Population Health Information Research Infrastructure (PHIRI) for COVID-19

World Congress on Public Health

Rome, May 3 2023

www.phiri.eu

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History and composition

Bottom up approach building on 2 consortiums:

- **BRIDGE Health (2015-2017)**
  - 31 partners in 16 countries representing 14 population health research networks in 9 population health research domains.
  - ➔ Concluded there is need for a Research Infrastructure (RI) on population health research

- **InfAct Joint Action (2018-2021)**
  - 40 partners from 28 EU countries: 20 public health or research institutes, 13 ministries, 3 universities and 4 others
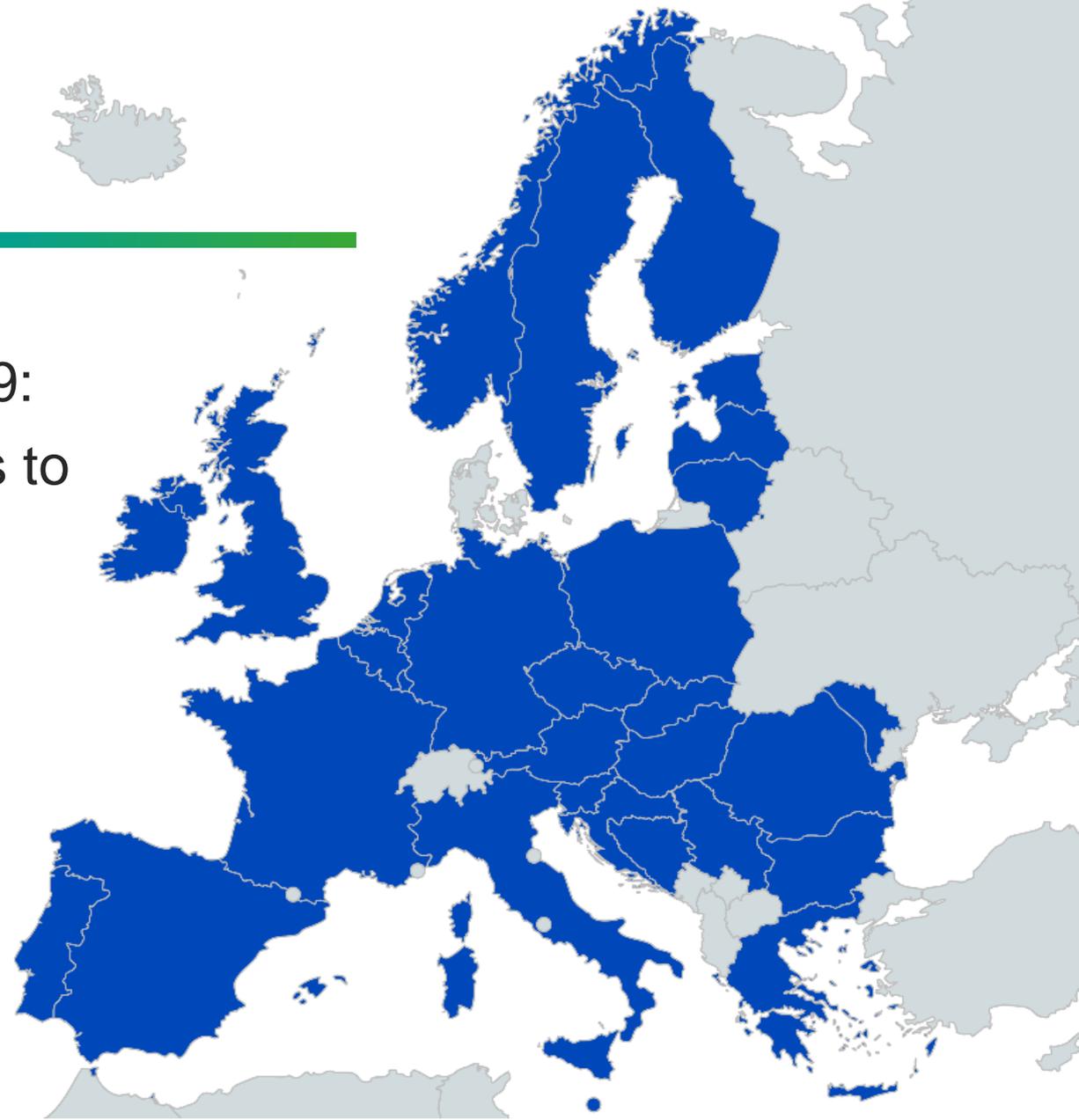 - ➔ Providing proof of concept by piloting RI elements

Map with InfAct Partners

What is PHIRI?

The Population Health Information Research Infrastructure for COVID-19:

- a **European mechanism**, that aims to
- facilitate and support **data-driven population health research**
- and **exchange of best practices**
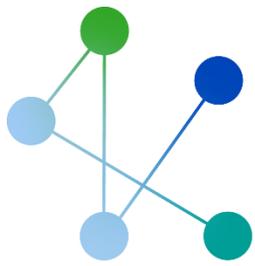- to support **decision making**

Map of PHIRI Partners

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PHIRI Introduction video

The Population Health Information Research Infrastructure (PHIRI): https://www.youtube.com/watch?v=yer5GNfGd8o

The Health Information Portal

Hanna Tolonen

Finnish Institute for Health and Welfare (THL), Finland
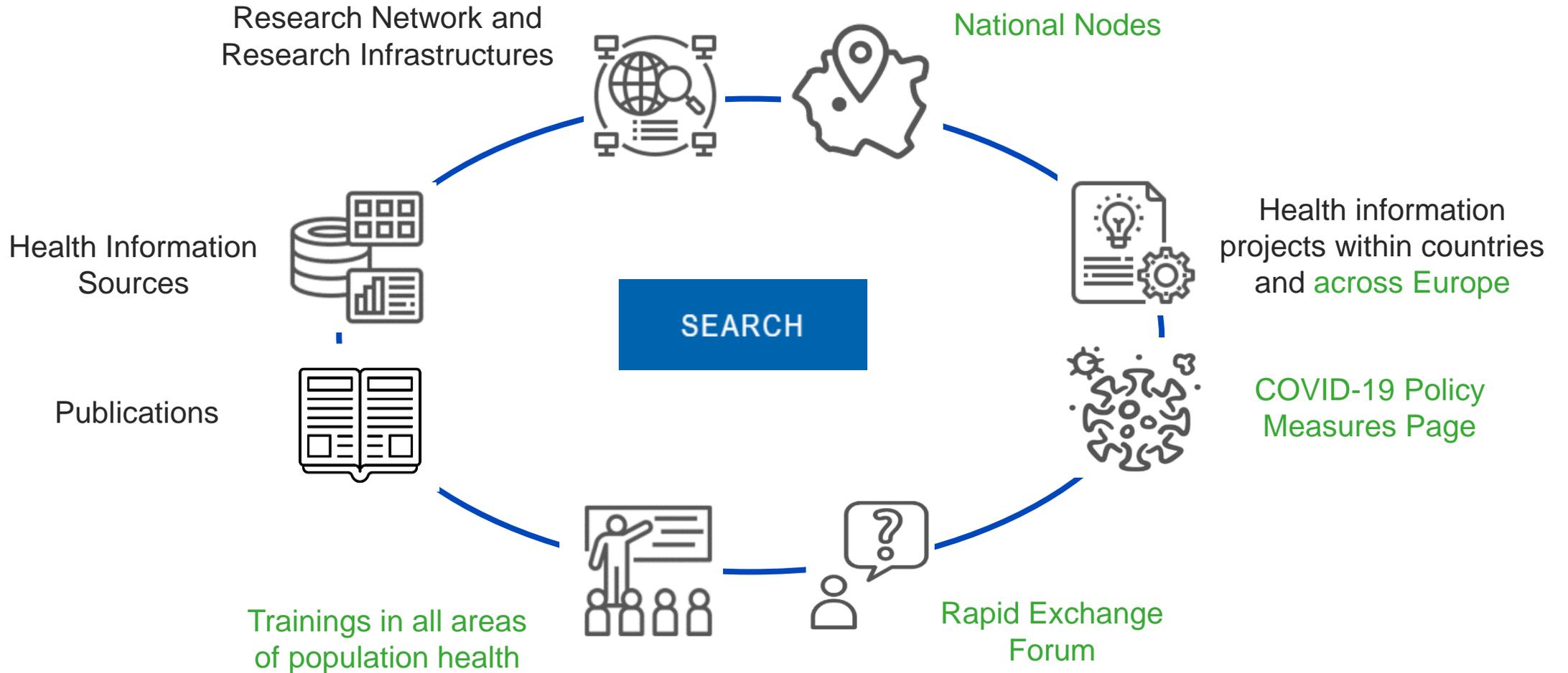
www.phiri.eu

Health Information Portal

- Provides a centralized, **one-stop-shop**, for researchers and policy makers to find population health information

- Enhances the secondary use of health information

- Uses **metadata standards** (DDI and Dublin Core) and Schema.org for its catalogues
  - ➡ supporting **FAIR principles** and interoperability

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Healthinformationportal.eu

Welcome to **the one-stop shop** that facilitates access to population health and health care data, information and expertise across Europe

FIND DATA

Fulltext Search

Country

- None -

SEARCH

233	327	74	14	132
data sources	publications	searches last month	research networks	health information projects

Overview

Research Network and Research Infrastructures

National Nodes

Health Information Sources

Health information projects within countries and across Europe

Publications

SEARCH

COVID-19 Policy Measures Page

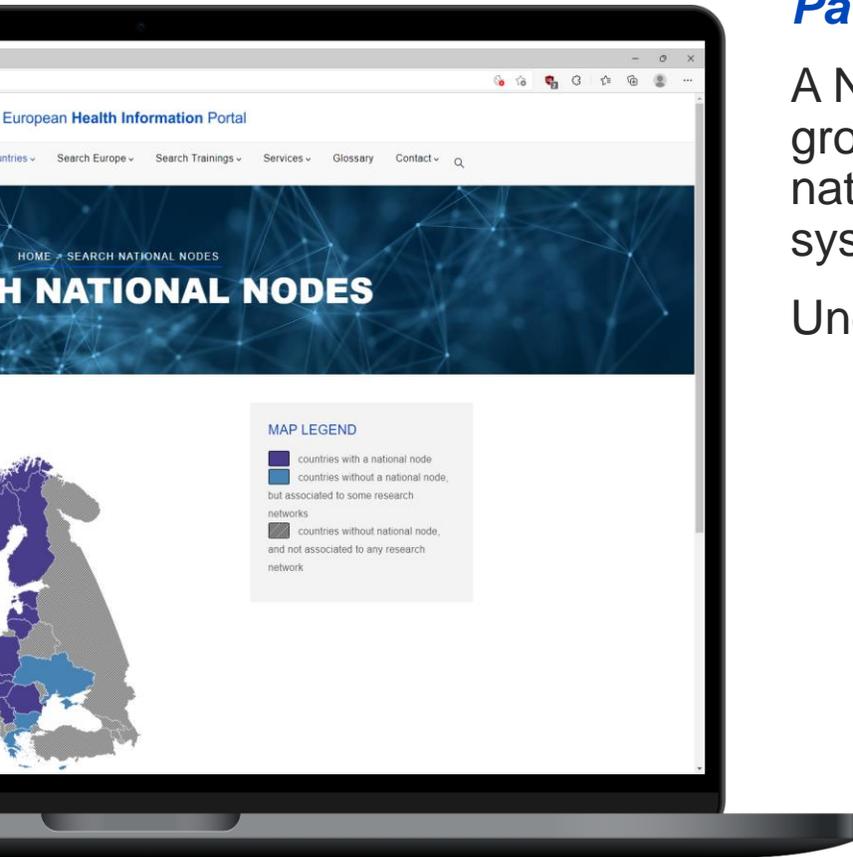Trainings in all areas of population health

Rapid Exchange Forum

National Nodes

Path: Search countries – Search National Nodes – Select country

A National Node (NN) is an organisational entity, often linked to a core group of national institutions or governmental units that function as a national liaison and brings together relevant national stakeholders in a systematic way

Under NNs, there is

- A general description of the NN including involved institutions and/or Ministries, key players in the field of health information, national data protection regulations, and information on health information infrastructure and management
- **Health information sources** for the country
- Different types of **publications**, including grey literature, on health information
- **National health information projects**
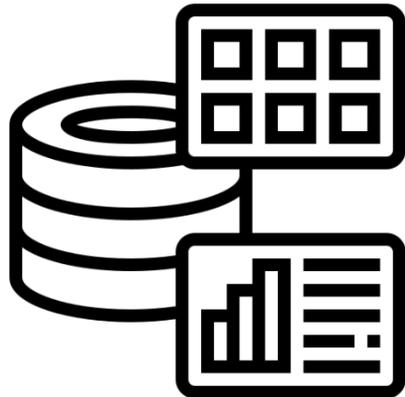
www.phiri.eu

Health Information sources

Path per country: Search countries – Search National Nodes – Select country – Health information sources

Path for all: Services – Find Data

The health information source tab provides structured information on

- Population registries such as cancer or mortality registries
- Health survey data
- Surveillance data for infectious diseases
- Hospitalizations (in- and out-patient)
- Healthcare resources, costs and activities
- Etc.

The template is mapped to *Schema.org*, further increasing the findability of the data

Publications

Path per country: Search countries – Search National Nodes – Select country – Health information sources

Path for all: Services – Find Publication

The publication tab provides information on:
- Scientific publications
- National Reports
- Policy briefs
- Portals/websites
- Grey literature
- Guidelines
- Etc.

The template will be mapped to **Schema.org**, further increasing the findability of the information provided

Health information projects within countries and across Europe

Path: Search Europe – Search European initiatives

Under the **European initiative** tab, you will find information on European projects and Joint Actions related to population health.
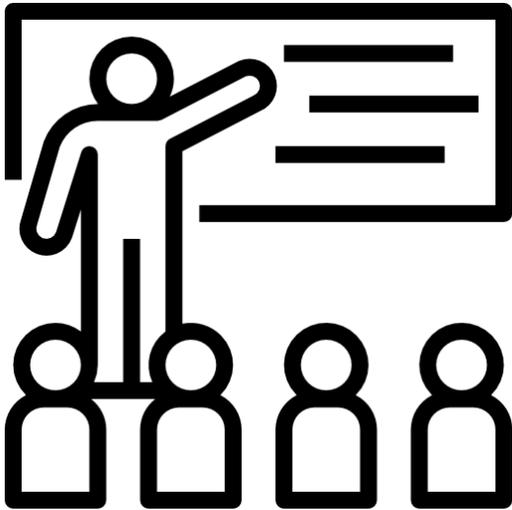
Path per country: Search countries – Search National Nodes – Select country – National Projects

Under the **National project** tab, you will find information on key national projects and Joint Actions related to population health.
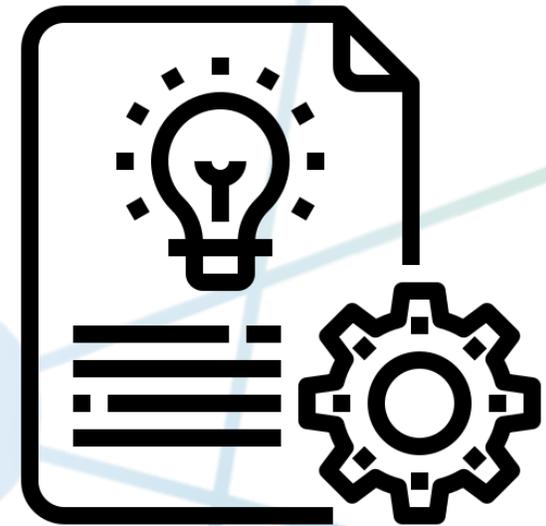
Trainings in all areas of population health

Path: Search Europe – Search European Research Network

In this section of the Health Information Portal, you can find information about available capacity building activities on COVID-19, population health and health information.

Highlights of the week are provided as well as detailed information on

- the aims of the trainings,
- target audience
- Duration
- Language
- Etc…

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COVID-19 Policy measures

Path: Search COVID-19 Measures – COVID-19 Policy Measures
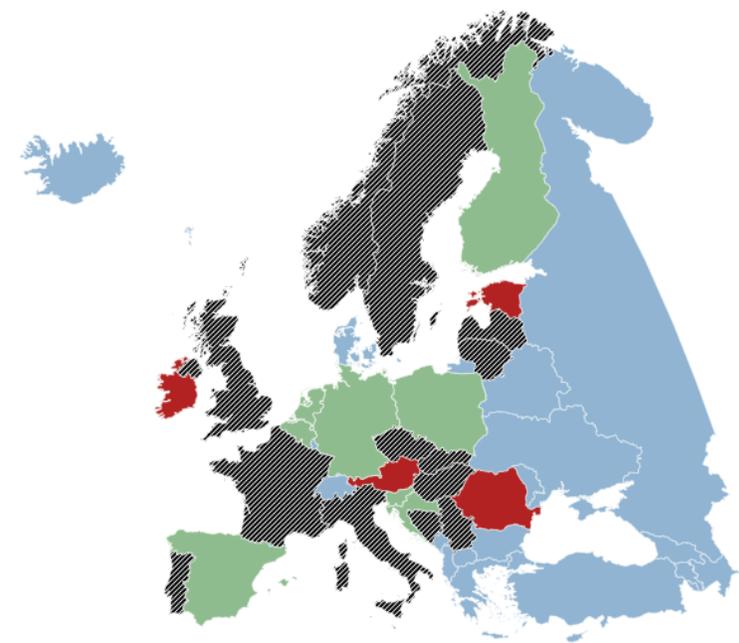
Discover which **policy measures are applied in European countries** to fight the COVID-19 pandemic.

You can display all measures for a given country by selecting its name in the list, or by clicking on the map

Choose a Country

- or -

Border restriction

Rapid Exchange Forum

Path: Search COVID-19 Measures – Rapid Exchange Forum

Within PHIRI, the Population Health Information Research Infrastructure, a Rapid Exchange Forum on COVID-19 developments is organized with key national and international health stakeholders to answer questions and discuss experiences related to the management of COVID-19.

This allows a **rapid exchange of information across countries** to learn from each other's challenges and best practices on:

- vaccination/testing/communication strategies,
- reaction to new variants,
- mortality indicators,
- long-term pandemic surveillance,
- impact evaluations of the pandemic ,
- Etc…

Rapid Exchange Forum at the WCPH

10:00 - 11:00 | Baalbeck Volubilis | Workshop
PHIRI Rapid Exchange Forum (REF): A key tool for cross-country exchange in times of crisis and beyond

Speakers

- **Claudia Habl**, Member of the Executive Board of the Austrian National Public Health Institute (GÖG) and Head of Dept. Leader of the PHIRI Work on Rapid Exchange Forum

- **Petronille Bogaert**, Head of unit EU health information systems at the Belgian Public Health Institute (Sciensano); President of EUPHA Public health monitoring and reporting section, Coordinator of PHIRI project

- **Hanna Tolonen,** Adjunct Professor of Public Health, Research Programme Director at the Finnish Institute for Health and Welfare (THL), Leader of the PHIRI Work on Health Information Portal

- **Luís Velez Lapão**, Professor of Digital and Health Information, Digital & Smart Health Care Laboratory Coordinator, Universidade Nova de Lisboa, Portugal-UNL project Lead of PHIRI

- **Neville Calleja**, Associate Professor, Director of the Department of Health Information & Research of the Maltese Ministry for Health Head of the Dept. of Public Health of the Faculty of Medicine & Surgery of the University of Malta; Maltese Coordinator of the PHIRI project
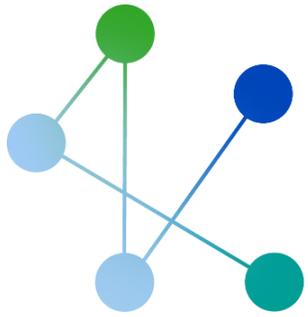
Users of the Health Information Portal

PRIMARY USERS

- **Researchers** in the public health sphere: researchers in public health and population sciences as well as epidemiologists, statisticians, pharmacist, health professionals, data scientists, ethicists, sociologists etc.

- **Data providers and developers** in various health information domains,

- **Policy and decision-makers** in national and international organisations and

- Other public active in the field of public health.

SECONDARY USERS

- **Non-governmental organisations and civil societies** in the public health and healthcare area,

- Media and journalists,

- **Students and educational organisations** of population health and health services,

- General population and

- Industry and private sector

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Thank you for your attention

healthinformationportal@sciensano.be
Follow us on Twitter: @PHIRI4EU

www.phiri.eu
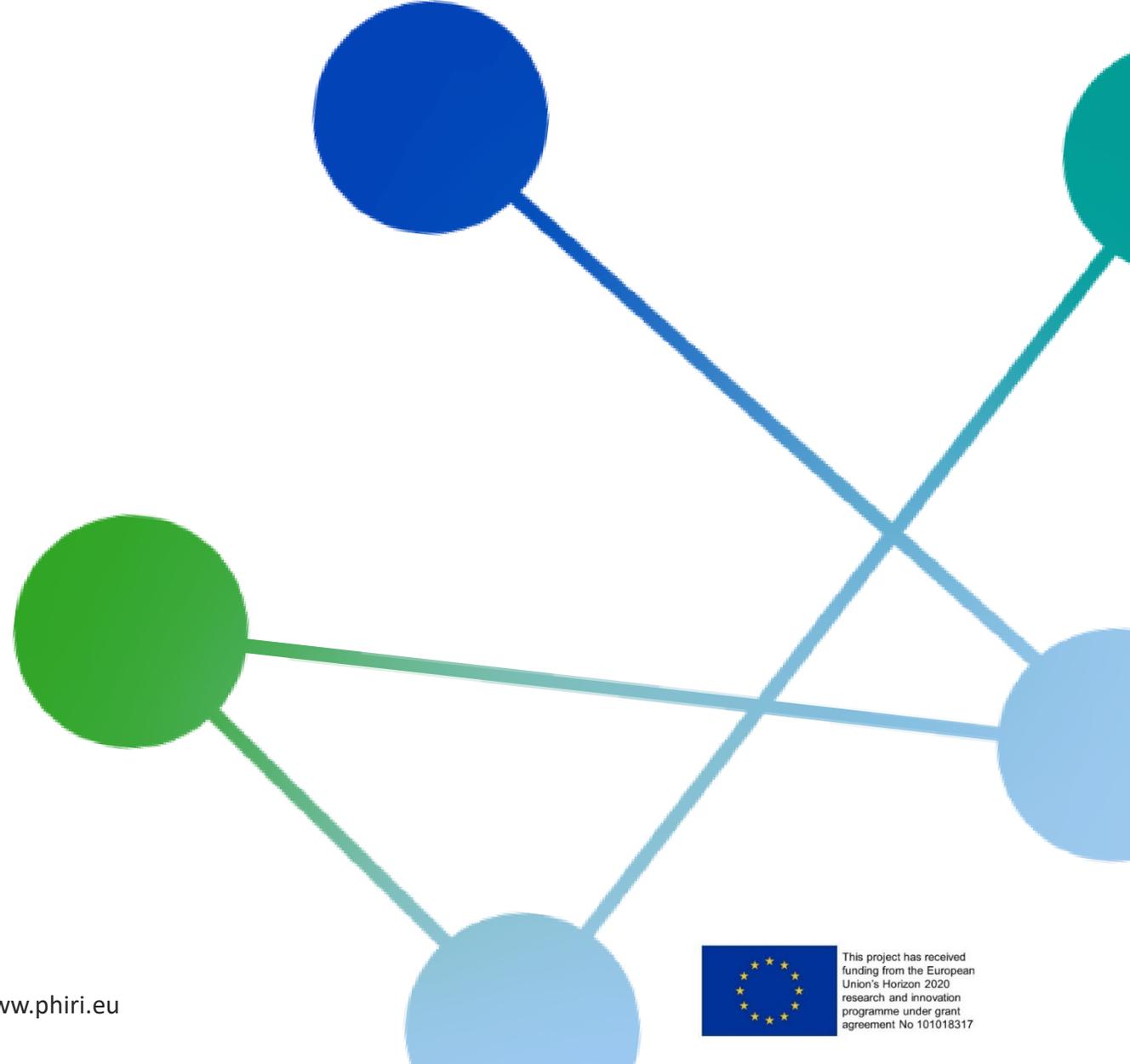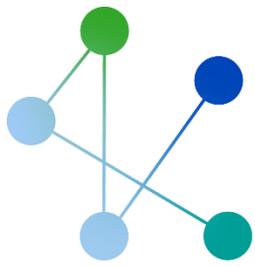
The National Nodes

Miriam Saso
World Congress on Public Health
Rome, May 3 2023

What is a National Node?

A National Node is an organizational entity, often linked to a national institution or governmental unit that functions as a *national liaison* and brings together relevant stakeholders in the country in a systematic way.

Why National Nodes?

- Health information activities are usually carried out by various institutes in countries

- Often regular communication is lacking between these institutes which may cause:

  o Duplication of activities
  o Hampered exchange of data
  o Lost opportunities for research and policy support
  o Limitation of data interoperability between institutes
 o Lack of knowledge sharing

Roles of a National Node

At national level

- Bring together the key national players in health information
- Share expertise at national level
- Promote FAIR data
- Support inter-institutional data linkage to increase research potential

At international level

- Contact point between the international initiatives and national players
- Provide national data and expertise to the Health Information portal
- Coordinate international data exchange and comparisons
- Facilitate collaboration with international networks and experts

Search National Nodes
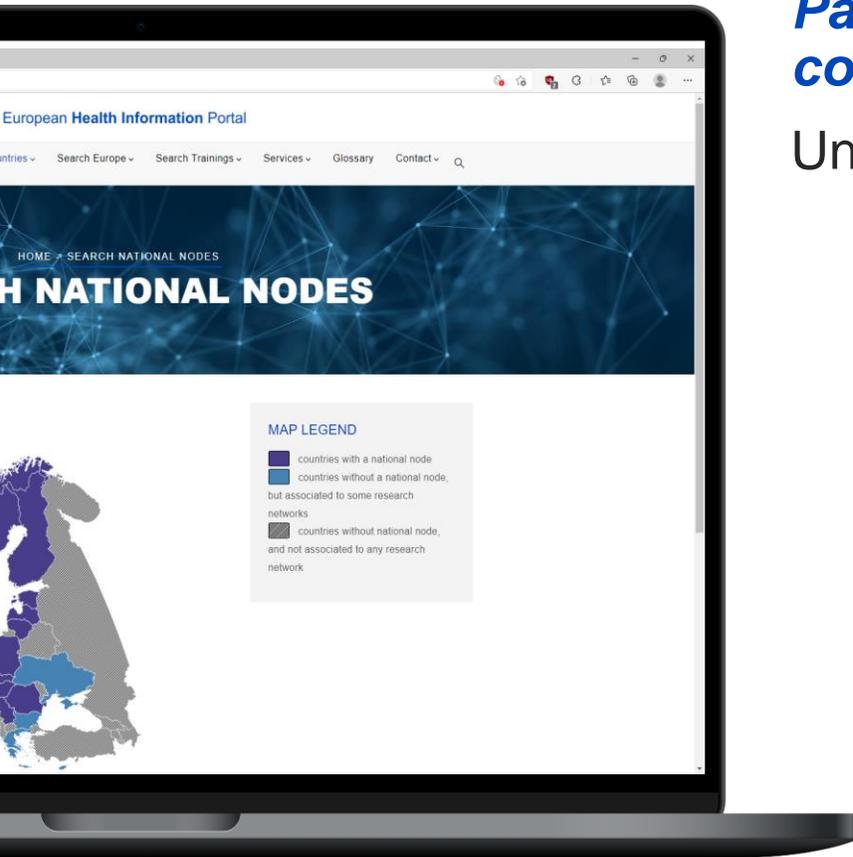
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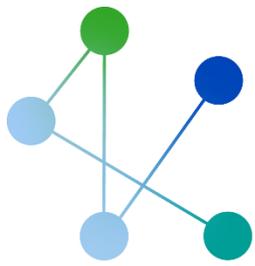- **National health information projects**

Slido

Join at Slido.com

#1819 225

1. On which population health topic would you like to find resources using the Health Information Portal?

2. What are other websites/ Portals that would benefit from being connected to the Health Information Portal to exchange information?

Cataloguing health information sources

Dr. Nienke Schutte
World Congress on Public Health
Rome, May 3 2023

www.phiri.eu

Sources on the Health Information Portal

Sources on the Health Information Portal

Metadata of a health information source

HOME - HEALTH INTERVIEW SURVEY

HEALTH INTERVIEW SURVEY

- Type of Information
- URL of the data source
- Description
- Governance & legal framwork
- Keywords & topics

| OVERVIEW | DEMOGRAPHICS | DATASET | CONTACT |

Acronym	HIS
Type of information	Survey/interview data
URL of the data source	

https://www.sciensano.be/en/projects/health-interview-survey

Description

A national Health Interview Survey (HIS) provides an overall picture of the health status of the population and allows to identify the main health problems, as well as the social and behavioral factors that influence them. This information enables health authorities to pursue a proactive health policy aimed at improving public health and addressing the needs of groups at risk. Researchers, experts and the press use the results of the HIS

Metadata of a health information source

- Countries
- Geo coverage
- Population
- Sex

Metadata of a health information source

HOME - HEALTH INTERVIEW SURVEY

HEALTH INTERVIEW SURVEY

- Data collection period
- Languages
- Personal identifier
- Level of aggregation
- Data access

OVERVIEW   DEMOGRAPHICS   DATASET   CONTACT

Data Collection Period

Language(s)   Dutch, English, French

Personal Identifier   Participant number

Level of aggregation   Individual

Terms of data access - URL   https://www.sciensano.be/en/node/55737/health-interview-survey-microdata-request-procedure

Terms of data access

The procedure for obtaining the HIS data is initially done by completing the electronic application form.

Metadata of a health information source

HOME - HEALTH INTERVIEW SURVEY

HEALTH INTERVIEW SURVEY

- Data Owner
- Contact details

| OVERVIEW | DEMOGRAPHICS | DATASET | **CONTACT** |

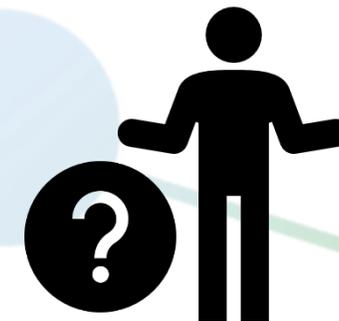|	
Data Owner(s)	Sciensano
Contact name	HIS team Sciensano
Contact e-mail	his@sciensano.be
Contact info (address)	

Sciensano
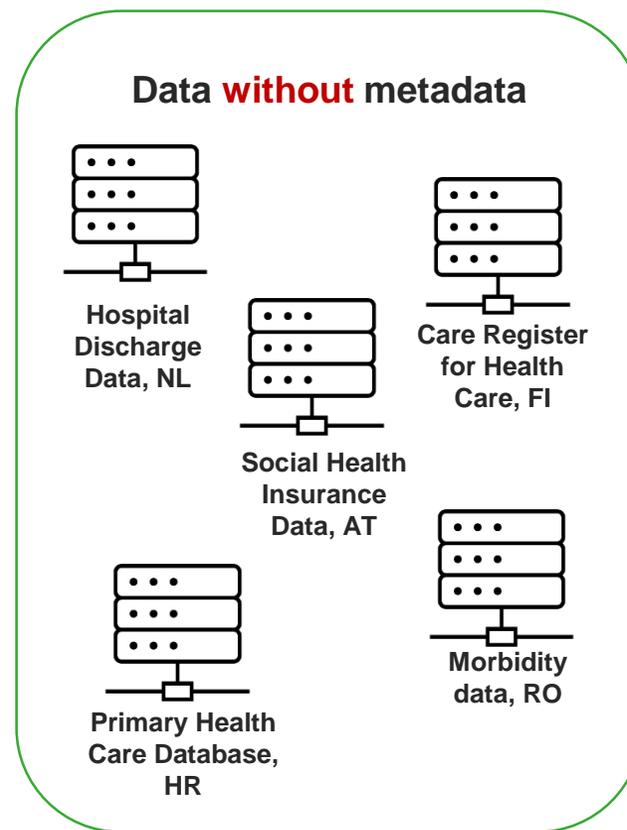Rue Juliette Wytsmanstraat 14
1050 Brussels
Belgium

Why metadata?

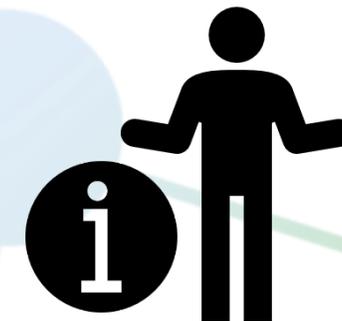For my research I need data on prevalence of NCD's in European countries. Where to find it?

Through my networks and internet search I was able to identify the following potential data sources

Data without metadata

- Hospital Discharge Data, NL
- Social Health Insurance Data, AT
- Care Register for Health Care, FI
- Primary Health Care Database, HR
- Morbidity data, RO

- What type of data are these?
- What age groups do they cover?
- What information do the variables cover?
- Who owns these data?
- How do I get access to these data sources?

Why metadata?

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Morbidity data, RO

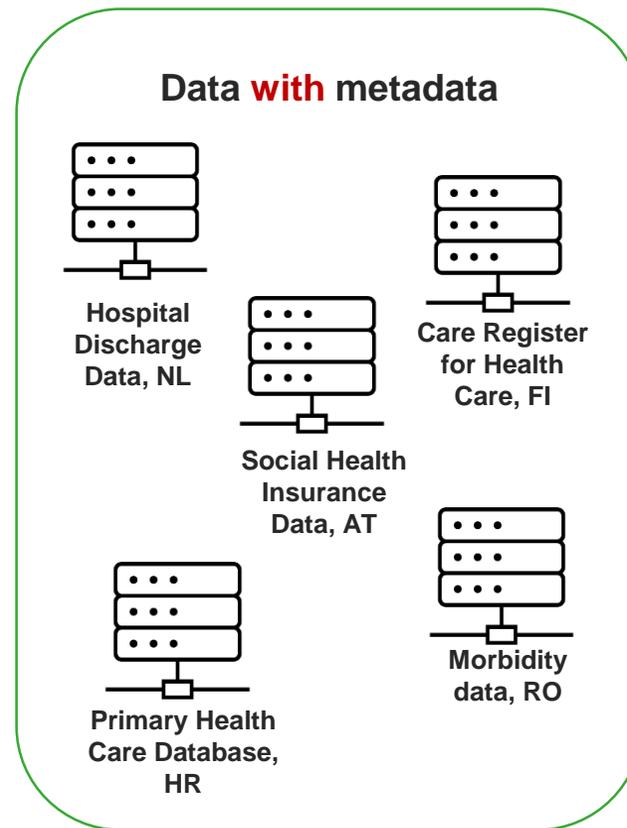Primary Health Care Database, HR

In structured format

- Data on hospitalizations
- Covers all 18+
- National coverage
- Basic background variables on sex, age and diagnostic information
- Contact details for access requests
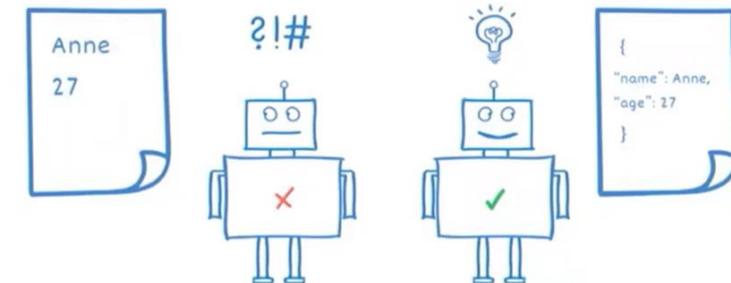
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Metadata on the Health Information Portal

Development process of the metadata elements:

1) Metadata elements developed by population health researchers
   - In order to accomodate all metadata relevant for population health information
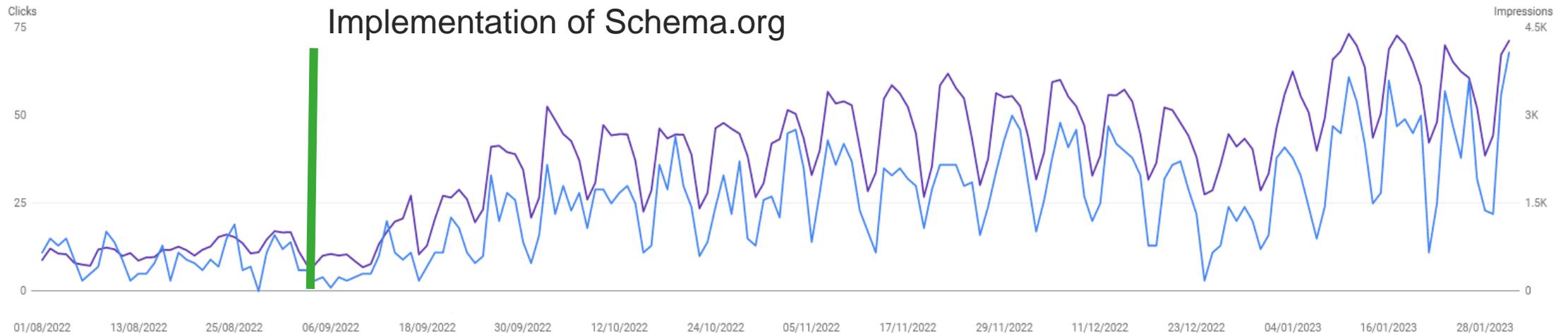
2) Mapping to schema.org
   - Schema.org is a metadata standard for the indexation of web pages
     - Improves machine to machine communication
     - Increases discoverability

Effects of Schema.org

The Health Information Portal: Google search analytics:

- Clicks: number of times a user clicked on a link provided by Google to the HIP.
- Impressions: how often someone saw a link of the HIP on Google.

35

Metadata on the Health Information Portal

Development process of the metadata elements:

1) Metadata elements developed by population health researchers
   - In order to accomodate all metadata relevant for population health information

2) Mapping to schema.org
   - Schema.org is a metadata standard for the indexation of web pages

3) Mapping to DCAT
   - DCAT is a vocabulary for publishing data catalogs on the web
     - Facilitates sharing of data & interoperability between data catalogs
     - Increases the discoverability of datasets
     - Allows federated search for datasets across catalogs in multiple sites
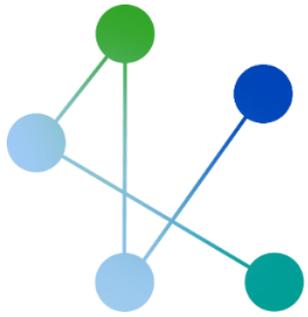
Metadata in the European landscape

Proposal for a regulation - The European Health Data Space published on May 3rd by the European Commission.

Section 5 – Article 55.1

*"The health data access bodies shall inform the data users about the available datasets and their characteristics through a **metadata catalogue**. Each dataset shall include information concerning the source, the scope, the main characteristics, nature of electronic health data and conditions for making electronic health data available"*

→The Health Information Portal has these metadata available in a standardized format

→The Health Information Portal can provide a starting point for the national authorities to create a catalogue

→Through an API these metadata are available for everyone

Thank you!

Name: Petronille Bogaert, Nienke Schutte, Miriam Saso, Pascal Derycke, Barthélémy Moreau de Lizoreux, Charles-Andrew Van de Catsyne
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