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Health data interoperability: a pilot study in Italy

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www.bridge-health.eu

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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 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

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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

il progetto cuore

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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

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Specific objectives of the pilot

- to verify operability for assessing development of risk conditions of major public health concern, consequent events, compliance of 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

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Data sources - ISS

ISS provides data collected from the National HES:

- systolic and diastolic blood pressure
- total, HDL, and LDL cholesterolemia, 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

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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

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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

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Web integration and interconnection system

- a specific software (Beaver), already used by the University of Milan Bicocca for elaboration and analysis of regional HCU data, has been update, 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

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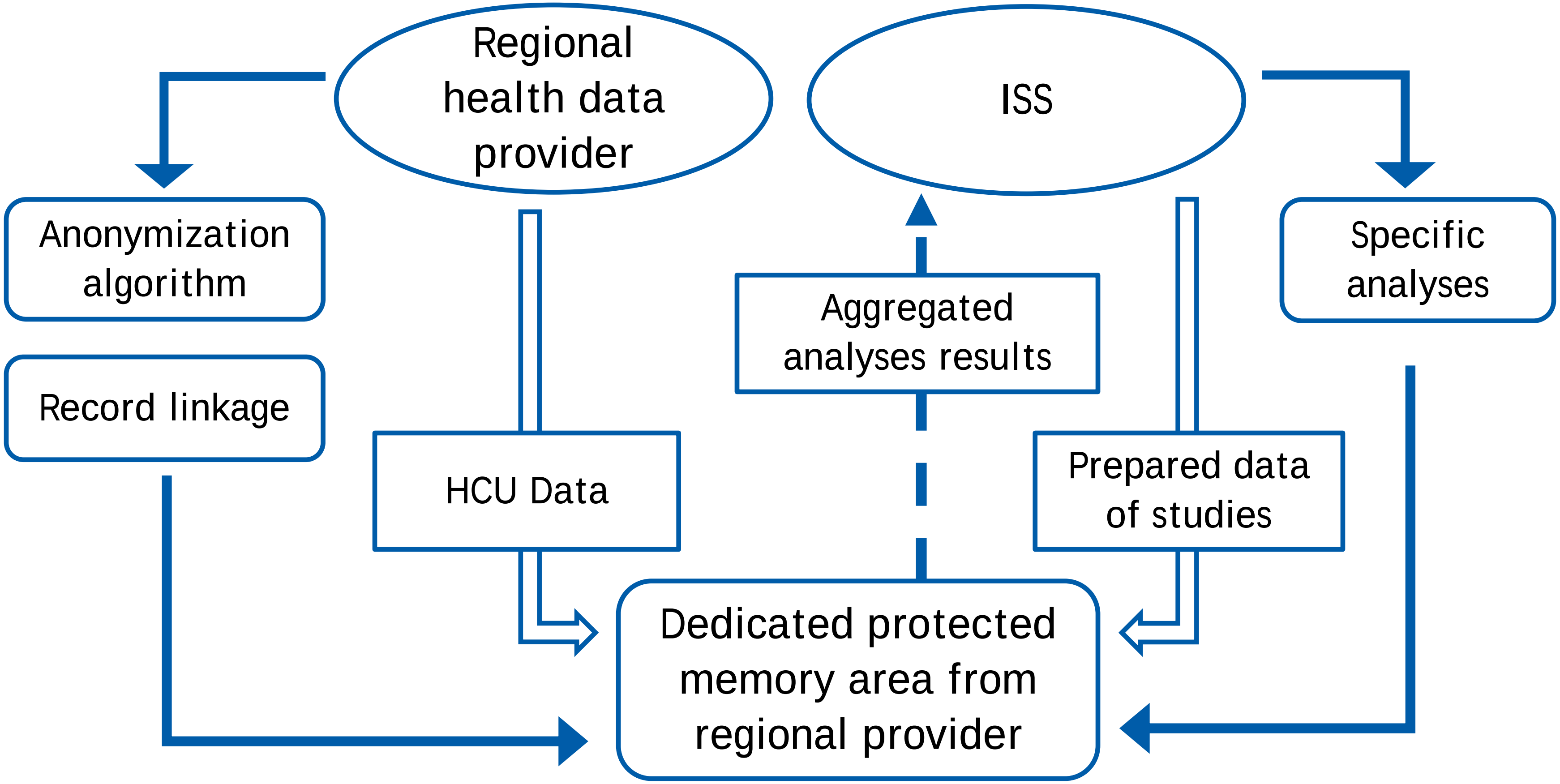
Record Linkage and Data Processing Procedures



Regional health data provider

ISS

Anonymization algorithm

Record linkage

HCU Data

Aggregated analyses results

Prepared data of studies

Specific analyses

Dedicated protected memory area from regional provider

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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

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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

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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

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CONCLUSIONS

The interoperability system can help to:

- make data available to all interested stakeholders for addressing several 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

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