DIPoH

Distributed Infrastructure on Population Health

Design and Feasibility Report

Stimulate innovative research

Increase capacity building

Improve interoperability

Strengthen population health information

Inform decision-makers

Advance scientific knowledge

Table of Contents

Executive summary

This report summarises the design and feasibility studies carried out towards the development of the Distributed Infrastructure on Population Health (DIPoH).

The report is composed of four main chapters:

1. Setting the scene,
2. Stakeholder consultation on the needs,
3. Assessing structural organisational entities, and
4. Technical and scientific design of DIPoH.

The general objective of the DIPoH proposal stems from the work in BRIDGE Health and InfAct. DIPoH aims to improve identification, access, assessment and reuse of population health data within the EU. DIPoH will bring together existing health information research networks and national population health information infrastructures including their data, expertise, scientific methods and technical tools in order to enhance high quality population health research leading to evidence synthesis and knowledge translation that ensures the return of investment to society and EU citizens.

The *first chapter*, setting the scene describes the existing health information landscape with its main players and the expressions by Member States (MS), the European Commission (EC) and other organizations to strengthen European health information and its underlying systems.

In the *second chapter*, the consultation of stakeholders is described. The consultations identified the national public health institutes' needs to strengthen the current EU health information system and their vision of an integrated and comprehensive EU health information system or infrastructure. Five key areas for improvement were identified:

1. International cooperation and coherence in EU actions of public health and public health research
2. Better data quality, availability and comparability for research and evaluating policies
3. Comparison and benchmarking among Member States and for the EU
4. Knowledge sharing and capacity building
5. Transfer of health information into evidence-based policy-making

The *third chapter* describes the assessment of different options of creating an organizational entity to respond to the identified needs. Within BRIDGE Health, using a multi-criteria analysis, the advantages, disadvantages and short-term feasibility were investigated for: strengthening or extending existing structures (ECDC, DG SANTE, JRC, Eurostat, WHO or OECD) or creating a new structure (a new agency, an RI, a Joint Action, or a supra-European structure). The most feasible option identified and agreed among MSs is the creation of a European Research Infrastructure (RI).

The *fourth chapter* sets out the development of the technical and scientific design of DIPoH. It describes DIPoH's services, structure, users and added value. It sets out its data flow architecture, landscape analysis, financial contribution models, stakeholders engagement

strategy, governance structure, stakeholder engagement strategy, preliminary data management plan and technology readiness levels. Two working groups, the BRIDGE Health Steering Committee and the European Commission's Drafting Group of the Expert Group on Health Information, prepared the content of the technical and scientific description of setting up a research infrastructure consortium through a consensus-driven modified Delphi technique. Following this process, InfAct was initiated to provide a proof of concept of the RI and further engagement of MS.

InfAct strengthened and completed the technical and scientific design of DIPoH. Additionally, multiple activities were initiated that support the development of DIPoH on a technical and political level. Different services are piloted and tested. The activities can be organised in five themes.

1. Governance and operation

InfAct tested the concept of National Nodes (NN) and supported their development. InfAct reached out to all MS/AC and provided a stepwise approach on how to set up NN. MS/AC's were regularly asked to report on their NN activities. 19 countries reported on their progress and feasibility. Various NN reported stakeholders were enthusiastic about the opportunity to liaise and want to further exchange in this format. DIPoH will further support the development of NN as the contact point and source for EU and national health information and data exchange.

BRIDGE Health and InfAct successfully brought together Research Networks (RN) across Europe to address interdisciplinary research questions. In BRIDGE Health, RN were stimulated to work on common transversal research questions through horizontal activities. Common answers were given to address health information inequalities, investigate health information on subpopulations, strengthening methods of data exchange and distributed analysis, research ethical and legal aspects of population health information, and develop knowledge translation methods. In InfAct, RN jointly developed and piloted criteria proving the scope, quality, impact and performance of RN.

InfAct also showed political support and sustainability for DIPoH is feasible. A thorough cost-book was developed. A significant amount of political support letters, memorandum of understandings, and collaboration agreements are gathered. Moreover, the strong support for the development of a population health RI is seen by the fact that in a very short time a practical use case of DIPoH was set up for COVID-19 (PHIRI).

Additionally, some of the governance structures of DIPoH were tested and found feasible. The Assembly of Members in InfAct was organised three times gathering Ministries of Health and Research across 20 MS/AC. Also the Coordination Office in InfAct is up and running which could evolve to DIPoH's Coordination Office.

The Health Information Portal has been launched in InfAct. The portal is developed and piloted with 4 country representatives (NN) and with 5 RNs to come up with the best way to present the metadata for the (future) users. Working together with the NNs and RNs within the scope of InfAct ensures that the platform is designed in a way that responds to the needs

of the user communities. It is also designed in a flexible way in order to respond to needs that may come up at a later stage as DIPoH progresses.

Finally, InfAct has actually piloted the development of a distributed infrastructure. So, via a privacy by design approach to data exchange and distributed analysis, InfAct has assessed the feasibility of complying with GDPR and Ethical principles, adapting to the organizational specificities of each data hub, assuring semantic interoperability across hubs and developing technological interoperability. Likewise, the feasibility of the development of the FAIR principles has been also tested. The successful empirical exercise yields arguments in favor of the feasibility of this kind of distributed approach, which is the basis for the sustainability of any research infrastructure of such a kind.

2. One-stop-shop for EU Health Information Research through Health Information portal

InfAct catalogued international health information collection networks, projects, indicators and data sets. This included (1) expert networks that collect comparable health data in Europe, as well as (2) previous and on-going health information generating projects with EU coverage. This catalogue functions as a knowledge repository and solid base to connect experts and build on work from the past.

Additionally, a cross-sectional study identified national data collected for population health monitoring/public health surveillance and health system performance assessment with standardized methods that are not incorporated into existing international datasets (e.g., WHO, OECD, Eurostat). The study made an inventory of identified projects/studies and their description in terms of data sources used, quality assessment of their data collection procedures, metadata-reporting standards used for data description, and availability and accessibility of health data and indicators.

3. Innovative research

InfAct facilitated various innovative research activities. Some of them are summarized here and can be taken forward with DIPoH.

Innovative use of data sources through health and non-health data linkage at aggregated and at individual level and artificial intelligence to estimate health indicators was investigated. Specific recommendations were proposed to tackle legal, technical, data governance and structural aspects.

A generic approach to predict a health outcome from linked dataset using machine-learning technique was developed and inspiring examples identified applying these innovative techniques in public health across European countries.

An innovative method was used combining health information with environmental health determinants to do epidemiological surveillance and for risk studies in health.

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, organisational, semantic and technical) was also investigated and case studies tested the distributed data analysis

4. Capacity building

InfAct carried out peer review assessments of health information systems in nine countries. The assessments stimulated actions to improve the assessed health information systems, and led to the identification of good practices. The assessments may continue on a more permanent basis in the framework of DIPoH capacity building program and services.

A European health information training programme was designed and piloted to improve the Member States' capacities in population health and health system performance analysis and monitoring to address existing inequalities. Accordingly, the European Health Information Training Programme (EHITP) was conceptualized as an umbrella for all current and future training activities in Europe, targeting professionals working in public health and health information at national or European/international level.

5. Knowledge translation research

InfAct and BAHCI developed: (i) a list of good-practice-approaches to health information development and a draft guidance for prioritisation at national level, (ii) an innovative tool to facilitate the generation and dissemination of health information to the targeted groups and (ii) Health-Information Impact framework to monitor knowledge translation capacity and practice.

The Distributed Infrastructure on Population Health (DIPoH) Design and feasibility study.

This document is compiled by InfAct's coordination team in Sciensano. It is composed from output and reports produced by the BRIDGE Health and InfAct Consortium. InfAct's ESFRI writing group provided additional support.

Co-funded by
the Health Programme
of the European Union

Glossary

Health information: All organised and contextualised data on health and health service activities and performance, at individual or aggregated at different population levels.

Knowledge translation: The appropriate exchange, synthesis and ethically sound application of knowledge to interventions that strengthen the healthcare system and improve health.

Health information systems: All activities and resources related to public health monitoring, intelligence, analysis, reporting and knowledge translation, importantly including structured data collection systems and analysis of knowledge gaps to feed research. Operating a health information system requires governance mechanisms and legal frameworks, inter-institutional relationships, principles and values.

Comparative population health research: Domain of science focusing on understanding differences in population's health status and population's exposure to health determinants as life styles, environment or health systems. The comparative nature lays on DIPoH's scope related to the use of Pan-European data, for cross-country comparisons including analyses by gender, age groups, and over time (secular trends), or other appropriate stratified variable.

Data reuse: Data collected by public institutions and research institutions as part of their health information systems (population- and disease-based registries, surveys and health examination surveys, electronic health records, administrative data, claims data, etc.) are gathered for purposes different to research. Reusing the wealth of data is a paramount opportunity for population health research.

Distributed Research Infrastructure: As opposed to centralised research infrastructures, this term implies the distribution of resources and procedures devoted to a common goal, in DIPoH, to develop population health research.

Interoperability: In a distributed research infrastructure, interoperability is a key feature for its governance and achievements. Following the European Interoperability Framework, interoperability refers to a) a full compliance with the legal and ethical provisions in each constituent node; b) an organisation that supports knowledge exchange and software transference across nodes; c) a compatible technological environment that supports the communication between nodes and allows the deployment of the computational tasks; and d) the existence of common data models that enables semantic standardisation across data sources.

Data model: In a distributed research infrastructure, data models are a formal description of data sources (entities, their attributes and their relationships) and metadata specific to a data source and/or a scientific study, that are the basis for semantic interoperability, thus allowing reliable comparative research.

I. Setting the scene

The health of populations draws intense political and societal attention throughout the European Union (EU). Europe faces major health-related challenges such as the rising and unsustainable health care costs that result from increasing life expectancy combined with increasing prevalence of chronic diseases, multi-morbidity and disability. The aging of the population requires more diversified healthcare services and places high demands on social services. Health care accounts for almost 10% or more of Gross Domestic Product (GDP) in almost all EU Member States (MSs), representing one of the largest, and most rapidly growing, expenses in Europe's national budgets [1-2]. Another significant challenge is tackling the marked geographic and social inequalities in health outcomes and health care between and within MSs. These disparities impede the goals of achieving equity and promoting productivity and well-being for all EU citizens. More broadly, population health impacts are major considerations for policy across all sectors and in particular those related to our changing environment, employment structures, and new health technologies, and vice versa.

High quality population health information systems with integrated health research capacities are needed to address these challenges [3]. Over the past years, Europe has gradually expanded its health research programs, many of which included EU health information projects that have provided useful research output and served as input for national and European decision-makers [4-7] However, there is currently no routine mechanism for including results of EU funded projects in the European Statistical System, as stipulated by 'Regulation 1338/2008 on the community statistics on public health and health and safety at work [8]. Previous major investments in data harmonisation and the development of methods and expertise go to waste as sustainability is not assured [9]. This lack of knowledge management results in loss of expertise, active data collection mechanisms and research capacity, and no return on EU investments. As concluded by the European Community Health Indicators (ECHI) and consecutive activities, "*further efforts at DG SANTE and Eurostat are needed towards a permanent health monitoring system*" [10].

Besides EU funded projects, health information activities are also carried out by both EU agencies and the European Commission. Under the lead of Eurostat, the European Statistical System provides a solid working basis for gathering and providing health data. This health data collection is complemented by initiatives undertaken by the World Health Organisation (WHO) and Organisation for Economic Co-operation and Development (OECD) as shown in Figure 1.1. The European Commission, WHO and OECD now coordinate a selection of statistical data collections and have increased their collaboration over the years. Eurostat, for example, as defined in the regulation 1338/2008, covers the following five areas of health information: health status and health determinants, healthcare, causes of death, accidents at work and occupational diseases and other work-related health problems and illnesses [11–13].

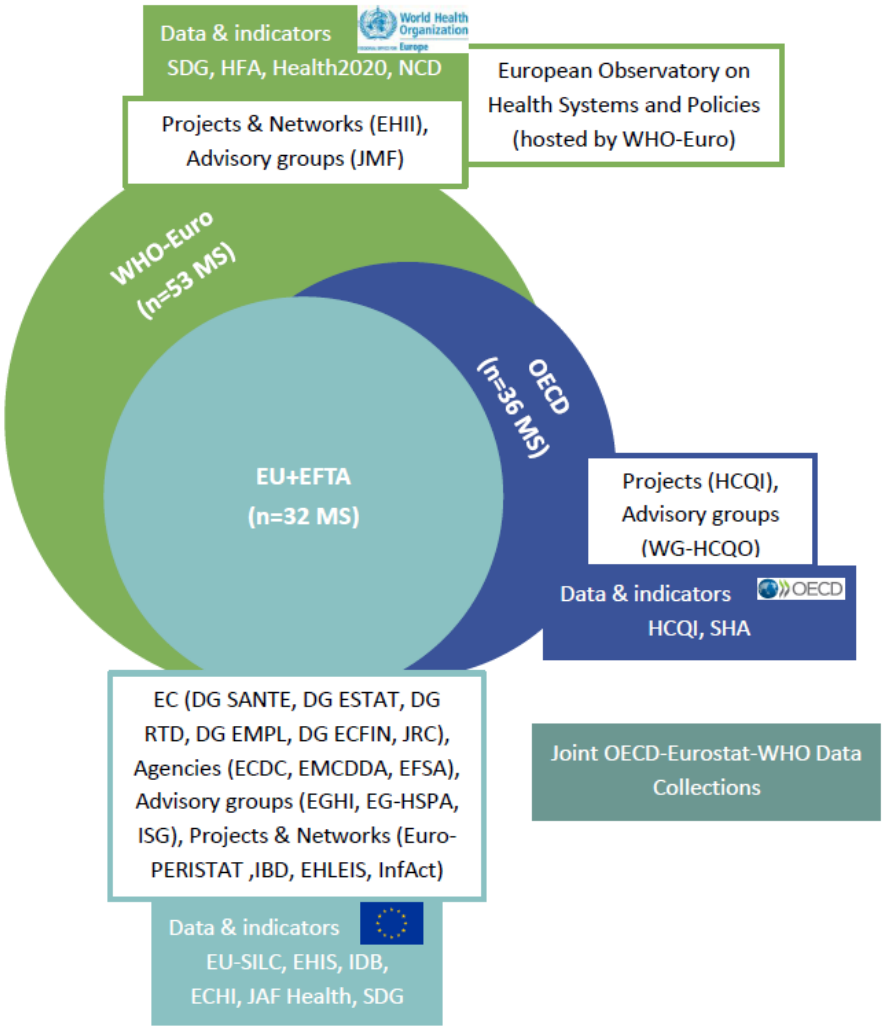


Figure 1.1 Health Information Landscape "European Region"

In the eyes of some stakeholders in the health information area, however, international organisations do not yet collaborate to achieve optimal efficiency [14] and gaps and deficiencies persist. Different health information areas are not systematically covered in the EU. There is no common health information strategy or reporting agenda and there are several different, but overlapping indicator sets.

The patchy status of health information in Europe has resulted in a complex and inefficient landscape for population health research in Europe. Overall funding remains fragmented, project-based and not sufficient to respond to the current health needs of the European population. There are large differences between MSs in both the quality and availability of health data, huge diversity of health information activities in Europe, widespread fragmentation of databases and registries and a general lack of sustainable policy-relevant health information research and activities.

Europe must invest in research, technology and innovation to develop sustainable solutions that will overcome those challenges and make the most of health spending and investments at EU and MS level. For example, advances in health information technology need to be optimised in order to reach their full potential to improve healthcare quality, achieve better

health-data exchange and reuse and support research on new care and preventive strategies. Pro-active policy and decision making should be based on accurate and up-to-date real-world data regarding population health dynamics and health system performance, and on thorough research outcomes resulting in a good and timely understanding of their determinants.

These goals are widely shared. A joint paper by the European Chronic Disease Alliance (ECDA), the European Public Health Alliance (EPHA) and the non-communicable diseases (NCD) Alliance notes that "*the existing gaps in the availability of relevant and comparable data remains a barrier to assessing the full implications of NCDs for individuals, communities, healthcare systems and economies. The lack of data prevents researchers and governments from assessing the impact and effectiveness of NCD policies, programmes and treatment on different population groups.*" and that "*The European Commission should…. financially support data collection and host an EU-wide health data system with registries for NCD incidence, prevalence, health outcomes, costs and key indicators on risk factors.… In synergy with the establishment of such healthy data system, effort should be made to elaborate new policy evaluation tools, such as complex and system evaluation methodologies, in order to assist researchers and governments in better evaluating what policies and actions work and why, and especially to better assess the combined effects of multiple interventions*" [15].

This calls for stronger and more systematic cooperation and exchange of data, knowledge and expertise to enable comparative research. Comparative research is defined as the analysis of population health status, determinants, and service use across countries and/or over time. The foundation for this lies in a sustainable and integrated supply of European and international population health research networks. This systematic way of sharing and facilitating health intelligence will identify common challenges, best practices and new research insights, which in turn will contribute to the generation of new data.

BRIDGE health and the Joint Action on Health Information (InfAct), both EU funded health information projects investigated the possibilities for creating an organisational entity that could take up these tasks. BRIDGE Health and InfAct are shortly described below.

References

1. OECD. Health at a Glance: Europe. 2018. https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-europe-2018_health_glance_eur-2018-en
2. Janssen Pharmaceutica NV. Investigating European health R&D– A pathway to sustained innovation and stronger economies. 2015. https://www.janssen.com/sites/www_janssen_com_bulgaria/files/pdf/Investing-in-European-Health-R&D.pdf
3. European Patients' Forum. Enhancing Value in European Health Systems. The Role of Outcomes Measurement. Consensus document. 2016. https://www.eu-patient.eu/globalassets/policy/patientssafety/value-of-health-consensus-document.pdf
4. European Commission. EU Health Programme 2014-2020. https://ec.europa.eu/health/funding/programme_en
5. European Commission. Health monitoring programme. https://ec.europa.eu/health/programme/policy/eight_programmes/monitoring_en

6. European Commission. Seventh Framework Programme of the European Community for research, technology development and demonstration activities 2014-2020. https://ec.europa.eu/research/fp7/index_en.cfm
7. European Commission. Implementation of the second Programme of Community action in the field of health in 2012.https://ec.europa.eu/health/sites/health/files/programme/docs/second_healthprogramme_implementation_2012_en.pdf
8. Regulation (EU) n° 1338/2008 on Community statistics on public health and health and safety at work, adopted in 2008.
9. Delnord M, Szamotulska K, Hindori-Mohangoo AD, Blondel B, Macfarlane AJ, Dattani N, et al. Linking databases on perinatal health: A review of the literature and current practices in Europe. EJPH 26: 422–30, 2016.
10. Zeitlin J, Mortensen L, Prunet C, Macfarlane A, Hindori-Mohangoo AD, Gissler M, et al. Socioeconomic inequalities in stillbirth rates in Europe: Measuring the gap using routine data from the Euro-Peristat Project. BMC Pregnancy and Childbirth 6 :15, 2016.
11. Regulation (EU) n°349/2011 on Community statistics on public health and health and safety at work, as regards statistics on accidents at work, 2011. https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:097:0003:0008:EN:PDF
12. Regulation (EU) n° 328/2011 on Community statistics on public health and health and safety at work, as regards statistics on causes of death, 2011. https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:090:0022:0024:EN:PDF
13. Regulation (EU) n°141/2013 on European Health Interview survey covers parts of the 2 first domains (health status and health determinants, 2013 https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ%3AL%3A2013%3A047%3A0020%3A0048%3AEN%3APDF
14. Ricciardi Walter. European Public Health News, EUPHA President's column. EJPH 23: 235–347, 2013. https://academic.oup.com/eurpub/article/23/2/345/683769
15. European Public Health Alliance. Joint paper - Towards an EU Strategic Framework for the Prevention of Non-communicable Diseases (NCDs). 2019. https://epha.org/joint-paper-i-towards-an-eu-strategic-framework-for-the-prevention-of-ncds/

A. The BRIDGE Health project

BRidging Information and Data Generation for Evidence-based Health policy and research (BRIDGE Health) is working towards a European health information and data generation network covering major EU health policy areas by promoting the coordination and convergence of existing key projects in health information.

The project was launched in May 2015 and ran until October 2017. It was coordinated by Sciensano (previously named the Scientific Institute of Public Health), Belgium and included 31 partners in 16 countries. It assured a knowledge transfer from past health and research frameworks in domains of population health and health system monitoring, indicator development, health examination surveys, environment and health, population-based injury and disease registries, maternal and child health, clinical and administrative health data collection systems and methods of health system performance assessment.

The main aim of the BRIDGE Health project was to work towards a comprehensive, integrated and sustainable EU health information system to support evidence-based health policy and research for the EU and Member States. The project reinforced and integrated expert and data provider networks to ensure optimal conditions for the implementation of this system. The BRIDGE Health project work was organised through vertical Work Packages (WP) and Horizontal Activities (HA). The different EU projects and 15 research networks involved in the design phase of DIPoH have initiated joint programming through horizontal activities as transversal multidisciplinary layers of health information (HI). Focus was given to reduction of HI inequalities, HI on subpopulations (gender, age,...), strengthening methods of data exchange and distributed analysis, ethical and legal aspects of population HI, and knowledge translation methods.The first overarching outcome of BRIDGE Health was a concept paper.

The concept paper provides interested Member States, candidate and EEA/EFTA countries with relevant information to make an informed decision on sustainable strengthening of the EU health information system. It describes the design of a research infrastructure and sets the bases for DIPoH.

For more information go to http://www.bridge-health.eu/.

B. The Joint Action on Health Information InfAct

InfAct *(Information for Action!)*, the Joint Action on Health Information, 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 and runs for three years. 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. Through country collaboration, InfAct streamlines health information activities, reduces the data collection burden and works towards a sustainable and robust data collection in Europe that facilitates and supports country knowledge, health research and policy making. Through its activities InfAct is piloting and carrying out some of the activities planned in DIPoH.

InfAct has the following main objectives:

- To develop the business case and roadmap for implementation of DIPoH,
- To assess health information systems in MS and regions,
- To develop a roadmap for training in health information with the objective to tackle health information inequality through Europe,
- To standardise health information instruments, tools and methods,
- To strengthen the health information efficiency for public health policy through new ways of using health and non-health data sources,
- To enhance the introduction of the interoperability of health data sources, and
- To enhance the translation of health information into public policy.

For more information go to https://www.inf-act.eu/.

II. Stakeholder consultation on the needs

Besides these statements of a need for change in the past, BRIDGE Health has undertaken a stakeholder consultation meeting with EU national public health institutes in March 2016 to further investigate the issues. The consultation is summarised here, but described in greater detail in the paper from Bogaert P et al[1].

The BRIDGE Health project organised a consultation meeting with the national public health institutes in the EU, since they are:

- the health information knowledge centres in the Member States, which make them potential key players in an EU health information system or infrastructure,
- policy supporting health researchers and the translators of research to policymakers, and
- contact points for national and international stakeholders allowing reflection of Member States' research and information needs.

The consultations aimed to identify the national public health institutes' needs to strengthen the current EU health information system and their vision of an integrated and comprehensive EU health information system or infrastructure. All 28 Member States' national public health institutes or corresponding institutes were invited to attend the meeting. A questionnaire was circulated before the meeting where participants were asked: what and if there is a need for an EU health information system, what could be the added value of such a system, and where improvements can be made in health information at EU level. During the meeting, the topics were further discussed in focus groups. The discussions were guided by moderators through a semi-structured interview. The consultation meeting was attended by 17 participants from 13 European countries. Ten responses to the questionnaires were received and the focus groups were composed of 14 participants in total.

The need to optimise the existing EU health information system again became obvious. Several core issues for improvement were identified in the consultation meeting with national public health institutes.

Five key areas for improvement were identified:

1. International cooperation and coherence in EU actions of public health and public health research
2. Better data quality, availability and comparability for research and evaluating policies
3. Comparison and benchmarking among Member States and for the EU
4. Knowledge sharing and capacity building
5. Transfer of health information into evidence-based policy-making

1. International cooperation and coherence in EU actions of public health and public health research

[1] Bogaert P, van Oyen H. An integrated and sustainable EU health information system: National public health institutes' needs and possible benefits. Archives of Public Health. 75: 3, 2017

Currently, a variety of EU institutions and projects perform activities on health information without a holistic approach or transparent co-ordination. There is no coherent EU health information strategy or health data governance. Several European initiatives are working towards a strategy, but are in an initial stage e.g. European Health Data Space. This gives rise to issues such as the many overlaps concurrent with enormous gaps, the chasm between projects' agendas and EU health priorities and the scarce uptake of research results into public (health) practice and policy. An overarching EU health information system or infrastructure can guide and co-ordinate the necessary activities in the areas of research, monitoring and knowledge translation, and provide a link between institutions and projects. There is an additional need for a discussion forum and it is essential to overcome silo mentalities (i.e. fragmentation by health information domain).

2. Better data quality, availability and comparability for research and evaluating policies

Standardised methodological approaches are needed in many areas which can be adapted to the national infrastructures and culture, and together with quality control activities enhance the availability, interoperability and comparability of data. There is a need to share data between countries. An EU health information system or infrastructure can provide the framework for this and involve key stakeholders at the Member State and EU levels such as national public health institutes or other data authorities, and health and healthcare authorities. It can prioritise the exchange of data, support the sustainability of data collection, improve the availability of data, and the reusage of collected data for evidence-based policy-making and high level research. There is a need to build trust on data and data use and look into privacy issues and how to deal with big data.

3. Comparison and benchmarking among Member States and for the EU

Working with an EU-wide health information system or infrastructure can support the sharing of information on population health and health systems across the EU. This would allow the Member States to have a more precise picture of the situation in their country and compare their outcomes to other Member States and regions. At the EU level, a more complete unified general picture of the public health situation can be generated. Comparing health information among EU-wide sets of health care providers, regions and countries allows health researchers to take advantage of the 'natural experiment' that is provided by the various types of interventions and practices that have been initiated throughout the EU. The availability and comparability of the data becomes even more essential then.

4. Knowledge sharing and capacity building to reduce health information inequality

Fostering EU-wide cooperation also enables the exchange of expertise and capacity building through strong health information and research networks as the Member States can learn from each other. This also means easier access to high quality data for researchers. Simultaneously, such an approach can address health information inequalities in Member States and the EU. International collaboration toward common best practices is essential to enable all countries to benefit from health and to support the production of multi-country statistics, research and other uses of data that serve the public interest. A lack of policy-oriented health research capacity is a problem in many of the Member States.

5. Transfer of health information into evidence-based policy-making

Having the appropriate data, tools and knowledge allows policymakers to respond effectively to population health and health systems' challenges and to evaluate policy measures. Resources available to Member States' health systems and EU institutions are diminishing. A strong governance and framework for health information would allow efficient resource allocation through better prioritisation and reduced duplication of activities, e.g. evaluation of aspects of cross-border care.

III. Assessing structural organisational entities

In a second step, BRIDGE Health assessed structural organisational entities or options to respond to the needs formulated during the stakeholder consultation with the national public health institutes described in the previous chapter. In 2016, BRIDGE Health investigated the possibilities to create an organisational entity that could take up the tasks that come with the need for strengthening the EU health information system. The study is summarised here, but described in greater detail in the paper from Bogaert et al[2].

The following elements are essential in the evaluation of different structures:

1. Acceptability and support of the Member States and the European Commission. Consideration also of the needs to be given to the appropriate governance of the structure, so that all relevant stakeholders are engaged without inhibiting progress.
2. Feasibility in short term and in the current legal, economic and political framework.
3. Financial sustainability with resources from both EU programmes and the Member States.
4. Ability to carry out research and simultaneously public health surveillance and monitoring in population health and health system performance.

Using multi-criteria analysis, the advantages and disadvantages are investigated of either strengthening existing structures or creating a new one. The different options were discussed in focus groups with National Public Health Institutes and BRIDGE Health work package leaders by using SWOT analyses and the criteria described in Annex 4 of the concept paper of BRIDGE Health[3].

A. Strengthen existing structures

At European level, various institutions and agencies carry out activities related to health information such as different Directorate Generals (DG) of the European Commission, decentralised agencies and international organisations. The advantage of working with an existing structure or a combination of existing structures is that, in general, the infrastructure and administration are already in place. There is a basic legal mandate and framework, and the political setting with existing networks is set up. Rather than creating something new, one can build on existing knowledge and expertise. However, current activities of existing structures can diverge from the role envisaged for the proposed EU health information system, as new domains are tackled, and strong political support would be needed to allocate resources and/or change activities. Various options can be considered; separately or combined. Table 4.1 provides an overview of strengths and weaknesses of various options.

Expanding tasks of Eurostat

[2] Bogaert P, van Oers, van Oyen H, for BRIDGE Health. Towards a sustainable EU health information system infrastructure: A consensus driven approach. Health Policy 122 (2018) 1340-1347

[3] BRIDGE Health Consortium. Bridge Health: Concept Paper. Technical Report BRIDGE Health N° WP1_2016_03 Available at: https://www.bridge-health.eu/sites/default/files/Technical%20Report%20WP1_2016_03_Concept%20Paper_final_V2_0.pdf

Eurostat already has long-standing experience with data and statistics. Its task to provide the EU with statistics at European level that enable comparisons between countries and regions, corresponds with the gaps of the current EU health information system and indicators could be included in the European Statistical System. Eurostat also has a legal mandate for the collection of health data as defined in the regulation 1338/2008 covering health status and health determinants, healthcare, causes of death, accidents at work and occupational diseases and other work-related health problems and illnesses. The weaknesses of selecting Eurostat are linked to the fact that Eurostat focusses on data and statistics which are to a majority not linked to public health. Eurostat provides strong governance on the statistical system, but does not provide this from a public health point of view which is needed in this context. Additionally, Eurostat has a wide range of activities, but as a statistical office it does not focus its work on translating data into knowledge for evidence-based policy-making.

Extension of the scope of the European Centre for Disease Prevention and Control (ECDC)

The major strengths of extending the ECDC are its focus on health and the fact that one can build on existing knowledge and expertise acquired through the work on infectious diseases. The ECDC has experience in managing large networks and carrying out capacity building. This centre is also mostly linked to public health functions and has existing links with the Member States. However, infectious diseases are the main focus of the ECDC and there is no wider mandate for health information in other domains. The visibility of the ECDC is linked to infectious diseases and there is no experience in non-communicable diseases. The name of the centre does refer to disease prevention and control which could fit within the need for strengthening the EU health information system. Adding one or more units within the ECDC focusing on wider activities than infectious diseases could tackle some of the issues. Finding the necessary political will and resources for this could be very challenging. This was also reiterated in the third ECDC evaluation[4].

Reorganisation of DG Health and Food Safety (SANTE)

The strength of DG SANTE is their existing knowledge and expertise in public health, in addition to their mandate of the health programme. However, the activities of DG SANTE orient towards policy rather than towards research. The operational capacity is also low and long-term continuity cannot be assured. The role of advanced health information tools in Europe is critical both for research and policy-making.

Extending work plan of DG Joint Research Centre (JRC)

The JRC has developed expertise and experience in certain aspects of health such as cancer and rare diseases. It translates health information for policymakers and can adjust its work plan according to the needs of DG SANTE. This, however, may limit the sustainability of its activities as they may change over time. The main focus of the JRC is not public health but research, and the institution has limited interaction with the Member States.

[4] Third external evaluation of ECDC (2013-2017). Available at: https://www.ecdc.europa.eu/en/publications-data/third-external-evaluation-ecdc-2013-2017

Outsource to the World Health Organization (WHO) Europe or the Organisation for Economic Co-operation and Development (OECD)

To avoid duplication of activities, outsourcing activities to the WHO or the OECD may be considered, similarly to what is currently done for the report "Health at a Glance". Both international organisations have expertise and experience in public health and core data set work. The weakness of working with such an organisation is that they are not solely EU-focussed and may therefore have their own agenda, different mandates and policy aims.

B. Create a new structure

A new structure allows more flexibility in terms of activities and scope. It can tailor its activities to current needs and demands. It can cover the gaps of existing structures and provide an overview of existing initiatives in health information. A new structure can also have a voice of its own for better advocacy and visibility. It can build on the knowledge and experience of previous EU projects using health information or health data. However, similar to existing structures, political support is needed and financing (mechanisms) need to be found. The strengths and weaknesses of chosen various options are described in Table 4.1 and 4.2.

Creating an independent new EU agency

Creating a new EU agency would, besides the strengths discussed above, also operate within the EU framework. It would have a strong legal basis and it is questionable why such an agency does not exist yet. In the current economic climate, it is however not realistic to set up a new EU agency, but it could be a long-term goal. A strong political will would be needed. BRIDGE Health also found out during discussions that current institutions may also perceive a new EU agency as threatening.

European Research Infrastructure Consortium (RI)

The strength of an RI is the relatively short term needed for its setup following a known procedure and the fact that an RI has a legal framework. It is a practical solution with a flexible format and financial framework. An RI can receive funding from e.g. the EU Health Programme. Research and development are part of the solution and international collaboration can be assured. An RI can grow and be built up. Moreover, good examples exist and can be learned from. As many other structures, sustainability cannot be assured. An RI is Member State-driven and therefore depends on the willingness of the Member States. In relation to the governance, a major drawback is that the European Commission cannot be a member of the RI and not all Member States need to be part of the RI, which means its success depends almost entirely on the willingness of the Member States. Additional weaknesses include its lack of mandate to steer health information in the EU.

Joint Action

A Joint Action is easy to be set up and can provide a transition between the BRIDGE Health project and any structure that may be created. This may be necessary as most other options (even setting up an RI, which is a rather medium-term solution) may take several years. The weakness of a Joint Action is that not all Member States need to participate, there is a lack of mandate and it is only a temporary solution as it is project based.

Supra-European structure

Creating a supra-European structure such as a Codex Alimentarius Commission may be prestigious and has high credibility and visibility, but it will not be EU-focussed. There is also no legal status and a high administrative burden.

Table 4.1: Strengths and weaknesses of using an existing structure

Strengthen existing structure	Strengths	Weaknesses

Expanding Eurostat's tasks	- Existing infrastructure
	- Existing expertise and experience
	  o Works with Member States
	  o Does data collection in health with EU regulation
	  o Has a baseline on indicators
	  o Has good knowledge of data
	- Deals with cross-cutting themes (other directorates outside of health)
		- Focuses on data and statistics
		- Majority activities not related to public health
		- Does not provide any governance involving Public Health structures in Member States
		- Has no focus and knowledge translation
		- Misses a link with Ministries of health since the main link of Eurostat is with statistical institutions within MSs

Extension of the scope of the European Centre for Disease Prevention and Control (ECDC)	- Existing infrastructure
	- Existing experience and success
	  o Managing large networks
	  o Capacity building in countries
	- Provides a link between existing work on infectious diseases and EU health information system
	- Is linked to public health function
		- Focusses on infectious diseases
		- Has no mandate for wider health information scope
		- Visibility only connected to infectious diseases
		- Has no experience on non-communicable diseases, life styles, health services research (outside the infectious disease domain)

Reorganisation of DG SANTE	- Existing infrastructure - Existing expertise and experience - Has mandate of health programme	- Politically oriented - Misses scientific dependence - Operational capacity - Long-term continuity

Strengthen existing structure	Strengths	Weaknesses
Extending the work plan of the Joint Research Centre (JRC)	- Existing infrastructure - Expertise and experience in cancer and rare diseases - Translates data into policy - Flexibility	- No public health focus - Research-oriented - Sustainability - Limited interaction with MS
Outsource: WHO, OECD	- Expertise and experience in public health - Core data set work - Avoid duplication - Expertise and knowledge on international comparison of health care systems	- Not EU-focussed - Own agenda, different mandate and policy aims - Little influence on EU - Sustainability

Table 4.2 Strengths and weaknesses of creating a new structure

Create new structure	Strengths	Weaknesses
Independent new EU agency	- Tailored to specific needs and demands - Visibility for public health - Have a voice of its own - Strong basis - Clear vision and goals - Operate within EU frame - Opportunity to innovate	- Not realistic in current financial climate due to high constraints - May be perceived as threatening to existing programmes - Needs to start from scratch - Needs strong political will - Long time to be set up - High governance/administrative costs
European Research Infrastructure Consortium (RI)	- Practical solution due to the availability of legal framework - Can be set up in relatively short term - Is flexible in format and financial contributions	- Is mainly research- and science-driven - Sustainability depends on funding provided by MS - Does not require involvement of all Member States

	- Research and development are part of the solution - Collaborate with international agencies - Can grow and be built up - Can receive EU funding from e.g. EU Health Programme - Examples of RIs are available from which experience can be used - Opportunity to innovate	- Depends on willingness of Member States - European Commission cannot be a full member - Lack mandate to steer health information in the EU
Joint Action	- Easy to set up - May be an interim solution	- Short-term solution - Not sustainable - Limited funding - Not all MS need to participate - Lacks mandate to steer health information in the EU
Supra-European Structure (e.g. Codex Alimentarius Commission)	- Prestigious, credible and visible	- No legal status - Administrative burden and coordination - Not EU-focussed

C. Combination of new and existing structures

Using the strengths of an existing structure, a new structure could be built to take up the activities that remain. The strength of this format is that existing institutions are not overridden, the role of coordination and governance could be taken up by an EU institution and a long-term way of working together could be established. One of the challenges would be the coordination between those structures. Many different options can be considered combining the options described above e.g. a health information division in ECDC where the policy thinking would happen, in addition to an RI which could incorporate research and data infrastructure.

D. An RI and the way forward

Compared to the other options, the strongest argument to support the setup of an RI is its feasibility in the relatively short term. An RI can become a European Research Infrastructure Consortium (ERIC)[5] [4]. An RI is a legal entity created by a decision of the European Commission. It has legal personality and a full legal capacity recognised in all EU Member States. In the current framework, reorganising, expanding or creating a structure dependent of the European Commission is not feasible.

In terms of financial sustainability, an RI is eligible as a sole beneficiary for several EU funding mechanisms including Horizon 2020 and successive Horizon Europe. The SHARE-RI has for example received grants by the EU commission (7th Framework Programme) and the US National Institute on Aging, which it spends on central services[6]. This alleviates the fact that an EU institution cannot be a member of an RI or ERIC. Members of an RI or ERIC provide in cash or in kind contributions as determined in the agreements or statutes. These contributions vary greatly among existing RIs and need to be discussed when drafting the statutes of an ERIC. For example, the BBMRI-RI Membership contribution model is stratified in groups according to the number of inhabitants: 20,000 € base contribution for Members whose number of inhabitants is below 3 million and 25,000 € whose number of inhabitants equals or exceeds 3 million[7]. Also, according to the RI regulation, an RI must carry out its principal task on a non-economic basis. However, it may carry out limited economic activities, provided they are closely related to its principal task. These activities can support the sustainability of the RI.

An RI is a tool to serve research across Europe and serve national health information infrastructures with high usability for the Member States and EU institutions. The basic internal structure of an RI is flexible and can be tailored to current needs and demands. As defined by its Members, an RI can set clear targets and objectives to focus efforts on priority research questions and make better usage of existing health information sources. An RI can ensure linkage with its stakeholders, including the scientific community, national infrastructures and international organisations. Through research, it can provide relevant

[5] ERIC Practical guidelines, Legal framework for a European Research Infrastructure Consortium. [cited 2016 Jun 16]. Available at: https://ec.europa.eu/research/infrastructures/index_en.cfm?pg=eric

[6] Annual Activity report 2013 and 2012. Heading C. Financial aspects. [cited 2016 Jun 16]. Available at: http://www.share-project.org/contact-organisation/shareeric.html

[7] BBMRI-ERIC Business Plan v21.1 03.12.2012 [cited 2016 Jun 16]. Available at: http://bbmri-eric.eu/bbmri-eric-publications

information for decision-makers, the necessary tools for research and has the capacity to bring different actors in health information together to strengthen health information in the EU. The willingness of institutes within the Member States, i.e. national public health institutes, to contribute to the setup of an RI is an important added value as in general these institutions are bridging research and policy.

An RI is a potential tool to support the goal of working towards more and better coordination in activities related to health information in the EU, as well as for facilitating the involvement of international organisations such as the OECD and the WHO. DG SANTE has indicated its preference for this option. The Member States have indicated that alternatives should be further investigated, but when evaluating each of the options based on different criteria including the short-term feasibility, it is clear that the RI is maybe not the preferred but the only feasible option. Ownership at Member State level will have to be taken in order to build an RI, since an RI is 100% Member State-driven and relies on the willingness of Member States.

Some other disadvantages need to be taken into account when choosing for the RI as it cannot respond to several important needs for better governance, coordination and priority setting for the EU health information system. Also, the urgency of a quick start and the possibility that creating an RI may not meet this deadline would make a Joint Action a feasible interim solution. In the long run, the RI can form a template for future arrangements once it established 'proof of concept'. The structure could then evolve to one of the other more ideal options such as a new EU agency or extending the remit of Eurostat or ECDC.

Taking this together, the BRIDGE Health project recommends the creation of an RI in health information as a tool to strengthen research and evidence-based policy. Aiming for the RI seems at this time the most feasible option to set important steps in the right direction and fulfilling some of the major criteria for an effective organisation. However, the urgency of a quick start and the possibility that creating an RI may not accommodate this urgency, would make a Joint Action a feasible interim solution.

IV. Technical and scientific design of DIPoH

The Concept Paper from BRIDGE Health recommended the creation of an RI as described in the previous chapter. The next step is the technical and scientific design of the RI. A consensus-driven modified Delphi technique was used to reach consensus on the technical and scientific design of DIPoH during BRIDGE Health [1]. Experts were consulted in two different existing working groups: the BRIDGE Health Steering Committee (SC) and the European Commission's Drafting Group of the Expert Group on Health Information (DG-EGHI). The study is summarised here, but described in greater detail in the paper from Bogaert et al [2]. The technical and scientific description was then further developed during InfAct by a ESFRI writing group in consultation with InfAct's Steering Committee, General Assembly and Assembly of Members meeting.

More specifically, consensus was reached on three aspects. First, that the infrastructure should facilitate interaction of networks at MS level and pan-European, and experts in health information by providing central governance and a more permanent structure. Second, the infrastructure should be distributed, with a central office coordinating the operation of distributed networks. Third, it should provide easy access to high quality and comparable data for purposes of research and policy making, and focus its activities around generating, managing, exchanging and translating health information.

A. The Distributed Infrastructure on Population Health (DIPoH)

Through the participation of countries, a distributed infrastructure on population health is the best position to support the access to, the sharing and reuse of research results and data, to provide countries with access to high quality HI. DIPoH will ensure the best available health intelligence by providing support towards the development of large-scale, integrated and sustainable data services for population health and health services research. DIPoH covers the domains of the population health framework (Figure 5.1). DIPoH contributes to cataloguing, curating and integrating information and knowledge generated by a critical and growing mass of European researchers and their international networks. In this way, it exploits the natural variation in health and healthcare in Europe.

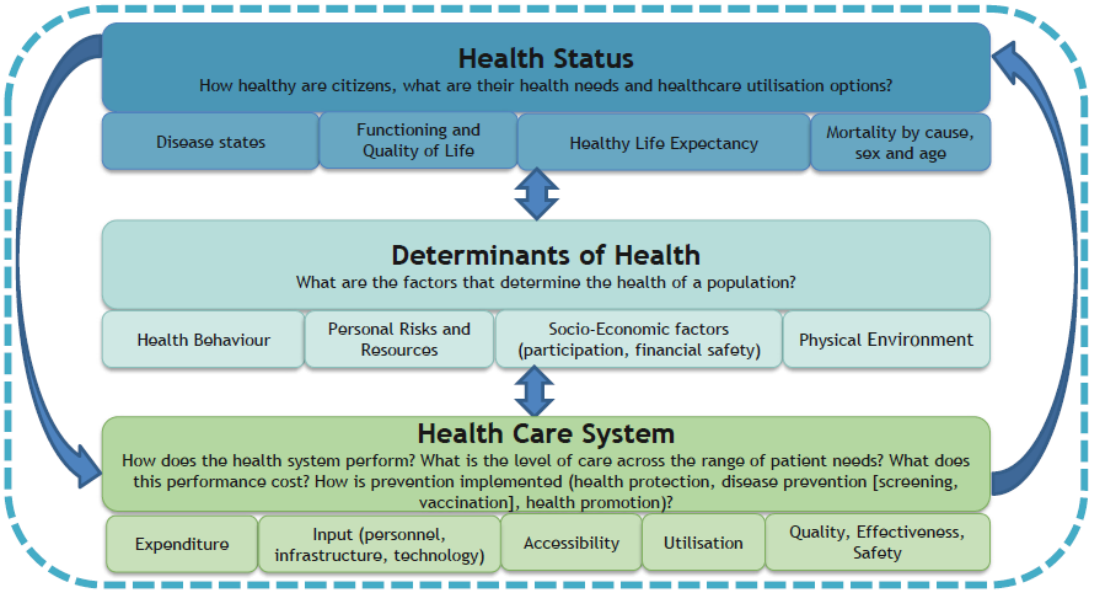


Figure 5.1. Schematic representation of a population health framework

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

DIPoH's **vision** is a sustainable infrastructure for improving health of populations and care in Europe.

The **mission** of DIPoH is to facilitate comparative research through identification, access, assessment and reuse of population health data within the EU to support evidence-informed policy-making processes.

DIPoH will bring together and make available information about health datasets, related expertise in different countries and tools for findable, accessible, interoperable and reusable data curation. Population and patient health data and health care systems data will be available at individual and aggregated level from many sources, among others, disease registries, administrative health and non-health databases, surveys and health examinations, and cohorts of populations and patients.

The objectives of DIPoH are:

- To provide the conditions necessary for rich new insights into the dynamics of population health, the most important influences on health and care, and the safety, quality, effectiveness and costs of interventions. DIPoH increases national health and wellbeing through better and more efficient health and social services.

- To strengthen comparative research, collaboration and exchanges of data, expertise and knowledge between countries. DIPoH contributes to more in-depth understanding on current health inequalities and enables more cost-effective high quality research.

- To strengthen the development of new research methods for knowledge translation research. DIPoH improves evidence-informed health and social policies, practices and technology.

B. 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 (Figure 5.2):

- 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. It will facilitate the identification and interaction with experts and research 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 actively promote interoperability and tackle health information inequalities: encouraging 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. Dynamic 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.

Fingure 5.2. DIPoH's four main activities

Good comparative information has proven essential for benchmarking, exchanging best practices and standardising and harmonising research tools and methods. DIPoH services support and strengthen research networks in the area of comparative population health research and comparative health system research within the EU and so improve the quality of data and research, reduce research inequalities by enhancing MSs coverage and work towards sustainability of these international networks.

C. DIPoH structure

The operational elements and governance structure are described in the document "Governance Structure of DIPoH" addressed under question 9.2. *Upload an organisation chart of the project organisation for the preparation* and are summarised here. Please consult this document for more detailed information.

DIPoH will be a distributed effort in the form of a networks of nodes. It will have a distributed structure connecting national nodes in EU countries and pan-European research networks through a central coordination office. A central facility will be needed for the coordination of all node related activities. This central office will include a web-based Health Information portal for the delivery of services, and services support unit. The expected nodes will include two types: national nodes (NN) units within MSs; and a growing number of participating Pan-European domain specific Research Networks (RN) and their research communities (Fig. 5.3).

Figure 5.3. The distributed structure of DIPoH

The central office represents the coordinating element of DIPoH across the different phases of its construction. The main role of the central office is to provide coordination, administrative and management support, strategic development and evaluation. During the construction phases, the central office will oversee the set-up of the Health Information Portal and development of DIPoH's services. Finally, in all DIPoH phases, the central office is the connecting pin between the DIPoH operational elements and the governing bodies, and with external stakeholders.

D. DIPoH users

DIPoH will serve a variety of users, of which the primary users are researchers in public health and population sciences e.g. epidemiologists, statisticians, health economists, data scientists, ethicists, sociologists, and other allied health professionals. The RI will enable researchers and their communities to perform excellent cross-disciplinary and data-intensive research. Expected benefits are:

- Better identification of population health data sources, access to and quality assessment of the data and reuse of the data
- Better access to existing knowledge and expertise
- Enhanced research capacity;
- Access to larger study populations and cohorts;
- Enhanced data access flow;
- Structured scientific exchange;
- Tackling the population health information inequality and health information research capacity within Europe;

- More efficient data access policies for cross-country exchange and analysis

For researchers already organised in networks, different types of research networks will benefit:

- Larger, more established pan-European research networks with a long time record and ongoing research activity indicating a sustainability based on the quality of the network, of the research and on the ability to find project funding. These networks have remained active and productive for many years. These networks need forms of support through a RI to optimise their growth, and ensure the sustainability of their data collections and research activities in order to advance research methodologies, increase the multidisciplarity and the interactions with other population health research domains

- Research Networks with a smaller number of participating countries that are promising, but would need capacity building support through the RI to become optimally effective and productive in terms of research efforts and output.

- Population health information infrastructures within public Institutions collecting and curating health data at national and regional level are strengthen through the RI to ensure the FAIRNESS of their data, to increase the capacity in digital preserving including the design and implementation of suitable strategies, policies, and procedures to maintain data usability, understandability and authenticity.

The secondary users are policy and decision-makers in national and international organisations both governmental and non-governmental organisations or civil societies, as the outcomes of the infrastructure will benefit their work.

Other users include:

- Other European level RIs linked to health and data sciences
- The healthcare sector
- Data providers/data owners and developers in various health information domains
- Students and educational organisations of population health and health services
- The media
- EU citizens and patients organisations
- Industry and private sector

The stakeholders engagement strategy (See Section V.J.) outlines more in detail how DIPoH Design intends to reach these stakeholders and the added value specifically per stakeholder.

E. DIPoH added value and potential limitations

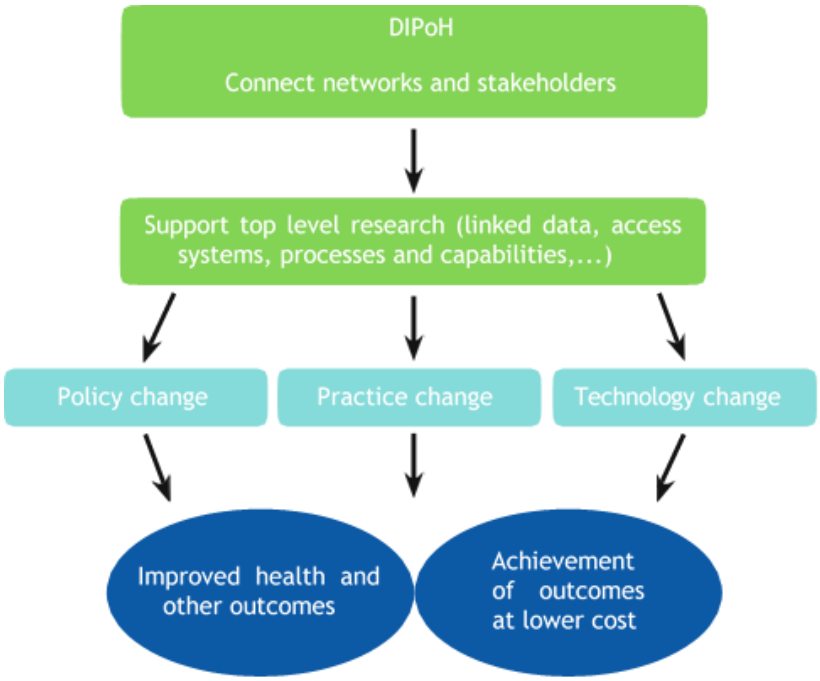


Figure 5.4. Value chain of DIPoH's impacts

1. Added value

Stemming from the experience of numerous population health research networks and a preliminary analysis of the need of such an infrastructure, DIPoH is mirroring recent developments in the fields of life sciences (e.g., BBMRI-ERIC, ELIXIR) and clinical research (e.g., ECRIN) and social science (e.g. CESSDA). Thus, DIPoH aims to develop a Pan-European RI covering leading-edge research on population health supported by a state-of-the-art distributed RI that supports innovative methodological, computational and technological solutions.

DIPoH will contribute to cataloguing and facilitating exchange of information and knowledge generated by a critical and growing mass of European researchers and their international networks. This will strengthen the synergy in the EU by facilitating comparative research, and facilitating the uptake of data innovations and the use of best practices in data collection, research, analysis, reporting and exchange including data linkage, and artificial intelligence, or the use of real world-data. DIPoH also provides access to advanced capacity building programmes promoting MS's adoption of shared health information methods. The result will be Pan-European use of data, methods, expertise and results and better involvement of national experts and population health information infrastructures in MSs. Developing, implementing and facilitating EU population health research will enable Members states to work together to effectively and efficiently develop, implement and monitor the societal impact and health outcomes of policies, to achieve a higher level and more equitable distribution of health and wellbeing across the European population.

Health determinants that operate across national boundaries can be better addressed through a coordinated RI that operates using standardised procedures. Comparing health information among EU-wide sets of health care providers, regions and countries allows

health researchers to take advantage of the natural experiment that is provided by the diversity of interventions and practices initiated throughout the EU. International comparisons of EU population health data and indicators, and cross-country health and health system data provide benchmarks that can inform health prevention and promotion targets. Selected indicators provide valuable comparative information on the extent of the challenges in MSs, as well as on measures taken to meet them.

The Health Information portal will provide stakeholders with: (1) a detailed catalogue of the existing data sources for population health research; (2) a detailed catalogue of the existing health research networks and their expertise; (3) recommendations on reuse of data for population health research taking into account the diverse legal and ethical requirements in Europe; (4) a detailed catalogue of common data models that can eventually foster multiple population health research questions; (5) recommendations on ready-to-use software for the implementation of the existing data models in different research questions and contexts; (6) recommendations on ready-to-use software for the analysis of data quality and the correction of data quality problems; (7) recommendations on ready-to-use software containing analytical scripts prepared for the implementation of distributed analysis and parallel computation; and, (8) a flexible and innovative capacity building programme.

A capacity building programme, together with the available expertise through existing research networks, will provide quality training and other capacity building activities. The program will be updated annually to address the dynamic demand for advanced use of health information tools. This will reduce inequalities in health information capacities between countries and improve evidence generation at national and cross-national level in Europe.

Through services and tools provided by the DIPoH Health Information portal, pooling and access of data from different data sources becomes easier, facilitating more cost-effective high quality research including cross-country comparisons. Through this research, benchmarking national results to neighbouring countries and countries with similar health care systems helps to identify possible points for improvement and a shared learning experience. As a result, EU health care systems will be made more effective. Also, access to large dataset for secondary analysis provides enough power to investigate effect of expected health determinants by several population subgroups providing more in-depth information about existing health inequalities. With this available information, evidence-based targeted prevention programmes and evidence-informed policy decisions to reduce health inequalities are possible.

Ultimately, through facilitating data source identification, access, assessment and reuse, the aim for the DIPoH is to provide large-scale, integrated and sustainable services that will serve improvements in population health science in Europe. A sustainable infrastructure on EU population health information will improve the availability of comparable, robust and policy-relevant evidence on the health of the EU populations, on the population-based determinants of health, and the efficiency of the European health systems. DIPoH partners are also engaged in the European Health Research and Innovation Cloud, the European Health Data Space and the European Open Science Cloud. Various joint submissions have been submitted to different calls which led to interaction with existing RIs.

2. Potential limitations

A number of weaknesses threaten the viability and feasibility of the RI and require attention.

First of all, the RI needs support and commitment from governmental structures responsible for health research as well as those responsible for health policies. However, both seem to suffer from tunnel vision and bridging this appears difficult. For improvements in health and health care to become reality, we need to convince research and policy that the two need each other.

Furthermore, although health is rated as one of the most important issues in peoples' lives, relatively little funding is available for population health research, including prevention, health promotion and knowledge translation. Whereas the research infrastructure can pull forces together to attract funding, the total pond to fish in will probably not become bigger over the coming years and in addition it may prove difficult to get MS governments to fund basic structure needed for the RI to function (see 'Project Organisation'). Financial viability is something to think through well in advance. Good landscape and market analysis (do not supply what is not demanded), as well as good insight into funding resources will increase chances of survival.

Also, many MS see health as a "national" issue, where there should be no "interference" from the EU. Considering the commonalities in the problems countries face, it seems remarkable that health ministries still hide behind the subsidiarity principle to keep their eyes turned mainly inwards. We need to make clear that international collaboration adds value to the national health system. It will require continued effort to convince MS that European collaboration in the field of Health Information is efficient. A prerequisite to this is that the RI will actually solve the lack of sustainability of collecting data and make them available.

A point of attention is that the RI will not have mandate to exercise any control over the (lack of) coordination with and between EU and other international organisations that play a role in health information. This lack of power may affect its efficiency in harmonising the European landscape.

Other possible points of attention are the timeframe needed to set up the RI (shaping the governance structure and services, etc) and the time needed to show the benefits the RI delivers.

The short and mid-term risks and benefits are presented in Table 5.1.

Table 5.1. SWOT analysis of DIPoH

Strengths	**Weaknesses**

• Can extend its activities and become larger over time
• Provide sustainable structure for
  o best practice exchange between Member States
  o data collection and regular assessment and analysis
• Link national and international experts, public health institutes and research institutes
• Capacity building and increased cooperation between national and international experts, public health institutes and research institutes
• Builds on existing research projects and national and international organisations
• Provides an holistic approach to population health monitoring and health system performance
• Better partake in EU funded research project
• Assist with elements of overarching project management
• Best practice exchanges between MSs and EU-population health information research networks
• Provide overview and coordination of EU health information activities and methodologies at MS-level and within expert networks
• Pooled resources for more effective data collection, dissemination and analysis
• Mutualised learning and data access to the Health Information portal
	• Consortium for the ESFRI application does not include all MS but already 10 letters of political support, 13 Memorandum of Understanding, 8 Letters of intent have been provided and more countries have indicated their interest some through letters of support.

Opportunities	Threats
• Uptake of innovations in the domain of EU population health data collection, reporting and use for surveillance and research • Flexible and responsive to MSs needs and EU political bodies • Increased opportunity to ensure FAIRness of population health data • Increased opportunities for data linkages across multidisciplinary partners and countries with full ELSI compliance • Landscape analysis and inclusion of researchers/stakeholders in other sectors that have an impact on health • EU population health data collection and enrichment of available datasets through linkages between the partners • Quality improvements in cause-of-death statistics, morbidity, disability and health statistics • Quality improvements in the use of composite health indicators (Healthy Life Years, Disability adjusted Life Years, …) • Potential for scale up • Interaction with national public health institutes • Integrated approach to population health monitoring and health system performance • Closing health information gaps by linking with other EU-RIs and contributing to global data and research initiatives such as the EOSC • Provide overview in population health information activities across Europe.	• Some institutions/EU research networks that are not part of the project do not find sufficient incentives to join the DIPoH (Low risk) • Users/data owners are not convinced that sharing of data is safe and do not want to participate in the process (Low risk) • EU MSs are sceptical of the return of investment for the DIPoH (Medium risk) • No workable solutions for a viable funding model on the long term can be found (Medium risk)

F. Research Networks and National Nodes

1. Research Networks and their contributions to DIPoH

Research Networks (RN) represent groups of collaborating researchers that collect, exchange, and harmonise health data and/or information on a particular health topic for population health research. These RNs, beyond research activities, often work on the setting up, the improvement and reporting of population health research methodologies, the validation and reporting of tools (such as, indicators, software for analysis, data visualization tools, reporting, and translational research methods), exchange of expertise or engagement in capacity building activities, and on methods to have their research results integrated in the public management and policies. The RNs will each need a nucleus to take care of harmonisation and quality control of data, organising exchange of expertise, processing of data and coordinating research and reporting efforts. In summary, the job of the RN will be to:

- Establish a critical mass in their thematic area via networking of researchers, joining expertise, undertaking common research efforts, sharing research facilities and contributing to capacity building
- Maintain, increase and exchange their scientific and technological excellence
- Generate new data and methods and strengthen their research capacity
- Facilitate and expand data access and sharing
- Develop a long lasting strong research base and regular data collection
- Facilitate the integration and transfer of new knowledge
- Deliver knowledge for policy making, anticipate scientific and technological needs and provide efficient scientific support for strategic decision-making in the specific field
- Enhance communication and visibility at the European and international level

In conclusion, RNs ensure that Europe has comparative data on topical health domains at its disposal, support a coordinated action in population health research, getting the most out of the existing national and regional health data repositories, and feed relevant information to policy makers.

DIPoH, comes in a bottom up approach. It built on work from two consortiums of health information EU projects. In BRIDGE Health (www.bridge-health.eu/), including 31 Consortium Partners in 16 countries representing 14 population health research networks in 9 population health research domains: (1) Reproductive, maternal, new-born, child and adolescent health (Euro-Peristat*, CHICOS, RICHE), (2) Health Expectancy and disability process (EHLEIS*), (3) European Core Health Indicators (ECHI*), (4) Health Examination Surveys (EHES*), Environmental Chemicals and Health (COPHES, ENRIECO), (5) Evaluation of Health Care Systems (Health Data Navigator), (6) Platform for population based registries (EUROCISS*, EUROBIROD), (7) Integrate health information systems (EuroHOPE), (8) Platform for administrative data on health care (ECHO*), (9) Integrated information on injuries (Euro-Safe). In the JA InfAct (www.inf-act.eu/), including 40 Consortium Partners from 28 EU countries and research networks (indicated in list above with *), streamlines health information activities that will contribute directly to the setup of DIPoH.

As such, DIPoH benefits from the accumulated experience of previous EU funded projects: the different population health research networks which were joined together through BRIDGE Health and the Joint Action InfAct. Both these 2 latter projects were, and are led by researcher in the domains of public health and HI. This fruitful collaboration will allow improved technical and conceptual collaboration in the further development of DIPoH.

Examples of Pan-European research networks included in DIPoH working on population health domains and some of the activities they have carried out towards the setup of DIPoH are:

- Euro-Peristat, (www.europeristat.com), 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; Euro-Peristat, coordinated by INSERM, uses its network of data providers in 28 MSs + Iceland, Norway and Switzerland to produced harmonised datasets for comparative assessments of maternal and child health and healthcare. It leverages its network of multidisciplinary experts (obstetricians, midwives, paediatricians, public health professionals, epidemiologists, data providers, parent representatives) to interpret and report on data and to generate high-impact research publications. Euro-Peristat is currently working with MSs to expand best practices related to data linkage to improve the quality and breadth of data available for monitoring. A particular focus is placed on improving data to monitor socioeconomic disparities in new-born outcomes because of their role in the cross-generational transfer of social inequalities.

- The European Health Examination Survey (EHES), (www.ehes.info), 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. EHES, coordinated by THL, has prepared standardised guidelines for collection of data on individual health status and determinants of health through surveys. It has also developed a training module for these issues as well as some reporting guidelines. All these are publicly available and can be included to the DIPoH Health Information portal.

- The European Health and Life Expectancy Information System (EHLEIS) (http://www.eurohex.eu/index.php?option=welcome), 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) focuses on essential EU health indicators

- European Collaboration for Healthcare Optimisation (ECHO) (www.echo-health.eu), is a research network on health care performance assessment that, using individual-level data, analyses population exposure to health care at geographic and hospital levels, and benchmarks care performance according to uneven utilisation,

unequal access to effective care, and variability in the provision of low-value care; ECHO developed a data model and RI for international healthcare performance research; specifically, the ECHO Data Model specification (https://zenodo.org/record/3253684#.Xbgyo02ouUk) can be used as part of the tools provided by the Health Information portal. An evolution of this data model is now in development to translate the specification to a distributed approach.

- IctusNet (www.ictusnet-sudoe.eu/en) has been proving the concept for the development of a log builder and an analytical pipeline for process mining in several European regions. Specifically, the docker with the distributed pipeline (https://zenodo.org/record/3230671#.Xbwd_L97kb1) can be used as part of the tools provided in the Health Information portal. In InfAct, IACS is expanding the IctusNet concept to other pilots and thus, other data models and analytical pipelines; in particular, to acute care of ischaemic stroke linking emergency and hospital care, to the development of an indicator of population resilience using electronic health records and hospital discharges, and to the analysis of dementia costs using primary care, hospital care, emergency care and prescription claims. Those distributed pipelines will be included as part of the Health Information portal once the works come to an end.

- International Collaborative on Costs, Outcomes and Needs in Care (ICCONIC), (https://icconic.org/) is a worldwide initiative that aims at reusing data of any kind to build cohorts of fragile and complex patients and analyse care utilization, costs and outcomes across their care pathway, comparing a variety of health systems. One of the ICCONIC sub-projects, the one focused on people with dementia, has inspired one of the case studies developed in InfAct; so, the design of the data model for the analysis of utilization and costs of patients with dementia in the context of a distributed infrastructure.

- European Burden of Disease Network, COST Action CA18218 (www.burden-eu.net) [Action Chair: Brecht Devleesschauwer]. The European Burden of Disease Network aims to serve as technical platform to integrate and strengthen capacity in burden of disease assessment across Europe and beyond. It currently has over 200 members from 38 European countries, 5 non-European countries, the World Health Organization, and the European Observatory on Health Systems and Policies. Amongst others, the COST Action is collecting information and drafting guidelines on how to calculate the disease burden for COVID-19 (https://www.burden-eu.net/outputs/covid-19).

2. Quality criteria for assessing Research Networks

To assess the scope, quality, impact and performance of these networks, InfAct defined a set of criteria [2]. By fulfilling several or all of these criteria Research Networks will serve the overarching aims and goals of DIPoH.

Research networks will be relevant for DIPoH if they:

- Cover a topical area (domain) that is part of the domains of the DIPoH research infrastructure, i.e. the domains of population health monitoring and/or health system performance assessment.

- Have a track record in international comparative research in that domain.
- Have a proven ability to link international experts and address information gaps in that domain.

Performance criteria for research networks
Below we list a set of performance criteria for networks with examples of their operationalization. This set of criteria helps to evaluate the performance of the networks and can function as a framework for a specific research network to assess its achievements and/or possible areas for improvement [2].

Policy relevance and impact of the research
The network:
- Covers a research area that was mentioned as being important in recent EU policy documents or EU regulations or in national or regional health policy documents of Member States (relevant).
- Provides research output and evidence that is expected by experts to be able to feed into effective and actionable health policy options and recommendations (actionable).
- Covers a research domain that has recently become a more urgent health policy priority in several countries or regions (urgent).
- Produces research reports/papers asked for by governing or healthcare managing bodies at local, regional, national or international level (effective).
- Produces new information and data from its research in a policy relevant format (policy briefs) (innovative).
- Uses its research expertise to create indicators that can be easily understood and used by health professionals, policy makers and other stakeholders (practical).
- Creates research output that evokes or contributes to health policy debates; recent policy documents refer to its publications (leading).

Uniqueness
The network:
- Is the only substantial research network in a specific domain or topic area in Europe (EU/EFTA).
- Performs original research based on new data collection or compilation of data from multiple sources for secondary use to create new federated databases.

Sustainability
The network:
- Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative).

Geographical coverage
The network:
- Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions.

- Collects data that are representative for a significant number of EU/EFTA regions and/or countries.

Scientific excellence
The network:
- Creates output with a high scientific quality as measured by publication of results in high impact journals and recognition by other experts, stakeholders and policy makers.
- Has a rigorous approach to fostering and improving the quality of its data and publications.
- Works on the harmonization of data and indicators, and on developing new methods and tools to serve its research domain in Europe.
- Has received funding from national and/or international funding organizations.
- Translates its research outcomes effectively and enables decision making to collect new or better data (can be measured by good practice guidelines, clinical recommendations, policy measures or regulations and laws that use its results).

Data management and access
The network:
- Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions.
- Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility.
- Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible.
- Strives to promote the principles of open science.

Governance
The network:
- Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects.
- Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities.

Liaising
The network:
- Brings together data collectors, researchers and stakeholders to integrate evidence generated by the network that supports the implementation of specific interventions and policies.
- Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains.
- Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient.

Capacity building
The network:

- Develops and implements innovative forms of capacity building. This can for instance take place by organizing expert exchanges (workshops and trainings); or
- Contributes to the development and dissemination of new methods and tools.
- Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building.

Advocacy and communication
The network:

- Advocates for its 'domain' and the relevance of its research outcomes and policy messages.
- Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings.
- Communicates its achievements and proceedings regularly in different media.
- Participates in national and international conferences.

Societal impact
The network:

- Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities.
- Creates output that generates local, regional or national discussions in media or political for a.

Expectations in summary
In summary, Research Networks of the DIPoH research infrastructure will:

- Maintain, increase and exchange their scientific and technological excellence.
- Establish a critical mass in their thematic area via networking of excellent researchers, joining complementary expertise, sharing research facilities, contribute to capacity building and training of new researchers as well as developing novel professional profiles if appropriate.
- Generate new data and methods and strengthen their research capacity.
- Facilitate the integration and transfer of new knowledge.
- Undertake common research efforts and provide support, either financial or in kind over a longer period of time, allowing for more significant and sustainable outcomes and results.
- Facilitate and expand data access and sharing.
- Facilitate proactive studies, sharing standardized and innovative measures in specific disciplines.
- Develop a long lasting strong research base and regular data collection.
- Enhance communication and visibility at the European and international level.
- Deliver knowledge for policy making, anticipate scientific and technological needs and provide efficient scientific support for strategic and political decision-making in the specific field.

3. Feasibility studies of Research Networks

By assessing the quality criteria of Research Networks, inherently the Research Networks have to prove their track record in the field and their ability to link international experts in their domain. This means the Research Networks have proven their maturity and have surpassed the need to prove their feasibility. Nevertheless, some Research Networks have carried out feasibility studies in the past. As an example, the feasibility study of EHES is presented.

The European Health Examination Survey

Feasibility of a European Health Examination Survey (FEHES) project was a project funded by European Union through the Programme of Community Action in the Field of Public Health (2003-2008). The objective of the project was to contribute to the development of the European Health Survey System by examining and analysing the feasibility of carrying out a European Health Examination Survey (HES) or repeated HESs in EU Member States.

The presented below if continued by the European Health Examination Survey (EHES) Project (2009-2011).

The key results of the Project are published in following three reports:

- Tolonen H, Koponen P, Aromaa A, et al. (Eds.) Review of Health Examination Surveys in Europe B18/2008, Publications of the National Public Health Institute, Helsinki 2008 Also available from http://urn.fi/URN:ISBN:978-951-740-843-1
- Tolonen H, Koponen P, Aromaa A, et al. (Eds.) Recommendations for the Health Examination Surveys in Europe B21/2008, Publications of the National Public Health Institute, Helsinki 2008 Also available fromhttp://urn.fi/URN:ISBN:978-951-740-838-7
- Tolonen H, Koponen P, Aromaa A, et al. Recommendations for Organizing a Standardized European Health Examination Survey B22/2008, Publication of the National Public Health Institute, Helsinki 2008 Also available from http://urn.fi/URN:ISBN:978-951-740-840-0

4. National nodes, feasibility and contribution DIPoH

The National Node (NN) fulfils two main roles: (i) coordination and governance of national health information; and (ii) health data management. These roles are not exclusive to one entity and can be performed by multiple entities within the country. Therefore, the roles of the NN may differ for each country and the total package of functions may include more than those activities relating to DIPoH, depending on the needs and wishes of each particular country. In general, the NN strengthens the national health system both by connecting the relevant national actors and by exchanging expertise in the international arena.

Coordination and governance

Within its first function, the NN is a group of experts and institutions that functions as the national liaising pin to DIPoH and is responsible for the representation of their country in the board and its committees. The experts will have a very good overview of the national and regional health information system(s) as well as the population health research programs and projects (know who has the data, what the data are like in general or knows whom to contact). The experts will also have adequate knowledge of what is going on in the European health information arena (WHO, OECD, Eurostat and other EU Directorates such as SANTE and RTD) in terms of their work and research initiatives on health information, data delivery, indicator development and policy relevant reporting. Furthermore, they will also be in contact with and support national experts that participate in existing or new research networks and organise temporary support for capacity building in relevant topics.

As NN's main function is coordination and knowledge brokering, NN's should be in close contact with the Health and Science Authorities, to link and exchange with national policy priorities for the international health arena. With their knowledgeable overview of the national health information system the NN experts will have a good grasp of the needs and priorities for improvement and possible support from the expertise that is present in DIPoH and its related networks.

Data management

The second role of the NNs seek to elicit and gather the knowledge on institutions and experts whose foundational business is the collection, curation and maintenance of national or regional data in MSs. These institutions and experts are in charge of providing the meta data, making data FAIR and ensuring interoperability of national or regional data, and defining the modality for reuse of data connected to the DIPoH Health Information Portal. These institutions and experts will also have good knowledge on the strengths and weaknesses of the different data sources in their country. They will guide DIPoH users on how to access the national or regional data, provide options of data linkages between different data sources, and provide access to data for reuse in certain formats, upon request from DIPoH-users.

One of the activities of InfAct, more specifically in WP7.1, is to assist Joint Action partners in setting up the NN function. The aim is to reach out to all MSs and associated countries to support them in the process of the development of the NN. In practice, this means that InfAct assists by providing a stepwise approach on how to set up the NN [3]. 19 countries reported on their progress. Various NN reported stakeholders were enthusiastic about the opportunity to liaise and want to further exchange.

Bellow you can find the state of play of NN activities in countries reflecting the feasibility of setting this up in countries:

1. Austria: First NN meeting expected to take place in December 2019 or Jan 2020- Coordinated by Gesundheit Österreich GmbH
2. Belgium: A NN meeting coordinated by Sciensano took place on 07/06/2019. Meeting conclusion: focal point will be active again by Federal Public Service Health, and will co-coordinate further meetings with Sciensano.

3. Croatia: NN meeting held in October 2019 organised by Croatian Institute of Public Health (CIPH). Participating stakeholders: Ministry of Public Administration, Institute for Expert Evaluation, Professional Rehabilitation and Employment of People with Disabilities, Ministry of the Sea, Transport and Infrastructure, Ministry of Croatian Veterans' Affairs, Bureau of Statistics, Croatian Pension Insurance Institute, Ministry of Justice, Croatian Employment Service, Ministry of Healthcare.
   The meeting included InfAct presentation, introduction of concept of national node, stakeholders introduction, discussion about utility of national node, next steps, next meeting agenda.
   Conclusions: Stakeholders very enthusiastic about the opportunity to liaise. There is a solid information exchange infrastructure, however not utilized well enough. Future plans - possibly include more stakeholders, exchange all of the health data available.
   Next steps: create a mailing list and exchange more detailed info about available information and potential to exchange them. Next meeting planned before end of 2019.
4. Cyprus: No plans for a NN meeting. However Potential stakeholders and coordinators were identified. Health information centres in Cyprus: Health Monitoring Unit (HMU) at the Ministry of Health, and Cyprus Statistical Services (CySTAT) at the Ministry for Finance.
5. Czech Republic: NN meeting planned for November 2019 by UZIS- The Institute of Health Information and statistics of the Czech Republic. Currently in the process of identification of relevant stakeholders at universities and research institutes.
6. Finland: The main actors meet regularly which could potential be seen as a NN, but there has been no meeting regarding InfAct. Social and Health Data Permit Authority Findata starts operating at the beginning of 2020. Findata is a one-stop shop for the reuse of social and health data.
7. Germany: The Committee for Health Reporting and Health Monitoring (GBEMON) at the RKI advises on the design and conceptual development of health monitoring and health reporting. It could be the nucleus for an enlarged national network on health information and advice on its development. The InfAct National Nodes Concept was discussed at the GBEMON meeting (Dec. 2019), and the committee agreed to take on the role of a National Node. The next GBEMON meeting will take place in June 2020, and we have suggested putting the topic of NN on the agenda. However, there might be time constraints due to new agenda items related to the COVID-19 pandemic.
8. Ireland: The Joint Health Data Liaison Group functions as a NN in the country. This group will play an important role in assessing the needs of key users of health data and developing the statistical potential of data sources in this field. It will also facilitate the effective exchange of information on all areas of health data between the main producers and users of such data. This is a joint venture between the Department of Health and the Central Statistics Office (NSI). It is jointly chaired by senior officials from both organisations. It is the plan to hold at least 2 meetings annually. Potential the activities of InfAct can be discussed during one of these meetings.
9. Italy: A project was launched by the National Center for Diseases Prevention and Control (CCM) of the Ministry of Health as support to the BRIDGE Health project: CCM-BRIDGE Project ‘Creation and development of the Italian network supporting

the European BRIDGE-Health project aimed at structuring and providing sustainability to European activities in the field of Health Information (HI)' with the aim of verifying and improving the availability of health information to organize and develop an integrated, sustainable and standardized National Health Information System (HI) to serve both as the Italian hub for a future European infrastructure and as a source of data, tools and methods for health research (2016-2017). ISS, involving also its President, is contacting all stakeholders that could be involved in setting up a national hub on health information. A comprehensive meeting has not been organised yet, but a preliminary meeting has been organised with the ISS President, the MoH representative in the JA AoM representative, and the ISS WP8 lead to discuss the necessary first steps to involve stakeholders to verify interest in a national hub, how to set up the national hub and which institute could coordinate the national hub.

10. Latvia: A meeting titled "a new opportunity for healthcare research" was coordinated by the Centre for Disease Control (CDPC is an institution of direct administration under subordination of the Minister for Health) and the University of Latvia. The participants included the Ministry of Health and additional stakeholders from health care institutions, researchers, and students. The meeting would initiate discussion on new data usage options. Open to follow up meetings or collaboration.
11. Netherlands: A NN meeting took place on 5th of November by RIVM. The meeting included the following stakeholders: CBS, Erasmus MC, Health RI, Nictiz, Nivel, RIVM, Trimbos, VWS, ZonMw. The meeting presented InfAct activities and the concept of a NN for health information in the Netherlands. The expectations of a NN and what can be the aims of such meetings. To conclude the participants agreed for RIVM to set up an initial plan for the NN concept and take the lead to further elaborate based on this meeting and to take first practical steps. RIVM prepared a practical action plan and is now in the process of discussing and implementing this with relevant partners. The Node has terms of reference, defining aims, scope, participants, roles, organization.
12. Norway: There is an already established node for data collection and curation, led by the Directorate of health. Stakeholders include: Ministry, Directorate of Health, NIPH, Directorate of eHealth, Regional Health Trusts, Vendor. Annual meeting with all stakeholders occur every Autumn (Sep. 3-4, 2019).Emphasis of these meetings is on infrastructure, technical quality and harmonized use of information models. In addition to the current node, Norway provided the idea for two additional potential NN based on InfAct priority:

    NN2 Health Data for Governance- lead by Directorate of Health. Currently not meetings take place or formalized group of key stakeholders exists. However, several formal and ad hoc groups based on specific issues (national and international).

    NN3 Health Data for Research and Industry- lead by NIPH or eHealth. Currently no annual general meetings take place or formalized group of key stakeholder exists. However, there is a national program aiming to build a Health Data Analytics platform, led by Directorate of eHealth.

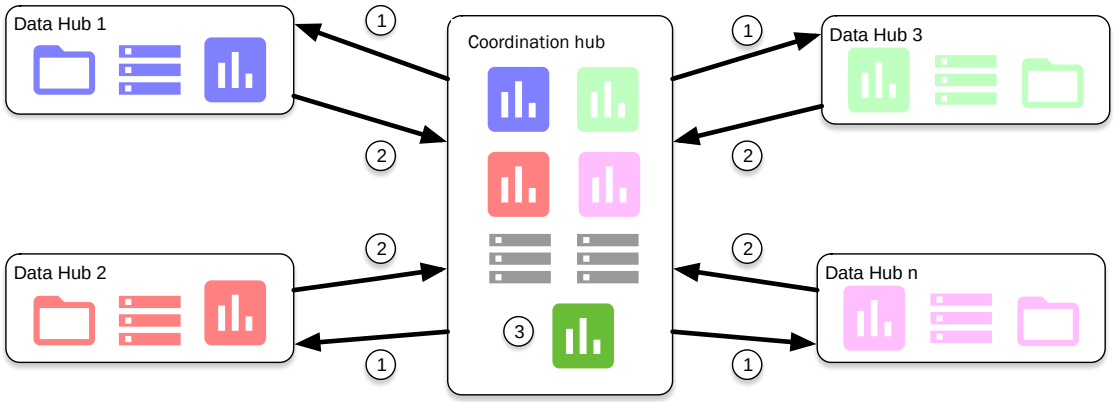
    An online conference for people who work with health information, such as the NIPH, the Directorate of Health, Statistics Norway and all the different health registries has also been suggested.

13. Portugal: Internal InfAct partners in Portugal are preparing for a NN meeting to address to creat a NN, it includes: DGS – Directorate-General of Health, ACSS – Central Agency for the Health System, INSA – National Health Institute, Infarmed – National Authority for medicines and health devices, SPMS – Shared Services of the Ministry of Health, INE- Portugal Statistics, and Academia – Faculty of Medicine of Lisbon, and the Universidade Nova de Lisboa.
    Discussions were held with DGS, INSA and IHMT (INFACT Partner), additional informal conversations with ACSS was held with positive perspectives. Full support from ESFRI Portugal was obtained.
14. Romania: A NN meeting with all stakeholders took place after the InfAct peer review HIS assessment (WP5.1). Coordinating institute is NIPH. There is no second meeting planned yet. But stakeholders expressed there is room for collaboration on common projects.
15. Serbia: Creation of NN announced during last meeting of IPH Network statistical representatives (October 10th). Recent HIS assessment in Serbia (WP5.1) brought together stakeholders (TC, June 11th).
16. Slovenia: There have been bi-annual meetings among stakeholders (National Institut of Public Health (NIJZ), Statistical Office of Republic of Slovenia (SURS), Institut of Oncology, Ministry of Health, Health Insurance Institute of Slovenia, Institute for Macroeconomic Research, Institute for Economic Research) since 2004, jointly held by National Institut of Public Health and Statistical Office of Republic of Slovenia as major health information providers. Also, there are yearly national conferences "Statistical Days" with the aim of information exchange. The last meeting was held on 14 June 2019 in Ljubljana. InfAct was presented in that meeting. InfAct was presented in the meeting 14 June 2019. The next meeting is planned in 2020, there is room for additions joint meetings.
17. Spain: Multiple health research structures of which ISCIII is the main leading institution. CIBER: joint decentralized research centres networks with legal entity. CIBER is a consortia integrated by research groups selected to develop a forefront scientific programme on different strategic fields of interest for the National Health System. RETICS: a Cooperative Research Thematic Network. Composed of an association of Centres and/or Research Groups from different Institutions or Regions, from the public or private sectors, with common research agenda.
18. Sweden: The PHAS leads the National Node for Health Statistics. The collaborating organisations include Statistics Sweden, the National Board of Health and Welfare, and SALAR. Meetings are held twice a year to discuss joint issues with international reporting of data and issues in lieu of international meetings in working groups. Hence the joint meeting is a forum for coordination and coherence at national level. Last meeting was held 26th Sept 2019. Next meeting planned in spring 2020. Potential to present InfAct in the next meeting.
19. United Kingdom: Creation of Health Data Research UK (HDRUK) in 2018, with the vision to work across the UK to exploit the extraordinary capability of informatics and to create a new type of research institute that leads the international agenda in health data science. By working in partnership with academia, NHS, Government, industry, charities and the public, the Institute will be a scientific driving force for new knowledge through data, bringing benefits to society by developing and apply

cutting edge data science approaches in order to address the most pressing health research challenges facing the public.
InfAct discussed at a number of meetings in 2019. Health data and analysis are devolved functions in the UK meaning that each of the four countries (England, Scotland, Wales, Northern Ireland) collects and conducts its own analyses. All physical meetings have been cancelled due to the COVID19 crisis. Each of the four countries has focused on COVID19 analyses and there is increasing collaboration across the UK in answering important policy questions around control and harm minimisation.
In Wales a total population cohort is being developed using multiple existing and new data sources and the Secure Anonymised Information Linkage (SAIL) system to respond to the COVID19 crisis. Intelligence feeds into the thrice weekly Welsh Government COVID19 Technical Advisory Cell that in turn feeds into SAGE (Scientific Advisory Group on Epidemics) and UK Government.

G. DIPoH's architecture

As opposed to a centralized architecture, DIPoH computational infrastructure is envisaged as a federated architecture (see figure) where the motion of raw data between the data hubs and a central repository does not longer exist, so that only the analytical techniques (scripts) move (step 1 in figure). In the hubs, partial results are computed (step 2) and then gathered in a coordination hub (step 3) that combines them to get an overall solution to the research questions (step 4).



A major advantage of this approach lays in the fact that all the analyses with individual-level data are performed in the data hub premises following their own governance rules and regulatory restrictions and avoiding the potential security risks of having sensible data in a single point and the legal restrictions of moving massive data outside regions or countries. In addition, due to the distribution of the analyses into federated data hubs, the magnitude of the potential is larger as the computing capacities multiply.

Three main challenges arise when using this type of distributed architecture: firstly, a common data model is required to ensure interoperability across data sources and data hubs; secondly, the level of complexity of the analytical pipeline is bigger than in a traditional approach as the techniques and algorithms should support the distributed

schema; and, thirdly, the amount of data accessed may erode trust in data holders and Data Protection Officers (DPO). The federated architecture should address these challenges as follows:

- In order to guarantee the interoperability between the data hubs designing a common data model (CDM) is required. A natural option for DIPoH will be building upon an existing CDM structure, such as the OMOP Common Data Model (see conceptual model in page 34 here https://github.com/OHDSI/CommonDataModel/blob/master/OMOP_CDM_v6_0.pdf).

- In order to allow the implementation of techniques and algorithms in a distributed manner while addressing DPO security and privacy concerns, DIPoH will resort to consolidated open access libraries; so, for example, *dislib* library that would allow privacy by design full distribution of statistical techniques; or, *dataClay* library that would allow uniform data management procedures among data hubs

Finally, the DIPoH infrastructure will be developed according to the FAIR principles (e.g., all the code, including data model, the analytical pipeline and the presentation of results, will be developed in open source programming languages and published open access in Zenodo and GitHub repositories) allowing not just the easy access to interoperable products but also the transferability of the methods and procedures to other research domains.

H. DIPoH landscape analysis

Health and care are in transition, moving away from one-size-fits all approaches into customised health (care) tailored to individual needs. These (relatively new) areas of personalised medicine and precision medicine create new possibilities for science and society and also have their own challenges for data- and knowledge collection, management and stewardship (including ethical, legal and social implications - ELSI). Current ESFRI landmarks (ELIXIR, BBMRI, INFRAFRONTIER and others) address these issues. However, in this day and age of increased appreciation for customised health care, it is also increasingly important that the greater picture is not lost. Societies can only function and pay their bills if a sufficient part of the population is in good health. It is important that data is collected in large representative samples of the population and continuously investigated to see where gains can be made, including gains possible through comparisons with other regions or countries. There is a need for continued effort to generate better coherence of health information activities in the EU, for example harmonisation of health indicators and monitoring tools across Europe and hosting health related-databases and their metadata on the full domain of health.

The ESFRI Health & Food RI landscape is consolidating firmly in the European Research Area (ERA) with currently 10 Landmarks (6 of which are ERIC's) and 6 Projects covering the vast remit of health, agri-food and the bio-economy. The broader landscape includes Energy, Environment, Physical Sciences & Engineering, Social and Cultural Innovation, e-Infrastructure (Reflection Group) and Data computing and digital research infrastructures.

What is lacking is the holistic view throughout human lifetime on the effect of lifestyle, the environment and health services on human health and disease, as well as the impact of health on society. The DIPoH can contribute to this bigger picture.

DIPoH will strengthen the ERA by providing joint access to better and comparable data, tools and methods. Joint research across Europe requires joint access to the data collections, across national frontiers. By interconnecting these collections and providing virtual access, DIPoH constitutes a key facilitator for transnational research in health information. This will give the ERA new impulses.

None of the existing ERICs deals with health information on population health and health system performance. Completing the landscape with DIPoH is crucial to better address the challenges that we face, notably in the provision of sustainable information on population health and health system performance. DIPoH appears as a legacy of EU Public Health actions having been able to take on board scientific-research techniques and tools to the field of health information, but not under DG RTD umbrella, which has been the typical start-up environment of ESFRI initiatives.

In order to generate readiness to meet the challenges and demands, the Health & Food RIs need to continue connecting with each other and with the entire scientific landscape, using their different competences and technologies at the service of the user community. Health & Food RIs provide complementary and synergistic infrastructure facilities, and contribute to building the ERA by among others, delivering synergies and highly interoperable research processes, creating seamless value chains, identifying and accelerating the development and integration of technologies into the infrastructures to meet emerging needs; generating opportunities to maximise the competitiveness of Europe's knowledge-based industry and the bioeconomy; providing training and education to current and future Research Infrastructure professionals; attracting and retaining world-leading scientists within the ERA.

Synergy can be created with other research infrastructures when it comes to translation of knowledge in medicine (EATRIS), use of samples (BBMRI), use of multicenter cohorts for clinical research (ECRIN), use of bioinformatics (ELIXIR, INSTRUCT), etc… as well as with the other fields which all share a link to health. Health Information RI could be the holistic link to the other health RI's as well as to RI's in other areas (see Table 5.2).

Synergy will also created by all RI's:
-joining in the FAIR principles (Findable, Accessible, Interoperable, Reusable) as a guide to data publishers and stewards and
-being interconnected through the European Open Science Cloud (EOSC) and European Open Science Space in virtually storing, sharing and re-using their data access across disciplines and borders. EOSC will ensure that computer science is an inherent part of the ERA.

The combination of research capability and capacity of ESFRI RIs and Integrating Activities (IAs) enhances the landscape and accelerates the transfer of data and technologies into services and innovation.

Other relevant initiatives to collaborate with

- Joint European research programme To-Reach (https://to-reach.eu/)
- Collaborative Data Infrastructure (CDI) EUDAT (https://www.eudat.eu/)
- Design studies, for example The European Cohort Development Project (ECDP, (https://www.eurocohort.eu/)

The various DIPoH partners through the InfAct consortium also participates in the HealthyCloud application for the European Health Research and Innovation Cloud. HealthyCloud brings together five recognized Research Infrastructures from the European Strategy Forum on Research Infrastructures (ESFRI), including health-related activities across Member States such as ELIXIR, ECRIN, BBMRI-ERIC, EATRIS and Euro-BioImaging; Joint Actions devoted to fostering the use of health data to perform better research on population health, innovative cancer control and eHealth technologies developments, such as InfAct, iPAAC and eHAction; public health institutions, health systems representatives and research institutions with long tradition of health data management, including IACS, Sciensano, THL, TMF, GÖG and SAS; world-class experts on High Performance Computing and cloud computing, including BSC, CSC, EGI and de.NBI Cloud; and top research and academic institutions with expertise in ethical, legal and societal aspects, FAIR principles, and health and biomedical sciences, such as UNILU, LUMC, SAS, EMBL, CRG, UB and UTARTU. By preparing the application close collaboration with exisiting RI was already fosters bringing together the worlds of exact and life sciences and population health.

Table 5.2. Selection of ESFRI landmarks and projects/ERIC most relevant to DIPoH

Name	**Full name** **[scope]**
BBMRI ERIC	Biobanking and BioMolecular resources Research Infrastructure [Biobanking]
EATRIS ERIC	European Advanced Translational Research Infrastructure in Medicine [Translational medicine]
ECRIN ERIC	European Clinical Research Infrastructure Network [Clinical research]
ELIXIR	A distributed infrastructure for life-science information [Bioinformatics]
EU OPENSCREEN ERIC	European Infrastructure of Open Screening Platforms for Chemical Biology
ESS ERIC	European Social Survey
ERINHA	European Research Infrastructure on Highly Pathogenic Agents

ISBE	Infrastructure for System Biology Europe [Systems biology]
INSTRUCT ERIC	Integrated Structural Biology Infrastructure
METROFOOD-RI (Food)	Infrastructure for promoting metrology in food and nutition [Food and nutritional metrology]
MIRRI (Food)	Microbiol Resource Research Infrastructure
CLARIN	European Research Infrastructure for Language Resources and Technology
DARIAH	Digital Research Infrastructure for the Arts and Humanities
SHARE	Survey of Health, Ageing and Retirement in Europe

I. DIPoH financial contribution model

The funding needs for the set-up and maintenance of first phases of DIPoH have been estimated at 4.6M €/year including in-kind contribution. However, DIPoH Design will further develop and suggest a business case model to enable informed deployment of DIPoH. The cost and financial framework include resources needed and revenue models, as well as the financial mechanisms that will determine and regulate economic flows among all stakeholders for the sustainability of the RI.

DIPoH's relies on it member contributions for its operational functioning and longevity. The DIPoH RI will have different types of contributors:

- Countries/MSs
- Researchers and Networks
- Data owners: universities, agencies, etc.

The income from membership contributions will depend on the final structure of committed partners and types of contributors (individual, network, organizations), which still needs to be decided during the preparatory and implementation phases of DIPoH. The possible sources of income of DIPoH are fee for services, direct funding, including membership fees and in-kind contributions that will enable the DIPoH to pay for its expenses.

Contributions will depend on the estimated costs of the services and functions and the de facto net revenues of DIPoH's services. The size of the contributions will also depend on the final structure of committed partners and types of memberships. For MS/AC, a direct financing structure will be developed based on: 1) a fixed fee, 2) a variable fee (possibly based on GDP). This model will come into effect once DIPoH legal entity has been established and DIPoH is operational.

For example: Contribution = xGDP + yP, the x and y may be higher at the start of the RI, if less than 30 MSs participate. Conversely, DIPoH can start with this type of contribution from a smaller group of countries plus an external contribution that decreases over time.

Beside the possible income as contributions from membership fees, there are possibilities for income from contracts (projects) by for instance, the EC, charities and the private sector. These need to be developed in a marketing strategy that would involve the development of a services portfolio, based on a thorough market analysis, prior lobbying and advocacy towards relevant stakeholders and potential customers.

Furthermore, MSs already invest substantially in kind by supporting and financing national data collections, by delivering data to and collaborating with international research networks. The costs of those numerous data collections for all EU MSs cannot be easily estimated, but they form the underlying basis for many international research networks that collect and compare international data. Moreover, the MS and their institutions often provide support in kind to do the extra work of sending harmonised and selected datasets international networks and in contributing to the following research output.

The international networks in turn each have one or more centres with experts that spend time and financial efforts in organising and managing the network and the data collection and analysis that goes with the work. DIPoH will also require a general membership fee from the networks. If the networks would 'sell' other assets through the health information portal a percentage fee could go to the RI as another option. All this results in a general picture of the possible sources of income (Fig. 5.5) of the RI in terms of fee for services, direct funding, including membership fees and in-kind contributions that will go into the RI and enable the RI to pay for its expenses.

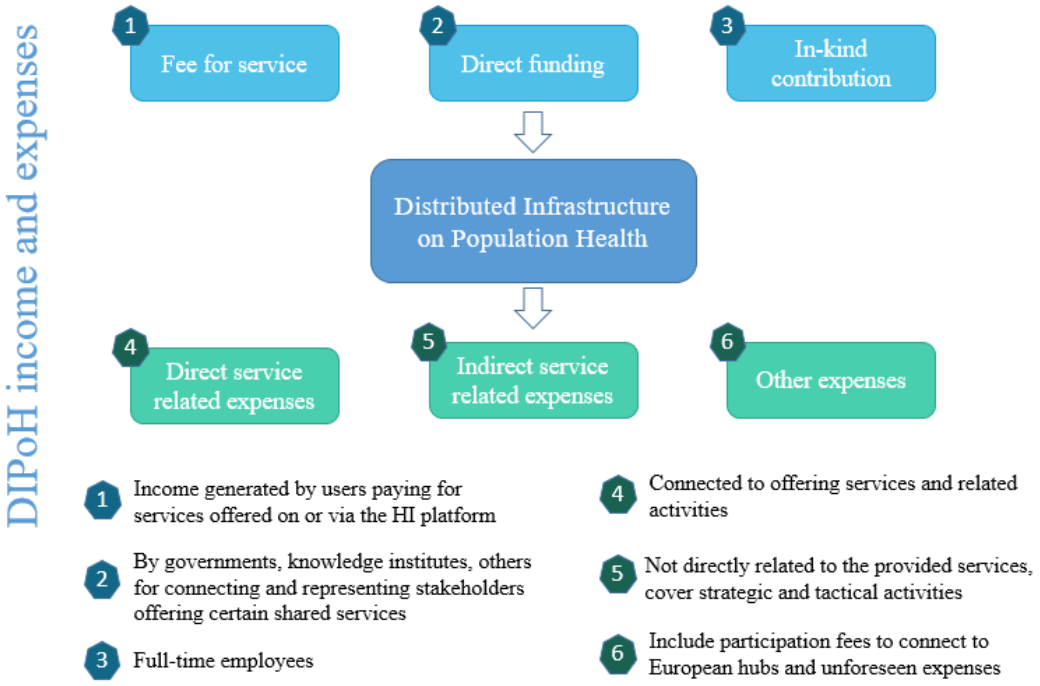


Figure 5.5: DIPoH income and expenses[8]

[8] Health Research Infrstructure. Business plan Health-RI. Presentation December 8, 2017.

J. DIPoH phases and succession of governance

DIPoH development will proceed in accordance to the stipulated ESFRI phases, each phase will be characterised by the following governing and management models:

- Proposal development phase (2018-2020) falls under a standard project management model.
- Preparatory and implementation phases (2021-2028) will follow an interim governance and management model.
- Operational phase (2028 onwards) will follow an operational governance and management model which will be finalised during the previous phases.

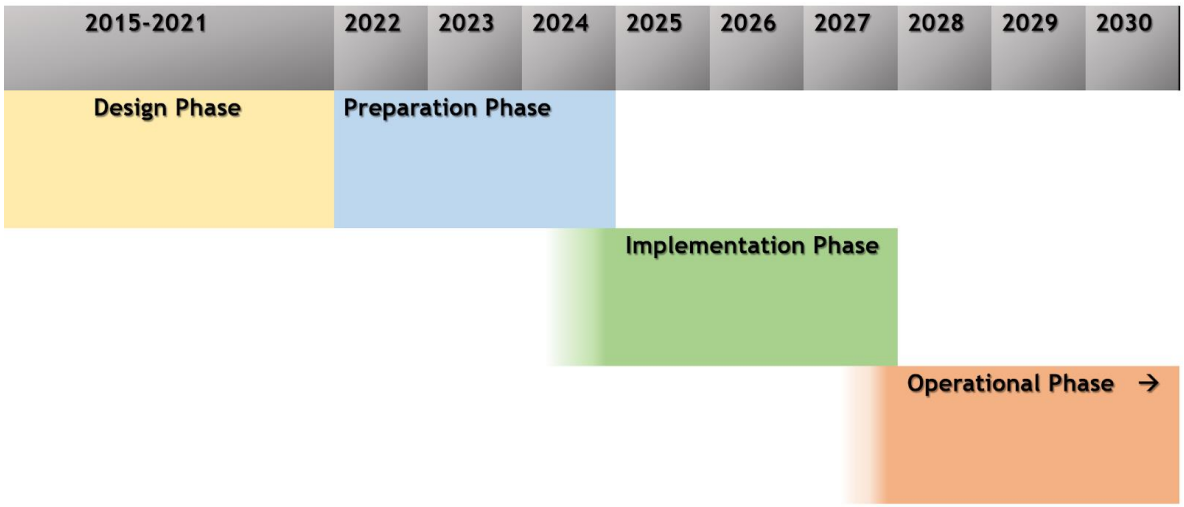


Figure 5.6. DIPoH phases

K. DIPoH's stakeholders engagement strategy

This section describes the strategy to engage stakeholders in DIPoH. Stakeholders can be data curators, data users and data holders. The focus is on reaching out to stakeholders working in health information across EU countries and to enhance their implications whilst being on the ESFRI roadmap and to have a broad reach on research communities that could liaise with DIPoH for a greater impact on the medical and non-medical determinants of health.

InfAct has already interacted with many partners in the EU health information landscape including other EU- RIs, European Commission, the European Public Health Association (EUPHA), academics and academic organisations such as the Association of Schools of Public Health in the European Region (ASPHER), the International Association of National Public Health Institutes (IANPHI) and others. It has also set-up regular Assembly of Members meetings which include representatives of Ministries of Health and Research to raise awareness of the need for DIPoH and advocate to increase its support among MSs. DIPoH will explore and compare methods for extending interaction and involvements to other groups such as patient and citizens groups, non-governmental organisations, and citizens at large.

Objectives

The purpose is to (1) raise awareness about DIPoH and the relevance of research on population health and its essential position in evidence informed guidelines and policy practice (2) inform the community about the challenges in EU health information and the solutions DIPoH can bring, (3) engage the research community in health information activities of DIPoH, (4) promote and support the use of the research evidence generated by DIPoH.

Target groups

The target groups are first and foremost population health research communities working at national and Pan-European level, and involved in international EU health research networks. As the ESFRI phase progresses, the Ministries of Health and the Ministries of Research within the MSs will be increasingly engaged to contributes to better access to existing knowledge and expertise at national level.

Researchers: A central tenant of the strategy will rely on promoting the services that will be available through the creation of the Health Information portal for EU Population health research. Through services, researchers will have facilitated access to high quality comparative data; generation of new research hypotheses; improved streamlining of research efforts; international comparison and learning through exchange and priority-setting; The added-value will lie in a much strengthened and well-integrated, world class population health research community in the EU. Population and patient health data and health care systems data will be available at individual and aggregated level from many sources, among others, disease registries, routine administrative health and non-health databases, surveys and health examinations, and cohorts of populations and patients. This will promote more and better spread research collaborations between national researchers in the EU/EFTA MSs, enhanced exchange of best practices among them, increased harmonisation of data and definitions, indicators, tools, guidelines and methods for the EU and its MSs. A large increase in well-accessible, comparable health data will be another important outcome.

Decision-makers: The RI will enable national and regional decision makers to make use of a well organised network of health research expert networks and knowledge repositories, to support evidence-informed decisions, priority setting and programme evaluation. The RI facilitates the availability of EU health information and integrates national data into an international context for better knowledge and stronger evidence to build on. The RI will provide a structure of exchange where policy makers can feed their own expertise back into the research community and can influence knowledge gaps being filled.

National and regional public health agencies, research agencies and health or national statistics offices: From the work by the research networks there will emerge exchanges of good practices and expertise among MSs in the area of interoperability and reuse of health data and about possible steps towards building 'big data' systems by data linkage and about the innovative use of artificial intelligence in this type of research. European harmonisation, standardisation and collaboration in this area is crucial for the future of European health research. The RI will in this way also be able to contribute to improvements in cross-border data exchange and research. This will profit the generation of EU real-world data, higher

data quality, the production of more comparable evidence to support policy continuity over long periods, larger study populations and cohorts, enhanced data access and research capacity.

EU Member States: MSs will benefit by having their researchers and experts participate in ever stronger international health research networks, with a broader and more sustainable flow of research data available for benchmarking, policy evaluation and implementation research. For some MSs it will mean opportunities to strengthen their national expertise, research potential and data availability. They would benefit from capacity building via the RI. The EU may also benefit from the RI by asking it or one of its participating networks to deliver comparative topical health reports, specific research syntheses or input from advisory and expert committees that are recruited from among the participating networks.

Healthcare providers: Exchange on best practices, capacity-building and skills development in the use of population health data collection and analyses (available through the Health Information portal).

Citizens: Better access to research evidence from the Health Information portal and streamlining of evidence-informed choices by citizens.

Administrators and data providers: reduction of administrative burden by harmonisation and reduction of duplication, improved training capacities

Funders: Better return on investment from research and routine data systems, optimised funding allocations. Public finances will deliver human and economic benefits. Health care is the second largest area of public spending by EU MSs and takes up almost 10% of GDP in most MS. A large part of this is spent on treating NDCs. NCDs significantly affect not only patients' life but also patient's working and social environment which, considering their scale, greatly affect societal stability. A substantial proportion of the direct and indirect costs of NCDs in Europe could be saved through preventative policies and actions [28]. Along the same lines: health inequalities have been calculated to account for about 20% of the total cost of healthcare and 15% of the total cost of social security benefits [29] .

An Australian analysis estimated that investing in public health data linkage and ensuring the accessibility for population health research will deliver considerable return on investment (from 12 to 16 to 1) [30]. A systematic literature review into the return on investment of public health interventions in high-income countries (covering health protection, health promotion, legislative, healthcare and wider determinants interventions on both local and national level) showed a median return on investment being 14 to 1 [31]. The authors concluded that public health budget cuts represent a false economy, as in the longer term they are likely to generate billions of pounds of additional costs to health services and the wider economy.

The Members of the Research Infrastructure (RI): there will be specific benefits directed at facilitating the establishment of new research projects in synergy with each other and having instant access to each other's expertise. This includes dialogues and seminars on key health information-related issues, connecting researchers, stakeholders and policymakers and different forms of knowledge and information. The RI will also coordinate the services that are offered for a fee (See Section 1.3a).

Other EU-RIs: The DIPoH will be an instrument to share on a European scale results obtained through national or international research activities. It will allow to interconnect researchers, their data models, methods and results across national and discipline borders. DIPoH will further explore how the population health EU-RI will integrate in the current European research landscape and liaise with other partner research networks taking part in the new EU Health Programme (Horizon Europe). This relies on outreach to the leads of these project to explore potential synergies for research on the population determinants of health at EU level and a workshop is planned. A first teleconference in the starting phase of the project with RI leaders will be an opportunity to receive feedback, share experiences and discuss joint problems and issues. If possible, meetings will take place face to face with other RI leaders; international conferences in public health (European Public Health Conference, European Health Forum Gastein) will provide further opportunities to increase the visibility of the project and engage other research communities.

None of the existing ERICs deals with health information on population health and health system. Completing the landscape with an RI on Health Information is crucial to better address the challenges that we face, notably in the provision of sustainable information on population health, including health status and health determinants, and health system performance. DIPoH appears as a legacy of EU Public Health actions having been able to take on board scientific-research networks, research techniques and tools to the field of population health information, but not under DG RTD umbrella, which has been the typical start-up environment of ESFRI initiatives.

Synergy will also be created by all RI's joining in the FAIR principles as a guide to data curators and publishers and stewards, and being interconnected through the EOSC in virtually storing, sharing and re-using their data access across disciplines and borders. EOSC will ensure that computer science is an inherent part of the ERA. The combination of research capability and capacity of ESFRI RIs and Integrating Activities (IAs) enhances the landscape and accelerates the transfer of data and technologies into services and innovation. Other relevant initiatives to collaborate with include: Joint European research programme To-Reach (www.to-reach.eu); Collaborative Data Infrastructure (CDI) EUDAT (www.eudat.eu); and other design studies, for example The European Cohort Development Project (ECDP, (www.eurocohort.eu) and private-public initiatives such as EMIF (www.emif.eu).

European Commission: Setting up DIPoH will require close cooperation with the European Commission throughout the different phases leading up to the establishment of a sustainable structure for EU population health research. This includes meetings with:

- Expert groups such as the European Expert Group on Health Information and Health System Performance.
- The different Directorates-General: DG SANTE, DG RTD, DG JRC, DG Eurostat, etc.
- The various agencies of the Commission: CHAFEA, ECDC, EMCDDA, etc.

International organisations: Project results will be communicated to different international organisations in the European and international health information landscape. This will build

on previous exchanges started during InfAct with the Organisation for Economic Co-operation and Development (OECD) and the World Health Organisation Europe (WHO)and The International Association of Public Health Institutes (IANPHI). IANPHI will also be a key partner in developing capacity-building material and services to provide on the Health Information portal for population health research.

L. DIPoH preliminary Data Management Plan

DIPoH will generate and/or collect information or data that will be subject of a detailed Data Management Plan. All the Consortium Partners involved will be required to make all information and data findable, accessible, interoperable and reusable, as foreseen in FAIR principles. The data management plan will also include an agreement for the joint management of ownership and access to key knowledge and DIPoH foreground, according to the European Open Data principles. The Data Protection Office team at Sciensano has provided guidance in preparation for the data management plan, and will provide further assistance during the course of the DIPoH development process.

Types of data to generate/collect

DIPoH is expected to generate or collect: (1) data from a survey conducted to elicit the research needs of researchers and policy makers in Europe; (2) meta-reports on existing experiences on population health research in Europe; (3) metadata from national data sources that could eventually serve as data origins for research purposes; (4) individual and aggregated data and metadata from different countries; (5) open source software and analytical tools generated by DIPoH or collected from other RIs; and (6) scientific manuscripts produced as a consequence of the project.

FAIRness of data

The data environment generated by DIPoH will be made public in the Health Information portal in accordance to FAIR principles and Open Data provisions. In turn, the data, metadata or tools collected from other institutions, research networks or data infrastructures will have a link to the original sites and be respectful with the data management provisions of the owners. The primary audience of the portal will be the research community. In any case, access to this data environment will be granted at this stage standard identification engines (e.g. persistent and unique identifiers such as Digital Object Identifiers) and stored in standard formats to allow the widest possible data exchange and reuse.

The Health Information portal will contain a standard searching protocol (e.g. DUBLIN core) to allow any potential user to have access according to their interests. Potential users include the scientific community, policy makers, public health professionals and the general public. Each entry should include at least:

- Unique internal persistent identifier of the document made public in the website;
- Name, acronym, authorship, publication date, and funding details;
- Type of document
- Key audience
- The key terms preferably headings from the MESH National Library terms

- Details on the terms of access (embargo, under subscription, etc.)

Data curation and preservation

As a general provision, DIPoH will develop a data management plan. The data management plan will contain a specific section on curation, maintenance and persistence of the data environment generated or collected by DIPoH. In the first case, assuring continuity and in the second case, assuring proper linkage to the original sources. It will assure record of any type of data generated or collected by DIPoH, with a focus on transparency and accountability in the methods and achievements. For that purpose, at the coordinating institute, Sciensano, the project will be audited both by internal and external audits under ISO9002. The data management plan and its documentation will be part of this audit. The data management plan will be also reviewed by the Data Protection Office at the coordinating Institute. Finally, data and results produced as a consequence of DIPoH's services will be stored in secured server of Sciensano.

M. Technology Readiness Levels

The Technology Readiness Levels (TRL) of the DIPoH Research Infrastructure varies between its components from Fundamental research (TRL1) to Technological researcher (TRL2-6). BRIDGE Health and InfAct have contributed to various levels of the development of DIPoH (Table 5.3). The contribution of InfAct to DIPoH are described more in length after the table.

- TRL 1 – basic principles observed
- TRL 2 – technology concept formulated
- TRL 3 – experimental proof of concept
- TRL 4 – technology validated in lab
- TRL 5 – technology validated in relevant environment (industrially relevant environment in the case of key enabling technologies)
- TRL 6 – technology demonstrated in relevant environment (industrially relevant environment in the case of key enabling technologies)
- TRL 7 – system prototype demonstration in operational environment
- TRL 8 – system complete and qualified
- TRL 9 – actual system proven in operational environment (competitive manufacturing in the case of key enabling technologies; or in space)

Table 5.3. The Technology Readiness Levels of DIPoH

Element		**Achieved during BRIDGE Health and InfAct**
One-stop-shop for EU health Information Research	Metadata catalogue of existing health information projects and networks	TRL2: A review of existing health information networks is conducted by InfAct and based on that formulation of metadata needs is prepared. TRL7: A prototype of the metadata catalogue of an initial set of network is being set up in InfAct and tested in operating environment (Health Information portal) (InfAct-WP5,7,8,9,10)

Element		Achieved during BRIDGE Health and InfAct
	Metadata catalogue of existing health information data sources	TRL2: A review of types of data different health information networks and national health information systems host is conducted by InfAct and based on that formulation of metadata needs is prepared TRL7: A prototype of the metadata catalogue of data sources has been set up and tested in operating environment (portal prototype) (InfAct-WP4, 7,8)
	ELSI and FAIR guidelines	TRL2: Several research networks have prepared their own ELSI and FAIR guidelines which have been summarised in previous project (BRIDGE Health) TRL7: ELSI and FAIR guidelines are demonstrated in the different settings and made available in the portal prototype (InfAct-WP10)
Innovative research in health information	Leading-edge study designs and analytical methods	TRL4: Several proofs of concept have been / are being tested in controlled environments (BRIDGE Health and InfAct) TRL5: Machine-learning techniques has been applied to the administrative health databases to estimate the prevalence of diabetes type I/II and to predict the incidence of diabetes cases (InfAct-WP9), Methodological guidelines are in the preparation phase to use linked data and machine learning techniques for population health research with practical examples of research studies (WP9).
	Semantic and technological interoperability across datasets (within and between countries)	TRL4: A review of existing research networks (BRIDGE Health) reveals that most of population health research has been conducted using rigid data schemas and centralised data infrastructures collecting aggregated information TRL3: Existing health data collection methods in EU by: i) reviewing and identifying standardized data collection methods and related quality assurance procedures; and ii) elaborating common procedures and guidelines for accessibility and availability of health information both for individual-based data and health indicators. TRL6: Use cases (InfAct-WP10) will demonstrate the feasibility of using common data models in distributed infrastructures implemented in real-life environments

Element		Achieved during BRIDGE Health and InfAct
Capacity building in health information	Standardised protocols and guidelines exists	TRL2: the baselines for a European Capacity Building strategy: As a flexible structure of courses and other capacity building activities, modules and training plans, covering all the areas related to Health Information easily tailored to tackle the different needs and inequalities. (InfAct-WP6) TRL4: Several EU level health information networks have prepared standardised protocols and guidelines which have been used in different studies (summarised by BRIDGE Health) TRL5: Distribution of existing protocols and guidelines through portal prototype for larger audience (InfAct-WP5, 7, 8, 9, 10)
	Static training materials	TRL3: Some EU level networks have prepared statics training materials (summarised by BRIDGE Health) E.g. Training material about BoD concept, methods and translation of BoD estimates into health policy is available on web-based platform (InfAct-WP9). TRL6: An online flagship course was designed and tested, addressing the following thematic areas: data analysis & interpretation, especially interoperability of data sources, derivation of European Core Health Indicators (ECHI) indicators and foresight/scenario analysis; transfer from data to policy, especially policy translation tools and data presentation. A database on training courses in health information is centrally hosted on web-based platform (InfAct-WP6)
	Interactive training materials/ webinars	TRL1: A review of existing interactive training materials is prepared in InfAct TRL7: The online flagship course provides specific interactive training materials on data collection methods, sources of data, metrics and indicators, especially related to health examination surveys; and data privacy and ethical issues (the EU General Data Protection Regulation - GDPR).
	A European level training programme for health information	TRL2: A review of existing training opportunities is conducted and a roadmap for future development is prepared in InfAct TRL7: A pilot of a flagship European health information training course has been carried out

Element		Achieved during BRIDGE Health and InfAct
		covering the fundamental aspects of health information (InfAct- WP6)
	Assessment of Health Information System	TRL7: To strengthen the capacity in nine European countries, peer health information system assessments have been carried out. Guidelines have been developed on how to carry out a health information system assessment in peer review format. It also performs a mapping exercise to assess national health information systems and establishes an information base where stakeholders can contact international expert networks, projects and organisational bodies collecting comparable health data.
Knowledge translation research for evidence based decision-making	Health Information impact index	TRL3: A review of existing tools and a prototype of the index has been developed within a post-doc project (BAHCI, H2020-MSCA-IF-2017, GA 795051), linked to InfAct
	Integration of research outputs in national policies	TLR5: a) MS involvement through health and research authorities; b) integration of the InfAct's outcomes into policies at regional, national and European level; c) strengthen national health information consortia involving health and research authorities through national nodes TRL6: The European health information training course provided a testbed for the use of knowledge translation research in health information (WP6)
	Innovation on health information for public health policy development	TRL5: Identifying inspiring examples from MSs with regards to innovation of data sources (i.e., use of data linkage and/or applying artificial intelligence) to estimate health indicators, which could be potentially useful to target priority public health actions and healthcare strategies. Development of best practices and guidelines to enlarge the set of morbidity indicators available across the EU using innovative techniques.
	Piloting interoperability for public health policy	TRL2: Methods and techniques used to get sound knowledge out of data linkage, sharing, management and reporting

Contributions to feasibility of DIPoH by InfAct

InfAct is a proof of concept of DIPoH. Various activities were piloted and tested. All outputs of InfAct can be found here: https://www.inf-act.eu/InfAct-outcomes. It further refined the business case and roadmap for implementation of DIPoH and developed governance structures, national nodes and research networks as described above. It worked towards political support and sustainability of DIPoH at national and international level based on the following pillars: a) MS involvement through health and research authorities; b) integration of the JA outcomes into policies at regional, national and European level; c) strengthen national health information consortia involving health and research authorities. It presented the concept of DIPoH to key international organisations, at various international conferences and interacted regularly with Ministries of Health and Research through Assembly of Members. All the presentations from the Assembly of Members can be found here: https://www.inf-act.eu/assembly-members. The Assembly of Members is planned to converge to the Assembly of Members of DIPoH. In the last Assembly of Members foreseen in the fall of 2020, a sustainability plan will be presented. This will present outputs of InfAct that have provided a proof of concept of activities foreseen in DIPoH. Also Technical Dialogues were hosted by InfAct where national experts could provide feedback to the construction and some of the activities of DIPoH piloted during InfAct.

1. Governance DIPoH

Summary of achievements related to governance of DIPoH:

InfAct developed a business case describing the whole RI that can be implemented after InfAct, building on previous work and taking into account new developments. It includes:

- Mission and vision of DIPoH;
- Short-term and long-term sustainable strategy;
- Analysis of the information needs of current health policies in MSs and the EU;
- Development of the final management structure;
- Identification of users and criteria for development of service definition;
- A scoping study to select and specify services with highest utility;
- A short-term and long-term time planning and cost estimation, including high and low estimates for the tasks to be executed and personnel involved;
- Added value of the DIPoH for its financers;
- Market space of DIPoH in the EU health information landscape.

Based on the experiences, pilots of the JA, the business case is translated into a 5-year operational HIREP-ERIC road map with a detailed work plan including specific objectives, outcome and deliverables.

InfAct developed an interim and final governance structure for DIPoH. The terms of reference of the Network Committee were developed.

InfAct supported the set-up of National Nodes on Health Information. The exact format is tailored to the MS' specific needs, but the basic structure will provide the basis for MS exchange of information after the end of the project.

InfAct has worked with key Research Networks, which will be at the core of a future RI, to gain insight on both their needs and contribution to the RI

Quality criteria that have been created by Research Networks to help monitor the performance of the networks and serve as guidance for new Research Networks can be used in the future and also by countries: When they would like to participate in an international network what standards should they pay attention to. These criteria can be used in this context.

InfAct prepared Letters of Political support, Letters of Financial commitment, Memorandum of Understanding, collaboration Agreements, which show interest in support for the RI.

A Health Information portal (single entry point) is set up and will be maintained after the project. The portal will be the gateway for potential users to make use of the services of DIPoH. 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.

2. One-stop-shop for EU health Information Research through Health Information Portal

The Health Information portal contains repository functions for technical reports and scientific articles, methods and tools, health information projects, indicators/data sets, information on national nodes, research networks, and training programmes. The website includes various search options, upload and reporting (summaries, tables, (geographical) tools as standard functionalities for community actions and discussion forums). The development makes use of standards as given by Inspire and the FAIR principles (Findable, Accessible, Interoperable, and Reusable). Together with the partners of InfAct and the network of networks, the portal will provide a catalogue of metadata of the health data sources that are available and useful for population health research. A structure of the web-based portal is developed and piloted with 4 country representatives (NN) and with 5 RNs to come up with the best way to present the metadata for the (future) users of the Health Information platform. Working together with the NNs and RNs within the scope of InfAct ensures that the platform is designed in a way that responds to the needs of the user communities of the future Research Infrastructure DIPoH. It is also designed in a flexible way in order to respond to needs that may come up at a later stage as DIPoH progresses.

Cataloguing international health information collection networks, projects and indicator/data sets

In InfAct we searched PubMed, Embase, Scopus, Google, Cordis and the CHAFEA project database for (1) expert networks that collect comparable health data in Europe, as well as (2) previous and on-going health information generating projects with EU coverage. The aim was to create a sustainable information base to be used on the EU health information infrastructure web portal. This catalogue will function as a knowledge repository and solid base to connect experts and build on work from the past. A manual for a sustainable update procedure will specifically accompany such a catalogue. InfAct also developed criteria to assess the scope, quality, impact and performance of research networks. By fulfilling

several or all of these criteria Research Networks will serve the overarching aims and goals of DIPoH.

Generating knowledge on data collection methods, and availability and accessibility of health information

A report on data collection methods and quality assurance for a common health information system is provided based on the findings of a cross-sectional study involving all MSs' representatives participating in InfAct. The study identifies national data collected for population health monitoring/public health surveillance and health system performance assessment with standardized methods that are not incorporated into existing international datasets (e.g., WHO, OECD, Eurostat). The study an inventory of identified projects/studies and their description in terms of data sources used, quality assessment of their data collection procedures, metadata-reporting standards used for data description, and availability and accessibility of health data and indicators. The report will contribute to the development and the sustainability of the European Health Information Portal by providing standardized and comparable health data collections, types of indicators and metadata reporting standards used in the projects/studies. The provided material, therefore, facilitate the assessment of health inequalities across EU countries in terms of data collection methods, quality assessment, availability, accessibility and comparability of health data and information. Sharing and dissemination of standardized and comparable health data collections is also facilitated through the Health Information Portal. The report could be used for training programmes on health data collection methods and quality assurance procedures.

3. Innovative research in health information

InfAct facilitated various innovative research activities. Some of them are summarized here and can be taken forward with DIPoH.

Innovation in health information for public health policy development

The use of data linkage and/or artificial intelligence (AI) to estimating health indicators is called as innovative use of data sources. The majority of European countries use data linkage in routine for public health surveillance and research purposes. However, the use of AI to estimate health indicators is not frequent at national institutes of public health and health information and statistics. Using linked data, 46 health outcome indicators, 34 health determinants and 23 health intervention indicators were estimated in routine by InfAct. 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:(i) more flexible data governance frameworks to support data linkage of different data sources should be encouraged, (ii) specific mandates to ensure data availability/access/capture and safe storage should be an integral part of a national/regional health information system, (iii) Differences in the implementation and interpretation of the EU General Data Protection Regulations (GDPR) and additional national regulations should be mapped and if possible harmonized across EU-MSs, (iv) more

collaborations and partnerships should be encouraged to build up capacities for using new health information related technologies, to share new methods, skills, experiences and data for comparative research studies among EU national institutes of public health, health information and statistics, (v) initiatives to strengthen national health information infrastructure should be encouraged and (vi) Ministries of health and research from European countries should provide their financial and political support for the development of integrated national health data hubs/data platforms to strengthen the national health information infrastructure[9].

Development of generic method case study using linked data and machine learning technique

InfAct developed a generic approach to predict a health outcome from linked dataset using machine-learning technique and identified inspiring examples applying these innovative techniques in public health across European countries. The final data set used to develop the ML-algorithm included 44,659 participants and 3468 variables were coded similar. Only 23 were selected to train different algorithms. The final algorithms was a Linear Discriminant Analysis (LDA) model based on number of reimbursements of 23 variables related to biological tests, drugs, medical acts and hospitalization without a procedure over last two years to predict the incidence of diabetes. This algorithm has a sensitivity of 62%, a specificity of 67% and an accuracy of 67%.We have identified 16 studies (12 studies related to data linkage, 2 studies applied machine learning and 2 studies used both data linkage and machine learning approaches) as inspiring examples from ten European countries.These studies covered 14 different domains of public health. Some of these studies applied classical statistical methods such as multilevel linear regression and some of these studies used artificial intelligence such as machine leaning techniques. These studies highlighted that different data collection method, lacking completeness of information or inaccessibility to certain information make challenging to analysing large linked datasets. Using linked data and AI, the methodological and data analysis aspects can be improved. The results of these studies are used to improve public health surveillance, developing prevention strategies, evaluating health care services and guiding health policy process. Inspiring examples help to learn from each other and to develop and adopt new methodological approaches[10].

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. Within the European Union, there are many non-health data that can be used in this context but the integration of such data remains a challenge because it heterogeneity and availability. In this case study, we are piloting “En-risk”, an easy-to-use java/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. The E-PRTR, maintained

[9] Haneef R, et al. “Innovative use of data sources: a cross-sectional study of data linkage and artificial intelligence practices across European countries”, Archives of Public Health. 2020

[10] Haneef R., et al. “Use of artificial intelligence for public health surveillance: a case study to develop a machine-learning algorithm to predict the incidence of Diabetes Mellitus”, (manuscript in preparation).

by the European Environmental Agency, contains annual data on more than 30,000 industrial facilities that reported emissions over a determined threshold of any of the selected 91 pollutants. It downloads the geographic coordinates for each facility from the official web of the E-PRTR, while the user can directly load health data into "En-risk". This way, health information is always stored and managed in the computer of the user in order to guarantee data protection. The application directly calculates: (i) the expected number of deaths or of cases of the selected disease, using as reference the rates by age group and sex for the whole country, and (ii) the distance from the municipal centroids (information obtained from the shapefile) to the location of all the industrial facilities included in the E-PRTR. These distances allow classifying municipalities as exposed or not exposed to industrial pollution. The formulation of the European Directive on Integrated Pollution Prevention and Control (IPPC) and the creation of the EPRTR enable Member States to incorporate information of industrial pollution sources from E-PRTR into health information system, which is homogeneous and comparable among European countries. En-risk facilitates the study of the relationship between pollutant groups, type of industrial sector and health effects such as cancer around all Europe. Its sustainability is guaranteed because is a normative tool that might improve interoperability of health information systems with non-health data, which would be included in machine learning algorithms in the future.

Assessing and piloting interoperability for public health policy

Semi-structured in-depth 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, organisational, semantic and technical).

Achieving interoperability with health data is a long process with many obstacles. Most key opinion leaders emphasize legal and semantic interoperability layer as a main barrier, while technical interoperability is no longer seen as a barrier unless practicing physicians and patients are involved. Other barriers emphasized by key opinion leaders were lack of funding, differences in health data in countries with decentralized governments and different interpretations of the GDPR that varied between countries, between different regions of a country and between different institutions. Other enablers, which were emphasized by key opinion leaders, were univocal health data in countries with centralized governments, pre-existing legislation for a specific topic in certain countries and continuation to a work done by pre-existing project. Such results would serve as a basis for publishing recommendations that are derived from key opinion leaders from different European cross-border projects dealing with sharing, linking and managing health data. It would also enable better optimization and utilization of health information systems across Europe and would facilitate the development of health information and research infrastructure based on cumulative experiences and know-hows from key opinion leaders.

Besides the assessment of inspirational experiences on interoperability, InfAct has actually piloted the development of a distributed infrastructure standing on the pillar of the European Interoperability Framework (EIF) and the FAIR principles. The solution proposed to build the DIPoH distributed infrastructure comes up from the reflections out of the

BRIDGE Health project[11] subsequently tested in WP10.4 in InfAct. So, via a privacy by design approach to data exchange and distributed analysis, InfAct has assessed the feasibility of complying with GDPR and Ethical principles, adapting to the organizational specificities of each data hub, assuring semantic interoperability across hubs and developing technological interoperability. Likewise, the feasibility of the development of the FAIR principles has been also tested. Pursuing that objective three case studies are being carried out. This three case studies (Table 5.4) are different as to capture different requirements in the development of a distributed infrastructures on population health research where any study design could be conducted; so, the questions of research, the data sources linked and reused, the data granularity required, the type and breadth of the outputs, and the data hubs are different and complementary.

This successful empirical exercise is yielding arguments in favour of the feasibility of this kind of distributed approach, which is the basis for the sustainability of any research infrastructure of such a kind. Among the lessons underpinning the feasibility of this distributed solution: a) no complaints with the accomplishment of GDPR or Ethical principles have been raised; b) the only organizational hindrance has been the availability of specific personnel devoted to the deployment of the pilot; no other organizational requirement has been observed as a barrier; and, c) data hubs are reasonably equipped (personnel and technological capacity) to deploy the scripts with the common data model and to run the analysis.

Under the hypothesis of a full implementation of this kind of infrastructure, some costs to take into account would be: a) a System Administrator or Data manager in the data hubs that liaising with the central hub will facilitate the deployment of the distributed solutions for data linkage, data extraction, data analysis y data reporting; b) a Domain expert or Data scientist that liaises with the central hub for a better interpretation of the intermediate outputs of the process; and c) even though there exists a reasonable capacity, these profiles may not be present everywhere so there should be a basic investment on capacity building the first year of involvement in such a kind of federated infrastructure.

Table 5.4. Use cases on designing a federated infrastructure

Use case	Aim	Data sources	**Common Data model** (main entities)	**Scope - Software Distribution**	Hubs
Monitoring population resilience	Elaboration of a population health indicator	Insurance data PC EHR Prescriptions Hospital stays	Individual Insurees Residence	Data model Specification (v1.0)	Wales NHS (UK) Aragon (ES)
Costs of dementia	Identification of 1-year follow up contacts and associate costs	Insurance data PC EHR Hospital stays Prescriptions ER data RHB contacts	Individual patients Care provider contacts Time stamps	Data model Specification (v0.1)	Aragon (ES) France (FR)

[11] Bernal-Delgado, E., Estupiñán-Romero, F. A data infrastructure for the assessment of health care performance: lessons from the BRIDGE-health project. *Arch Public Health***76,** 6 (2018). https://doi.org/10.1186/s13690-017-0245-1

		Billing data			
Stroke care pathway	Discovery of the actual care pathway for Acute Stroke patients	Insurance data ER data Hospital data	Individual patient Care provider contacts Time stamps Event	Complete solution: Docker with Open source log builder Open source software for Process Mining (v1.10)	Aragon (ES) Lombardia (IT) Norway (NO) HU Zagreb (HR) Latvia (LV) Portugal (PT)

4. Capacity building in health information

Health information system assessments

Experts from nine EU countries implemented peer-reviewed assessments of each other's national HIS. The methodology applied for these peer assessments is derived from the methodology developed and piloted by WHO Regional Office for Europe in the framework of the WHO European Health Information Initiative (EHII). In InfAct, this methodology has been adapted to make it suitable for peer-review assessments. An important distinction is that InfAct assessments were initiated and executed at the level of health information institutions and experts. The peer assessments have 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 lead to the reduction of health information inequalities between countries. The experiences of the nine countries have been documented and evaluated in order to establish to what extent these objectives have been met, and how the methodology could be improved for future application. The developed methodology of peer-reviewed assessment may be used as a suitable tool to identify gaps in national HIS, and increase HI capacity across Europe. Furthermore, the assessments may continue on a more permanent basis in the framework of DIPoH capacity building program and services. Finally, the feedback from the InfAct peer review assessment experience is being used extensively in the revision of the WHO support tool for future assessments carried out in the region.

Health information training programme

A flagship programme of training was designed to improve the member states capacities in population health and health system performance analysis and monitoring to address existing inequalities. Accordingly, the European Health Information Training Programme (EHITP) was conceptualized as an umbrella for all current and future training activities in Europe, targeting professionals working in public health and health information at national

or European/international level. It was considered necessary to have a sustainable capacity building programme in health information that focused on the following areas: data analysis and interpretation, especially interoperability of data sources, derivation of European Core Health Indicators (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 General Data Protection Regulation (GDPR).A pilot course will test this program and the evaluation of this initiative should contribute to the consolidation of a roadmap for capacity building in health information, in terms of: (i) clarifying concepts regarding the professions around public health activities, (ii) addressing research gaps on HIS topics and its relationship with public health activities, (iii) identifying the need of a capacity building program on health information, (iv) having a flexible program, in which MS and European institutions develop initiatives according to their specific needs, (vi) strengthening the collaborative network among EU MS and international institutions, among others.

Burden of disease capacity building

The Joint Action has emphasized the potential role of burden of disease measures to provide actionable population health information across Europe. In that context, a set of three Burden of Disease workshops were planned. The overall objectives of these workshops were to raise awareness, share knowledge and experience, and provide mutual support and to integrate BoD indicators in the public health policies across Europe. The first workshop was mainly focussed on the concept and methodology of BoD across the Member States, the second one was about the use of BoD methodologies/data in public health policy and practice and the third is to highlight the effect of choices of estimation methods, quality of data sources, and other contextual factors relevant to issues of comparability. At the end of the third workshop, a rationale/good practice approach to conduct a national BoD study (i.e., why should a country want to perform a BoD study, what methodologies are available and what are the benefits for performing national BoD studies?) in a given member state would be developed.

5. Knowledge translation research for evidence based decision-making

Within InfAct, a Delphi survey was conducted to compile and review national priority setting strategies, creating an overview of health information prioritisation across EU Member States and associated countries. The outcome is a list of good-practice-approaches to health information development and a draft guidance for prioritisation at national level. The documents will be presented on the web-based portal in order to be available for and affect the working practices of those involved in developing health information systems.

To tackle inequalities in health reporting across EU MS and to make health information adequately accessible and available, a guidance document on good practice for health reporting is drafted based on the results of a web-based desk research conducted within InfAct. The guidance will be applicable at national as well as international level and is expected to be an innovative tool to facilitate the generation and dissemination of health information to the targeted groups.

National health information (HI) systems provide data on population health, the determinants of health and health system performance within countries. The evaluation of these systems has traditionally focused on statistical practices and data production, but it is also important to consider data (re)use for health intervention, and policy development.

In the Health-Information (HI) Impact framework, 4 domains to monitor knowledge translation capacity have been identified (https://academic.oup.com/eurpub/article/30/4/648/5606752). The HI-Impact Index, is a new tool which is based on this conceptual framework and provides 30 criteria to assess : i) the quality of HI data and evidence, and ii) HIS responsiveness, iii) the level of stakeholder engagement with the evidence, and iv) knowledge integration in civil society and across sectors.

The HI-Impact Index has been pretested in InfAct and could be implemented in routine for continuous monitoring of knowledge translation, and HI uptake by key stakeholders within European countries.

V. Conclusions

A lot of work has gone into the design of DIPoH. The work has been initiated over ten years ago and has brought together a strong scientific community and committed stakeholders. An in depth analysis was made to go forward with the development of the RI. This report describes all the achievements made towards its technical and scientific design and development. Its scientific excellence was developed and its position in the landscape was defined. The socio-economic impact of DIPoH became even clearer after the COVID-19 outbreak, reiterating the need for an RI in population health. The user community and the strategy to enlarge it was defined. InfAct piloted and assessed the feasibility of various its activities as described in the previous section. Overall, DIPoH has reached a level of maturity and is unique in what it can offer the scientific community across Europe.