



InfAct final General Assembly meeting 21-22 January, 2021

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Day 1 - 21/01/2021

Participants Day 1

Alexandra Cucu, Alicia Padron-Monedero, André Beja, Andrew Smith, Anne-Marie Yazbeck, Anselm Hornbacher, Ausra Zelviene, Barthélémy Moreau de Lizoreux, Boris Bikbov, Brecht Devleesschauwer, Brigid Unim, Cahill Alan, Carlos Dias, Catarina Carreira, Catherine de Muysen, Christian Léonard, Claudia Dima, Claudia Habl, Dimitra Lingri, Dimitrios Sarikizoglou, Elsi Haverinen, Enrique Bernal Delgado, Giovanni Nicoletti, Hamid Hassen, Hana Marie Broulíková, Hanna Elonheimo, Hanna Tolonen, Heidi Lyshol, Herman Van Oyen, Hrvoje Belani, Indre Petrauskaite, Inga Selecka, Irisa Zile, Isabel Nogueira, Isabella Röhring, Ivo Rakovac, Jakov Vukovic, Jakub Hrkal, Jane Idavain, Janis Misins, Jennifer Zeitlin, João Vasco Santos, Jone Jaselioniene, Juliane Fluck, Karolina Węgrzyn, Kenneth Anthony Eaton, Kenneth Grech, Kim Vyncke, Leonor Nicolau, Linda Abboud, Luigi Palmieri, Luís Lapão, Maja Krstic, Mare Ruuge, Marie Delnord, Mariken Tijhuis, Martin Thissen, Merike Rätsep, Metka Zaletel, Mika Gissler, Miriam Saso, Naslene Zilvine, Neville Calleja, Nienke Schutte, Ondrej Majek, Zeynep Or, Patrizia Theurer, Paulo Nogueira, Peter Achterberg, Petronille Bogaert, Philibert Marianne, Philippe Roux, Ramón Launa Garces, Reli Mechtler, Rodrigo Sarmiento, Romana Haneef, Rosalyn Keys, Sandra García Armesto, Sarah Craig, Sari Kauppinen, Sarka Dankova, Scoutellas Vasos, Seila Cilovci, Sheona Gilsenans, Spela Jakop Dukic, Stefan Mathis-Edenhofer, Stefanie Seeling, Tadek Krzywania, Tatjana Kofol, Tomasz Wiśniewski.

Agenda Day 1

Nr	Thursday 21/01/2021 (13:00-15:30)	Speaker	Time
1	Welcome	Philippe Roux <i>DG SANTE, European Commission</i> Herman Van Oyen <i>Sciensano, Belgium</i>	13:00
2	The Joint Action on Health Information (InfAct) and the road to the Distributed Infrastructure on Population Health (DIPoH)	Miriam Saso <i>Sciensano, Belgium</i> Petronille Bogaert <i>Sciensano, Belgium</i>	13:15
3	Showcasing the Health Information portal	Metka Zaletel <i>NIJZ, Slovenia</i>	13:40
Break			14:00
4	<p>Room 1: data sources for decision makers</p> <ul style="list-style-type: none"> Finding the data and experts: the added value of a one-stop shop connecting experts for evidence based decision making Bringing networks together Interoperability through inspiring cases DIPoH's contribution to the use of ECHI Data accessibility and availability <p>Room 2: data sources for researchers</p> <ul style="list-style-type: none"> Data collection methods and procedures Interoperability: the federated infrastructure Use of non-health data bases for health surveillance The Health Information Portal: access and potential services 	<p>Moderator: Claudia Habl <i>GöG, Austria</i></p> <p>Presenters: Hanna Tolonen <i>THL, Finland</i> Mariken Tijhuis <i>RIVM, The Netherlands</i></p> <p>Moderator: Enrique Bernal-Delgado <i>IACS, Spain</i></p> <p>Presenters: Jakov Vukovic <i>CIPH, Croatia</i> Luigi Palmieri <i>ISS, Italy</i></p>	14:15
5	The added value of DIPoH to the Research Infrastructure landscape	Andrew Smith <i>Elixir</i>	14:45
6	Continuity and next steps regarding data sources	Linda Abboud <i>Sciensano, Belgium</i>	15:00
7	Concluding remarks	Herman Van Oyen <i>Sciensano, Belgium</i>	15:15
End of day I			15:30

See slides [here](#)

1. Welcome, Philippe Roux (EC -DG SANTE)

A better use of and access to health information is fundamental both for research and policy-making. To make the most out of investments, investment choices should be evidence based and should build on high quality outcomes of projects such as Bridge Health and InfAct. The sustainability of such an infrastructure is very important, together with the simplification of processes, reducing the efforts and creating synergies with other projects.

It is important to streamline the activities regarding handling population health information and reduce health information inequalities. Gaps in data collection strategies should be identified and interoperability and comparability should be improved. Health information integration in policymaking is key. We have to create adequate data ecosystems and deploy data science strategies. This current crisis is exemplary herein. The European Union should play a bigger role in the health field and it should pay special attention to e-Health.

The European Health Data Space (EHDS) will be an integrate part of building a better health system for Europe. The PHIRI (Population Health Information Research Infrastructure) project is a real example of how you can build upon the partnerships and outcomes of InfAct. The result of the work in InfAct and the recommendations provided in this meeting will be examined thoroughly. The sustainability, digital transformation and resilience are key issues to be moving forward in the future.

2. The Joint Action on Health Information (InfAct) and the roadmap to the Distributed Infrastructure on Population Health (DIPoH), Petronille Bogaert (Sciensano)

InfAct is the Joint Action on Health Information. It is a 36 months project funded by the European Commission and includes 40 partners in 28 EU and associated countries (AC). It builds on the BRIDGE Health project and other initiatives in health information.

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.

InfAct's goals are to strengthen national and EU health information systems by:

1. Establishing a sustainable research infrastructure which will support population health and health system performance assessment
2. Strengthening European health information and knowledge bases and health information research capacities to reduce health information inequalities
3. Supporting health information interoperability and innovative health information tools and data sources.

The different work packages in InfAct have all contributed to the conceptualisation of the Distributed Infrastructure on Population Health (DIPoH).

The current challenges in health information include fragmentation, inequalities and are project based, and demonstrate the need for an EU health information infrastructure.

The framework of DIPoH focuses on population health, and includes health status, determinants of health and health care system performance. It is unique in that it covers the population as a whole (healthy and non healthy) and fills in a current gap in the Research Infrastructure landscape in Europe.

DIPoH is built in a distributed structure including a central office and distributed National Nodes and domain specific Research Networks. DIPoH offers four core services: a one-stop shop for EU health information research; innovation research in health information; capacity building; and knowledge translation research for evidence based decision-making.

The InfAct Joint Action has contributed in different outcomes to the development and piloting of the services of DIPoH. We will discuss and showcase these outcomes during this meeting and the specific breakout sessions.

3. Showcasing the Health Information Portal, Metka Zaletel (NIJZ)

One of the main outcomes of InfAct is the set-up of the Health Information Portal (HIP) as the entry point for the one-stop shop for population health information in EU. The main aim is to connect, to enable exchange of knowledge and of information, to promote cooperation within and between countries and research networks.

It serves as the basis for Distributed Infrastructure on Population Health (DIPoH).

Some of the key features of the Health Information Portal (HIP) include:

- Connectivity: research networks and national nodes are connected
- Key words: Conceptual model is built in Research Networks and National Nodes to enable search functions.
- Searchable content: Live HIP will encourage cooperation within and between countries and Research Networks

National Node (NN) = A network of national stakeholders working with the health information and being owners/controllers of health and health care data

Research Network (RN) = Existing health domain specific research networks (e.g. EHES, EuroPeristat, ECHO,...)

Live presentation: www.healthinformationportal.eu

4. Break out session day 1

Room 1 for Policy Makers: Claudia Habl (GOG), Hanna Tolonen (THL) & Mariken Tijhuis (RIVM)

This session focused on InfAct outcomes that are relevant for policy and decision-makers. The session summarizes the benefits of the one-stop shop presented through the One-stop shop and the networks of DIPoH.

1. One-Stop shop for health information in Europe

DIPoH will offer a One-stop shop integrating population health information, data and expertise by:

- Providing the best knowledge available for evidence-informed and timely policy-making
- Optimising instruments to facilitate the provision and uptake of latest and best evidence on population health for decision making
- Closing the gaps of population health Information in Europe
- Ensuring the collection and provision of information follows “FAIR” data principles, and the data portal will adhere to the GDPR.

2. Network of Networks

InfAct initiated the setup of National Nodes (NN) in EU partner countries with high added value for policy makers:

- NN bring together regional/national stakeholders in health information in a more systematic manner
- NN facilitate discussions on core issues on health information domains (nationally and internationally)
- Provide a ‘spider web’ role

Another fundamental element in DIPoH are the Research Networks (RN)

- RN represent a group of collaborating experts that collect, exchange, harmonise and analyse data and information on a shared health topic.
- RN generate new data and research output, improve research methods and tools, develop standards and guidelines, and contribute to international research capacity building to support health policies and healthcare management.

National Nodes and Research Networks provide expertise for decision making.

3. Data accessibility & availability

InfAct reviewed existing data collection methods, metadata reporting standards and reuse of population health data. Additionally, it assessed accessibility and availability for research from different existing research networks and international organisation across EU. This contributes to guidelines to standardise data collections and quality assessment methods to be part of DIPoH.

DIPoH’s health information portal supports availability, accessibility, comparability and secondary use of health data and information generated by stakeholders of the National Nodes and Research Networks across Europe. It ensures compliance with FAIR principles: Findable, Accessible, Interoperable, Reusable.

4. Interoperability

InfAct mapped cross-national inspirational experiences on data reuse for both public health research and monitoring initiatives gaining insight in enablers and barriers to cross-border linkage and sharing of health data.

5. The ECHI indicators

The European Core Health Indicators (ECHI)-initiative is an example of a successful project-based initiative that will benefit from a sustainable health information infrastructure where MS and EC can collaborate on its maintenance.

The ECHI indicators are the core of a European public health monitoring system and are the result of the European Commission and MSs guided collective efforts since 1998.

InfAct catalogues existing indicator sets in Europe. The list currently contains 88 indicators, ~60 implemented across EU addressing demographic and socioeconomic aspects, health status, health determinants and health interventions. They provide a 'snapshot' of European Union public health and health care:

- They provide a good basis for national health reporting international comparisons of public health
- They have assisted in structuring national health information systems & standardising European health indicator reporting

InfAct assessed the different ways to bring sustainability to the current ECHI indicators, demonstrating how DIPoH's health information portal can ensure a sustainable after-life for project results and research findings allowing regular updating under one umbrella.

Questions discussed:

- Are there plans to create awareness about the portal?
We are working on proving awareness of the portal by having this as a gateway that is separate from projects (whether it is InfAct, DIPoH or PHIRI).
- What kind of information will be included on the ECHI indicators on the Portal? Will the database be shifted here as well?
We are working on creating a stable location for the ECHI indicators on the portal.
- Is there any good example of a National Node that could enlighten the other Member States to develop a National Node?

InfAct has prepared a stepwise approach for setting up a National Node and initiate multiple meetings for partner MSs to discuss and provide experience on different national nodes in MS/AC. This will also be part of the services of DIPoH and will be taken forward through PHIRI.

Room 2 for Researchers: Enrique Delgado-Bernal (IACS), Luigi Palmieri (ISS) & Jacov Vukovic (CIPH)

This session focused on the InfAct outcomes relevant for researchers.

1. The data collection methods and procedures for Health Information support across EU countries

InfAct assessed health data collection methods and procedures for Health Information support across EU countries by reviewing institutional websites and EU research networks. This task also developed recommendations based on these findings in EU Research Networks. The use of different reliable population health data sources in public health research activities is essential for development and implementation of evidence-based interventions and policy.

As part of DIPoH, Research Networks could play a major role in tackling health data and information inequalities by enhancing quality, availability, accessibility of health data and data sharing across European networks. Research Networks can help to prevent the fragmentation of research activities, collected health data and information.

2. Use of non-health data bases for health surveillance

InfAct investigated the use of data linkage and the use of artificial intelligence (AI) in routine public health activities, and identified main obstacles to link different data sources.

This activity within InfAct concluded that a sustainable national health information system and a robust data governance framework, allowing to link different data sources, are essential to support evidence-informed health policy development. At the same time, building analytical capacity in national institutes is necessary for improving the use of linked data in order to improve the quality of public health surveillance and monitoring activities.

These outcomes have contributed to the potential innovation in health information service development of DIPoH.

3. Leveraging interoperability to build a federated research infrastructure in Europe

InfAct piloted the federated research infrastructure through case studies. A number of hubs have been able to deploy a complete exercise, thus:

- Building a common data model on stroke care
- Implementing an analytical pipeline using an open source ready-to-use solution
- Running the scripts at home, not moving micro-data to a central hub, and
- Sending back a relevant output to the coordination hub for further meta-analysis

Through this exercise, the feasibility of the federated structure is piloted while ensuring privacy and safety provisions of the different data hubs; exploring governance procedures and common data models; and building capacity.

4. The Health Information Portal: Access and services

DIPoH's Health Information Portal provides a user friendly gateway to a map population health information and expertise in EU and is designed to respond to current and future needs of researchers in population health. This includes:

- Metadata catalogue of national data collections and Health Information sources
- Information about current and ongoing research, existing research networks, their work, outputs, and their domain of expertise
- Overview of international organisations working in health information and provides hyperlinks to these organisations and their relevant activities and outputs
- Overview of trainings and workshops available in EU
- Access to DIPoH trainings, and expert support
- Innovation in Health Information: Innovative use of data sources, Health indicator estimates from linked data and advanced statistics, Best practices in population health research, Computing services, Interoperability services and standards.

Questions discussed:

- How do you deal with the fact that registers have different structures in different countries? One central R script will not work.

You have to have an agreement on a common data model. Then you implement the script, let it run multiple times and debug. The final version should be able to run in each of the data hubs.

- What services would have a real added value for you as researchers?

There is a need of knowing what data is out there and who is in charge.

The register based data are underexplored, in terms of research as well as policy making. This project will also help to get this organized at a national level.

- What would your expectation be towards the data owners, for the future we have to support the people that have to provide the metadata. What do we as researchers expect from data owners to facilitate research?

Sharing of the data and cross-country research are very important.

5. The added value of DIPoH to the Research Infrastructure landscape, Andrew Smith (Elixir)

Connections between Research Infrastructures (RI)'s are of utmost importance. DIPoH can work closely with other RI's on the ESFRI roadmap, examples are giving for interactions with Elixir.

The European Open Science Cloud (EOSC) is an example of the EU underlining the importance of bringing RI's together. The connection of the infrastructures is a political

priority and there are opportunities for funding and investments because of that. There are also opportunities to collaborate bilaterally.

Finally, from the experience of Elixir it is noted that there is a need for the 'nodes' to collaborate, nationally and internationally. The COVID-19 pandemic required integration of health portals; good example of how we should connect datasets through the COVID-19 data portal.

6. Data sources next steps, Linda Abboud (Sciensano)

Summarising what has been presented today with regards to InfAct activities and outcomes towards the setup of the one-stop shop, InfAct has:

- Reviewed existing data collection methods, metadata reporting standards and reuse of population health data
- Assessed data accessibility and availability for research
- Catalogued existing health indicator sets in Europe (ECHI)
- Developed a network of networks for DIPoH
- Mapped interoperability enablers and barriers for data sharing and reuse
- Investigated the use of data linkage of different data sources and the use of artificial intelligence (AI) in routine public health activities
- Piloted distributed research infrastructure

All the assessments and outcomes of InfAct have contributed to conceptualising the Distributed Infrastructure on Population Health (DIPoH).

Furthermore, for containing the work towards DIPoH, InfAct has advocated across MSs bringing support for the development of DIPoH. So far DIPoH has received the following support:

- 10 EU/AC countries have provided Political support through ministries, 8 of which also signed Memorandum of Understanding (MoU) through partner institutes.
- A total of 12 institutes from EU/AC countries have signed Memorandum of Understanding (MoUs), 1 MoU pending from France (HDH-FR and SPF).
- 8 EU Research Networks signed letters of intent for collaboration.

The next steps of DIPoH include the launch the Health Information Portal and connecting further with Research networks, EU Countries and their National Nodes. At the same time, the work started in InfAct for DIPoH will continue in PHIRI, the European Health Data Space the European Open Science Cloud other H2020 initiatives.

Questions discussed:

- In what shape will the political support come? Why have some countries not signed a support letter yet?

When MSs sign the political support letter it is effectively indicating that they are in favour of the development and setup of DIPoH, it doesn't include financial investments yet. Once DIPoH is on the ESFRI roadmap it will work towards becoming a legal entity and then we can work with membership fees, so commitment from MSs will then be shaped differently.

With regards to the process of receiving support so far, in some countries many changes were taking place in the ministries, which delayed the expression of support. Even though the DIPoH proposal (for the ESFRI roadmap 2021) has been submitted, we are continuously looking for support.

- Could you please name the countries that have showed support?

Memorandum of Understanding signed by institutes in Austria, Belgium, Croatia, Czech Republic, Finland, Germany, Malta, Portugal, Romania, Slovenia, Spain, The Netherlands.

7. Closing remarks, Herman van Oyen (Sciensano)

One important evolution in Europe is the call for setting up a European Health Data Space (EHDS). Within InfAct, the experience we have gained with the networks and national nodes puts us at the forefront in contributing to this development. We would have never achieved all of this when we would have just worked at national level.

Tomorrow we will, amongst others, focus on capacity building, as it is important to overcome health information inequalities.

Day 2 - 22/01/2021

Participants Day 2

Alexandra Cucu, Alicia Padron-Monedero, André Beja, Angela Fehr, Anne-Marie Yazbeck, Anselm Hornbacher, Ausra Zelviene, Barthélémy Moreau de Lizoreux, Brecht Devleesschauwer, Brigid Unim, Catarina Carreira, Christian Léonard, Dimitrios Sarikizoglou, Elena-Petelos, Elsi Haverinen, Francisco Estupiñan-Romero, Giovanni Nicoletti, Hanna Elonheimo, Hanna Tolonen, Heidi Lyshol, Herman Van Oyen, Hrvoje Belani, Indre Petrauskaite, Inga Selecka, Irisa Zile, Isabel Nogueira, Isabella Röhring, Ivo Rakovac, Jakov Vukovic, Jakub Hrkal, Jane Idavain, Janis Misins, João Vasco Santos, Jone Jaselioniene, Juliane Fluck, Karolina Węgrzyn, Kenneth Eaton, Kenneth Grech, Linda Abboud, Luigi Palmieri, Luís Lapão, Maja Krstic, Mare Ruuge, Marie Delnord, Mariken Tijhuis, Mariusz Duplaga, Martin Thissen, Merike Rätsep, Metka Zaletel, Miriam Saso, Naslene Zilvine, Natasa Peric, Neville Calleja, Nienke Schutte, Patrizia Theurer, Paulo Nogueira, Petronille Bogaert, Philibert Marianne, Philippe Roux, Reli Mechtler, Rodrigo Sarmiento, Romana Haneef, Rosalyn Keys, Sandra García Armesto, Sarah Craig, Šeila Cilovic Lagarija, Sheona Gilsean, Stefan Mathis-Edenhofer, Stefanie Seeling, Tadek Krzywania, Thomas Ziese, Tomasz Wiśniewski, Vasos Scoutellas, Verónica Gómez, Zeynep Or.

Agenda Day 2

Nr	Friday 22/01/2021 (9:30-12:00)	Speaker	Time
1	Welcome	Christian Leonard <i>Sciensano, Belgium</i> Herman Van Oyen <i>Sciensano, Belgium</i>	9:30
2	The Joint Action on Health Information (InfAct): capacity building activities and innovative tools for population health	Miriam Saso <i>Sciensano, Belgium</i> Linda Abboud <i>Sciensano, Belgium</i>	09:45
3	<p>Room 1: tools, guidelines and capacity building for decision makers</p> <ul style="list-style-type: none"> • Prioritisation in health information development and recommendations • Application of best practices with topic specific reports • Health information system assessment and benefits for capacity building in a peer review format <p>Room 2: tools, guidelines and capacity building for researchers</p> <ul style="list-style-type: none"> • Machine learning techniques • Reporting on health data guide • School on health information experience in increasing health information skills for researchers and future roadmap • Toolkit Burden of Disease developed for researchers for producing better indicators 	<p>Moderator: Thomas Ziese <i>RKI, Germany</i></p> <p>Presenters: Stefanie Seeling <i>RKI, Germany</i> Neville Calleja <i>Ministry of Health, Malta</i></p> <p>Moderator: Herman Van Oyen <i>Sciensano, Belgium</i></p> <p>Presenters: Luís Lapão <i>UNL, Portugal</i> Romana Haneef <i>SpFrance, France</i></p>	10:00
Break			10:30
4	InfAct sustainability plan	Isabel Noguer <i>ISCIII, Spain</i>	10:45
5	European perspective for setting up a Research Infrastructure for population health	Kenneth Grech <i>Ministry for Health, Malta</i>	11:00
6	Regional perspective for added value of DIPoH	Sandra García Armesto <i>IACS, Spain</i>	11:10
7	Strengthened knowledge and expertise on health information: continuity and next steps	Petronille Bogaert <i>Sciensano, Belgium</i>	11:20
8	Concluding remarks	Anne-Marie Yazbek <i>CHAFEA, European Commission</i> Herman Van Oyen <i>Sciensano, Belgium</i>	11:45
End of day II			12:00

See slides [here](#)

1. Welcome, Christian Leonard (Sciensano)

The collection of validated data in a collaborative manner, to trade between countries better public health knowledge, is essential. We need to pay attention not only to the way data is collected, but also to the content of the data, what they are reflecting, what they signify, because data means more than figures. Data has to reflect concepts.

Data collecting and data analysis are not value neutral. By choosing the data to use in a model, researchers lose certainly a part of the necessary objectivity, which has to characterise a scientific work. They defend some values (social, ethical and philosophical values). However, we need to be aware of the of non-moral authority of data collection. We should promote awareness in researchers in public health and that their choices are characterised by moral values. That means that people who are in charge in collecting data have to anticipate the way the data will be used.

In general, researchers adopt implicitly or explicitly a utilitarian approach. The goal of utilitarian approach is the maximisation of health. And the better solution is the one that gives the highest results. With this approach, who suffer the most are the minorities. Yet, the utilitarian approach is certainly not the only one. There are other sources of inspiration, but to create a space of alternative approaches, we have to collect the data we need. And if this data does not exist, we have to propose the registration and the production of new data. That should be our duty and an engagement we have to take if one of the goals of this project is to tackle inequalities in health information. That is a necessary condition to conceptualise and realise a better world, a world with more solidarity, a world with less moral evaluation of the oldest lifestyle, a world where the erasing of inequalities is no more a dream, but a real possibility.

2. The Joint Action on Health Information (InfAct): capacity building activities and innovative tools for population health, Linda Abboud (Sciensano)

Presenting in short the objectives of InfAct and the different Work Packages that, in the past 3 years, implemented different tasks and activities towards the development of the conceptualization of a Distributed Infrastructure on Population Health (DIPoH).

We have presented to you the four services of DIPoH:

- One-stop shop for EU health information research
- Innovative research in health information
- Capacity building in health information
- Knowledge translation research for evidence based decision-making

Yesterday we focused on the one-stop shop which is presented through the Health Information Portal. We also presented some innovation aspects that were piloted in InfAct. Today we will present to you the different capacity building activities that took place in InfAct.

The maturity of DIPOH is presented through a general overview of practical achievements of InfAct and its predecessor BRIDGE Health in the format of Technology Readiness Levels (TRL). This is presented throughout the four services of DIPOH to showcase the different developments.

3. Break out sessions Day 2

Room 1 for Policy Makers: Thomas Ziese (RKI), Stefanie Seeling (RKI) & Neville Calleja (MFH)

1. Prioritization in Health Information development and recommendations

Health information should support public health policy action (agenda-keeping) and point to emerging public health issues (agenda-setting). However, it is unclear how the health information for national health reporting is prioritized and whether there are there “good-practice” approaches to prioritizing health information.

The research conducted within InfAct reported that:

- There are structured HI prioritization processes
- The respondents give preference to a formal, horizontal process for HI prioritization which includes different experts and stakeholders
- National health targets and strategies are desired guiding instruments for health information prioritization
- National Public Health Institutes are desired and feasible stakeholders in all HI prioritization processes

InfAct developed recommendations for prioritization process for policy makers:

- Continue to promote science-base, transparency and comprehension in health information prioritization
- Develop a guidance for ‘Good Practice health information Prioritization’ and use project results as starting point for joint efforts among EU MS

2. Application of best practices with topic specific reports

The presentation focused on highlighting the best practices for innovative use of health information to demonstrate the value of health information infrastructure as data exchange networks and for public health policy process across the Member States.

The results of the research found that:

- The majority of the countries have the capacity to link data on a routine basis. Yet, fewer countries routinely link health data to other databases.
- The data linkage has the potential to improve the comprehensiveness and the quality of health information across European countries for patient care and public health monitoring.
- Data linkage helps to evaluate patients care trajectories and outcomes and the impact of various factors on health system performance. At the same time, it can

improve possibilities for measuring the impact of population risk factors, including social disadvantage on health outcomes.

3. Health Information System assessment and benefits for capacity building in a peer review format

A pilot exercise in which 9 countries evaluated each other's health information systems in a peer review format has provided a learning experience. This results in a clear indication that health information system assessment is needed to decrease health inequalities and motivate leaders to act. A meaningful assessment of the health information system of a country has the potential to bring relevant changes and improvements in the country assessed.

Room 2 for Researchers: Herman Van Oyen (Sciensano), Romana Haneef(SPF) & Luis Lapão (UNL)

1. Guidance for Health Reporting

In order to develop public health measures to protect and promote the health of the population, health information must be adequately made available to the relevant target groups. This means that different requirements arise for the format, the communication channels for dissemination and the preparation of the information. InfAct aimed to provide a comprehensive overview of the formats and target groups of national health reporting in EU MS/AC.

On this basis, a guidance document with general recommendations for good practice in national health reporting was drafted, focusing on desirable and feasible quality criteria and standards for the preparation of public health reports.

Health reporting is rather heterogeneous in EU member states. A total of 8 categories with a variety of quality criteria for public health reports were identified (ranging from Scientific Standards to Databases, to Prospective Approach). To ensure sustainability, the guidance document will be disseminated (conferences, publications, included in trainings).

2. Machine learning techniques and public health surveillance (methodological guidelines)

The estimation of health indicators from linked administrative data is challenging due to several reasons such as variability in data sources, data collection methods resulting in reduced interoperability and timeliness, availability of a large number of variables, lack of skills and capacity to link and analyse big data.

InfAct developed guidelines to support researchers to estimate population based health indicators based on Machine Learning approaches. A checklist for methodological guidelines was developed.

3. Recommendations to perform a Burden of Disease study

Finally, recommendations to perform a burden of disease study were developed. The InfAct project has emphasized the potential role of Burden of Disease (BoD) approaches. COST Action BoD would support this approaches.

For those countries that are considering undertaking their own Burden of Disease (BoD) study, recommendations on minimum requirements for such a study, which if widely adopted would harmonise and facilitate efforts by European countries, to perform national BoD studies were developed within InfAct. This is also seen as a capacity building exercise achieved within InfAct and may be taken further as part of DIPoH.

4. School on HI experience in increasing HI skills for researchers and future roadmap

Health Information is important for EU strategic development. Health knowledge and information capacities vary across EU member states and the need to reinforce common practices and methods to improve the collection, management and use of health information is recognized. InfAct implemented a training school with the aim to contribute to increasing knowledge on availability and use of standardized Health Information methods to common practices in EU member states and associate countries. The training was divided in 5 days with 5 main topics each day. The course topics were selected aiming to contribute for the convergence in using European standard methods and were based on HI fundamentals, plus innovative contributions from the InfAct work packages and experts.

The training addressed fundamental Health Information tools and methods used by public health professionals. This pilot served as a basis for the European Health Information Training Programme and Strategy, with a clear example of a course that could be offered by DIPoH in the future. Thus, contributing to a sustainable improvement of capacity and equity in Europe.

Questions discussed:

- What is the future of applying machine learning techniques for population health research? Can I use this in my own institute? Can we use these guidelines?

Yes, you can; we have examples of studies in other countries that can be a big help. The key thing for machine learning is that you have to have a very good research question and then think of what kind of data you need to answer that question.

- What was/were the topic(s) attendants to the School were struggling most with?

All the sessions were online and although that is different than a real session, it went very well and the participants were very motivated. A struggle among professionals was the GDPR aspect. This could be given more attention, as this is a quite important, but also difficult topic.

- Given the complexity of the GDPR, could it be an important service to be developed by DIPoH to guide the researchers?

Definitely. We need to look from both the side of the data collectors and data users.

- Are the materials of the trainings widely available?

For security reasons, only participants of the training had access to the website. Soon we will have them publicly available on the Health Information Portal.

- Considering the demand for the school, do you feel that there is a high demand for this type of skill programs?

Yes we are planning to have a second training school, including new topics and/or go a bit more in depth, for example on the GDPR issues.

- If you look at the concept of DIPoH (and PHIRI), the health information portal should also include sections on training. Also as we're working with different research networks; they should be able to use the portal to promote the different courses that they are doing.

We will be targeting lifelong learning; as the world is changing, we try to create trainings for juniors as well as for seniors.

- Regarding the BoD recommendations: what would be the reasons for EU member states to have their own national BoD study done?

Through the global BoD study, there is already a wealth of information available. For international comparisons it is relevant to build on this exercise. However, performing a local exercise also has some indirect advantage for the health information system at the national level; it could be seen as 'the cherry on the cake' in terms of validity and completeness of the national health information system as it can aid in improving the quality of these data. In addition, you will get in contact with the local stakeholders AND you will be building capacity in BoD assessment. Performing a national BoD study has many favourable consequences, it is, however, resource demanding. Depending on the organization of the national institute this may or may not be feasible. It is important to create a clear overview what kind of resources and skills are needed and to generate a realistic view to see what is possible in our country. Nevertheless, in an ideal world you have both: international comparisons AND a clear view of your own local data.

- Can you also improve the international estimates by performing a local BoD assessment?

It can also serve as some kind of sensitivity exercise; this will allow you to identify key areas where there are important differences, compared to the international BoD exercises.

4. Sustainability Plan, Isabel Noguera (ISCIII)

The Council of the EU invited the European Commission and MSs to cooperate to establish a sustainable EU Health Information System and urged to look into a Research Infrastructure as a tool. The InfAct major expected outcome is to build a sustainable infrastructure on EU Health Information through improving the availability of comparable, robust and policy-relevant health information on population health research.

The InfAct strategy to develop a sustainability plan includes: looking for technical support, awareness and feasibility to integrate InfAct outcomes through Technical Dialogues (TD) and Fact Sheets representing the outputs; and looking for political support and guidance through

engagement with the Assembly of Members (AoM) consisting of representatives of ministries of health and research.

InfAct's sustainability plan refers back to its initial objectives:

1. Establishing a sustainable research infrastructure which will support population health and health system performance assessment
 - InfAct developed a business plan for the Distributed Infrastructure on Population Health (DIPoH) including the governance and management structures, users and services.
 - Developed the Health Information Portal which is set up independently of any project.
 - Strengthened core elements of DIPoH by engaging with National Nodes and Research Networks.
 - Through the application for ESFRI roadmap which was submitted, support was received from a total of 14 countries and 8 networks.

2. Strengthening European health information and knowledge bases and health information research capacities to reduce health information inequalities
 - Manual to carry out HIS assessments in Peer-review format.
 - Good-practice-approach for prioritising HI at national level.
 - Guide to promote the integration of BoD indicators in public health policies across Europe
 - First European Training School on Health Information

3. Supporting health information interoperability and innovative health information tools and data sources.
 - Proposal on data collection and data sharing methods.
 - Guidance on good practice for health reporting.
 - Roadmap for innovative use of data sources.
 - Methodological guidelines for using data linkage and machine learning techniques
 - Inspiring indicators: using non-health databases for public health surveillance and composite health indicator for monitoring NCD
 - Report on interoperability at the EU level.

The sustainability of InfAct's outcomes will proceed through the spinoff PHIRI (as a use case for DIPoH) and other EU initiatives.

5. European perspective for setting up a Research Infrastructure for population health, Kenneth Grech (MoH- MT, EGHSPA)

From the point of view of a person outside the InfAct consortium who was involved in the external evaluation committee my outlook on InfAct is the following:

InfAct has tackled, through its activities, different challenges: Fragmented data sources; Duplication; Data gaps; Lack of comparative information sources; Inoperable data systems; Imbalanced health information and research capacities within member states, especially for smaller MS.

These challenges were exacerbated, as a courtesy of COVID-19, as we need more and better:

- Access to robust timely data and information
- Comparable population based data
- Cross-border sharing of data
- Rapid policy decisions based on evidence
- Appropriate monitoring and evaluation systems
- Routine systematic linkage of data and evidence

From the European perspective, and from my experience from the European Expert Group on Health Systems Performance Assessment (HSPA) the added value of setting up DIPoH at European (not only EU) level is:

- A single harmonized source of information, through the one-stop shop
- An alternative option (not duplicating) current infrastructures
- Greater use of AI and digital tools to source and analyse data for research and policy purposes
- A move from assessment to action/change - linkage to policy change and policy making

However, one aspect that needs to be considered, is how to sustain DIPoH: the Health Information Portal needs to guarantee and sustain the information flow, but this depends on the sharing of (meta)data and information/research findings from both national and European sources/data hubs and data owners; the creation of political will & ownership is crucial (currently, political support is expressed by 10 countries and 12 institutional MoUs); the governance structure must be robust & appropriate, with transparent funding mechanisms; It is important to 'assert' research and policy relevance if it is to succeed (e.g. of COVID-19); finally it should not increase burden on data hubs, especially for smaller states.

6. Regional perspective of the added value of DIPoH, Sandra Garcia Armesto (IACS)

From a point of view from a system that has a mandate for development research and innovation, DIPoH is an 'enabler'. It is the final part to allow your researchers to actually be more excellent in the way they do research, but also the research we will need to develop in the future.

From a regional point of view, we are quite advanced, however we work with data of our own population. Therefore, the added value of DIPoH and its EU umbrella we are able to reach millions of data. Both our research and our ability to answer questions of policy makers improve exponentially. Also, from the regional perspective, the only way to link and have international networks is to be able to comply and participate in these types of infrastructure.

Currently, the momentum has been built at an incredible speed. The time is now! This is also clear at an EU level through the recently published Data Governance Act and the developments towards the European Health Data Space, and we should be part of it.

An example is the COVID-19 Data Share Research Platform (EMBL - EBI/ELIXIR): a infrastructures for human-virus biology. What was missing was a piece on how the COVID-19 crisis is affecting the general health population, which is now going to be filled by PHIRI and DIPoH in the future.

The beauty of what DIPoH is proposing and the other initiatives going in that same direction is: We are very conscious of the need not to duplicate, but we should not be afraid of creating synergies (with current EU initiatives). It is clear from what already exists, a research infrastructure on population health is what is still missing in the current landscape. PHIRI is now demonstrating that this works and semantical and technical interoperability is possible. We are in a very good position to take this forward and sustain it, and to make sure that it is interoperable with the rest of the data already available.

7. Strengthened knowledge and expertise on health information: continuity and next steps, Petronille Bogaert (Sciensano)

Especially during the COVID-19 pandemic, many questions remain unanswered and data gaps persist. Partners at the core of the COVID-19 response teams have indicated a strong need to structurally exchange between countries. Countries needed to discuss with counterparts, share concerns and compare the measures taken, and this was not possible in international forums. The need for a Research Infrastructure on population health became clearer.

PHIRI stands for Population Health Information Research Infrastructure. It is a project financed under the Horizon 2020 from the Directorate-General Research and Innovation. It is divided in 9 work packages and it is driven by the work of 41 partners (27 National Institute of Public Health or Research or Disease Control, 7 Universities, 7 Ministries of Health) in 30 countries.

The objectives of PHIRI are:

- To provide a Health Information Portal for COVID-19 with FAIR catalogues on health and healthcare data for structured information exchange across European countries. To link different data sources and to use Pan-European data in a GDPR compliant, federated way.
- To provide structured exchange between countries on COVID-19 best practices and expertise. It allows researchers to provide relevant and evidence based information ready for use in research, and decision-making processes.
- To promote interoperability and tackle health information inequalities. PHIRI supports researchers and public health bodies to research queries related to COVID-19 and provides capacity building for management of COVID-19 relevant population health and healthcare data.

PHIRI is the rollout towards implementation of DIPoH. Many of the aspects in the future work of PHIRI directly build on work of InfAct and contribute to DIPoH.

8. Concluding remarks, Anne-Marie Yazbeck (CHAFFEA- Project officer)

I picked up on an interesting term “courtesy of COVID-19” I think it is a very good term as the situation shock up a lot of people, also here in the European Commission (EC). Your

meeting has presented many terms that are parallel to the priorities currently in the EC such as: informed decisions, improved interoperability and innovation.

One of the 4 pillars of financing aspects from the EC is dedicated towards Health Information. Keep your eyes open for different calls!

Additional information: CHAFEA is going to become HADEA, and the EU health programme is going to be called EU4Health with 5 billion euros budget.

Your project was instrumental in all this. It is clear InfAct was built on BRIDGE Health and is now continuing through PHIRI and it is most likely you will go forward in the next couple of years. This would not have been possible without the dedication of the coordinators and all the partners in this consortium.

Special thanks for Prof. Herman Van Oyen!

9. Concluding remarks, Herman Van Oyen (Sciensano)

I thank all the partners in this consortium. This was work that we only could do together. I'd like to thank everyone for the opportunity to be a part of this. Let's look to the future. In contrast to 'I will be back', I say: let's continue, and we know the way!

The activities around PHIRI and the other projects are very important. I would like the audience representing the MSs to take a look at the invite to join us in DIPoH. If you participate in PHIRI you're not necessarily a member of DIPoH, as we would need some political commitment as well. It is important to have a system that incorporates the total population. I would like to reiterate what Sandra said: we need an infrastructure for research, development AND innovation. Data is important for the economic developed in your own country AND in the EU as a whole.