INFACT
Joint Action on Health Information

Room II (researchers)- Data collection methods and procedures

21 January 2021

Presenter: Luigi Palmieri
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InfAct General Assembly

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Background

- Data collection methods, metadata-reporting standards and usage of data for health monitoring (HM) and health system performance assessment (HSPA) are not uniform in Europe
- The lack of infrastructures for health data sharing in EU limits data usage and comparability within and between countries

This topic will focus on main results from InfAct regarding health data collection methods and procedures for Health Information support across EU countries

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Reviews

i. Review of institutional websites

OECD
The Organization for Economic Co-operation and Development

eurostat

World Health Organization
REGIONAL OFFICE FOR Europe

ii. Review of EU research networks

EUROCISS

EUBIROD

EuroSafe
European Association for Injury Prevention and Safety Promotion

European Community Health Indicators Monitoring ECHIM

EHES
Measuring the Health of Europeans

EURO PERISTAT

ECHO
EUROPEAN COLLABORATION FOR HEALTHCARE OPTIMIZATION

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Survey on research networks/projects

1. GENERAL CHARACTERISTICS OF THE RESPONDENTS

- 5 questions
- socio-demographic characteristics of the respondents

2. SOURCE OF INFORMATION/DATA SOURCES

- 15 multiple choice questions
- Project/study background information

3. QUALITY ASSURANCE PROCEDURES IN DATA COLLECTION

- 2 multiple choice questions
- Relevance, accuracy, timeliness, punctuality, comparability, coherence, accessibility, clarity coverage, internal reliability

4. AVAILABILITY

- 4 multiple choice questions
- availability of micro or macro data, formats, and metadata

5. ACCESSIBILITY

- 3 multiple choice questions
- the physical conditions under which users can obtain data: where to go, are access to data free or restrictive, etc.

Main results from the Review of research networks

57 research networks, collecting data on various health topics and representative at national or international levels, were identified
In these networks, data are mainly collected through administrative sources, health surveys and cohort studies
Less than half provide information on quality assessment of their data collection procedures
Most networks share macrodata through articles and reports
Microdata are available from less than 10 networks
A request for data access is required by 14 networks, of which three apply a financial charge
Few networks, 8, share data with other research networks or specify the metadata-reporting standards used for data description

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Main results from the Survey

91 research networks/projects were identified in 18 EU countries

only 33% of the projects share data with EU research networks

less than 50% of the projects follow meta-data reporting standards for data description

only 34% of the projects evaluate the quality criteria of punctuality and accessibility

microdata are never accessible in open access; macrodata in 34% of the projects only

The cross-sectional study and the evaluation of RNs underline that evidence produced by research is not always available, accessible, comparable or usable for research purposes and policy making in and across EU countries

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Main recommendations based on the survey findings and the assessment of EU RNs

- The use of different reliable population health data sources in public health research activities is essential for development and implementation of evidence-based interventions and policy
- Quality assessment of health data and information is fundamental to obtain accurate, reliable and valid data
- Adherence to guidelines and protocols on standardized procedures in data collection, analysis and reporting is essential to ensure the comparability of research outputs
- Adherence to FAIR Data Principles consents to make data *findable*, *accessible*, *interoperable*, and *reusable*
- RNs could play a major role in tackling health data and information inequalities by enhancing quality, availability, accessibility of health data and data sharing across European networks
- To support effective and sustainable projects and RNs will prevent the fragmentation of research activities, collected health data and information

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Room II (researchers)- Use of non-health data bases for health surveillance

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Presenter: Luigi Palmieri
National Public Health Institute-ISS, Italy

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Background

- The availability of health data generated from different sources is increasing with the possibility to link these data sources with each other
- however, linked administrative data can be complex to use and may require advanced expertise and skills in statistical analysis
- a survey was implemented across European countries in order to:
  - investigate the use of data linkage at the individual level and/or the use of artificial intelligence (AI) in routine public health activities
  - identify the related estimated health indicators and health determinants of non-communicable diseases
  - identify the main obstacles to link different data sources

Use of Non-health Data sources

Linkage of data sources: Non - health administrative data sources with health administrative data sources

- For Research (clinical, epidemiological, public health)
- For Public health surveillance
- To Support public health policy decisions

R Haneef, M Delnord, M Vernay et al, Archives of Public health 2020

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Examples of different combinations of data linkages

S/No	Countries	Different combinations of data linkages (health with non-health data sources)*
1	Belgium	Educational attainment with mortality database
		Census with mortality database
2	Denmark	National patient health register with education, income, housing, transfer payments, socioeconomic status, criminal statistics, etc.
3	Estonia	Genomic database with EHRs (in progress)
4	France	UV light and air pollution exposure with national health database (in progress)
5	Germany	Socioeconomic data with EHRs at the metropolitan level for small area estimation (in progress)
6	Ireland	Census data with mortality database
7	Norway	National health registries with land and housing, road and transport, GIS databases, etc.

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R Haneef, M Delnord, M Vernay et al, Archives of Public health 2020

Conclusions

- the majority of European countries have integrated data linkage in their routine public health activities but only a few use AI
- a sustainable national health information system and a robust data governance framework, allowing to link different data sources, are essential to support evidence-informed health policy development
- building analytical capacity in national institutes is necessary for improving the use of linked data in order to improve the quality of public health surveillance and monitoring activities

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Room II (researchers)-
Leveraging interoperability to build federated research infrastructures in Europe: lessons from InfAct JA

21 January 2021

Presenter: Jakov Vuković
Croatian Institute of Public Health

InfAct General Assembly

Name: Enrique Bernal-Delgado
Institution:Institute for Health Sciences IACS
Country: Spain

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Methodological approach

To leverage interoperability we have built on three case studies:

- Monitoring resilience
- Spending in patients with dementia
- Variation in care pathways for acute ischemic stroke

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Details on the stroke care pathway

Use case	Aim	Data sources	Common Data model (main entities)	Software Distribution	Hubs
Stroke care pathway	Discovery of the actual care pathway for Acute Stroke patients	Insurance data ER data Hospital data	Individual patient Care provider Contacts Time stamps Event	Complete solution: Docker with open source Log builder and Process Mining (v1.10)	Aragon (ES) Marche (IT) HU Zagreb (HR)

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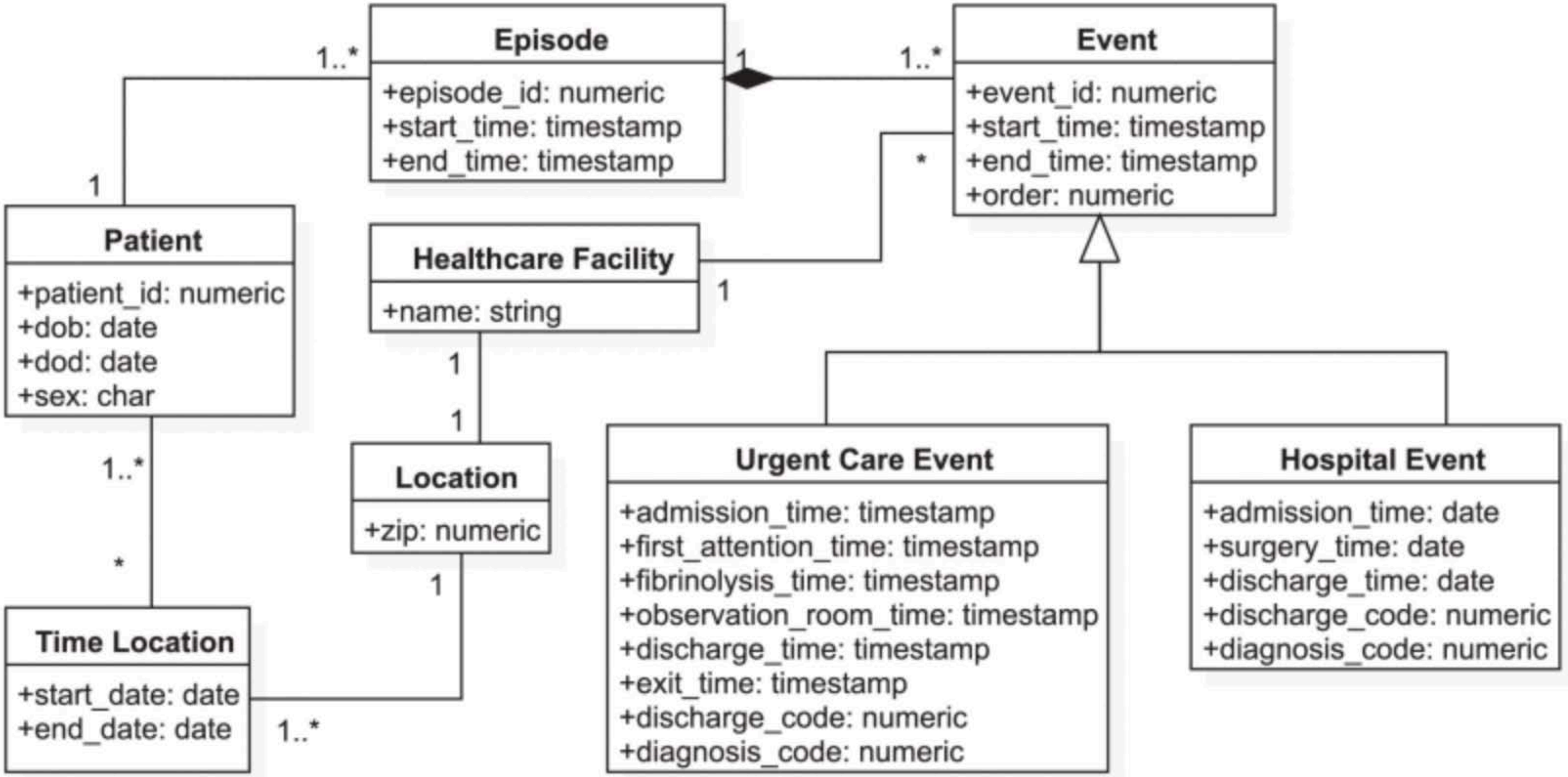
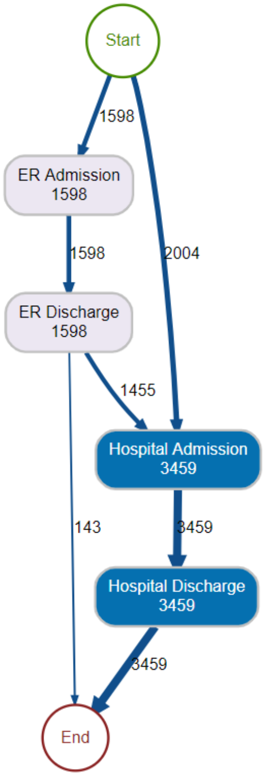
Five steps to complete the “stroke care”pilot

research question – how stroke patients move across acute care
common data model – based on routine data

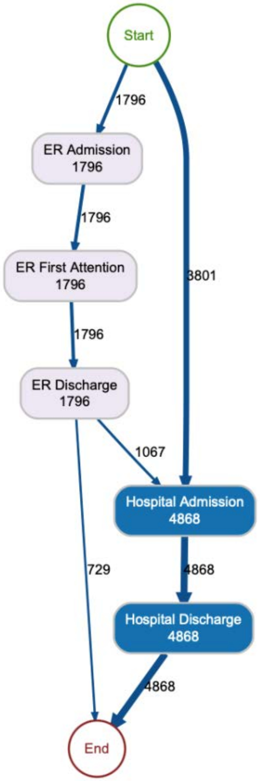


Output:

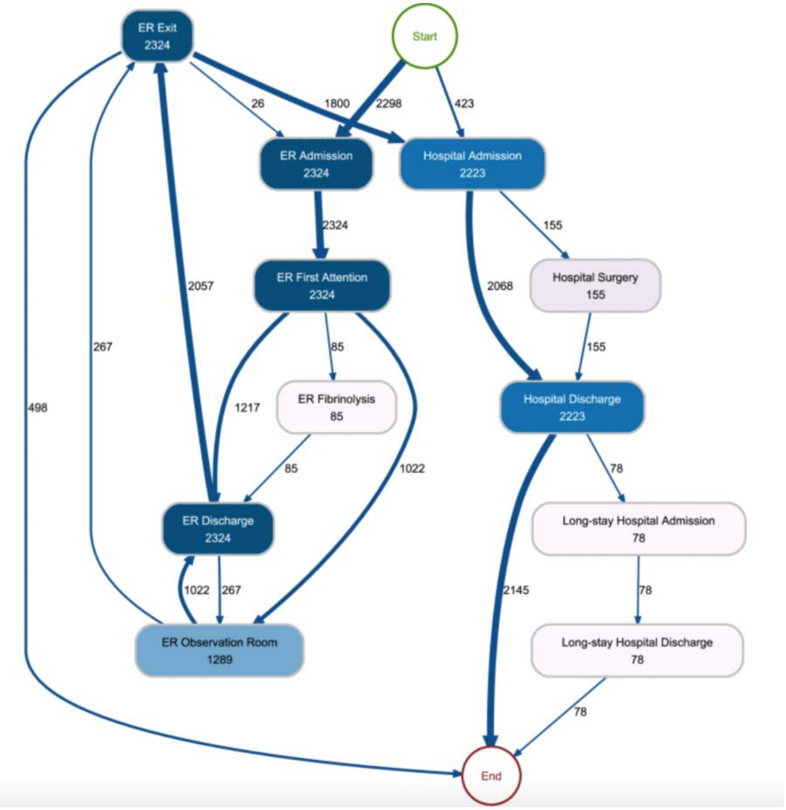
Comparable stroke care pathways delivered in a FAIR *.html file



Marche (IT)



Zagreb (HR)



Aragon (ES)

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Lessons out of this pilot

In the piloted InfAct JA federated research infrastructure, **a number of hubs have been able to deploy a complete exercise, thus:**

- Building a common data model on stroke care
- Implementing an analytical pipeline using an open source ready-to-use solution
- Running the scripts at home, not moving micro-data to a central hub, and
- Sending back a relevant output to the coordination hub for further meta-analysis

The exercise has entailed:

- Ensuring that privacy and safety provisions of the different data hubs;
- Setting up governance procedures and roles within the federation;
- Overcoming the uneven granularity and/or specificity of data across hubs;
- Building an adapted common data model, securing that all hubs can get a meaningful output;
- Building capacity to allow all hubs the full deployment of the pilot

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Room II (researchers)- The Health Information Portal: Access and services

21 January 2021

Presenting: Jakov Vuković
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InfAct General Assembly

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Health Information Portal- the Frontend

- Provide user friendly gateway as a map to population health information and expertise in EU

- Designed to respond to current and future needs of researchers in population health

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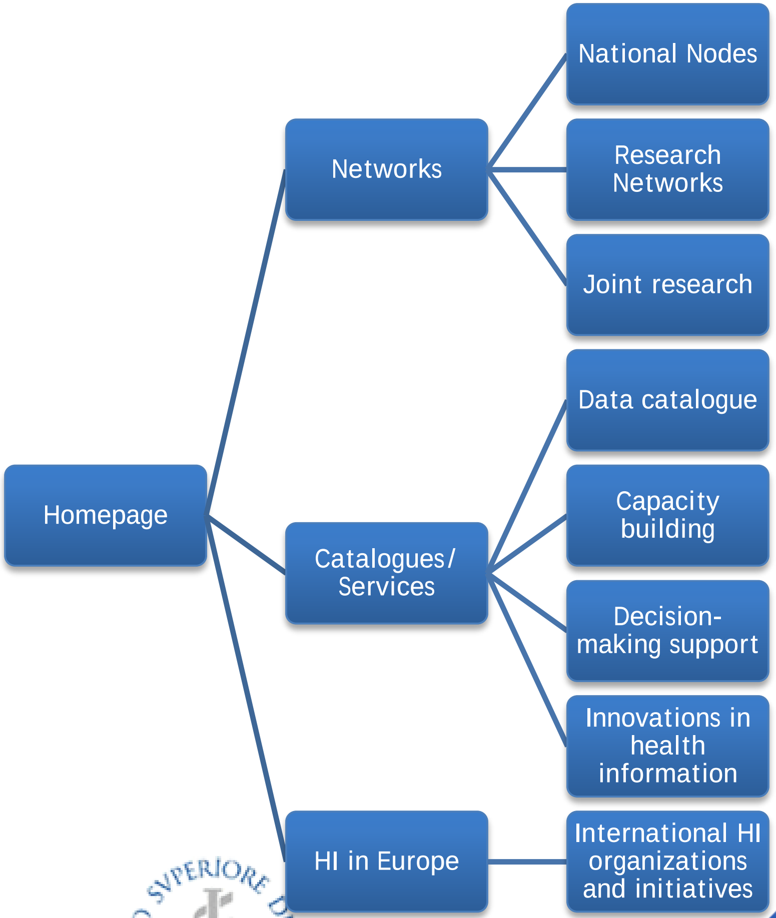
Researchers will have access to



- Homepage
  - Networks
    - National Nodes
    - Research Networks
    - Joint research
  - Catalogues/ Services
    - Data catalogue
    - Capacity building
    - Decision-making support
    - Innovations in health information
  - HI in Europe
    - International HI organizations and initiatives

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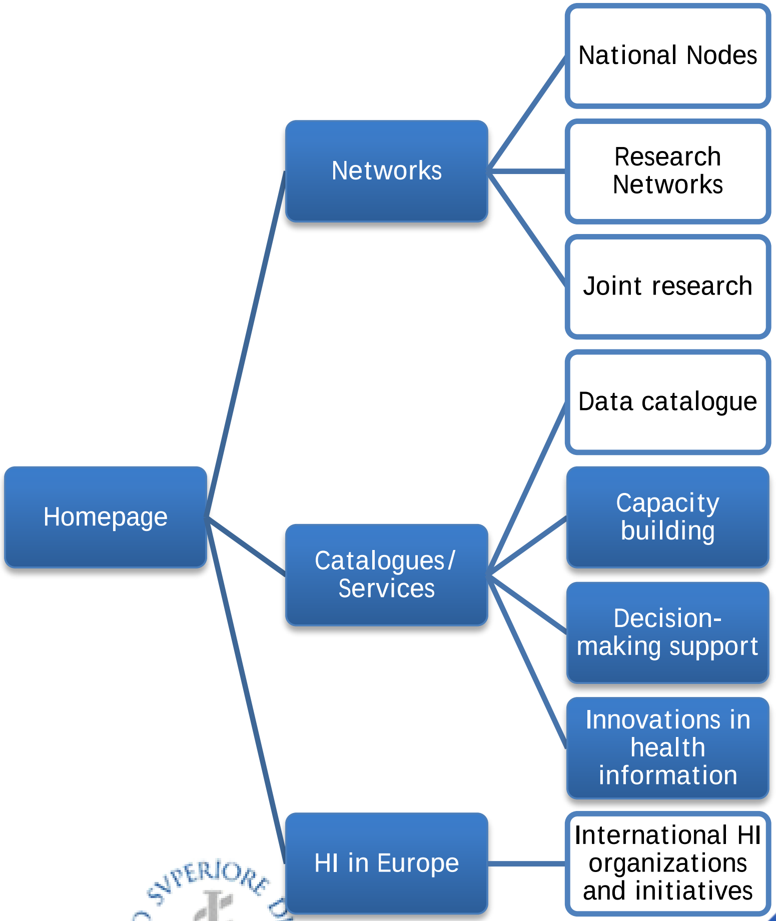

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1. Metadata catalogue of national data collections and Health Information sources
2. Information about current and ongoing research, existing research networks, their work, outputs, and their domain of expertise
3. Overview of international organisations working in health information and provides hyperlinks to these organisations and their relevant activities and outputs

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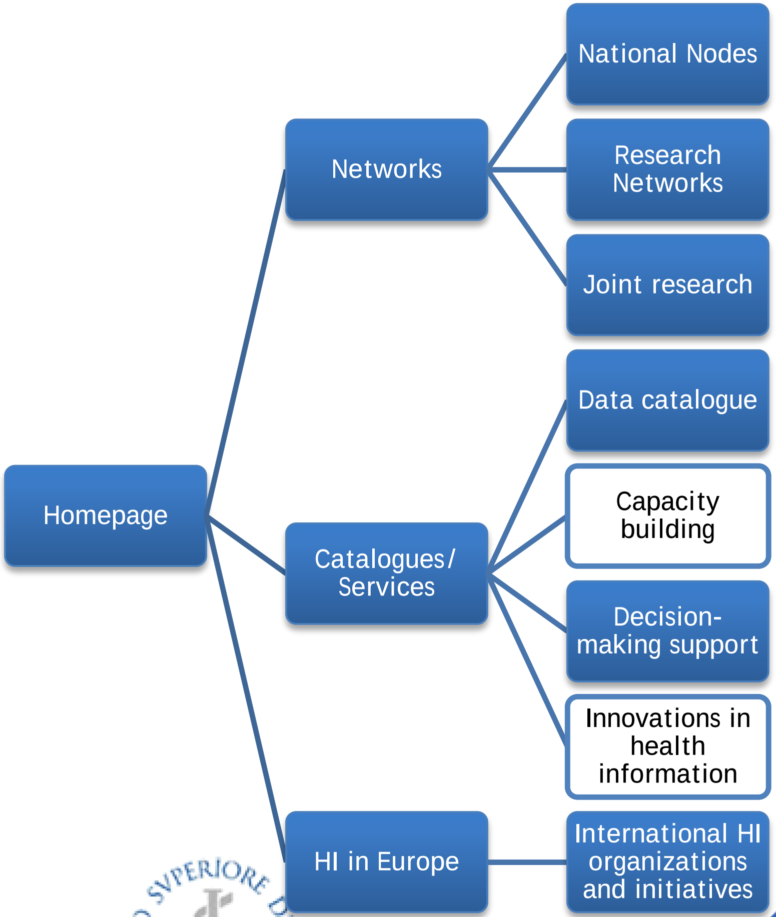
Researchers will have access to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Innovations in health information
HI in Europe
International HI organizations and initiatives

4. Overview of trainings and workshops available in EU
5. Access to DIPoH trainings, and expert support
6. Innovation in Health Information:
   - Innovative use of data sources
   - Health indicator estimates from linked data and advanced statistics
   - Best practices in population health research
   - Computing services
   - Interoperability services and standards

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Access modes

- All open source software and information on the Health Information Portal will be widely accessible to all.
  - → ensuring open, interconnected, data-driven research across Europe.

- Specific benefits will be available for DIPoH members directed at facilitating the establishment of new research projects in synergy with each other, and having instant access to each other’s expertise.
  - → promoting country collaboration and cross-border synergies.

DIPoH will

1. Curate knowledge
2. Facilitate data availability, comparability and use
3. Use technical solutions and overcome research challenges with a federated infrastructure approach
4. Enable new methodologies and research developments
5. Increase knowledge sharing, expertise and training
6. Increases capabilities and expertise

➔Provide the necessary conditions for rich new insights into the dynamics of population health, healthcare interventions, and technological development

Thank you!

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