

A DISTRIBUTED INFRASTRUCTURE ON POPULATION HEALTH

DIPoH



Stimulate
innovative
research

Increase
capacity
building

Improve
interoperability

Strengthen
population
health
information

Inform
decision-
makers

Advance
scientific
knowledge





Co-funded by
the European Union

This document is intended for the purposes of early evaluation by national authorities, including governmental departments, research councils and academies.

For more information contact infact.coordination@sciensano.be

A Distributed Infrastructure on Population Health DIPoH

Background

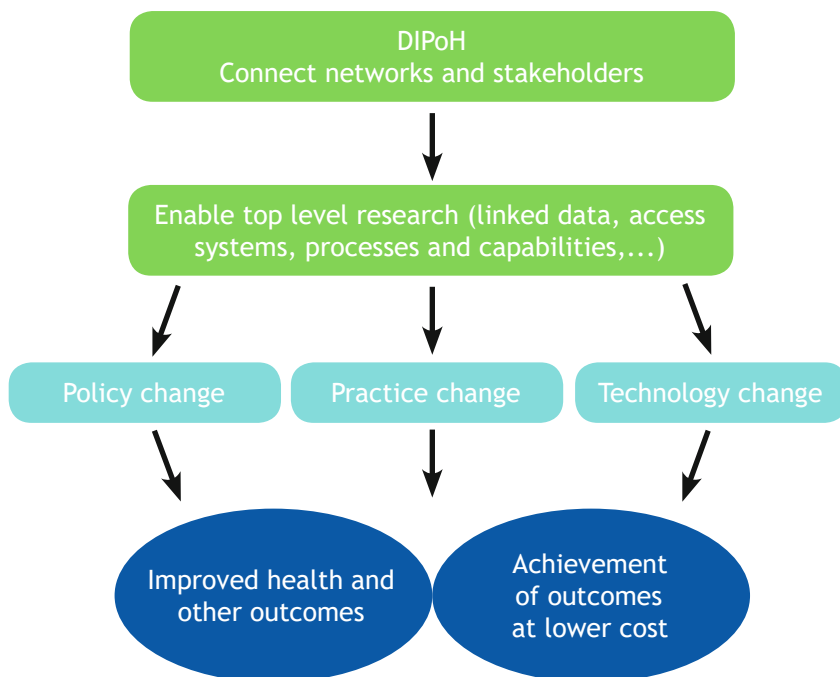
Ageing populations, persistent inequalities and rising healthcare costs are big challenges for all European countries. To promote healthy and safe citizens, a strong public health intelligence is needed.

Europe has a wide variation in the distribution of health in populations. Effective secondary use of already existing health information and linkage of different data sources provide opportunities for high-level comparative research between countries. Through this research we can obtain new insights in healthcare interventions, technological development and evidence to support policy-making (Figure 1).

Key points

- The Research Infrastructure DIPoH will support high-level health research by facilitating the identification, the access, the assessment and reuse of data.
- DIPoH will combine a central coordination office, national nodes across EU countries and pan-European research networks on specific population health topics.
- DIPoH will do 4 activities: provide a one-stop shop for population health data, develop innovative methods, build capacity and develop knowledge translation research.

Figure 1. Value chain of DIPoH's impacts

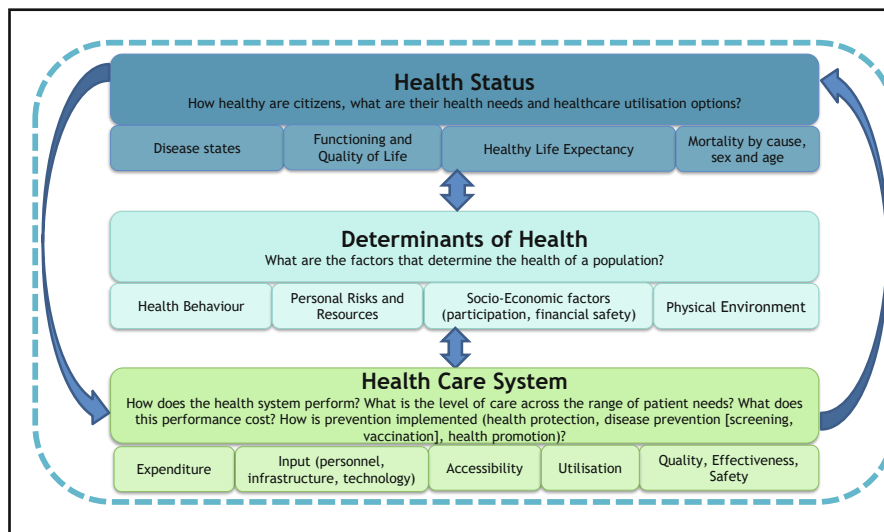


What are the health challenges we face?

Healthcare accounts for more than 8% of the GDP in most EU Countries. Health, defined by health status, health determinants and healthcare systems, is an important part of European citizens' priorities. Healthy citizens are a prerequisite for economic sustainability.

Yet, our societies are confronted with ageing populations, increasing burden of disease and multimorbidity, persistent inequalities and growing pressure on health systems. To tackle these challenges timely supply of high quality population health intelligence is needed. We need a solid European structure providing information on population health, entailing activities and resources related to health status and wellbeing, determinants of health and the health systems (Figure 2), through structured data collection and analysis of knowledge gaps for research.

Figure 2. Schematic representation of a population health framework



Why DIPoH?

European countries have a wide range of lifestyles, environmental exposures and different health(care) systems providing a large natural experiment to be investigated. Through pan-European comparative studies, these underlying determinants of population health can be investigated and new solutions can be identified. Linking different data sources allows researchers to generate larger, more powerful datasets. These will provide rich new insights into the dynamics of population health, into the most important influences on health and care, and into the safety, quality, effectiveness and costs of interventions.

It is important that collected and used data represent the target population well. In-depth and continuous investigations of the data can reveal areas of improvement and provide opportunities for benchmarking between regions or countries. DIPoH supports the sharing of research methods, research results and data through the participation of countries. Moreover, DIPoH aims at strengthening the development of methods for knowledge translation research. DIPoH wants to improve evidence-informed health and social policies, practices and technology, and to increase national health and wellbeing through better and more efficient health and social services.

What will DIPoH contribute to EU health research?

Currently, population-level data on health and healthcare are scattered over different databases, institutions, projects and research networks. Data generally lack interoperability and are often difficult to find, to access and to reuse (un-FAIR). There is no holistic view throughout human lifetime on the effect of lifestyles, environments and health services on human health and diseases, as well as the impact of health on society. Also, large disparities exist in health information systems and in health research capacities in EU Member States. DIPoH will tackle these issues and will provide countries with access to high quality information on population health. This improved quality, includes harmonization and interoperability and will strengthen the research capacity in Member States and allow to provide European and international perspectives to national data.

For years, health researchers, Member States, the European Commission and the European Parliament have all stated that structural action on health information is required, illustrating the need for action.

What are the main objectives of DIPoH?

DIPoH, the Research infrastructure on Population Health will provide support towards the development and use of large-scale, integrated and sustainable data services for population health and health services research. The RI will contribute to cataloguing, curating and integrating information and knowledge generated by a critical and growing mass of European researchers and their international networks.

DIPoH will strengthen the synergy in the EU by facilitating comparative research, efforts at data linkage, pan-European use of data, methods, expertise and results and better involvement of national experts.

DIPoH will help researchers ensure that their research is findable, accessible, interoperable and re-useable and create ever-stronger research networks. Population and patient health data and healthcare systems data will be available at individual and aggregated level from many sources. These sources are among others disease registries, administrative health and non-health databases, surveys and health examinations, and cohorts of populations and patients.

Box 1. Obesity, based on which measurement?

In Finland, information about the prevalence of obesity can be calculated using data from different sources such as medical records, health interview surveys and health examination surveys. Based on medical records, only 2% of the population would be obese. In the same population, 25% are classified as obese based on their measured height and weight (i.e. having a BMI of at least 30) during a health examination survey. These prevalences represent different aspects of obesity. The 2% represents the proportion of population treated for obesity and overweight related health problems, while the 25% is the proportion of the Finnish population being obese based on objective measurements of height and weight. This example illustrates how the same health outcome can be viewed from many different aspects depending on the available data. Therefore, it is essential to understand the data one uses. Interpretation can be affected by data collection methods, definition of data items, and how well selected datasets cover intended target populations. To be able to control these, researchers need to have adequate metadata information from existing datasets. In the case of population prevalence of obesity, measured BMI would be needed instead of data on obesity-related hospital visits.

What services will DIPoH provide?

In order to reach the above objectives, DIPoH will provide large-scale, integrated and sustainable services to population health scientists through four main activities:

- Setting up a **one-stop shop**: DIPoH will be a library containing information on health status, health determinants, and healthcare data and their metadata as well as methodologies used. It will facilitate the identification, access, assessment and reuse of European data for research on the health of populations and on healthcare systems and outcomes.

- Investing in **innovation** in population health information development and use to support health researchers using pan-European data in a distributed way, linking different data sources and making their research meet FAIR (Findable, Accessible, Interoperable and Reusable) and ELSI (Ethical, Legal and Social Issues) standards.
- **Building capacity** to promote interoperability and tackle health information inequalities: learning about the management of data on population health and healthcare starting from the phase of designing data collections to analysis, reporting, preservation and curation. Training of the health research community involves both the data producers, data curators and data users.
- Assisting the health research community in developing methods for **knowledge translation research** to support decision-making processes. This is the return of investment to society improving the health of the European citizens and increasing the efficiency of our healthcare systems and policy decisions.

How will DIPoH be organised and who will be involved?

DIPoH will have a distributed structure with a central coordination office, national nodes across EU countries and pan-European research networks and their research communities. Good examples of the latter are: Euro Peristat, a research network focusing on pregnancy and infancy, benchmarking on a set of 30 indicators. Its results are used in many countries to underpin policy and practice guidelines changes. EHLEIS, a research network addressing the increasing societal urgency of ageing populations to assess whether life years gained are healthy. It produces yearly country reports in a format that is useable for decision makers. Similar research networks focusing on healthcare research are ECHO-health and Euro-HOPE. A central function of DIPoH will be a web-based health information portal, a gateway between researchers and available health information.

National institutes and public health institutes can be involved as main health data providers. They may liaise to their national research networks and ministries of health and research.

Who will be the users of DIPoH?

The Research infrastructure will serve a variety of users:

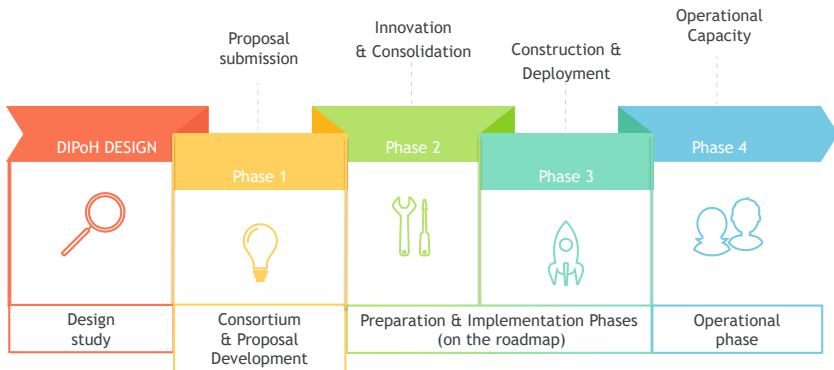
- the research communities and individual researchers in public health and population sciences such as epidemiologists, statisticians, health economists, data scientists, health professionals, ethicists, and sociologists
- population health data owners and curators
- citizens, non-governmental organisations, patient organisations and civil societies
- the researchers in other domains that want to connect their data sets to population health data
- national public health research institutes liaising with key stakeholders in countries
- policy- and decision-makers in national and international organisations (both governmental and non-governmental), especially national and EU public health and health management authorities
- the healthcare sector
- students and educational organisations
- European and pan-European research infrastructures and agencies
- industry and the private sector.

What is the status? What is the road ahead?

Following the BRIDGE Health project (31 institutions in 16 countries), a consortium of 28 EU/EFSA countries is currently preparing (within the Joint Action for Health Information, <https://www.inf-act.eu/>) the foundations for DIPoH. An application for the ESFRI roadmap (2021) is in preparation. Ministries will have the opportunity to provide feedback and indicate whether they have interest in joining the development of the DIPoH concept in the ESFRI roadmap through letters of political support or expressions of financial commitment.

In addition, an application for a Design Study, DIPoH Design, has been submitted (November 2019), which aims to further elaborate on relevant DIPoH components (Figure 3).

Figure 3. The development steps of DIPoH. DIPoH Design will provide an evidence-based study for the development and operation of this new Research Infrastructure



www.inf-act.eu