

A DISTRIBUTED INFRASTRUCTURE ON POPULATION HEALTH (DIPoH)

SUMMARY



Stimulate
innovative
research

Increase
capacity
building

Improve
interoperability

Strengthen
population
health
information

Inform
decision-
makers

Advance
scientific
knowledge



The Distributed Infrastructure on Population Health DIPoH

DIPoH high-level summary

Background

Ageing populations, persistent inequalities and rising healthcare costs are big challenges for all European countries. Healthcare accounts for more than 8% of the GDP in most EU Countries. Population 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. To promote healthy and safe citizens, a strong public health intelligence is needed.

Effective secondary use of existing health information and linkage of different data sources provide opportunities for high-level comparative research between countries. However, currently, population-level data on health and healthcare are fragmented and scattered. Data generally lack interoperability and are often difficult to find, access, assess and reuse (un-FAIR). There is no holistic "life course" view on the effect of lifestyles, genomic profile, social and physical environments and health services on the dynamics of 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 (MS).

A solid European structure providing information and evidence on population health is needed. A new Research Infrastructure (RI) provides activities and resources related to health status and wellbeing, determinants of health and the healthcare systems. It strengthens collaboration and networks that deal with structured EU-wide existing data collections and supports analysis of knowledge gaps for research. European differences and variations in health and care provide the perfect natural experiment for innovative research. As a result, new insights can be obtained on population health dynamics, healthcare interventions, technological development and evidence to support policy-making (Figure 1).

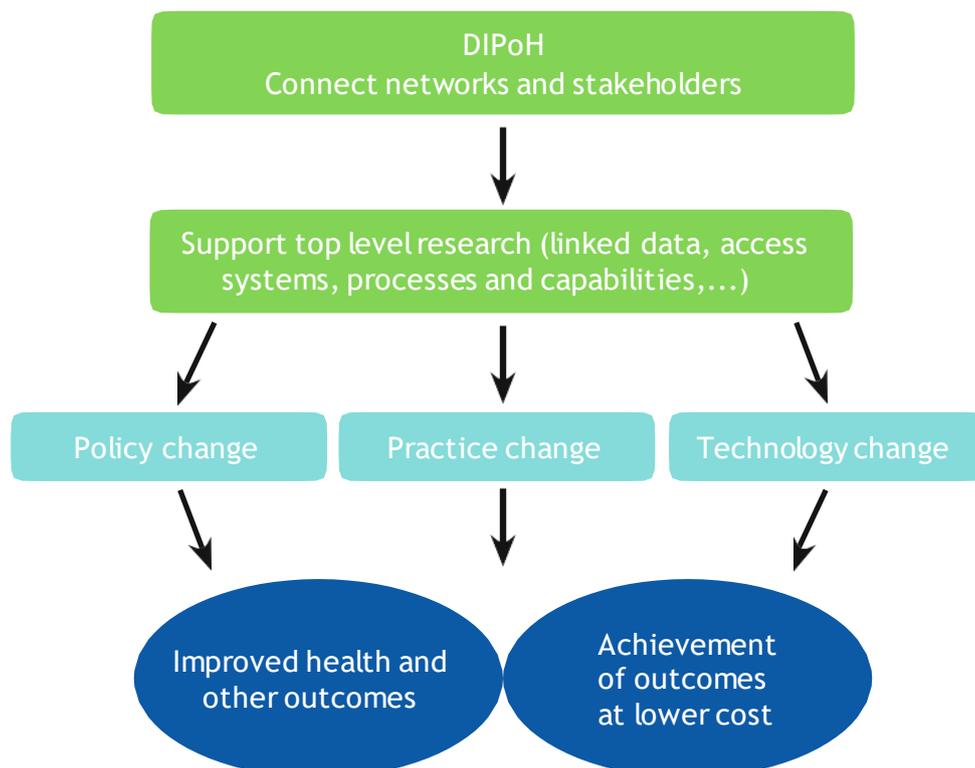


Figure 1. Value chain of DIPoH's impacts

DIPoH's main objectives: integrating and strengthening health information networks across Europe.

DIPoH aims to catalogue and curate knowledge generated by a critical and growing mass of European researchers and their international networks. DIPoH facilitates the identification, access, assessment, and reuse of population health data across Europe and ensures research is interoperable and in line with ethical and legal requirements.

The objectives of DIPoH are:

- To improve collaboration and exchange of good practices between European countries regarding collection, evaluation, accessibility and reuse of health data, and to promote sharing of expertise.
- To provide better integration and strengthening of research networks and population health data sources in Europe, through metadata catalogues and trainings.

DIPoH services

In order to reach the above objectives, DIPoH will provide integrated and high quality services to population health scientists through four main activities:

- Setting up a **one-stop shop**: DIPoH will develop a library containing catalogues on information, data and metadata on health status, health determinants and health care data, as well as methodologies used, reports and guidelines. It will facilitate the identification, access, assessment and reuse of European data, experts and networks that perform 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 and their networks in using pan-European data in a distributed way, linking different individual and aggregated 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 and information on population health and healthcare starting from the phase of designing data collections to analysis, monitoring, reporting, preservation and curation. Training of the health research community involves both the data producers, data curators and data users.
- Strengthening 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.

DIPoH structure

DIPoH will have a distributed structure connecting national nodes in EU countries and pan-European research networks through a central coordination office. The national nodes represent institutes involved in health information in a country. The national node liaises between DIPoH and their regional and national health information stakeholders and relevant ministries. Examples of Pan-European research networks included in DIPoH working on population health domains 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;
- The European Health Examination Survey (EHES), a research network focusing on health status and determinants of health based on data collected through health examination surveys, surveys including questionnaires, physical measurements and collection of biological samples in representative population samples;
- The European Health and Life Expectancy Information System (EHLEIS), a research network addressing the increasing societal urgency of ageing populations to assess whether life years gained are healthy. EHLEIS is the European branch of a global network REVES. It produces yearly country reports in a format that is useable for decision makers;
- The European Community Health Indicator Monitoring System (ECHIM) and the European Collaboration for Healthcare Optimization (ECHO), research networks focusing on essential EU health indicators and their development on health status and healthcare systems; and
- The European Burden of Disease Network (EBoDN), a technical platform for integrating and strengthen the capacity in burden of disease assessment in Europe. The network supports evidence-informed decision making as the BoD methodologies allows for prioritizing diseases and identifying the strongest contributors to diseases and death.

A central function of DIPoH will be a web-based health information portal that serves as a gateway between researchers and available health information.

DIPoH user communities

DIPoH will serve a variety of users:

- Research communities and individual researchers in public health and population sciences such as epidemiologists, statisticians, sociologist, health economists, data scientists, health professionals, ethicists;
- Population health data owners and curators;
- Regional and national public health research institutes liaising with key stakeholders in countries;
- European and pan-European RIs and agencies, as well as international organisations that also deal with health information;
- Researchers in other domains such as social and behavioural sciences, clinical and biomedical science, biology and OMICs that want to connect their data sets to population health data;
- Policy- and decision-makers in regional, national and international organisations (both governmental and non-governmental), especially national and EU public health and health management authorities;
- Citizens, non-governmental organisations, patient organisations and civil societies;
- Students and educational organisations; and
- Industry and other private sectors.

Maturity and sustainability

DIPoH comes in a bottom up approach. This proposal builds on the accumulated experience and work from multiple health programme actions over the past ten years. Council conclusions have specifically urged MSs to investigate the option of a sustainable RI as a potential tool, leading to the set-up of two major European Projects: the [BRIDGE Health](#) project and the [Joint Action on Health Information](#) (InfAct). BRIDGE Health (2015-2018) included 31 Consortium Partners in 16 countries representing 14

population health European research networks in 9 population health research domains such as health system monitoring, indicator development, health examination surveys, environment and health, population injury and disease registries, clinical and administrative health data collection systems and methods of healthcare systems monitoring and evaluation. InfAct (2018-2021) includes 40 Consortium Partners from 28 EU countries appointed by ministries of health representing public health institutes, health research institutes, different ministries, and universities.

The cumulative experience and activities implemented in these consortiums provide a robust compilation of scientific and technical feasibility studies and reports, and a strong basis for the development and operation of a new RI.

DIPoH builds on existing research networks that have been successful in developing pan-European research and have been operating at regional and national levels. Moreover, in preparation for DIPoH, InfAct has been working in MSs with national nodes bringing together institutions that constitute the technical and legal infrastructures of the national health information systems.

European Research Infrastructure landscape

Currently, the ESFRI Health & Food RIs landscape is consolidating firmly in the European Research Area (ERA) with 10 Landmarks and 6 Projects covering the vast remit of health, agri-food and the bio-economy. However, none of the existing RI/ERICs deals with information on population health and health systems. A holistic view throughout human lifespan on the effect of lifestyles, the physical and social environment, health services on human health, as well as the impact of health on society, is lacking.

Therefore, DIPoH is uniquely placed to fill this gap in the current RI landscape, as no other infrastructure is capable of dealing with population health.

DIPoH preparatory and implementation phases

DIPoH development will proceed in accordance to the stipulated ESFRI phases: the preparatory and Implementation phases, and then the operational phase. DIPoH preparatory and implementation phases are planned between 2021 and 2029.

