

# Assembly of Members 12th of March 2019





Co-funded by the Health Programme of the European Union

# "Assembly of Members" 12th of March 2019

This meeting is organised by InfAct and hosted by Instituto de Salud Carlos III.





Assembly of Members | 12th of March 2019 Escuela Nacional de Sanidad Aula Pittaluga Instituto de Salud Carlos III | Av Monforte de Lemos 5 28029 Madrid | Spain | e-mail: InfActSpain@isciii.es or infact.coordination@sciensano.be Website: www.inf-act.eu | Twitter: @JA\_InfAct © 2019

# TABLE OF CONTENT

| Programme   |
|---|
| InfAct overview   |
| Speakers biography9   |
| Policy paper: The Health Information Research Infrastructure 17 |
| Summary work packages   |
| WP 1-3  |
| WP 4  |
| WP 5  |
| WP 6  |
| WP 7  |
| WP 8  |
| WP 9  |
| WP 10   |

### Tuesday 12 of March 2019 (09:00-16:30)

Instituto de Salud Carlos III (ISC III), Av Monforte de Lemos 5, 28029 Madrid. Location: Escuela Nacional de Sanidad. (Pabellón 7). Aula Pittaluga.

09:00-09:30 Welcome by the Instituto de Salud Carlos III Raquel Yotti, ISCIII, Spain

> Welcome and introduction by the chair Terms of Reference Neville Calleja, Ministry of Health, Malta

### 09:30-11:15 Introduction InfAct Herman Van Oyen, InfAct and Sciensano, Belgium

The current EU health information system: challenges and needs Linda Abboud, InfAct and Sciensano, Belgium

The concept of the Health Information Research Infrastructures: rational, goals and added value Petronille Bogaert, InfAct and Sciensano, Belgium

Case study Euro-Peristat: research networks in public health Marie Delnord, Euro-Peristat and Sciensano, Belgium

Improving health information and health information systems through InfAct: what's in it for MS. Enrique Bernal-Delgado, Institute for Health Sciences (IACS), Spain

- 11:15-11:45 Coffee break
- 11:45-13:15 The importance of research for policy making: the health system performance example Josep Figueras, European Observatory on Health Systems and Policies

Group discussions: expectations of and benefits for Ministries of Health and Research

- 1. What are your needs and expectations for health information on EU level?
- 2. Why or why not an EU health information infrastructure?

13:15-14:45 Lunch

### 14:45-16:00 Group discussion: conclusions Neville Calleja, Ministry of Health, Malta

The ESFRI roadmap: benefits and long-term approach Inmaculada Figueroa, ESFRI Executive Board Member

The ESFRI application by InfAct Herman Van Oyen, InfAct and Sciensano, Belgium

16:00-16:30 Programme and objectives for the next two Assembly of Members (AoM) Isabel Noguer, Alicia Padron, ISCIII, Spain

> View from the European Commission Philippe Roux, DG SANTE

Concluding remarks Neville Calleja, Ministry of Health, Malta



# **INFACT OVERVIEW**

Current EU health information systems are fragmented, dispersed, and difficult to access. This leads to incomparability and inequality in health information between and within EU Member States (MS).

The Joint Action on Health Information (InfAct - Information for Action) is working towards a sustainable infrastructure for EU health information for evidence-based health policy and research. It improves the availability of comparable, robust and policy-relevant health status data and health system performance information.

InfAct was launched in March 2018 and will run till February 2021. It is coordinated by Sciensano in Belgium, and includes 40 partners from 28 EU and associated countries. Through country collaboration, InfAct streamlines health information activities, reduces the data collection burden and works for a sustainable and robust data collection in Europe that facilitates and supports country knowledge, health research and policy making.

Work package 4 (WP) seeks opportunities for sustainable integration of InfAct's outcomes into regional, national, and international policies. This activity is led by Instituto de Salud Carlos III in Spain. To foster involvement of MS, WP4 brings together representatives from Ministries of Research and Health around Europe in an Assembly of Members (AoM). The AoM provides a platform for MS to give feedback and political guidance to InfAct's counterparts, and foster dialogue for long-term projection of InfAct's activities. The AoM acts as liaison with their national research and public health authorities. Additionally, it will create a consensus on a strategic vision for a sustainable infrastructure for EU health information. Major decisions on the way forward will be taken through a Memorandum of Understanding (MoU).

A policy paper developed within InfAct aims to provide interested MSs, candidate and EEA/EFTA countries with relevant information to make an informed decision on setting up a Health Information Research Infrastructure on EU level. The policy paper can be found on page 17.

Visit our website www.inf-act.eu or contact the AoM organising team at InfActSpain@isciii.es or infact.coordination@sciensano.be for additional information.



# SPEAKERS BIOGRAPHY



### Raquel Yotti

Raquel Yotti, Director Instituto de Salud Carlos III (ISCIII), Spain

Dr Raquel Yotti, specialist in cardiology, is a clinical researcher for the National Health System with a solid background. She was graduated in Medicine and Surgery at the Complutense University of Madrid in 1998, and was conferred a PhD from the same university in 2006.

She is an expert in cardiac imaging and genetics-based heart diseases, and her on-site work has been focused on directly caring for patients and their families at the inherited heart disease consultancy, and performing complex diagnostic testing, such as cardiac MIR scans and the interpretation of genetic studies.

Until her appointment in September 2018, she was the head of the Clinical Cardiology Department at the Gregorio Marañón General University Hospital (HGUGM), and associate professor of the Department of Bio-engineering and Aerospace Engineering at the Carlos III University in Madrid. Throughout the last 18 years she has simultaneously worked in the fields of research activity, on-site care, lecturing, and, most recently, health management.

Dr. Yotti's research career has been closely linked with ISCIII over the last 15 years. Since 2009, as the lead researcher she has managed a line of research

In 2017 thanks to funding provided by ISCIII for foreign placements for research staff, she completed a placement as a visiting professor at the Harvard University Medical School Department of Genetics. She has been a member of the board of assessment for projects of the Committee for Cardiovascular Diseases of the ISCIII and has participated as an external assessor of research groups of the AAC (Andalusian Agency of the Knowledge). She has written more than 50 scientific articles in magazines of the first quartile of her area of specialisation.



#### **Neville Calleja**

Director Department for Policy in Health - Health Information and Research, Ministry of Health, Malta

Prof Neville Calleja qualified as a medical doctor in 1999 and proceeded to study Medical Statistics and Public Health after his medical training. He qualified as a specialist in public health medicine in 2006 and was awarded Membership of the Faculty of Public Health in the

UK in 2011. In 2013, Neville completed his PhD studies on the statistical correction of misclassification of disease status between self-reported and examined health surveys. He has been employed at the Directorate for Health Information and Statistics within the Ministry responsible for Health since 2001, taking on its helm in 2007, and also served as Acting Chief Medical Officer during 2014. Prof Calleja has fifteen years of experience lecturing medical statistics, epidemiology and public

health to all health care professionals, together with ethical and scientific review of projects at local and international level. He is also active at European level in the field of Health Information for both the European Commission and WHO (Europe), as chair of the European Health Information Initiative within WHO(Europe). As part of the Chief Medical Officer's office, Neville has been long involved in the drafting of strategies and the planning of capital projects within the Ministry for Health in Malta. Within JA InfAct, he is leading Task 5.1 which is piloting a peer-review health information system assessment methodology in nine participating countries.



#### Herman Van Oyen

Director epidemiology and public health, Sciensano, Belgium and Coordinator, InfAct

Prof. Dr. Herman Van Oyen, MD, Dr. PH, MPH, DTM&H studied at the Department of Epidemiology, The Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland and obtained the degree of Doctor of Public Health (Dr.PH) in 1990. The doctoral research focused on

epidemiologic methodological questions and was entitled "Cardiovascular disease in the elderly. Associations with body mass". Prior to the doctoral degree he obtained a Master of Public Health, Department of Epidemiology, The Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland in 1987. His basic training is in medicine (Doctor of Medicine, Surgery and Obstetrics, Faculty of Medicine, State University, Gent, Belgium, 1981) and tropical medicine (Diploma of Tropical Medicine, Prince Leopold Institute of Tropical Medicine, Antwerpen, Belgium, 1981). Herman Van Oyen is director of the Scientific Directorate Epidemiology and public health and is professor at the University Gent, Department of Public Health. His current research focus on: (1) health information, leading the EU project InfAct (Information for Action) (2) translational research, supervising a Marie-Curie postdoctoral project: BACHI (Bringing a Health Claim to Information) (3) composite health measures such as health expectancies (4) ageing and disability process(5) epidemiologic and survey methods.

Herman Van Oyen is Editor-in-Chief of Archives of Public Health and Editor of International Journal of Public Health .

Herman Van Oyen is member of several national and International boards, a.o. the College of the Belgian Superior Health Council, where he chairs the workgroup Public Health Genomics.



### Linda Abboud

Project Researcher, InfAct and Sciensano, Belgium

Linda Anna Abboud is a project researcher at the Unit EU health information systems at Sciensano, the Belgian Federal Public Health Institute in Brussels. She is part of the coordinating team of the Joint Action on Health Information (InfAct) which aims to prepare the transition towards a sustainable EU health information system

infrastructure for both public health and research purposes. She holds an MSc in Global health from Maastricht University (NL) specialised in delivering innovations, context appropriateness and medical mobility, and recently graduated from Antwerp University (BE) with an MSc in Epidemiology. During her studies she worked on public health research projects in Ghana, India, the Netherlands and Belgium. Prior to this she served as the coordinator of the Health Rights Unit at the Galilee Society in Israel focusing on health promotion, and advocating for the health rights of Palestinians in Israel.



### **Petronille Bogaert**

Project Researcher, InfAct and Sciensano, Belgium

Petronille Bogaert is project researcher and functional head of unit EU health information systems at Sciensano, the Belgian Federal Public Health Institute in Brussels. Her work primarily focusses on the Joint Action on Health Information (InfAct) which aims to prepare the transition towards a sustainable EU health information system

infrastructure for both public health and research purposes. This includes the coordination of the project and involvement in different Work Packages. In WP5, she is leading the evaluation of task 5.1 on the assessment of health information systems in nine European countries. Previously, she coordinated the BRIDGE Health project, the predecessor of InfAct. She is a graduate from the European Master of Public Health, a double master degree in the University of Sheffield (UK) and Jagiellonian University (Poland). She specialised in health economics and governance of health systems. She also holds a Bsc and Msc in Biomedical Sciences at the Katholieke Universiteit Leuven and is PhD candidate at Tilburg University. She came to the Sciensano from the European Commission DG SANTE's Unit on Health Information and France's Ministry of Social Affairs and Health.



### Marie Delnord

Project Researcher, Euro-Peristat and Sciensano, Belgium

Dr. Marie Delnord holds an MA in Child Development, an MSc in Paediatrics and community health, and a PhD in Epidemiology. Her research is focused on international comparisons of health status indicators, and methods to strengthen European public health surveillance. She has

worked for over 7 years as Euro-Peristat project manager at Inserm, the French National Institute of Health and Medical Research. She is currently a Marie Skłodowska-Curie research fellow at Sciensano, the Belgian Federal Institute of Public Health.

Her project entitled BAHCI: Bringing a Health claim to Information, provides insight on the mechanisms that drive the use of evidence in health policy and practice.



### Josep Figueras

Director, European Observatory on Health Systems and Policies, WHO Europe

Josep Figueras, MD, MPH, PhD (econ) is the Director of the European Observatory on Health Systems and Policies. In addition to WHO, he has served other major multilateral organizations such as the European Commission and the

World Bank. He has served as policy advisor in more than forty countries within the European region and beyond. He is a member of several governing, advisory and editorial boards including member of the board of the European Health Forum Gastein. He is honorary fellow of the UK faculty of public health medicine; received the Andrija Stampar Medal for excellence in Public Health and a Doctorate Honoris Causa from Semmelweis University and has twice been awarded the EHMA prize. He is currently visiting professor at Imperial College, and external examiner at London, Maastricht and Cork Universities. He was director of the MSc in Health Services Management and lecturer at the London School of Hygiene & Tropical Medicine

His research focuses on comparative health system and policy analysis and is editor of the European Observatory series published by Open University Press. He has published a wide range of volumes in this field, the last five on: Health Systems Governance (2015) Economic crisis: impact and implications for health systems policy in Europe (2014) Health systems, health and wealth: assessing the case for investing in health systems (2012) Health professional mobility and health systems in the EU (2011) and Cross border health care in the EU (2011)

health systems in the EU (2011) and Cross border health care in the EU (2011)



## Enrique Bernal-Delgado

Senior Health Services Researcher, Institute for Health Sciences (IACS), Spain

Enrique Bernal-Delgado MD PhD has a Master Degree in Public Health and in Health Economics. After a period as Visiting Scholar in The Dartmouth Institute at Dartmouth Medical School in United States, he founded the group on Health Services and Policy research (ARiHSP) at the

Institute for Health Sciences in Aragon where currently holds the position of senior scientist. His research areas are unwarranted variations in healthcare performance, comparative effectiveness research in complex interventions, and secondary use of health data in health services and policy research.

The two more representative projects are the Atlas of Variations in Medical Practice in the Spanish Health System, and ECHO, European collaborative depicting healthcare performance in five European countries. As a sequel of both projects, he led a work package in BRIDGE Health and currently in IctusNet where the group explores the use of big data analytics in the evaluation of Acute Stroke in five southwest European countries. In the Joint Action InfAct (https://www.inf-act.eu/) the group is co-leading a work-package aimed at assessing and piloting Interoperability for Public Health Policy research in Europe.

A substantial part of his activity relates to the translation of research results into policy making at national and international level. He holds the Spanish counterpart of the European Observatory on Health Systems and Policies, WHO Europe whose main output is the Health System Review for Spain, a health policy analysis of the Health System reforms. He is actively advising the OECD Health Division Projects and invited as international expert in events fostered by the European Commission or the European Parliament.



### **Isabel Noguer**

Director National Centre for Epidemiology, Instituto de Salud Carlos III (ISCIII), Spain

Isabel Noguer Zambrano was born in Sevilla. She holds a degree in Medicine and Surgery, a Master's degree in Public Health from the National Public Health School of Rennes (France) and is a Doctor in Medicine from the Rey Juan Carlos University.

Before she passed the government exams to work in the Public Administration (Medical Examiner's Office), she specialized in cardiology. Since 1982, she has worked in the field of Epidemiology, Public Health and Administration/Health Management, at various Institutions and hospitals in Andalusia, the former INSALUD, the Ministry of Health, Social Services and Equality (MSSSI), the Instituto de Salud Carlos III (ISCIII), and the Pan American Health Organisation (PAHO) in Washington DC.

Before 1993, she took on responsibilities in the field of Hospital Management and Information Systems in Andalusia and in INSALUD. She then worked for over ten years in Epidemiological Surveillance Systems and Control of the HIV/AIDS epidemic,

at the MSSSI and in the ISCIII, and she collaborated actively with the Retrovirus Laboratory of the Centro Nacional de Microbiología. She lead and participated in national and international research projects in the field of HIV/AIDS and tuberculosis. She collaborated with the Escuela Nacional de Sanidad (National School of Public Health) and other international schools of public health where she taught Public Health and she directed the HIV/AIDS training programmes of the Spanish Agency for International Development Cooperation and the MSSSI.

Between 2005 and 2009, she held the post of Deputy Director General of International Research Programs and Institutional Relations at the ISCIII, which launched what is today the European Research and Projects Office, and promoted the international presence of the ISCIII and internationally funded research projects. In 2010, she chaired the Horizontal Drugs Group during the Spanish Presidency of the Council of the European Union and in 2011, she won a call for a Management position at the PAHO/WHO, in Washington DC. Since her recent return to the MSSSI, she has held the position of Executive Advisor at the Directorate General of Public Health, Quality and Innovation.

Isabel has contributed actively in international forums in the field of public health, epidemiological surveillance and healthcare research in the European Union, the WHO, the PAHO and other international organisations. She has worked as an advisor at the World Bank on HIV/AIDS and STD projects in India, Brazil and Argentina. Since 2009, she has been Chairperson of the International Advisory Committee at the Instituto de Salud Pública Ricardo Jorge de Lisboa. She has directed publications of the World Bank and the PAHO/WHO and has contributed with numerous papers in national and international magazines. Isabel Noguer Zambrano is a member of the Sociedad Española de Epidemiología (Spanish Society of Epidemiology).



#### Alicia Padron

Program Director, National Centre for Epidemiology, Instituto de Salud Carlos III (ISCIII), Spain

Dr. Alicia Padron-Monedero holds a degree in Medicine and Surgery (1994) and a Ph.D. in Preventive medicine and Public Health from the Autonomous University from Madrid (Spain). InfAct WP4 (Sustainability). Before she passed the government exams to work in the Public Administration

(Directorate General of Public Health from the Autonomous Community of Madrid), she specialized in Oral and Maxillofacial Surgery.

She currently works as Program Director at the National Centre for Epidemiology (Instituto de Salud Carlos III, Madrid, Spain) in the Department of "Aging, neurodegenerative diseases and mental health". She is also a research collaborator at the Department of Preventive Medicine and Public Health (School of Medicine) of the Autonomous University from Madrid. She has previously worked in Preventive medicine and Public Health in the University of Miami, and in the Autonomous Community of Madrid.

Her main areas of research are: chronic diseases, including its determinants and the natural history of the disease in relation with the ageing process; mortality in the elderly and mental health. Her numerous scientific articles, from national and international research projects, have been published in prestigious international journals.



### **Philippe Roux**

Head of Unit 'Country Knowledge and Scientific Committees', DG Health and Consumers, European Commission

Mr. Roux started his career in the French Social sector in 1985. During the same time, he studied social sciences, European law and Public Health. He worked with DG V (Employment and Social Affairs) from 1990 to 1998 in

support of the development of the EU initiatives related to drug prevention. In September 1998, he joined the European Monitoring Centre for Drugs and Drug Addiction where he contributed to the development of the framework and tools for the evaluation of the EU action plans on drugs and was from 2002 deputy Head of Unit in the "Interventions, law and policy" Unit of the Agency. He joined SANCO Health Determinants Unit in 2005 to work with the Nutrition and Physical Activity team with responsibilities in the coordination of the Diet, Physical Activity and Health European Platform. In July 2013, he became Head of the Health Determinants Unit and since March 2016 Head of the Unit Country Knowledge and Scientific Committees.



# POLICY PAPER

# The Health Information Research Infrastructure

### 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. EU countries<sup>1</sup> share the ambition of improving citizens health, tackling health inequalities, providing optimal prevention and universal access to safe, effective and efficient healthcare in a financially sustainable way.

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 investments, health policies and decision-making must be based on robust evidence from research on population health and health systems from high quality and timely data. International comparative research, benchmarking and exchange of best practices is indispensable for strengthening the evidence base for national and international decision-making on health and health systems.

## Gap analysis

At present, there are three main challenges that hinder the availability, accessibility and use of high quality health information<sup>2</sup> for research and policy-making.



The collection and usage of data on population health and health system performance is highly fragmented in Europe and needs coordination and strengthening. Much of the evidence and knowledge remains either unused for research purposes, **dispersed**, **difficult to access**, **or incomplete** in important areas. An example is the limited data on non-communicable diseases, even though they are the main cause of death and poor quality of life and high healthcare costs in the EU<sup>3</sup>.

<sup>1</sup> This includes EU Member States, EFTA and EEA countries.

<sup>2</sup> Health information is understood here as all data, evidence and knowledge that determines health and health service performance at individual or population level to facilitate research, promotion, prevention, care and support policy-making.

<sup>3</sup> Foreman KJ et al. Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016-40 for 195 countries and territories. Lancet. 2018 Nov 10;392(10159):2052-2090. Epub 2018 Oct 16.

Better health information governance is needed to facilitate data collection and bring together research networks in Europe, and ensure that the generated knowledge is robust and accessible.



Under the lead of Eurostat, the European Statistical System provides a solid working base for gathering and providing essential health data. However, beside this core activity by Eurostat and other international institutes and organizations, a wide range of health data collection and research activities are **funded through ad hoc projects**. This results in important and relevant output, but causes a **lack of research continuity**, **lost expertise, data collection mechanisms, fading research capacity, and dissolving networks**<sup>4</sup>.

Mechanisms are needed to feed the knowledge and know-how generated by these networks and projects into a more permanent structure, to ensure a longterm continuity and more sustainable financing sources.



Large differences can be found in terms of **availability**, **quality**, **and comparability** of health data and information between and within countries. This makes it difficult to learn from each other. Without health information, evidence based policy is difficult to achieve. Moreover, health information tends to be poorest in areas where health itself is poorest. This does not allow to assess the full magnitude of health inequalities across the EU<sup>5</sup>, let alone to identify appropriate, targeted action.

Better support and coordinated action are required to reduce health information inequalities across the EU, to support countries in better use of their health data and improve the quality and comparability of data.

### The way forward

The need to establish a sustainable and integrated health information infrastructure at EU level has been recognised by individual Member States, as well as, by the European Commission (EC) and the Council of the European Union<sup>6</sup>. A previous project

<sup>18</sup> 

<sup>4</sup> M. Verschuuren, et al., Public health indicators for the EU: the joint action for ECHIM (European Community Health Indicators & Monitoring), Archives of Public Health 2013, 71:1-12

<sup>5</sup> Health inequalities in the EU – Final report of a consortium. Consortium lead: Sir Michael Marmot. http://ec.europa.eu/health/social\_ determinants/docs/healthinequalitiesineu\_2013\_en.pdf

<sup>6</sup> Council of the European Union. Council conclusions on the "Reflection process on modern, responsive and sustainable health systems". Brussels, 10 December 2013. [cited 2016 Jun 16]. Available at: http://www.consilium.europa.eu/uedocs/cms\_data/docs/pressdata/en/lsa/140004.pdf

called BRIDGE Health<sup>7</sup>, has investigated possible solutions and different structures for a comprehensive, integrated and sustainable EU health information infrastructure to support research and evidence-based policy-making for EU countries.

A European Research Infrastructure is found to be the most feasible solution to solve the current limitations. An integrated approach offers the governance and coordination for a sustainable structure that will effectively underpin the entire research lifecycle and provide expertise, knowledge, and access to linked, reliable and precise health information.

The Joint Action on Health Information (InfAct) brings together 40 institutes and ministries from 28 countries across Europe. The aim of InfAct is establishing a **Health Information Research Infrastructure**. This work builds on the accumulated experience of several EC-funded projects. Within InfAct, partners will apply for the European Strategy Forum on Research Infrastructures (ESFRI) roadmap. ESFRI contributes to the development of a strategic roadmap by selecting vital new European Research Infrastructures for the next 10-20 years. The ESFRI application is based on expression of political support by at least three Member States, and a wide scale of inter-institutional agreements such as agreements with national public health institutes. Successfully applying for the ESFRI roadmap provides the Health Information Research Infrastructure with a stamp of **scientific excellence**, **Pan-European Research** Infrastructure Consortium (ERIC) on health information.

### Health Information Research Infrastructure

The Health Information Research Infrastructure will facilitate health information research by bringing together existing Pan-European research networks, supporting the development of new ones and gathering country specific experts in health information on a single web-based platform. The Research Infrastructure will operate through an integrated system of distributed nodes. These will sustainably work together under one governance structure and ultimately improve the health of European citizens. A comprehensive overview of the assets, activities and impact of the Health Information Research Infrastructure can be found in annex I.

The ideas of sustainability, connecting, supporting decision-making and improving health in Europe is taken up in the mission and vision of the future Research Infrastructure (Figure 1).



<sup>7</sup> BRIDGE Health. Bridge Health: Concept Paper Technical Report BRIDGE Health N° WP1\_2016\_03 Available at: http:// www.bridge-health.eu/sites/default/files/Technical%20Report%20WP1\_2016\_03\_Concept%20Paper\_final\_V2\_0.pdf Bogaert P, et al. Towards a sustainable EU health information system infrastructure: A consensus driven approach. Health Policy (2018), https:// doi.org/10.1016/j.healthpol.2018.10.009

# VISION

A sustainable infrastructure for the best health knowledge improving population health and care in Europe

# **MISSION**

Connecting and advancing comparative health research for well-informed (inter)national decision-making

Figure 1: Vision and mission Health Information Research Infrastructure

# The services

The Research Infrastructure will focus on the following four services:



Figure 2: The services of Health Information Research Infrastructure

### 1. One-stop-shop for EU health information research

The Research Infrastructure is a one-stop-shop for population health and health systems research enabling health information driven research. It pools data, research experts, research networks, guidelines and tools on a single web-based platform. It facilitates and supports the development and hosting of virtual and FAIR <sup>8</sup>(Findable, Accessible, Interoperable, and Reusable) data repository platforms for research. It provides central coordination for EU countries to share data and exploit economies of scale by facilitating the extension of existing data repositories and its reuse. The platform provides a forum to foster multilateral research cooperation to form and expand research networks.

### 2. Innovative research in health information

The Research Infrastructure supports methodological cutting-edge and innovative research developments. This includes the development of new and more efficient methods and tools for data collection, quality assessment, (re)use, analysis, interpretation, reporting, disseminating, knowledge uptake and archiving. More specifically, the development of new research methodology with respect to the analysis of big data and data linkage, use of new emerging data sources, and priority setting and horizon scanning to inform policy-making.

### 3. Capacity building in health information

The Research Infrastructure provides methodological and technical expert support for the development of comparable, standardised and accessible data and indicators for health status and determinants, health services and health systems. It enhances best practice exchange between countries and support mutual learning by focused capacity building in health information driven research through dedicated training programmes and mobility programs. Newly developed methodologies will be taught to enhance the expertise of the health information research workforce across Europe and thus tackle health inequalities.

### 4. Decision-making based on evidence based research

The evidence and knowledge produced by research are not always readily usable and may need further analyses, syntheses and translations to inform policy-making. The Research Infrastructure supports researchers and institutions in charge of health and health related research to optimise their output to better inform policymakers and citizens.

### The users

The Research Infrastructure will serve a wide scale of different users, of which the primary users are researchers in public health and population sciences as well as epidemiologists, statisticians, pharmacist, health professionals, data scientists, ethicists, sociologists etc. The secondary users are policy and decision-makers in national and international organisations both governmental and non-governmental organisations or civil societies, as the outcome of the infrastructure will benefit their work. Other users include:

- The healthcare sector.
- Data providers and developers in various health information domains.
- Students and educational organisations of population health and health services.
- The media and the general population.
- Other European level infrastructures.
- Industry and private sector.

### National added value

The Research Infrastructure facilitates the availability of EU health information and integrates national data into an international context for better knowledge and stronger evidence to build on. The pooled knowledge provides a better view of the national situation and trends in both population health and health system performance. In addition, the availability of expertise and training strengthens national research capacities and offers more options to share and find best practices in other countries. This provides the opportunity for better national investments based on evidence-based knowledge. Finally, it contributes to developing stronger national health information systems and strengthen the evidence base that supports well-informed decision-making at all levels.

### Added value in European health information landscape

The Health Information Research Infrastructure is the missing piece of the puzzle in the current European landscape of health information. The services provided by the Research Infrastructure are not meant to duplicate current activities by international organisations such as WHO, OECD, and EC, but to fill the gap. The Research Infrastructure brings together EU networks of experts that perform comparative research in the field of population health and/or health system performance. It provides long term continuity, pooled research opportunities, and a stable structure to accommodate these networks. It ensures return of investment provided by MSs towards health information activities. Most importantly, the Research Infrastructure is EU focused and works for the benefit of the MSs in a bottom up manner, whilst liaising with international organisations.

### Next steps

The ESFRI application is now in the process of development by a core writing group within InfAct and is expected to be submitted by the summer of 2020. Additional political and scientific support for the development of the ESFRI roadmap application is sought. Your expression of interest in supporting our cause is highly appreciated.

### Definitions

Health information is defined as:

"All data, evidence and knowledge on health and health service performance at individual or population level to facilitate research, promotion, prevention, care and support policy-making"

Health information system is defined as:

"An integrated effort to collect, process, analyse, report, communicate and use health information and knowledge to influence policy and decision-making, programme action, individual and public health outcomes, and research"

| INPUTS/ASSETS   | <b>OUTPUTS/ACTIVITIES</b>  | <b>OUTCOMES/IMPACT</b>   |
|---|--|--|
| What we invest and have available   | What we do and who we reach  | What is our short-term impact?   |
| Building blocks for a strong organization<br>Governance, experience, commitment<br>Our special assets<br>Experts, good practices, networks<br>Experience with project and network<br>development<br>Senior investigators and project developers<br>Senior investigators and project developers<br>Output and experience from previous<br>research<br>Good practices, tools, methods, evidence<br>National nodes for health information<br>Direct access to national resources | Provide services to our research networks<br>Build and expand platform functionalities<br>Support data management and exchange<br>Support cross-national capacity building<br>Support project development and fundraising<br>Provide services to policymakers and<br>stakeholders<br>Build a policy portal for health information<br>Assess national health information systems  | A comprehensive set of research networks<br>More comparable data for research<br>More equal national research capacities<br>More effective use of existing data<br>More efficient use of research funds<br>Improved knowledge transfer<br>A common research agenda<br>Better data and indicators for health policies   |
| Our ambitions and values  | How we work on impact and<br>future strength   | What is our long-term impact?  |
| Be a reliable and desirable research partner<br>We believe in European research<br>collaboration<br>Work with stakeholders in the field of<br>health and health care and citizen oriented<br>research<br>Aim for equity, sustainability, quality,<br>efficiency<br>Aim for FAIR data<br>Better health and care is our core business<br>We work for the public good  | Liaise, communicate, teach and advocate<br>Liaise with stakeholders and decision-makers<br>Liaise & coordinate with other ERIC's<br>Collect & distribute information and news<br>Organize our advocacy and communication<br>Organize conferences, meetings and fora<br>Develop and implement knowledge<br>brokering<br>For health professionals and policymakers<br>Reach out to NGO's, citizens and private parties<br>Reach out to NGO's, citizens and private parties<br>ldentify and support new partner networks<br>Identify and support new partner networks<br>Identify and support new partner networks<br>Support knowledge transfer research<br>Forpport knowledge transfer research<br>Support cost-effectiveness research<br>Support horizon scanning and priority setting | A stronger, sustainable EU health research<br>infrastructure<br>Full grasp of population health, determinants of<br>health and their trends<br>Understanding health system dynamics<br>Mature national health information systems<br>The leads in comparative EU population health<br>research<br>Better EU health and well-being<br>Efficient European healthcare systems<br>Health is wealth: stronger economies |

# POLICY PAPER: ANNEX 1

Overview of Health Information Research Infrastructure assets, activities and impact

# INFACT WORK PACKAGES

InfAct carries out its work through ten work packages (WPs):

| WP 1-3 | Coordination, Dissemination, Evaluation                               |
|--------|---|
| WP 4   | Integration into national policies and sustainability                 |
| WP5    | Status of health information systems in the EU                        |
| WP6    | Strengthening health information capacity                             |
| WP7    | Provide proof of concept for a sustainable structure                  |
| WP8    | Tools and methods for health information support                      |
| WP9    | Innovation in health information for public health policy development |
| WP10   | Assessing and piloting interoperability for public health policy      |



# WP 1-3

Coordination, Dissemination, Evaluation

### Aim and objectives

Coordination: The aim of this work package is to manage the Joint Action and to systematically monitor its activities. This includes the day-to-day follow-up of the scientific, administrative and financial aspects. WP1 ensures that the contractual obligations are fulfilled and ensures the expected results are delivered as planned. It also establishes relationships with potential future stakeholders and advocates for health information and InfAct. More specifically, InfAct communicates with: the relevant directorate Generals and Expert Groups of the European Commission, the Organisation for Economic Co-operation and Development (OECD), the World Health Organisation Europe (WHO), and other relevant international associations, projects and organisations such as IANPHI, ASPHER, EUPHA, TO-REACH, other Joint Actions, etc.

Dissemination: InfAct wants to ensure that the activities carried out by InfAct reach their target audience. InfAct aims to spread the information about its activities through publications, meetings, workshops, leaflets, a promotional video, a website and social media.

The purpose is to (i) raise awareness about the relevance of health information and the need for a sustainable infrastructure among Member States and associated countries, (ii) inform the community about the challenges in EU health information, (iii) engage the community in health information activities, (iv) promote and support the use of the outcomes of InfAct in the community.

Evaluation: WP3 evaluates the project. It is based on two processes: an internal evaluation and an external evaluation. The internal evaluation is practical and consists of a periodic evaluation in collaboration with the WP leaders. It also includes WP peer-review of the deliverables. The external evaluation produces critical reviews of the outcomes, tracks the progress of the project and provides strategic recommendations for the project. It is organised by external stakeholders with expertise in EU-wide action in the domain of public health with focus on health information (health status and health systems) and research.

## WP leads and co-leads

WP1

Sciensano, Belgium

WP2

- Sciensano, Belgium
- Gesundheit Österreich Gmbh, Austria

WP3

- Institute of Hygiene, Lithuania
- Sciensano, Belgium

Integration into national policies and sustainability

## Aim and objectives

The importance of creating solid and sustainable health information lies at the core of InfAct. WP4 works to develop a sustainability plan and a follow-up method supporting the InfAct outcomes, activities and best practices to be integrated in regional, national and international health research and policy-making. This includes fostering the involvement of MSs, EU departments, and international institutions, in the development and progress of InfAct's goals.

### **Tasks**

- 4.1 Set up an Assembly of Members (AoM) consisting of representative of Ministries of Health and of Research from the MSs. The AoM will agree on the way forward and discuss structural alternatives for long-term projection of InfAct's activities, legal/data protection context, evidencebased policy recommendations and the sustainability plan. The AoM will act as liaison with their research, national health system and national Public Health authorities.
- 4.2 Policy dialogues between national nodes and InfAct partners, to raise awareness and acceptance in decision-makers on innovative actions to improve EU health information systems. Fact sheets are developed and used in these meetings, reporting on the main outcomes of InfAct. The dialogues will include the discussion on translating InfAct's results and innovative outcomes into policies and decision-making, and integrating evidence into health information systems.
- 4.3 Develop a sustainability plan to integrate the findings of InfAct into EU/MS protocols. It translates InfAct's results into MS Health Information systems, with the insight and consensus provided in the meetings with WP leaders, Ministries of Health and Research representatives, national nodes, and international partners (Tasks 4.1 and 4.2).

27

## WP leads and co-leads

- Instituto de Salud Carlos III, Spain
- Santé publique France, France

Status of health information systems in the EU

### Aim and objectives

Focusing on national health information systems, WP5 performs a mapping exercise to assess health information systems. With a view to creating a one-stop shop, WP5 also establishes an information base where stakeholders can find and contact international expert networks, projects and organisational bodies collecting comparable health data on public health issues or health system performances. Additionally, WP5 gathers and assesses methods and processes used at national levels to prioritise health information, aiming to identify good practice examples for national and a European prioritisation strategy.

## Tasks

- 5.1 Carry out an assessment of health information systems in 9 countries. This exercise aims to address health information inequalities between countries through peer-review. This process supports the participating MSs in identifying action points for direct and long-term improvement and strengthening of their health information systems, and all MSs through the presentation of the process as good practice example. The assessment is carried out using an adjusted WHO health information system assessment tool.
- 5.2 Catalogue international health information collection networks and projects on population health-oriented topics, health system/health services-oriented topics, indicator generating projects and related health indicator projects with EU coverage. It also catalogues existing indicator sets in Europe and create an inventory of issues most relevant for reducing the reporting burden in the EU. By collaborating with WHO, OECD, Eurostat and EC, task 5.2 continues the indicator mapping exercise initiated by EHII and addresses concrete possibilities to reduce reporting burden.
- 5.3 Draw up a framework to structure and facilitate the prioritisation of health information in MSs and, with it, the selection of indicators. Prioritisation in health information development is needed to ensure that the available indicators provide appropriate information for public health policy action (agenda-keeping) and point to emerging public health issues (agenda-setting).

### WP leads and co-leads

- Robert Koch Institut, Germany
- Ministry of Health, Malta

Strengthening health information capacity

### Aim and objectives

To further tackle the current inequalities within Europe, WP6 aims to contribute to increase health information capacities. Health information is often taught in different courses or as modules of information systems or as part of epidemiology courses, but most of the courses are vertical with focus on one or only some topics. WP6 maps and summarises current programmes in population health and health system performance analysis and monitoring in MSs. Furthermore, WP6 aims to develop a flagship training programme to improve MS capacities in population health and health and health system performance analysis and monitoring.

### Tasks

- 6.1 Mapping needs, capacities and education/training programmes in health information across MSs. Data is collected from key informers, such as MSs representatives, and relevant EU and WHO projects. The mapping covers a published literature search, a scoping search of internet sources, and is complemented with case studies to deepen understanding.
- 6.2 Design a flagship training programme to improve MS capacities in population health and health system performance analysis and monitoring, based on the results of 6.1. It covers different components such as health status monitoring, health care performance and health care outcomes, health system performance and policy translation. The capacity building programme is oriented towards professionals working in public institutions, and strongly builds on e-learning tools.
- 6.3 Pilot the capacity building programme in several MSs, and provide evaluation for its feasibility, coverage of required components, cost, target audience etc. Guidelines and recommendations are produced and contribute to an improved version of the capacity building programme.
- 6.4 Develop a business case and roadmap for sustainable capacity building programme for MSs. This includes the description of already existing capacity building actions and how these should be maintained and further developed; areas of health information for which adequate capacity building activities are missing; and ways to obtain future funding for development and maintenance of a health information capacity building programme.

## WP leads and co-leads

- Ministry of Health, Portugal
- National Institute for Health and Welfare, Finland

Provide proof of concept for a sustainable structure

### Aim and objectives

WP7 carries out a proof of concept of a sustainable organisational structure that supports EU-centred research activities in the area of health data and information. The main objective of the structure is to support population health monitoring and health system performance assessment with the aim to foster evidence-based (health) policy. This involves refining the concept of a Health Information Research Infrastructure as a basis for a future European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy (HIREP-ERIC). WP7 also prepares an application for the European Strategy Forum on Research Infrastructures (ESFRI) roadmap.

### Tasks

- 7.1 Bring together National nodes (NN) and domain specific nodes (DSN) as part of the research infrastructure and create a sustainable network of networks. First, by developing guidelines on setting up NNs based on good practices and experiences by MS during the JA, and assists in setting up NNs and in identifying the consortium lead. Second, by developing criteria and procedures for the inclusion and selection of DSNs and an evaluation process including the requirements for sustainability for DSNs.
- 7.2 Develop a business case and roadmap for implementation for the Health Information Research Infrastructure. The business case is then translated into a 5-year operational roadmap for the fully functioning HIREP-ERIC with a detailed work plan including specific objectives, outcome and deliverables.
- 7.3 Draw up of the interim and final governance structures of the Health Information Research Infrastructure.
- 7.4 Design of a website providing the support platform for the Health Information Research Infrastructure. The site contains repository functions for technical reports and scientific articles, methods and tools, health information projects, indicators/data sets, information on NNs, DSNs, training programmes collected in the JA.

### WP leads and co-leads

- Sciensano, Belgium
- National Institute for Public Health and the Environment, The Netherlands

Tools and methods for health information support

## Aim and objectives

WP8 provides guidance at EU level on methods for implementation of high standard health information instruments, tools and methodologies. It summarises existing experiences in EU on health data and indicators by reviewing and identifying existing standardised data collection methods and common procedures; prepare best practices in accessibility, availability, and reporting in health information; maintain and develop identified standardised data collection methods and related quality assurance procedures. WP8 also contributes to improved and sustainable use and usability of ECHI, according to technical and content updates and links to policy.

### Tasks

- 8.1 Generate knowledge on data collection methods, and availability and accessibility of health information. The task summarises existing knowledge on standardised health data collections, used methods and procedures, quality assessment procedures, and availability and accessibility procedures covering different data sources for health status determinants and HSPA.
- 8.2 Investigate the sustainable use(ability) of the ECHI-shortlist and its future implementation and alteration process. Provide technical updates, actionable content, flexible format/structure and aligning with other international organisations.
- 8.3 Provide guidance for accessibility, availability and reporting of health information including quality of data/indicators and quality of reporting. This by developing a guidance document for MSs and regions which provide standardised and comparable health reports. Starting from evidence, good practices and case studies on health reporting, this document facilitates quality assurance and guidance for health reporting in MSs and regions.
- 8.4 Coordinate networks of experts involved in the InfAct and structure definition of nodes. This includes providing a standard approach and common rules for selecting and involving health experts and for defining structure and criteria for setting up national nodes.

## WP leads and co-leads

- Istituto Superiore di Sanità, Italy
- National Institute for Public Health and the Environment, The Netherland
- National Institute of Public Health, Slovenia

Innovation in health information for public health policy development

### Aim and objectives

Building on existing health information gaps, WP9 assesses the potential use of new data sets for public health policy purposes. WP9 considers new ways of using existing data, data linkage, mathematical modelling and other techniques. Additionally, WP9 works towards enlarging the set of morbidity indicators available across the EU at different geographical levels and in a timelier way to inform the development of future regulations.

### Tasks

- 9.1 Identify inspiring examples from MS with regards to innovative use
  of data sources that target priority public health actions and healthcare
  strategies. This task identifies new indicators on health and its
  determinants, and investigates the potential of modelling techniques to
  enhance the scope of existing indicators. Experiences are shared on the
  use of these new indicators, promising sources and modelling techniques.
- 9.2 Develop and propose generic and shared methods, best practices and standards to define, construct, validate, and disseminate relevant and reliable new indicators from innovative data sources. This task prepares guidelines for developing and testing specific new indicators to assess performance of integrated healthcare systems.
- 9.3 Apply the developed best practices in 9.2 to health indicators for a limited number of priority public health targets that are of interest. This allows for having multi-country results and trends at different geographical levels.
- 9.4 Develop composite indicators to monitor the burden of disease(BoD). This task includes organised workshops on BoD: integrating BoD into national accounts; describe criteria to be fulfilled by BoD studies, data analysis/reporting to advice political action; develop expertise and capability to undertake country studies; and to promote a cross-EU approach to identify and address causes of morbidity.
- 9.5 Explore mechanisms for the uptake of indicators into the regular EU data collection system (Eurostat regulations), WHO and OECD.

### WP leads and co-leads

- Santé publique France, France
- · Institute of Hygiene, Lithuania

Assessing and piloting interoperability for public health policy

## Aim and objectives

Motivated by the need to establish a holistic European model and data infrastructure able to translate data, information and knowledge into support for policymaking using services based on data linkage, data sharing, data management and knowledge development, and stemming from a number of case studies, WP10 pilots the methods and techniques required to reach this goal. This is developed based on the building blocks defined in the European Interoperability Framework (EIF), and get inspiration from the EIF for e-Health. WP10 maps, structures and pilots interoperability levels defined by the EIF as a support for policy making using services based on data linkage, sharing and management, and knowledge development.

## Tasks

- 10.1 Map and identify a number of best practices in the MS with the focus on public health surveillance and/or research, where interoperability, data linkage, data sharing and data management, data security and privacy issues play an important role.
- 10.2 Based on results from 10.1, analyse how legal and organisational interoperability was or is being addressed. The exercise also includes the analysis of enablers and barriers linked to these two EIF domains. Outcomes are reported to public health stakeholders, particularly policymakers.
- 10.3 Based on results from 10.1, analyse how semantic and technical interoperability was or is being addressed. The exercise also includes the analysis of enablers and barriers affecting these two EIF domains. Solutions that have been successfully implemented in other infrastructures like research infrastructures are also analysed.
- 10.4 Carry out empirical case studies on interoperability, data linkage, data sharing and data management in a number of topics of interest for public health policymaking in Europe. The different case studies provide insight into the methods and techniques used to get sound and relevant outputs from different data sources in different countries. The case studies also provide insight into the enablers and barriers that influence interoperability achievement and focus on identification of key issues in relation to the new European General Data Protection Regulation.

## WP leads and co-leads

- Croatian Institute for Public Health, Croatia
- Instituto Aragonés de Ciencias de la Salud, Spain



Assembly of Members | 12th of March 2019 Escuela Nacional de Sanidad Aula Pittaluga Instituto de Salud Carlos III | Av Monforte de Lemos 5 28029 Madrid | Spain | e-mail: InfActSpain@isciii.es or infact.coordination@sciensano.be Website: www.inf-act.eu | Twitter: @JA\_InfAct © 2019



Responsible editor: Myriam Sneyers - General Director - Sciensano - Juliette Wytsmanstreet 14 - 1050 Brussels - Belgium