INFACT
Joint Action on Health Information

Deliverable 4.5 : Sustainability Plan

October 2020

Escuela Nacional de Sanidad, Instituto de Salud Carlos III | Avenida Monforte de Lemos 5 |Madrid | Spain| e-mail: InfActSpain@isciii.es|
Website: www.inf-act.eu|Twitter: @JA_InfAct

This project is co-funded by the Health Programme of the European Union

Table of Contents

Executive summary 3

Key InfAct outcomes 3

Aim of Sustainability Plan 4

I. Introduction 7

II. Main goals of InfAct 8

III. Main outcomes of InfAct and sustainable proposals 10

A. Research Infrastructure (RI) final proposal 10

1. Distributed Infrastructure for Population Health (DIPoH) 10

2. Proof of concept for a sustainable structure on health information 11

3. Creating a sustainable network of networks 12

4. Health Information Portal 13

B. Health information tools and innovative proposals 14

1. Health data collection methods and procedures 14

2. Cataloguing international health information collection networks, projects and indicator/data sets 14

3. A sustainable European Core Health Information (ECHI) shortlist 15

4. Guidance for health reports and good practice in health reporting 15

5. Roadmap for innovative use of data sources 15

6. Best practices for innovative use of health information 16

7. Methodological guidelines for estimating health indicators using linked data and Machine Learning Techniques 16

8. A generic method case study and inspiring examples and Machine Learning Techniques 16

9. Use of non-health databases for health surveillance 17

10. Composite health indicator for monitoring Non Communicable Diseases (NCD) 18

11. Assessing and piloting interoperability 18

C. Capacity building. Translating sustainable outcomes into training proposals 19

1. A manual to carry out HIS assessment in peer review format 19

2. Good-practice-approaches for prioritizing HI at national level 20

3. Burden of disease 20

4. Health Information Training Program and roadmap for sustainability 21

IV. InfAct contribution to new initiatives 22

V. Member States Position on InfAct main outcomes and long-term projection 22

A. Technical Dialogues..22
B. Assembly of Members..24
VI. Recommendations for knowledge translation and sustainable initiatives 25
References..28
Appendices..29

Executive summary

The current situation in the area of health information (HI) covering chronic diseases and Health System Performance (HSP) shows that there have been successful projects that have incorporated their outputs into European health information systems (HIS). Nevertheless, data on population health in the EU is fragmented, difficult to access, project-based and prone to inequalities across European countries.

The Joint Action (JA) on Health Information (InfAct), built from previous works as the BRIDGE project, develops collaborative action to set up a sustainable infrastructure for EU health information. The major outcome expected is a sustainable infrastructure on EU HI through improving the availability of comparable, robust and policy-relevant health information on population health and health system performance.

InfAct is working towards the sustainability through a follow up method for supporting InfAct outcomes, activities and best practices to be integrated in regional, national and EU international policies. For achieving such task, InfAct activities include: (i) supporting sustainability and integration of the Joint Action health information outcomes in MSs and associated countries through an Assembly of Members, (ii) raising awareness and acceptance among decision-makers and national technical experts on innovative actions to improve EU HI systems via Technical Dialogues and (iii) providing a sustainability plan integrating feed-back from Member States (through the Assembly of Members and Technical dialogs) and InfAct outcomes.

In the process of defining the new infrastructure MSs have provided technical and political feedback through the Technical Dialogues and the Assembly of Members. Both boards, support the implementation of DIPoH despite their concerns regarding EU involvement, organizational and financial issues involved. They also support the incorporation of the tools for health information methods, national HI priority setting, best practices and innovative proposals developed within InfAct.

Key InfAct outcomes

- DIPoH will provide support towards the development and use of large-scale, integrated and sustainable data services for population health and health services research. The Research Infrastructure (RI) will contribute to cataloguing, curating and integrating information and knowledge generated by a critical and growing mass of European researchers and their international networks.
- DIPoH will strengthen the synergy in the EU by facilitating comparative research, efforts at data linkage, pan-European use of data, methods, expertise and results and better involvement of national experts.
- An integrated network of networks, constituted by National Nodes (NN) and Research Networks (RN) will perform high-quality comparative research that focuses on regional, national and local health and health care issues, to support policy-making or health system improvement in a timely and effective way.

- A health information portal was designed in a way that responds to the needs of the user communities of the future Research Infrastructure DIPoH.
- InfAct has developed different tools to improve methods and procedures for health data collection, a guidance for health reports with recommendations for health reporting, and suggestions for an update and sustainable governance structure of the shortlist for European Health Indicators, among other initiatives.
- InfAct devised the roadmap of innovative use of data sources, identifying best practices for using health information and is currently developing the methodological guidelines, which could systematically guide MSs for using linked data and machine learning techniques to estimate health indicators for public health research.
- InfAct has designed new composite indicators to improve the monitoring of Non Communicable Diseases (NCD), as “En-risk” an interactive application tool, which uses European non-health databases of industrial pollution and its association with mortality for public health surveillance, and the ratio between hospital admissions and deaths to explore the geographical variability of morbidity and mortality in a country.
- InfAct has assessed interoperability by in-depth interviews 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) and is piloting interoperability through three case studies to capture different requirements in the development of a distributed infrastructure on population health research.
- InfAct contributed to capacity building in European countries, by applying HIS assessments in peer review format in 9 countries, identifying strengths and weaknesses in the national HIS under assessment and stimulating actions to improve the assessed HIS. 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.
- A flagship programme of training was designed to improve the Member States (MSs) capacities in population health and health system performance analysis and monitoring to address existing inequalities. 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.

Aim of Sustainability Plan

The aim of this document is to introduce the sustainability plan of InfAct, which is divided in 3 main categories: (1) The proposal of a new Research Infrastructure, (2) Capacity building and (3) New health information tools and innovative proposals, and point out the potential limitations but also its added value as a sustainable proposal, which are listed below

A new Research Infrastructure: The Distributed Infrastructure on Population Health (DIPoH).

- Business plan and proof of concept for a sustainable EU structure
- The set-up of 19 National Nodes on Health Information.
- Coordination with key Research Networks.
- Business case describing the whole RI to be implemented.
- The governance structure
- A web-based portal as the basis for the future DIPoH
- Application for the ESFRI Roadmap 2021, submitted in September 2020

Health information tools and innovative proposals ready to be implemented in EU-EEA:

- Report/proposal on data collection and data sharing methods
- Catalogue of international HI collection networks
- Sustainable information based on knowledge repository to connect experts
- Guidance on good practice for health reporting.
- Roadmap for innovative use of data sources. Methodological guidelines to estimating health indicators using data linkage and machine learning techniques
- Inspiring indicators: En-Risk and Composite health indicator for monitoring NCD
- Report on Assessing and piloting interoperability at the EU level.
- Sustainable European Core Health Indicators (ECHI), updating its technical content.

Tools on Capacity building ready to be implemented in EU-EEA:

- Manual to carry out HIS´s assessment in Peer-review format.
- Good-practice-approach for prioritising HI at national level.
- Promote the integration of BoD indicators in public health policies across Europe by raising awareness, sharing knowledge and experience, and provide mutual support.
- Health Information Training Program designed to improve MSs Capacities in population health and health system performance analysis, both addressing inequalities.

Limitations for InfAct's outcomes future translation into National and EU health policies

- Moderate p**olitical support from MS and EU institutional involvement**
- Structural and functional **country variability** that affects: Feasibility and delays in the inclusion of innovative approaches in national HIS.
- **Resources** at all levels to deal with innovations.
- Exceptional circumstances (COVID-19)

Sustainable proposal:

- DIPoH concept for the ESFRI application submitted (September 2020)
- New tools for improving population health data, available and ready to be implemented.
- A capacity building program designed, piloted and flexible to face current and future needs.
- Need of stronger EU and country involvement to achieve a wider implementation in order to better support health decision-making, EU population health and EU added value.

InfAct: Sustainability Plan

I. Introduction

The right to health is considered one of the most basic human rights and plays a fundamental role in all societies. Moreover, a healthy population is a prerequisite for economic productivity and prosperity. The COVID-19 crisis has made that even clearer. EU countries share the ambition of improving citizens´ health, tackling health inequalities, providing optimal prevention and universal access to safe, effective and efficient health care in a financially sustainable way [1].

Health systems are one of the most important contributors to population health. However, population ageing, technical innovations in health care, and growing citizen expectations increase financial constraints on health systems. On the other hand, increasing national health expenditures need to be able to meet growing demands. Health information, including data on health, health determinants and health systems performance in Europe allows for oriented research to increase the knowledge base and underpin policy decision-making.

To make the most of health spending and investments at EU and Member State level, health policy and decision-making must be based on robust evidence in the form of high quality and timely data on population health and health systems and thorough research outcomes.

The current situation in the area of health information (HI) covering chronic diseases and Health System Performance (HSP) shows that there have been successful projects that have incorporated their outputs into European health information systems (HIS) [2]. However, in general, data is fragmented and difficult to access. In addition, most health information activities are project-based; therefore there is no long-term use or planning. Moreover, there are inequalities in quality and research capacities across European countries.

Previous projects and Joint Actions have highlighted the need of a comprehensive, comparable and sustainable HIS. For the Health programme initiatives of the period 2008-2013, several actions on health monitoring and data were funded by the European Commission (EC) to create an effective and sustainable network for health technology assessment across Europe as Euro-peristat, European Health Examination Survey (EHES), and Eurosafe among others. Other actions were also funded in relation to the European Core Health Indicators for monitoring and comparing health outcomes between EU countries, which would support policy-making processes.

During the Third Health Programme of the EC to be developed from 2014 to 2020, one of the general objectives was to encourage innovation and increase sustainability of the health systems. Among those projects, Bridging Information and Data Generation for Evidence-based Health policy and research (BRIDGE Health) was carried out from 2015 to 2017, and its aim was to prepare the transition towards a sustainable and integrated EU health information system for both public health and research purposes. BRIDGE Health assessed different structural and institutional options including a comprehensive European Research Infrastructure Consortium (ERIC) in health information and delivered a concept paper describing the scope, tasks, activities and governance structure for a future EU HIS to be further developed and established. This proposal has been the starting point of InfAct.

Following the recommendations of the Council of the European Union, the Commission and its MSs were invited to cooperate with the view of establishing a sustainable and integrated EU HIS. More specifically, the Council Conclusions urged to explore the potential of a comprehensive European HI research infrastructure as a tool [2].

The Joint Action (JA) on Health Information (hereinafter referred to as InfAct) built on previous work further develops collaborative action to set up a sustainable infrastructure for EU health information. InfAct started in March 2018 and will run for 3 years and 3 months, bringing together 40 institutions from 28 EU MSs and associated countries. More information can be found on our website www.inf-act.eu.

The major outcome expected of the JA is a sustainable infrastructure on EU HI through improving the availability of comparable, robust and policy-relevant health information on population health and health system performance. InfAct is working towards the sustainability of such an infrastructure through a follow up method for supporting InfAct outcomes, activities and best practices to be integrated in regional, national and EU international policies. For achieving such task, InfAct activities include: (i) supporting sustainability and integration of JA health information activities in MSs and associated countries through an Assembly of Members, (ii) raising awareness and acceptance among decision-makers and national experts on innovative actions to improve EU HI systems via Technical Dialogues and (iii) providing a sustainability plan to integrate the findings of InfAct in EU/MSs protocols.

The purpose of this document is to present the plan for sustainability focused on InfAct outcomes. This Sustainability Plan includes the feedback on InfAct outcomes provided by National Experts in the Technical Dialogues and the insights and recommendations given by country representatives of Ministries of Health and Research.

II. Main goals of InfAct

Through country collaboration, InfAct streamlines health information activities, reduces the data collection burden and facilitates and supports country knowledge, health research and policy-making. InfAct is focused on: (i) providing tools and methods for HI support through innovation for public health policy development and research, and (ii) integrating population health and health care information systems into a sustainable EU research infrastructure. It will contribute to reduce HI inequalities by strengthening country capacities and enhancing HI priority setting, methodologies and practices.

In the following table a summary of the Work Packages (WP) of the Joint Action and their tasks are introduced.

Table 1: InfAct Work Packages

WP Number	WP Title
WP1	Coordination
WP2	Dissemination
WP3	Evaluation
WP4	Integration into national policies and sustainability: With 3 main areas of work: i) organizing Technical dialogs with National experts to discuss about feasibility of integration InfAct results into country policies. ii) Organizing AoM in order that the high health and research authorities approve and integrate InfAct outcomes into policies. Iii) Based on InfAct results WP4 is in charge of preparing a sustainability plan.
WP5	Status of health information systems in MSs and regions: It seeks to tackle inequalities in health information quality by outlining national HI prioritization processes. It also performs a mapping exercise to assess national HIS and establishes an information base where stakeholders can contact international expert networks, projects and organisational bodies collecting comparable health data.
WP6	Strengthen EU countries health information capacity: It aims at reducing HI inequalities between and within MSs by developing a capacity strengthening baseline programme at EU level to support critical areas of HI use and management.
WP7	Proof of concept of a sustainable infrastructure on HI. Its aim is to develop the business case and the roadmap for implementation of an European Research Infrastructure on Population HI for research and evidence-based policy, through governance structures, national nodes and research networks
WP8	Tools and methods for health information support: It aims at summarizing 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 and reporting both for individual-based data and health indicators.
WP9	Innovation on health information for public health policy development: to strengthen the HI efficiency for public health policy through new ways of using health and non-health data sources. It is aimed at identifying inspiring examples from MSs with regards to innovation in the use 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 health care strategies. This would help developing best practices and guidelines to enlarge the set of morbidity indicators available across the EU using innovative techniques.
WP10	Assessing and piloting interoperability for public health policy: The main objective is to thoroughly describe the methods and techniques used to get sound knowledge out of data linkage, sharing, management and reporting.

The sustainability plan aims to integrate all InfAct outcomes in tree main areas:

1) A sustainable research infrastructure: Development and consolidation of a solid infrastructure on EU health information, through improving the availability of comparable, robust and policy-relevant health status data and health system performance information. This infrastructure is based on existing research and public health networks operating at country level and will provide and share health data and tools, promote research and inform health policy and decision makers.
2) In the area of innovation in health information, InfAct focuses on developing guidance and recommendations, based on data linkage, interoperability and new analytical proposals and indicators for population health research. InfAct connects different HI sources, projects and networks to the EU Research infrastructure.
3) Capacity building on all new and innovative procedures and proposals have been foreseen in order to cover all MSs and engage international partners.

All these outcomes have been looking for sustainability and integration into EU health policies by systematically involving high representatives from EU-MSs through their health and research authorities, all represented in the Assembly of Members (AoM). We also considered crucial to involve national experts at head of HIS and providing technical guidance to their health and research authorities. That forum was represented by the Technical Dialogues, where InfAct partners and national experts discussed about the added value and feasibility of InfAct outcomes.

III. Main outcomes of InfAct and sustainable proposals

A. Research Infrastructure (RI) final proposal

1. Distributed Infrastructure for Population Health (DIPoH)

DIPoH is designed to provide support towards the development and use of large-scale, integrated and sustainable data services for population health and health services research. The RI will contribute to cataloguing, curating and integrating information and knowledge generated by a critical and growing mass of European researchers and their international networks. DIPoH will strengthen the synergy in the EU by facilitating comparative research, efforts at data linkage, pan-European use of data, methods, expertise and results and better involvement of national experts. DIPoH will help researchers ensure that their research is findable, accessible, interoperable and re-useable and create ever-stronger research networks. These objectives will be achieved through the following activities:

- **A one-stop shop**: DIPoH will be a library providing a data catalogue on health status, health determinants, and health care data and their meta-data as well as methodologies used. It will facilitate access and (re)use of European data for research on the health of populations and on health care systems.

- Investing in **innovation** in health information development for population health research to support health researchers using pan-European data in a distributed way. Linking of different data sources and making their research meet Findable, Accessible, Interoperable and Reusable (FAIR) and Ethical, Legal, and Social Implications (ELSI) standards[3].
- Providing **capacity building** to promote interoperability and tackle health information inequalities: learning about the management of data on population health and health care starting from the phase of designing data collections to analysis, reporting and preservation and curation. Training of the health research community involves both the data producers and data users.
- Assisting the health research community in developing methods for **knowledge translation research** to support decision-making processes. This is the return of investment to society improving the health of the European citizens and increasing the efficiency of our health care systems and policy decisions.

Several of these activities have already been piloted and implemented through InfAct as described below and are summarized in the table of the annex 1 (The Technology Readiness levels of DIPoH).

An **European Strategy Forum on Research Infrastructures (ESFRI) Roadmap** application for the setup of DIPoH has been presented in September 2020. EU-Ministries of Health and Science have provided feedback. At the time of submission some of them expressed their interest in joining the development of the DIPoH concept for the ESFRI Roadmap through 12 Memorandum of Understandings, 10 letters of political support, 3 expressions of financial commitment and 8 letters of intent. InfAct continues to increase MSs involvements

2. Proof of concept for a sustainable structure on health information

Summary of achievements supporting long term functioning of the RI:

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

- InfAct has worked with key **Research Networks**, which will be at the core of a future 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 that can be used in the future for new Research Networks and also by countries: These criteria could be used when countries want to participate in an international network or set up a new network.

- InfAct developed a **business case** describing the whole RI 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 pilot experiences, the business case has been translated into a 5-year operational road map with a detailed work plan including specific objectives, outcome and deliverables.
- ✓ InfAct proposed and developed an interim and final **governance structure** for DIPoH. The terms of reference of the Network Committee were developed. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 7.3 Governance structures of a sustainable health information system)
- ✓ InfAct received from EU-MSs Letters of **Political support**, **financial commitment**, **Memorandum of Understanding and collaboration Agreements**, showing their interest in supporting DIPoH.
- ✓ A health information portal (single entry point) was set up and will be maintained after the project. It is hosted on www.healthinformationportal.eu. The portal aims to 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.

3. Creating a sustainable network of networks

In many EU MSs and associated countries, health information activities are scattered over several institutes. Regular coordination and communication among these institutes is often missing. This leads to duplication of activities, limited interoperability and linkage of data between institutes, inhibited exchange of data and loss of opportunities for research or policy support. Furthermore, at EU level HI activities are scattered as well and there is no structure in place to support EU-centred research activities in the area of population health and health system performance to support evidence-based Policy. To increase communication among key players in a systematic way, InfAct provides support to countries in developing a National Node (NN). Setting up this NN brings forth discussions on core issues in health information domains that are nationally and internationally relevant for the country. Bringing together the regional/national stakeholders makes it possible to: (i) Share expertise on health data and information at regional/national level; (ii) Share on-going activities at regional/national level; (iii) Update on initiatives, meetings and expert groups at EU level and (iv) Join forces for better research and policy support at national level. To do this, InfAct initiated a national node survey to investigate the current status regarding any meetings that brought together health information stakeholders or partners at a national/regional level. Based on the collected experiences, InfAct developed a stepwise approach to set up a NN. The stepwise approach provides european countries with guidelines on how to set up, define, and organise a NN. InfAct keeps a record on the current status of the NN in the partner countries. Countries presented their NN during the General Assembly meetings and subsequent NN meetings. Opportunities for best practice exchanges and support have been organised through these regular meetings. Furthermore, for the development of a sustainable network of networks, InfAct works together with European Research Networks (RN). These are active networks of national and/or regional experts from several countries that perform comparative research in a specific population health area. InfAct has identified criteria and procedures for the selection and inclusion of RNs in the DIPoH. This integrated network of networks will perform high-quality comparative research that focuses on regional, national and local health and health care issues, to support policy-making or health system improvement in a timely and effective way. By investing in and supporting NNs and RNs, InfAct takes a step forward in promoting critical European mass in population health via networking of excellent researchers, joining complementary expertise, sharing research facilities, contributing to European capacity building and training new researchers, which might ensure long-term sustainability. The combined outcomes of this network of networks of national data providers across Europe and expert networks, will allow to identify common challenges and priorities, exchange best practices, and ultimately support the provision of high quality evidence that is fit-for-use in policy-making and practice. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 7.1 A sustainable network of networks).

4. Health Information Portal

InfAct prepares the functional design of a web-based platform as the basis for the future DIPoH. The website will contain a repository function for:

- Technical reports and scientific articles,
- Data collection, processing, analysis and dissemination methods and tools,
- Health information projects,
- Indicators/data sets,
- Compiled information on NNs and RN
- Training programmes, and
- Information on financial source.

The development of the platform makes use of standards as given by INSPIRE[4] and FAIR principles (Findable, Accessible, Interoperable, and Reusable). Together with the partners of InfAct and the network of networks, the platform provides a catalogue of metadata of the health data sources that are available and useful for population health research. A structure of the health information 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 DIPoH. 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 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. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 7.4 Health Information web platform; This task links to Deliverable 8.4 Coordinating networks of experts and Deliverable 5.2 Cataloguing networks and projects)

B. Health information tools and innovative proposals

1. Health data collection methods and procedures

There is heterogeneity in data collection methods and procedures, and lack of available, accessible, comparable or reusable EU-health data and information for research purposes and policy-making within EU countries. These aspects limit health data usage and sharing within and across MSs. Health data collection methods, quality assurance, metadata reporting standards, and availability and accessibility of health information across MSs were identified through a structured questionnaire, developed and administered to all MSs' representatives participating in InfAct. A report on data collection and data sharing methods was developed based on the findings of the cross-sectional study. As part of the InfAct HI portal for HI research in EU, the report facilitates the assessment of health inequalities across EU countries in terms of quality, metadata reporting standards, availability, accessibility and comparability of health data and information. It also facilitates sharing and dissemination of standardised and comparable health data collections, which are essential for research and evidence-based policy-making. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 8.1. Health Information System development: data collection and quality assurance for a common health information system (already provided but not published on the website yet) and Deliverable 8.3.Guidelines for accessibility and availability of health information).

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

Over the years, international comparative projects and networks have come and gone. Not necessarily because they were no longer needed, but because it is inherent to the funding system and the maintenance of networks that are not embedded in a sustainable infrastructure. In InfAct we searched PubMed, Embase, Scopus, Google, Cordis and the CHAFEA project database for (i) expert networks that collect comparable health data in Europe, as well as (ii) previous and on-going health information generating projects with EU coverage. The aim was to create a sustainable information base to be integrated in the EU health information portal (www.healthinformationportal.eu; see deliverable 7.4). This catalogue will function as a knowledge repository and solid base to connect experts and build on work from the past. Its functional development is aligned with the development of the Portal and takes into account a sustainable update procedure. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 5.2. Cataloguing health information networks, projects and indicator sets).

3. A sustainable European Core Health Information (ECHI) shortlist

The list provides a ‘snapshot’ overview of European public health (and care). It is the result of consecutive EU-wide projects representing a collective MSs effort, implemented in 2012. However, no sustainable form of governance or updating procedures are in place. InfAct provides recommendations for a governance structure and formal procedures for regularly updating the ECHI shortlist. In addition, it provides practical suggestions for technical updates of the metadata (documentation sheets), for new indicators and for a modernised format for structuring the ECHI. The European Commission (DG Sante and DG Estat in particular) is seen as an important partner, with a role in securing policy relevance, technical commitment, financial sustainability and possibly legal status. The DIPoH may also have a role in this. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 8.2. Sustainable ECHI process from technical, content and user perspective)

4. Guidance for health reports and good practice in health reporting

A web-based desk research of health reporting formats and target groups showed that public health reports are the most frequently used health reporting format across EU-EEA and mainly aim at scientists/researchers and politicians/decision-makers. Based on the results of a literature review, earlier projects and exchange with experts, quality criteria for standardised and comparable public health reports were derived and compiled into a guidance document. This guidance for the preparation of public health reports is supplemented by general recommendations for good practice in national health reporting, which can also be applied to other formats for the communication of health information like short reports, fact sheets or social media channels. The aim of the guidance is to facilitate making health information adequately available to the targeted groups and as a basis for evidence-based decision-making while reducing inequalities in health reporting across EU. The guidance is applicable at national as well as international level, and integration into an EU HIS will further enhance sustainability. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 8.4. Guidelines for MSs and regions for health reports).

5. Roadmap for innovative use of data sources

The use of data linkage and/or artificial intelligence (AI) to estimating health indicators called as innovative use of data sources. The majority of European countries use data linkage routinely 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 routinely. 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. (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 [5]. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 9.5 Road map for uptake of indicators – opportunities and obstacles).

6. Best practices for innovative use of health information

Best practices for innovative use of health information for data networks demonstrate the value of a DIPoH and the benefits of using linked data from different RN to perform comparative research studies among European countries. In this context, two studies are on-going: 1. Use of data linkage and advanced statistics in the reporting of perinatal indicators in Europe and 2. Evaluating the efficiency of health care systems in managing high-need high-cost patient's network.

7. Methodological guidelines for estimating health indicators using linked data and Machine Learning Techniques

We are developing the methodological guidelines, which could systematically guide MSs for using linked data and machine learning techniques to estimate health indicators for public health research. These guidelines would contain seven important contents: (i) rationale and objective of the study (i.e., research question), (ii) study design, (iii) study population/sample, (iv) linked data sources, (v) study outcomes, (vi) data preparation and (vii) data analysis. We described these aspects with examples of different studies. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 9.4. Tool kit to produce better health indicators).

8. A generic method case study and inspiring examples and Machine Learning Techniques

We developed a generic approach to predict a health outcome from linked datasets using machine-learning (ML) technique and identified inspiring examples applying these innovative techniques in public health across European countries. The final data-set used to develop the ML-algorithm included 44,659 participants and 3468 variables that were coded uniformly. Only 23 variables 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 the 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 10 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 methods, lacking completeness of information or inaccessibility to certain information make it 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, develop prevention strategies, evaluate health care services and guide health policy processes. Inspiring examples help to learn from each other and to develop and adopt new methodological approaches [6].

9. Use of non-health databases for health surveillance

The combination of health information with environmental health determinants is important for epidemiological surveillance and for risk studies in health. Within the EU, there are many non-health data that can be used in this context but the integration of such data remains a challenge because of heterogeneity and availability. 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 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, HI 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 E-PRTR enable MSs to incorporate information of industrial pollution sources from E-PRTR into health information systems, 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.

10. Composite health indicator for monitoring Non Communicable Diseases (NCD)

The analysis of the epidemiological patterns of NCD should include an integrated study of morbidity and mortality, describing their geographic variability and, if detected, examining their causes. This study analyses the ratio of age-adjusted hospital morbidity and mortality rates (HMR) for the following NCDs in Spain: ischemic heart disease (IHD), cerebrovascular disease (CVD), chronic obstructive pulmonary disease (COPD), and prostate, breast and lung cancer. Demographic and geographical variability was observed for all the diseases studied, in particular for CVD, with higher proportional mortality in the Southern region of the country. These results should be further explored with potential associated factors and examining specific case-management approaches at hospital level that could explain the trends observed in the HMR in Spain. The HMR is a tool that uses standardized methods and is based on routine data sources and traditional analytical procedures in public health information systems. This indicator allows for a better understanding of regional variability between and within countries, and can also be useful for health planning and prevention.

11. Assessing and piloting interoperability

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). Transcripts of the semi-structured interviews were analysed qualitatively by framework analysis.

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 General Data Protection Regulation (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 projects. 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 optimization and better utilization of health information systems across Europe and would facilitate the development of health information and research infrastructure based on cumulative experiences and know-how from key opinion leaders. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 10.1. Report: Interoperability landscape in Europe)

Besides the assessment of inspirational experiences on interoperability, InfAct has actually piloted the development of a distributed infrastructure taking as pillars the European Interoperability Framework (EIF) and the FAIR principles. 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 (Annex 2) are different as to capture different requirements in the development of a distributed infrastructure 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: i) no complaints with the accomplishment of GDPR or Ethical principles have been raised; ii) 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, iii) 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: i) a System Administrator or Data manager in the data hubs that liaises with the central hub will facilitate the deployment of the distributed solutions for data linkage, data extraction, data analysis and data reporting; ii) a Domain expert or Data scientist that liaises with the central hub for a better interpretation of the intermediate outputs of the process; and iii) even though there exists a reasonable capacity, these profiles may not be present everywhere so there should be a basic investment on capacity building in the first year of involvement in such a kind of federated infrastructure. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable10.2. Technical report: interoperability implementation).

C. Capacity building. Translating sustainable outcomes into training proposals

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

Experts from nine EU countries implemented peer reviewed assessments of each other's national HIS. 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 that took part in the exercise 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 the 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. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 5.1 Pilot HI system peer assessment and review of experience)

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

Health information guides public health interventions (agenda-keeping) and points to emerging public health issues (agenda-setting). In order to fulfil these functions, health information needs to be duly prioritised, ensuring that relevant public health issues are identified and that public health interventions respond to real needs. Little can be found in the literature on health information prioritisation methods and procedures in Europe, including the selection of indicators. We tried to close this gap with an online two-round Policy Delphi survey that was distributed to EU MSs and associated countries' representatives. The expected outcome is a list of good-practice-approaches to health information development and guidance for prioritisation at national level. The document will include criteria, methods and structured prioritisation processes as well as stakeholder involvement. We also aim to draw insights into the inclusion of good-practice-approaches in the prioritisation of health information in the respective countries, as well as analyse the connection between health information and health targets both national and international. Guidance for prioritisation of health information for national health reporting enhances comparability of health information systems across the EU and associated countries. The guidance could be further developed into a health information prioritisation strategy at the European level for establishment of an EU health information system. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 5.3. Prioritisation in HI development and recommendations)

3. Burden of disease

Three workshops on Burden of Disease (BoD) have been developed. The overall objective of these workshops is 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 focused on the concept and methodology of BoD across the MSs, the second one is about the use of BoD methodologies/data in public health policy and practice and the third is set to highlight the effect of choices of estimation methods, quality of data sources and other contextual factors relevant to the issues of comparability. Along with that, an overview of the national indicators of BoD at national level has been carried out using the country profiles produced by Global Burden of Disease (GBD) metrics, which provide a measure of priority health conditions and risk factors, a summary breakdown of major causes, and an appreciation of health sector performance, according to the GBD methodology[7]. 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 MS will be developed.

4. Health Information Training Program and roadmap for sustainability

A flagship programme of training was designed to improve the MSs 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 focuses on the following areas: data analysis and interpretation, especially interoperability of data sources, derivation of ECHI indicators and foresight/scenario analysis; transfer from data to policy, especially policy translation tools and data presentation; data collection methods, sources of data, metrics and indicators, especially issues related to health examination surveys; and data privacy and ethical issues, especially how to deal with requirements of EU GDPR. A pilot course was developed to test this program as the First European School on Health Information focused on the development of Health Examination Surveys (HES) from data collection to knowledge translation. The evaluation of this initiative was extremely positive and have provided the basis 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 MSs and European institutions develop initiatives according to their specific needs, and (vi) strengthening the collaborative network among EU MSs and international institutions, among others. As mentioned above, such roadmap for sustainability on health information started from identifying HI needs across Europe, from which the European Health Information Strategy has emerged. This strategy included the development of the 1st European School on Health Information, lessons learnt from the course, other INFACT outcomes, and the dynamic network of health information experts that this initiative established. The 1st European School on Health Information contributed to understand that comprehensive training on health information was possible and could reduce inequities. Many participants came from European Easter and Southern countries, which we identified the countries with larger shortages of HI resources. The success of this initiative opened the opportunity to organize the 2nd European School on Health Information in 2021, which represents another milestone for the sustainability of EHITP. The long-term sustainability will also include an annual European Health Information Programme (EHIP), which will be a structured collection of capacity building initiatives to be issued this year and will be available in the DIPoH health information portal. These initiatives include international capacity-building courses and workshops. (e.g., WHO, ASPHER, ECDC, Universities, and Public Health Institutes) and programmes organized within the INFACT/PHIRI/DIPoH network. It requires mechanisms should be developed to support MS, mostly to address HI inequities. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 6.2 A flagship training programme to improve MSs capacities in population health and health system performance analysis and monitoring, Deliverable 6.3 Training Piloting and Flagship Training Programme Evaluation and Deliverable 6.4 Road map for capacity building programme).

IV. InfAct contribution to new initiatives

InfAct has led to a spin-off project that builds on its work and underlines its recognition and added value. The Population Health Information Research Infrastructure (PHIRI, H2020-IBA-INFRA-CORONA-2020, 101018317) for COVID-19 that will start on November 2020 funded by the European Commission Directorate-General for Research and Innovation has the aim of facilitating and supporting open, interconnected, and data-driven research through the sharing of cross-country COVID-19 population health information and exchange of best practices.

PHIRI it is a practical use case for ultimately developing a DIPoH. In the COVID-19 crisis it contributes to filling the gap of an urgently needed rapid exchange of data and information between countries and links with other initiatives on health information at national and European level.

InfAct also actively engages in various other relevant projects and proposals in health information. It is represented by some of the InfAct consortiums members in the European Health and Innovation cloud proposal by Healthy Cloud (H2020-SC1-BHC-2018-2020, 965345), unCOVer (H2020-SC1-PHE-CORONAVIRUS-2020-2-RTD,101016216), EGI-ACE (H2020-INFRAEOSC-2020-2, 101017567) and the upcoming Joint Action TEHDAS (HP-JA-2020, SEP-210710594).

V. Member States Position on InfAct main outcomes and long-term projection

A. Technical Dialogues

Several aspects were outlined during the first (September 2019) and second (September 2020) Technical Dialogue (TD) in order to incorporate new tools and innovative indicators into national and EU HIS.

First, there was a consensus about the ***added value*** of the already advanced proposal in terms of promoting Member States (MSs) mutual learning and cooperation. In addition, InfAct outcomes were considered relevant for defining priorities and for decision makers.

Second, the integration and access to different data sources, with an adequate level of quality, accuracy and robustness were considered important goals.

Third, there was a concern about issues related to the application of measures from the European General Data Protection Regulation (GDPR), that could affect Health Information's interoperability, which must be tackled at national and EU level. Moreover, there are differences in the interpretation and implementation of the GDPR in different countries. To address and overcome these differences, InfAct will provide options to perform data linkage, sharing, management and reporting respecting GDPR regulation. In any case, anonymization of data was considered an important concern, for this reason an EU-consensus guidelines were encouraged.

Fourth, NTE (National Technical Experts) asked for more specific results to properly discuss feasibility, which is a relevant issue regarding different country functional and organisational approaches.

Fifth, with the aim of translating these results into policies, NTE highlighted the need of involvement of national data providers.

Sixth, regarding capacity building experiences, NTE provided insights in the framework of a stronger MSs involvement and coordination among them in terms of curricula for public health training within Europe and a flexible approach to integrate new evidence and learning from country experiences.

Seventh, DIPoH was considered a proposal with an important added value. The need of an EU health information infrastructure was highlighted, but its feasibility was a concern due to the financial future sustainability and country political commitment. Although it was detailed that DIPoH will be built on the current financing structures that research networks are already operating. Additional governance and financing options were presented in the ESFRI roadmap.

Eight, the set-up of National Nodes on Health Information was considered important for the Health Information Infrastructure, and it was considered positive that they were flexible to be adapted to the specificities of each countries. There was agreement on the added value of the national networking, but it was highlighted that the EU institutions should also participate and support it. Moreover, It was also highlighted the need of stronger EU-MSs coordination and collaboration to achieve and sustain main InfAct outcomes, since main steps to move forward to a DIPoH and NN counterparts in some countries are not functionally established.

The complete minutes of both Technical Dialogues are provided in advance to the members of the fourth AoM in October 2020. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 4.4. Reports on key holders and relevant EU- international partners meeting (Technical Dialogues))

B. Assembly of Members

So far, InfAct held 3 AoM with representatives from MoH and MoR from participating countries. Main recommendations raised by AoM from high representatives were:

First Assembly of Members (March 2019) country representatives highlighted the following aspects regarding InfAct:

- All countries welcome a unique infrastructure gathering research, best evidence to inform policies and health information systems for health management.
- MSs/Associated Countries need one-stop shop to provide quality and comparable data for decision-making in a timely manner.
- There is a need of linking research and health management in order to increase evidence-based health policy.
- Funding such an infrastructure remains a concern, since for being useful in terms of EU HIS most countries should be involved and provide national data in a standardized manner.
- A research Infrastructure does not need many countries involved. Although, the aim to gather in one stop-shop research results and health information for health management and policies, will not be met if only few countries participate.

In the Second Assembly of Members (November 2019), the following aspects were the most urgent to address according to country representatives:

- Alternatives for funding and for the design of the research infrastructure (RI), apart from the business plan for the ESFRI roadmap and the ERIC/DIPoH, were required.
- Funding of such infrastructure will depend on political commitment across EU MSs and associated countries. At the highest political level decision depends on clear future return of investment and a benefit/added value at the national level.
- A more precise definition of expenses that should be covered by MSs is needed.
- Clarify the role of the European Commission in supporting the RI, as supporter of HIS and partner involved in InfAct.
- Current Research Nodes might not see the added value of such RI as one stop shop. To address that gap a strategy to build confidence/added value among existing Research Networks is needed.
- The importance of the NN and the RN was stressed, but further clarification was needed about their definition. It was highlighted the huge economic effort that requires the establishment of a national hub (for example in France). It was also stressed the huge diversity of formats within countries to perform hubs and its consequences in terms of efficiency.

- Information was required about the central office location.
- It was required a formal proposal that Ministry representatives could submit to their Ministers.

An additional AoM was also held in June 2020 to update MSs on the development of InfAct activities and to provide detailed response to the information requested by the representatives in the former AoM. The main conclusions of the meeting were:

- Country representatives highlighted the work on setting up DIPoH, the importance of building the national nodes and considered that the proposal is well articulated at national and European level.
- Country representatives welcomed setting up a Population Health Information Research Infrastructure (PHIRI) for COVID-19 as a practical use case of DIPoH, because it fills a gap of rapid data exchange between countries and recommended the linkage with other initiatives on HI at national and European level.
- By September 2020 ten countries had already given their political support and twelve institutions have signed the Memorandum of Understanding to the DIPoH infrastructure.
- Among the barriers to provide political support, country representatives mentioned: (i) some countries needed also to guarantee financial support before signing the letter of political support, (ii) in others, the responsibility of funding belongs to the Ministries of Science, (iii) in some of them the internal process of application at national level was over so they should wait for the next year call and (iv) the remaining countries would support an enlargement of scope of ECDC rather than the research infrastructure.

Information and feedback exchange with country representatives will continue until the fourth AoM in October 2020 and after the end of the project, in order to prepare the implementation of the DIPoH and build sustainability. (More information will be available by the end of the project on our website www.inf-act.eu. Deliverable 4.2. Reports on AoM Assessments).

VI. Recommendations for knowledge translation and sustainable initiatives

Based on InfAct outcomes and feedback received from Health and Research authorities in EU MSs and associated countries, the JA InfAct propose an exercise of MSs join collaboration in order to integrate, develop and implement most activities and innovative proposals that, based on its efficiency and scientific evidence, help to improve health information and decision making.

Among other initiatives InfAct strongly recommends:

To promote the implementation of the Distributed Infrastructure on Population Health (DIPoH). InfAct has developed the full business plan (following the requirement of the

AoM) and the proof of concept for a sustainable EU structure for health information. This includes the development of the core elements for the future implementation of DIPoH. The summary of achievements supporting long term functioning of the RI include:

- ✓ The set-up of National Nodes on Health Information.
- ✓ Coordination with key Research Networks.
- ✓ Quality criteria
- ✓ Business case describing the whole RI that can be implemented after InfAct.
- ✓ The governance structure for the RI
- ✓ A web-based portal as the basis for the future Research Infrastructure DIPoH that will be maintained after the project.

Ministries of Health and Science have provided feedback and some of them expressed their interest in joining the development of the DIPoH concept for the **ESFRI Roadmap 2021** application that was submitted by September 2020. At the time of submission the MSs support was expressed through 12 Memorandum of Understandings, 10 letters of political support, 3 expressions of financial commitment and 8 letters of intent.

Regarding health priority setting, methodology and practices, the following tools have been developed by InfAct and are ready to be implemented in EU MSs:

- Report on data collection and data sharing methods to facilitate the assessment of health inequalities across EU MSs and associated countries in terms of quality, metadata reporting standards, availability, accessibility and comparability of health data and information. It will also facilitate sharing and dissemination of standardised and comparable health data collections.

- Catalogue of international health information collection networks, projects and indicator/data sets. A sustainable information base to function as a knowledge repository and solid base to connect experts and build on work from the past.

- Guidance on good practice for health reporting. To fill the gap in public health science between gaining new knowledge and its translation into practice and policy. A sustainable tool to facilitate the generation and dissemination of health information to the targeted groups and promote access to high-quality EU-comparable information.

- Sustainable European Core Health Indicators (ECHI) list updating its technical contents. The list provides an overview of European public health (including care). The European Commission (DG Sante and DG Estat in particular) is seen as an important partner, with a role in securing policy relevance, technical commitment, financial sustainability and possibly legal status.

- Roadmap for innovative use of data sources. The routine use of data linkage and/or artificial intelligence (AI) for public health surveillance and research purposes to estimating health indicators and the Methodological guidelines to estimating health indicators using linked data and machine learning techniques.

- The use of inspiring indicators: Use of non-health databases, like environmental health determinants, for health surveillance (En-Risk). Composite health indicator for monitoring Non Communicable Diseases (ratio of age-adjusted hospital morbidity and mortality rates) describing their geographic variability and, if detected, examining their causes.

- Report on Assessing and piloting interoperability at the EU level. Describes the methods and techniques used for the cross-border linkage and sharing of health data through four interoperability layers (legal, organisational, semantic and technical).

- Manual to carry out Health Information System assessments in Peer review format. InfAct assessments were initiated and executed at the level of health information institutions and experts and resulted in the identification of strengths and weaknesses in the national HIS under assessment, stimulated the improvement of HIS and the exchange of good practices and may lead to the reduction of health information inequalities between countries.

- Good-practice-approaches and guidance document for prioritising health information at the national level. The document includes criteria, methods and structured prioritisation processes as well as stakeholder involvement. The guidance could be further developed into a health information prioritisation strategy at the European level for the establishment of a EU health information system.

- To integrate BoD indicators in the public health policies across Europe by raising awareness, sharing knowledge and experience, and provide mutual support.

- Health Information Training Program designed to improve the MSs´ Capacities in population health and health system performance analysis and monitoring to address existing inequalities.

References

[1] European Council, Council conclusions on the "reflection process on modern, responsive and sustainable health systems"available at http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/140004.pdf, accessed 6 June 2020

[2] The BRIDGE Health Project, Bridging Information and Data Generation for Evidence-based Health Policy and Research, available at https://www.bridge-health.eu, accessed 29 April 2020

[3] National Human Genome Research Institute, Ethical Social and Legal Implications Research Program, available at https://www.genome.gov/Funded-Programs-Projects/ELSI-Research-Program-ethical-legal-social-implications. accessed 27 July 2020

[4] European Commission, INSPIRE Knowledge Base, available at https://inspire.ec.europa.eu/ accessed 10 August 2020

[5] 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

[6] 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)

[7] Institute of Health Metrics and Evaluation. Country Health Profiles, available at http://www.healthdata.org/results/country-profiles, accessed 5 June 2020

Appendices

Annex 1. The Technology Readiness 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)
	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-WP4,5, 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	TRL4: A review of existing research networks (BRIDGE Health) reveals that most of population health research has been conducted using rigid data

Element		Achieved during BRIDGE Health and InfAct
	across datasets (within and between countries)	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
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

Element		Achieved during BRIDGE Health and InfAct
		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 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) MSs 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

Element		**Achieved during BRIDGE Health and InfAct**
		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 health care 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

Annex 2: Inspirational case studies for piloting interoperability.

Case study	Aim	Data sources	CDM (Main entities)	Software distribution	Hubs
Monitoring resilience	Elaboration of a population health indicator	Insurance data PC HER Prescriptions Hospital stays	Individuals Insurees Residences	Data model specification (v1.0)	Wales NHS (UK) Aragon (ES)
Costs of dementia	Identification of 1-year follow up contacts and associated costs	Insurance data PC HER Prescriptions Hospital stays ER data RHB contacts Billing data	Individual patient Care provider Time stamps	Data model specification (v0.1)	Aragon (ES) France (FR)
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 Events	Complete solution Docker with open source Log builder and process mining analysis (1.10)	Aragon (ES) Marche (IT) Norway (NO) HU Zagreb (HR) Latvia (LV)