

Health Information Portal

Deliverable 7.4

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Executive summary

This is Deliverable 7.4 of Work Package (WP) 7 of the Joint Action on Health Information (hereinafter referred to as InfAct) with project number 801553. collaboration, Through country InfAct streamlines health information sustainable activities across Europe. lt builds towards and a infrastructure on EU health information and strengthens its core elements based on capacity building, health information tools and political support.

WP7 developed the proof of concept for the Distributed Infrastructure on Population Health (DIPoH). As part of this WP, in collaboration with Task 8.4., Task 7.4 designed a web based platform providing the single entry point to DIPoH's one-stop shop, called the Health Information Portal.

By means of the Health Information Portal, DIPoH brings together National nodes (NN) and Research Networks (RN) as part of the DIPoH and create a sustainable network of networks.

This document provides a brief summary of the Health Information Portal and its sections, while providing screenshots of the portal for illustration. The portal is publically available through www.HealthInformationPortal.eu

I. The Health Information Portal -in brief

For the first time, catalogs of population health information sources from national and international organizations are findable through a single European Health Information Portal.

WHAT DOES THE HEALTH INFORMATION PORTAL OFFER NOW?

The Health Information Portal is a one-stop shop facilitating access to population health and health care data, information and expertise in Europe. The Portal provides catalogs on:



Data sources and data providers or data managers



Information on National Nodes and Research Networks



Health information projects within countries and across Europe

WHAT WILL THE HEALTH INFORMATION PORTAL OFFER IN THE NEAR FUTURE?

The Health Information Portal will offer the services and tools necessary for researchers to access and link different data sources and to use Pan-European data in a GDPR compliant, federated way. The Portal will include a focus area on activities related to the management of COVID-19 to further support researchers and policy makers:



Training and capacity building in all areas of population health



A toolbox for legal and ethical guidelines



Publications, reports, guidelines and articles

The Portal is designed to be part of the Distributed Infrastructure on Population Health (<u>DIPoH</u>). DIPoH is a product of the Joint Action on Health Information (<u>InfAct</u>, 2017-2021).

DIPoH has led to the implementation of the Population Health Information Research Infrastructure (PHIRI, 2020-2023) as a roll out of DIPoH in the area of COVID-19.

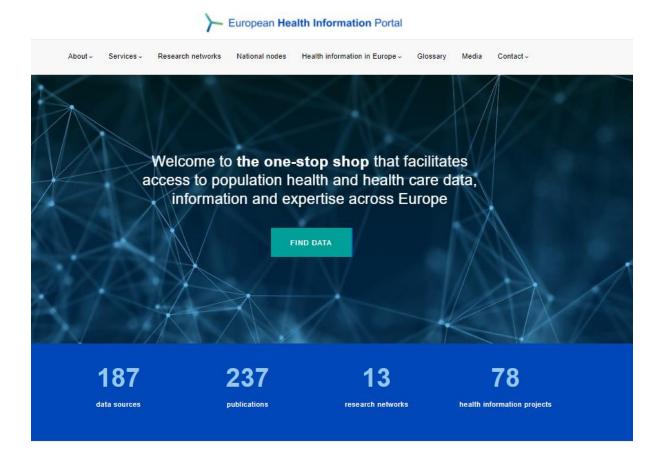
II. The Health Information Portal illustrated

Launched on May 31st, 2021, the Health Information Portal is available at <u>www.healthinformationportal.eu</u>. The following section provides an illustrated overview of the different sections of the Health Information Portal.

A. Homepage

The homepage provides an overview of: The current sources, publications, research networks and projects available; the goal of the Health Information Portal; the available repositories; a link to the FAIR catalogues; a services and support help function and a form to subscribe to the newsletter.

Important to note, the homepage already includes a link to the search function of the available information in the Health Information Portal.



GOAL OF THIS PORTAL

What data is available across Europe? How can I access it? If we want to reap the value of data, it needs to become both more visible and far more accessible. This is facilitated through the Health Information Portal. Find the network, expert, data or publication you are looking for in Europe without having to search each country individually.

REPOSITORIES

This website contains a repository function for







We need you!

Help us providing complete and accurate health information: register and start contributing to this portal

REGISTER HERE



FAIR catalogue

The development makes use of standards as given by the FAIR principles (Findable, Accessible, Interoperable, and Reusable). The portal now offers a FAIR catalogue with overviews of COVID-19 population health data sources, studies and capacity building excercises. The essential actors to provide the necessary information to feed the portal are the networks of the National Nodes (NN), based on the Joint Action on Health Information (InfAct) framework

READ MORE

The portal was developed as part of the activities of the Joint Action on Health Information (InfAct) as a cornerstone of the Distributed Infrastructure on Population Health (DIPoH). The Population Health Information Research Infrastructure (PHIRI) is expanding the reach of the portal to also include population health information, data and expertise related to COVID-19.



B. About

The About section provides an overview of the description of the Health Information Portal, the project team, and the user groups.

As illustrated below, the description of the Health Information Portal provides the aim of the Health Information Portal, and an explanation of the National Nodes (NN) and Research Networks (RN).



HEALTH INFORMATION PORTAL

On this page you can find all the information on the Health Information Portal as developed in The Joint Action on Health Information (JA InfAct). This page includes a description of the National Nodes (as defined in InfAct) and a manual for the National Nodes to add information to the Health Information Portal. Please note that this Portal is a work in progress: in PHIRI WP4 we expand, update and improve this portal.

The aim of the Health Information Portal is to provide access to population health and healthcare data across Europe. The portal will be the gateway for potential users to make use of the services of the Research Infrastructure on population health that was ideated in InfAct and that will be implemented in PHIRI and DIPOH.

The Health Information Portal contains catalogues for population health data, tools, experts, and guidelines; capacity building and trainings information; Innovation in health information tools and methodologies; and decision-making support that will help researchers to find and access population health information in timely manner.

WHAT IS THE HEALTH INFORMATION PORTAL?

The Health Information Portal is a web based platform which is developed within InfAct as a basis for the Health Information Research Infrastructure. The portal will be the gateway for potential users to make use of the services of the Research Infrastructure. These include the catalogue for population health data, tools, experts, and guidelines; capacity building and trainings information; Innovation in health information tools and methodologies; and decision-making support.

Please find more information on this Portal on the InfAct-website

WHAT IS A NATIONAL NODE (NN)?

The 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. The relevant stakeholders may include, for example, the national statistical office, the national public health institutes, representatives from ministries of health, research and/or science, and others. In addition, the NN may function as a discussion and advisory forum in matters of health data and information both for national or international matters. Examples include aspects of the governance of data, indicators and health reporting at the international level and health information stakeholders at national level.

WHAT IS A RESEARCH NETWORK (RN)?

A Research Network (RN) is an active network of national and/or regional experts from several countries that perform comparative research in a specific health area (information domain).



The Project Team section describes the current projects working towards the setup of a fully operational Distributed Infrastructure on Population Health (DIPoH), ensuring the sustainability of the Health Information Portal as an integral part of DIPoH.





INFACT

The Joint Action on Health Information InfAct (Information for Action!) is a 36 months project funded by the European Commission. It builds on the BRIDGE Health project and other initiatives in health information. The project was launched in March 2018. It includes 40 partners in 28 EU and associated countries.

Through country collaboration, InfAct streamlines health information activities across Europe. It builds towards a sustainable and solid infrastructure on EU health information and strengthens its core elements based on capacity building, health information tools and political support. Read more about our mission and vision here.

PHIRI

PHIRI's goal is to set up a research infrastructure to facilitate and generate the best available evidence for research on health and well-being of populations as impacted by COVID-19. PHIRI will allow for better coordinated European efforts across national and European stakeholders to generate the best COVID-19 population health knowledge. In doing so, PHIRI will lay the foundation to build a Distributed Infrastructure on Population Health (DIPoH) to be used to overcome future crisis and ensuring the sustainability of the project. The intent is to support research across Europe through the identification, access, assessment and reuse of population health and non-health data to underpin public health policy decisions. This will be achieved through a close collaboration with 41 partners across 30 countries over a period of 36 months starting in November 2020. The project is divided in 9 ambitious work packages with three transversal topics. PHIRI builds on the achievements of the BRIDGE Health and the Joint Action on Health Information (InfAct) projects.

DIPOH

The Distributed Infrastructure on Population Health (DIPoH) aims to develop a Pan-European state-of-the-art Distributed Infrastructure on Population Health. DIPoH will strengthen the synergy in the EU by facilitating comparative population health research efforts through the identification, access, assessment and reuse of high quality, reliable and comparable population health data (health status, determinants and care use) across EU health systems. DIPoH contributes to meet current challenges facing our societies related to ageing, multimorbidity, health inequality and increasing health care cost.

C. Services

DIPoH will provide large-scale, integrated and sustainable services to researchers and policy-makers with four services:

- One-stop shop for EU health information research: providing metadata catalogues on health and health care data sources, research networks, guidelines and tools. It facilitates access and (re-)use of European information on population health and health care systems.
- 2. Investing in **innovation** in health information development for population health research: supporting researchers in using pan-European health data in a distributed way, linking different data sources and making their research FAIR and ELSI compliant.

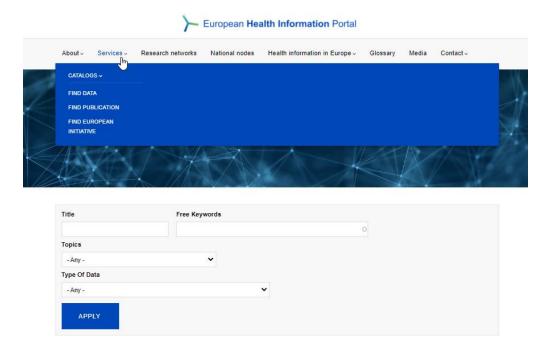


- 3. **Building capacity** to actively promote interoperability and tackle health information inequalities: encouraging exchange of best practices and expertise regarding population health and healthcare research starting from the phase of designing data collections to analysis, monitoring, reporting and curation. Dynamic training of the health research community involves both the data producers, data curators and data users.
- 4. Strengthening the health research community in developing methods for **knowledge translation research** to support decision-making processes: improving the health of the European citizens and increasing the efficiency of both our health care systems and policy decisions.

In order to provide the services, the Health Information Platform will take on specific activities and functions provided in the Services section. These include:

- Health information catalogues
- Supporting actions for innovation in health information research
- Services related to capacity building
- Decision-making based on evidence-based research

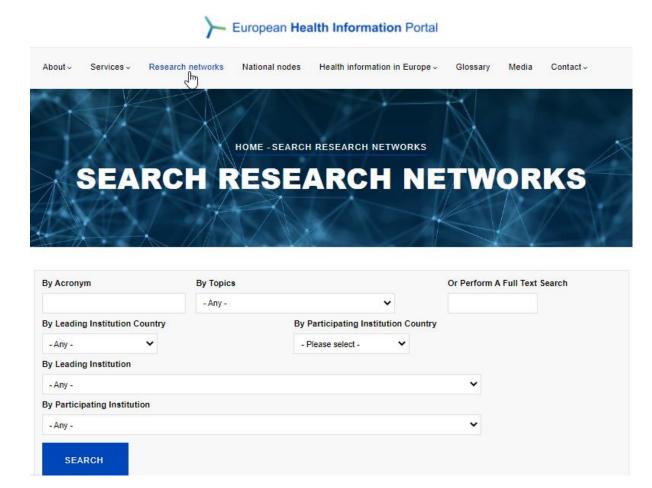
Currently, InfAct has developed the FAIR catalogues in the services section, as illustrated below. The catalogues enable a search function using keywords specific data sources, specific publications and European initiatives related to population health information.





D. Research Networks

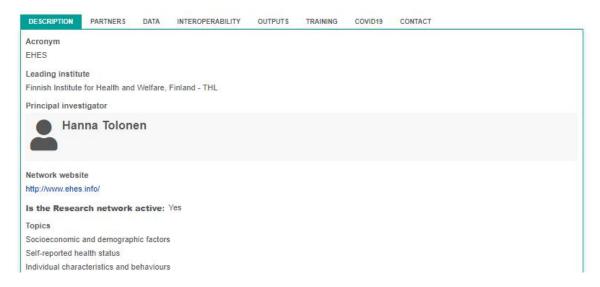
The Research Networks section provides a search function to find currently active European Research Networks that have signed a letter of intent with DIPoH. The descriptions is organized in a systematic way in order to provide the same standardized information about each network. This allows the users to search through different keywords.



The illustration below provides an example overview of the European Health Examination Survey network. The Health Information Portal lists the coordinator and partners of the networks, the type of data, and interoperability of the data collected, outputs, training and contact point. Furthermore, due to the COVID-19 pandemic, an additional section was added to indicate COVID-19 related activities and data collected by the network.







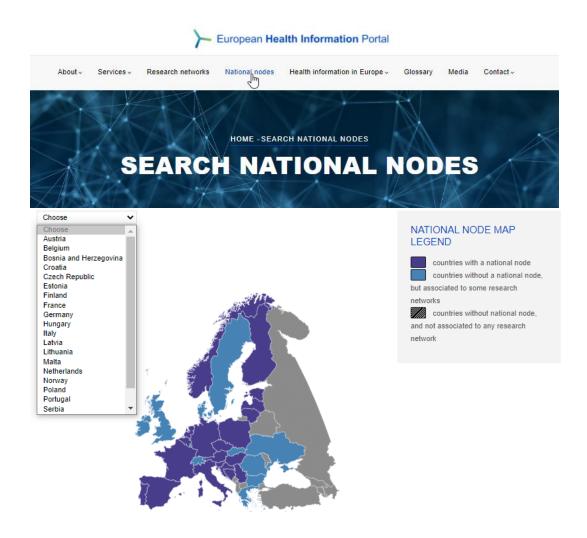
E. National Nodes

The National Nodes section provides a map of Europe where a country may be selected. This section also provides a search function with available different keywords. Each country provides the following information on the National Node and health information:

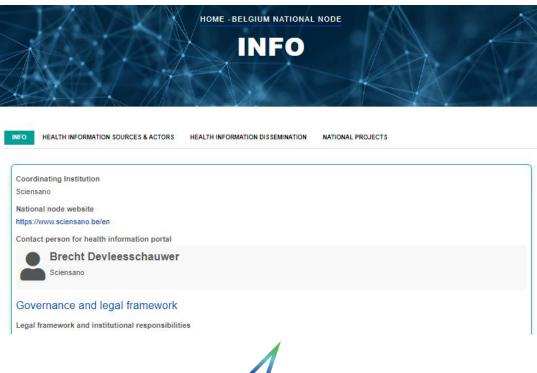
- General information: The coordinating institute of the national node within the country; the governance and legal framework; health information sources and main players; the health information structure and management
- Health information sources and actors
- Health information dissemination
- National projects

See below the National Nodes map for selecting the EU countries.





The following is an illustration for the National Node of Belgium:



F. Health information in Europe

The section serves as a guiding portal to all health information related activities, reports, and initiatives in Europe. This includes International organizations international such as the organizations under the European Commission, the OECD, WHO Europe, etc. This section also lists European research infrastructure that are relevant and collaborate with DIPoH. The European Initiatives list European projects in health information that were found to create a living repository (D5.2 Creating a catalogue of EU health information projects and networks). Finally, a separate page is dedicated to elaborating on the European Core Health Indicators (ECHI).



G. Glossary

The Glossary section lists relevant important terms used in population health information.

H. Media

This section will be further developed to provide information on news about DIPoH, social media, layman reports for journalists, job opportunities and hyperlinks to possible communication between the partners of DIPoH.

I. Contact

The Contact page provides support manuals for stakeholders that are going to provide information about their National Node (national data sources, actors, dissemination activities, etc.) or Research Networks. An contact form is available to leave feedback or questions related to the Health Information Portal.



Disclaimer:

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