy and ethical issues
Specific objectives of the pilot

• to verify operability for assessing development of risk conditions of major public health concern, consequent events, compliance to treatments and lifestyles in the general population

• to compare prevalence and occurrence of specific diseases by socio-economic level and risk condition at base line
ISS provides data collected from the National HES:

- systolic and diastolic blood pressure
- total, HDL, LDL cholesterol, triglyceridemia, fasting blood glucose
- weight, height, BMI, waist-to-hip ratio
- smoking habit
- physical activity
- food information including alcohol consumption (EPIC questionnaire)
- history of cardiovascular diseases and cancer
- ECG coded by Minnesota code for myocardial infarction, angina pectoris, atrial fibrillation
- stroke, TIA, left ventricular hypertrophy, intermittent claudication
Data sources - Regions

Healthcare utilization (HCU) databases:

- archives of residents receiving assistance from NHS, vital status and dates of entry and exit from NHS
- database of HDR from public and private hospitals
- database of outpatient prescriptions of treatments reimbursed by the NHS and delivered by regional pharmacies
- database of prescriptions of treatments directly administered in outpatient and day-hospital and reimbursed by the NHS
Data sources - Regions

- database of outpatient services, including specialist visits, laboratory analyses and diagnostic procedures performed in the services accredited to the NHS
- database on regional emergency activities
- archive of co-paid exemptions, providing information on all beneficiaries of co-payment exemptions
Web integration and interconnection system

- a specific software (Beaver), already used by the University of Milan Bicocca for the exclusive elaboration and analysis of regional HCU data, has been updated, modified and integrated
- the new web-based system extends operability to integration, processing, and elaboration of different health data sources, included ISS population studies
- a unique and absolute novelty in the Italian landscape in relation to availability and utilization of health data for research
- a big step towards an integrated Health Information System
Data quality issue

- routine administrative data are collected for expense and services managing purposes (not for research)
- quality level of administrative data can vary by region
- availability and accessibility of data can vary by region

To overcome such issues:

- preventive activities for checking and cleaning administrative data are needed
- increasing use of data improves quality and standardisation
- the web system for interoperability includes training sections on analysis methods and data quality
Ethical issue and privacy

- sensitive data are used for record linkage and analyses
- Italian NHS is regionally organised with high level of autonomy at local level
- accessibility and use of health data is then very difficult and varies by region according to ethical and privacy rules and laws locally applied

*This make the interoperability system very difficult to be implemented in Italy*
Ethical issue and privacy

To overcome such issues:

• participants to ISS epidemiological studies signed an informed consent enlarged to use of data for public health purposes
• the pilot project will be submitted to the Ethical Committee
• specific regional agreements will be signed by ISS
• all data record linkage, elaborations and analyses will be performed in a dedicated and protected area under regional control
CONCLUSIONS

The interoperability system can help to:

• make data available to all interested stakeholders for addressing several health policy and research questions

• make data available to the interested researchers to avoid use of data for serial analyses by single researcher instead of use of data in parallel by more researchers

• improve timeliness of follow-up and results

• improve quality of health and administrative data