

# What is InfAct?

The name of this project - InfAct - stands for Information for Action. In this European project 41 institutions in 28 countries were involved. The project was launched in March 2018 and was meant to be finished in January 2021, but due to COVID-19 it was extended until May 2021.

More information here:  
<https://www.inf-act.eu/>



## Mission and vision

The **mission** of InfAct was to build a strong EU health information system infrastructure and strengthen its core elements.



The **vision** of InfAct was to improve the use of health information data and expertise for a healthier Europe.

## The goals ...



... were to strengthen national and EU health information systems by:

- ▶ Establishing a sustainable EU research infrastructure to support population health and health system performance assessment
- ▶ Strengthening European health information and knowledge bases, as well as health information research capacities to reduce health information inequalities
- ▶ Supporting health information interoperability and innovative health information tools and data sources

# Why did we need this?

*For almost a quarter of a century now, there have been discussions on the need for an improved EU health information (HI) system.*

## Health information

Is all organised and contextualised data on population health and health service activities and performance, individual or aggregated, that improves health promotion, prevention, care and policy-making.

Different HI programmes were organised in a vertical way and resulted in a fragmented and project-based EU HI system. The current EU HI system lacks sustainability, coherence and comprehensiveness. Additionally, data collection mechanisms do not allow for methodological robustness or systematic approaches.

## A health information system

is the total of resources, stakeholders, activities and outputs enabling evidence-informed health policy-making. Health information system activities related to all phases of population health monitoring.

These are data collection, interpretation (analysis and synthesis), health reporting, and knowledge translation.

Large differences were found in terms of quality and, as a consequence, comparability of HI between and within Member States (MS). This makes it difficult to learn from each other and challenges the equity in health as poor HI and poor health have a tendency to coincide. If a country or a group of countries have developed good practices, mechanisms are lacking to disseminate these into EU-wide actions. These observations contrast the statements that policymaking should be evidence-informed and generated by comprehensive and adequate HI systems.

For EU MS, strengthening the EU HI systems:



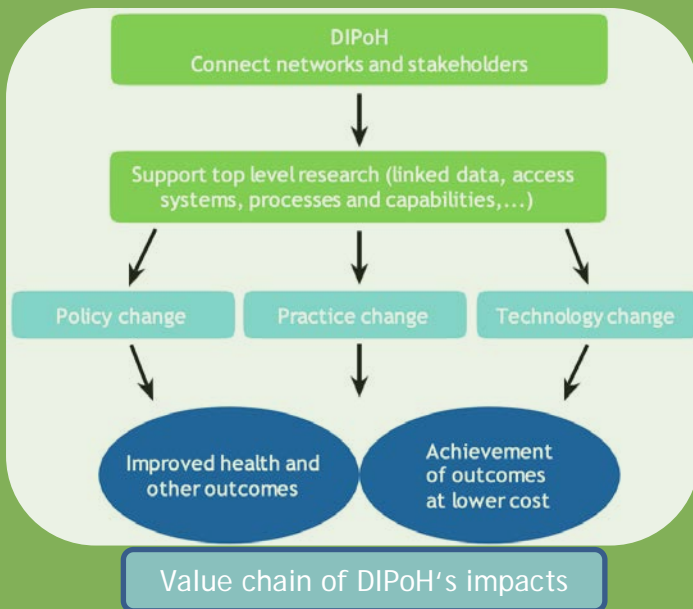
- + enhanced coherence and sustainability;
- + allowed data harmonisation, collection, processing and reporting;
- + allowed for comparison and benchmarking of health data;
- + increased knowledge sharing and capacity building;
- + strengthened the transferability of HI.

# What did we achieve?

## *Establishing a research infrastructure*

To facilitate the identification, access, assessment, and reuse of population health data and information across Europe...

...a [Distributed Infrastructure for Population Health \(DIPoH\)](#) was established.

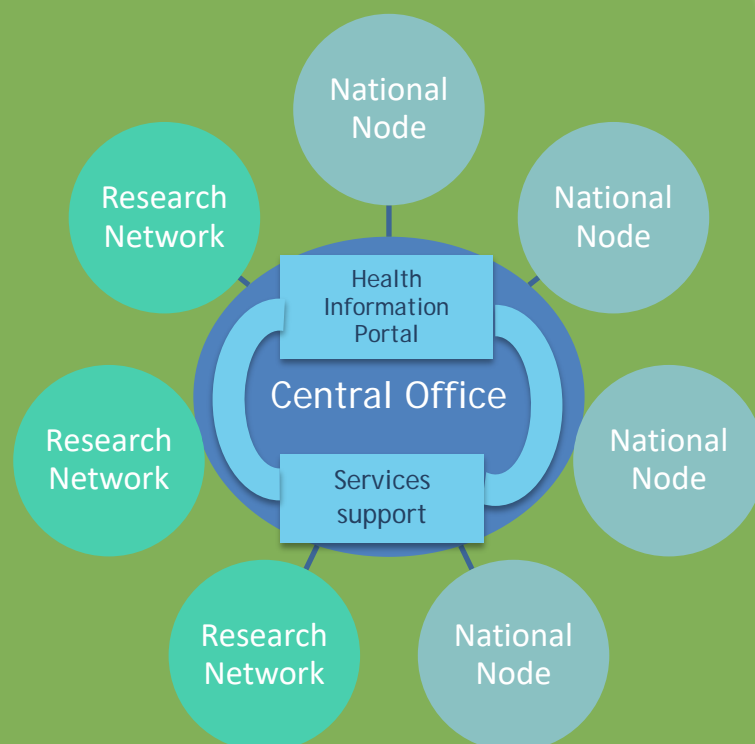


DIPoH will contribute to cataloguing, curating and integrating information and knowledge generated by a critical and growing mass of European researchers and their international networks. DIPoH will strengthen the synergy in the EU by facilitating comparative research, efforts at data linkage, pan-European 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. These objectives will be achieved through the following activities:



InfAct supported the set-up of 19 [National Nodes](#) on Health Information. While the format in each country is tailored to the specific national needs, the basic structure provides the basis for exchange of information between countries. This will be sustained after the end of the JA.

InfAct has worked with key [Research Networks](#), which will be at the core of a future DIPoH, to gain insight on both their needs and contribution to DIPoH.



A health information portal (single entry point) was set up and will be maintained after the project. It is hosted on [www.healthinformationportal.eu](http://www.healthinformationportal.eu). The portal aims to be the gateway for potential users to make use of the services of DIPoH. These include catalogues for population health data, tools, experts, and guidelines; capacity building and trainings in information; Innovation in health information tools and methodologies; and decision-making support.

DIPoH will fill a gap in the Research Infrastructure landscape as it covers health information, data on the population as a whole (healthy and non healthy), facilitates secondary use of routine data sources, includes individual and aggregated level data. The infrastructure will boost national population health research.

## A total of...

**11** Ministries provided political support letters

**16** Institutes signed a Memorandum of Understanding

**8** Research Networks signed a letter of intent

## Capacity building. Translating sustainable outcomes into training proposals

A manual to carry out HIS assessment in peer review format.

Experts from nine EU countries implemented peer reviewed assessments of each other's national HIS using a WHO HIS tool. In InfAct, this methodology has been adapted to make it suitable for peer review assessments. The peer assessments had beneficial effects on several levels. They resulted in the identification of strengths and weaknesses in the national HIS under assessment. This then stimulated actions to improve the assessed HIS, and led to the identification of good practices that may now be used in countries that were not taking part in this InfAct task. Through stimulating the improvement of HIS and the exchange of good practices, InfAct contributed to capacity building in European countries, which in turn may have contributed to the reduction of health information inequalities between countries. More info here: [www.inf-act.eu/wp5](http://www.inf-act.eu/wp5)



Good-practice-approaches for prioritizing HI at national level.


Health information guides public health interventions and points to emerging public health issues. In order to fulfil these functions, health information needs to be duly prioritized, ensuring that relevant public health issues are identified and that public health interventions respond to real needs. With an online two-round Policy Delphi survey EU MSs and associated countries' representatives were engaged to identify prioritization practices. The outcome is a list of good-practice-approaches to health information development and guidance for prioritization at national level. More info here: [www.inf-act.eu/wp5](http://www.inf-act.eu/wp5)

Burden of disease.

Three workshops on Burden of Disease (BoD) took place. They were visited by 40 participants from 25 countries. The overall objective of these workshops was to raise awareness, share knowledge and experience, and provide mutual support and to integrate BoD indicators in the public health policies across Europe. Along with that, an overview of the national indicators of BoD at national level has been carried out using the country profiles produced by Global Burden of Disease (GBD) metrics. Finally, a toolkit to produce Burden of Disease indicators was developed. More info here: [www.inf-act.eu/wp9](http://www.inf-act.eu/wp9)

Health Information Training Program and roadmap for sustainability.

A flagship programme for health information training was designed to improve the MSs capacities in population health and health system performance analysis and monitoring to address existing inequalities. The European Health Information Training Programme (EHITP) is an umbrella for current and future population health information training activities in Europe, targeting professionals working in public health and health information at national or European/international level. Topics can include: data analysis and interpretation, especially interoperability of data sources, derivation of ECHI indicators and foresight/scenario analysis; transfer from data to policy, especially policy translation tools and data presentation; data collection methods, sources of data, metrics and indicators, especially issues related to health examination surveys; and data privacy and ethical issues, especially how to deal with requirements of EU GDPR. A first European School on Health Information was organized in the fall of 2020. 25 participants came from 20 European countries. The long-term sustainability will also include an annual European Health Information Programme (EHIP), which will be a structured collection of capacity building initiatives organized across Europe and will be made available on DIPoH's Health information Portal: [www.HealthInformationPortal.eu](http://www.HealthInformationPortal.eu). More info here: [www.inf-act.eu/wp6](http://www.inf-act.eu/wp6)



## *Health information tools and innovative proposals*

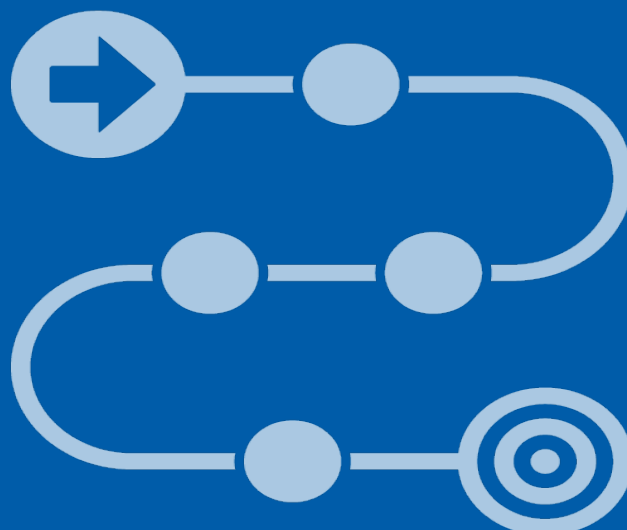
- 1 Health data collection methods and procedures.** Health data collection methods, quality assurance, metadata reporting standards, and availability and accessibility of health information across MSs were identified across Europe. As part of the InfAct HI portal for HI research in EU, the report facilitates the assessment of health inequalities across EU countries in terms of quality, metadata reporting standards, availability, accessibility and comparability of health data and information. It also facilitates sharing and dissemination of standardized and comparable health data collections, which are essential for research and evidence-based policy-making. More info here: [www.inf-act.eu/wp8](http://www.inf-act.eu/wp8)
- 2 Cataloguing international health information collection networks, projects and indicator/data sets.** Over the years, international comparative projects and networks have come and gone. In InfAct we searched database for expert networks that collect comparable health data in Europe, as well as previous and on-going health information generating projects with EU coverage. The aim was to create a sustainable information base to be integrated in the EU health information portal ([www.healthinformationportal.eu](http://www.healthinformationportal.eu)). This catalogue will function as a knowledge repository and solid base to connect experts and build on work from the past. More info here: [www.inf-act.eu/wp5](http://www.inf-act.eu/wp5)
- 3 A sustainable European Core Health Information (ECHI) shortlist.** The list provides a 'snapshot' overview of European public health (and care). It is the result of consecutive EU-wide projects representing a collective MSs effort. However, no sustainable form of governance or updating procedures are in place. InfAct provides recommendations for a governance structure and formal procedures for regularly updating the ECHI shortlist. In addition, it provides practical suggestions for technical updates of the metadata (documentation sheets), for new indicators and for a modernized format for structuring the ECHI. More info here: [www.inf-act.eu/wp8](http://www.inf-act.eu/wp8)
- 4 Guidance for health reports and good practice in health reporting.** A web-based desk research of health reporting formats and target groups showed that public health reports are the most frequently used health reporting format across EU-EEA and mainly aim at scientists/researchers and politicians/decision-makers. Based on the results of a literature review, earlier projects and exchange with experts, quality criteria for standardized and comparable public health reports were derived and compiled into a guidance document. More info here: [www.inf-act.eu/wp8](http://www.inf-act.eu/wp8)

**5 Roadmap for innovative use of data sources.** The use of data linkage and/or artificial intelligence (AI) to estimating health indicators is called innovative use of data sources. The use of AI to estimate health indicators is not frequent at national institutes of public health and health information and statistics. The complex data regulation laws, lack of human resources, skills and problems with data governance, were reported by European countries as obstacles to routine data linkage for public health surveillance and research. To address the above-mentioned obstacles and to increase the uptake of innovative and high-performance technologies in public health activities, we propose the following recommendations to tackle legal, technical, data governance and structural aspects. More info: [www.inf-act.eu/wpg](http://www.inf-act.eu/wpg)

**6 Best practices for innovative use of health information.** Best practices for innovative use of health information for data networks demonstrate the value of DIPoH and the benefits of using linked data from different research networks to perform comparative research studies among European countries. In this context, two studies are on-going: 1. Use of data linkage and advanced statistics in the reporting of perinatal indicators in Europe and 2. Evaluating the efficiency of health care systems in managing high-need high-cost patient's network. More info: [www.inf-act.eu/wpg](http://www.inf-act.eu/wpg)

**7 Methodological guidelines for estimating health indicators using linked data and Machine Learning Techniques.** We developed the methodological guidelines, which could systematically guide MSs for using linked data and machine learning techniques to estimate health indicators for public health research. These guidelines contain seven important contents: (i) rationale and objective of the study (i.e., research question), (ii) study design, (iii) study population/sample, (iv) linked data sources, (v) study outcomes, (vi) data preparation and (vii) data analysis. We described these aspects with examples of different studies. More info: [www.inf-act.eu/wpg9](http://www.inf-act.eu/wpg9)

**8 A generic method case study and inspiring examples and Machine Learning Techniques.** We developed a generic approach to predict a health outcome from linked datasets using machine-learning (ML) technique and identified inspiring examples applying these innovative techniques in public health across European countries. More info: [www.inf-act.eu/wpg](http://www.inf-act.eu/wpg)



**9 Use of non-health databases for health surveillance.** The combination of health information with environmental health determinants is important for epidemiological surveillance and for risk studies in health. We piloted “En-risk”, an easy-to-use web interactive application tool that merges, at country level, the information of The European Pollutant Release and Transfer Register (E -PRTR) and the municipal mortality or morbidity data to perform an exploratory spatial analysis of association between them by type of industrial facility. More info [here](#).

**10 Composite health indicator for monitoring Non Communicable Diseases (NCD).** The analysis of the epidemiological patterns of NCD should include an integrated study of morbidity and mortality, describing their geographic variability and examining their causes. The study, done during InfAct, analyses the ratio of age-adjusted hospital morbidity and mortality rates (HMR) for the 6 NCDs in Spain. This indicator allows for a better understanding of regional variability between and within countries, and can also be useful for health planning and prevention.

**11 Assessing and piloting interoperability.** Interviews were conducted with key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data with a goal to better understand the enablers and the barriers to the cross-border linkage and sharing of health data through four interoperability layers (legal, organizational, semantic and technical). InfAct also piloted the development of a distributed infrastructure taking as pillars the European Interoperability Framework and the FAIR principles. This successful empirical exercise is yielding arguments in favour of the feasibility of a distributed approach, which is the basis for the sustainability of any research infrastructure of such a kind. More info here: [www.inf-act.eu/wp10](http://www.inf-act.eu/wp10)





# What is next?

In November 2020 a new project started. PHIRI (Population Health Information Research Infrastructure) is a roll-out of DIPOH. It facilitates the exchange of the best available evidence and expertise for research on health and well-being of populations as impacted by COVID-19. The project builds on the BRIDGE Health project and the Joint Action InfAct. It includes 41 partners in 30 different countries.



More info at [www.PHIRI.eu](http://www.PHIRI.eu)

InfAct actively engages in new projects in health information:

- 🤝 HealthyCloud [healthycloud.eu](http://healthycloud.eu)
- 🤝 unCOVER: Unravelling Data for Rapid Evidence-Based Response to COVID-19 [uncover-eu.net](http://uncover-eu.net)
- 🤝 EGI-ACE: Advanced Computing for EOSC (EGI-ACE) [egi.eu/projects/egi-ace](http://egi.eu/projects/egi-ace)
- 🤝 The Joint Action Towards the European Health Data Space TEHDAS [tehdas.eu](http://tehdas.eu)



# Where can I find more information?



<https://www.inf-act.eu/>



[https://twitter.com/JA\\_InfAct](https://twitter.com/JA_InfAct)