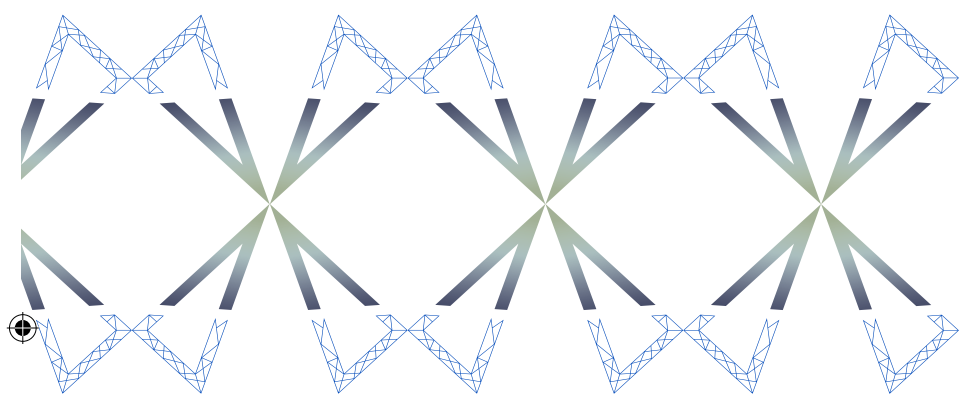
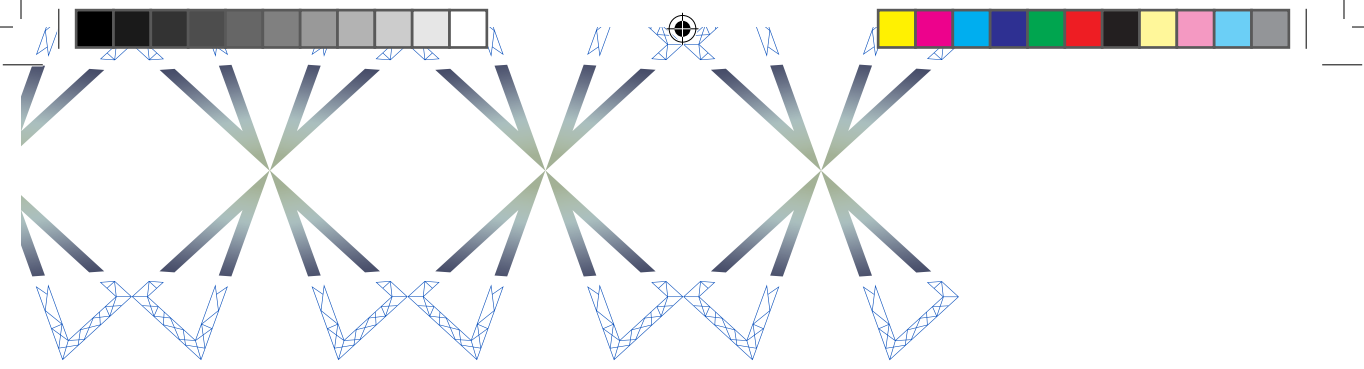
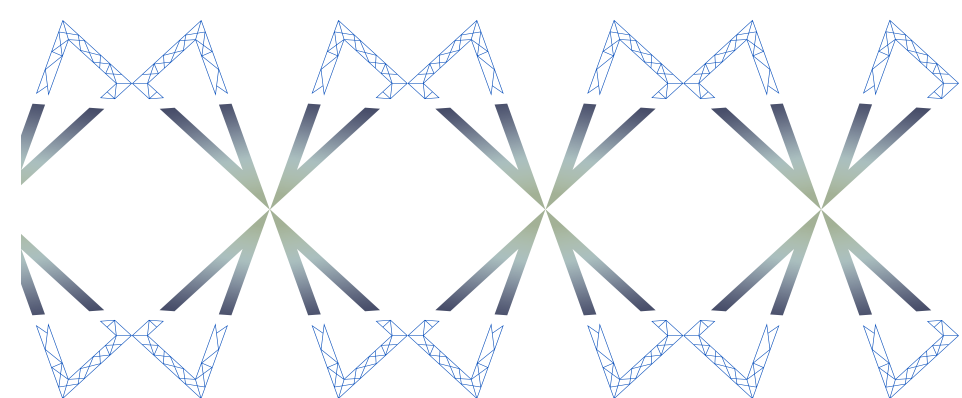




Assembly of Members

13th of November 2019



Co-funded by
the Health Programme
of the European Union



“Assembly of Members”

13th of November 2019

This meeting is organised by InfAct with the support of Sciensano and Instituto de Salud Carlos III.



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PROGRAMME

Wednesday 13th of November 2019 (10:00-17:00)

- 1** Welcome by Sciensano
Joris Van Loco, Sciensano, Belgium

Welcome and introduction by the chair
Thomas Ziese, Robert Koch Institute, Germany
- 2** The Distributed Infrastructure for Population Health (DIPoH)
Business case Part I
The rationale
The structure
The services
Linda Abboud, InfAct and Sciensano, Belgium
Petronille Bogaert, InfAct and Sciensano, Belgium
- 3** Technical Dialogue: Illustration of services through fact sheets
Isabel Noguer, Alicia Padron, Instituto de Salud Carlos III, Spain
Romana Haneef, Sante Publique France, France
Enrique Bernal-Delgado, Institute for Health Sciences (IACS), Spain
- 12:00** Lunch
- 4** The importance of health information research for informing policy
Marieke Verschuuren, Public Health consultant
- 5** The Distributed Infrastructure on Population Health (DIPoH)
Business case Part II
The national nodes and research networks
The finances
Hanna Tolonen, National Institute for Health and Welfare, Finland
Mariken Tijhuis, Rijksinstituut voor Volksgezondheid en Milieu, The Netherlands
- 15:30** Break
- 6** The ESFRI application by InfAct
Herman Van Oyen, InfAct and Sciensano, Belgium
- 7** Programme and objectives for the next Assembly of Members (AoM)
Isabel Noguer, Alicia Padron, Instituto de Salud Carlos III, Spain

Concluding remarks
Thomas Ziese, Robert Koch Institute, Germany
- 17:00** End



INFAC T 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 Member States 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. Decisions on the way forward will be taken through a Memorandum of Understanding (MoU).

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





SPEAKERS BIOGRAPHY



Joris Van Loco

Sciensano, Belgium

Joris Van Loco graduated as Engineer in Chemistry and Agricultural Industries, postgraduate in Quality Assurance. Scientific Director of the Chemical and Physical Health Risks department in Sciensano (Belgium). The Department is involved in exposure assessment and lab analysis of contaminants and additives in food, consumer goods, human samples and in hazard characterization, dietary intake studies and risk and health impact evaluation of chemicals. He is author of more than 100 scientific papers in this field. Member of the Superior Health Council workgroup Nutrition, Member of the administrative board of Nubel, Member of Flemish Food Chemistry Society and representative for Belgium at EUCHEMS Food Chemistry division. Invited lecturer at the KULeuven and ULg.



Thomas Ziese

Robert Koch Institute, Germany

Dr. Thomas Ziese studied human medicine at the universities in Berlin, Bristol and Edinburgh. From 1992-1993, he worked as researcher at the Max-von-Pettenkofer-Institute in the Federal Health Office. From 1994-1996, he was a trainee in the “European Programme for Intervention Epidemiology Training (EPIET)”, Centers of Infectious Diseases, Stockholm and worked as researcher in the AIDS-Center of the Federal Health Office. Since 1996, he is Head of the Unit Health Reporting at the Robert Koch Institute (RKI). This unit is responsible for the National Health Reporting in Germany. Thomas is Principal investigator for the project “Burden 2020” which aims to establish a national burden of disease calculation. He has been involved in different EU projects for more than 20 years, including the development of the European Health Interview Survey (EHIS), the European Community Health Indicators (ECHI), and most currently InfAct.



Herman Van Oyen

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,



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.

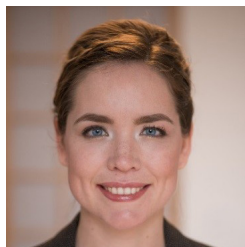


Linda Abboud

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

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.



Hanna Tolonen

Finnish Institute for Health and Welfare, Finland

Adjunct Professor (public health) Hanna Tolonen has a PhD in public health and epidemiology, MSc in Statistics and Specialist Qualification in Management degree. She is working as a Research Manager in the Department of Public Health Solutions in the Finnish Institute for Health and Welfare and serves also as a deputy health of the unit. She is coordinating the European Health Examination Survey (EHES) Network. She has worked over 20 years in the field of standardization of health examination surveys. In 1990's she started in the WHO MONICA Project which has been one of the largest cardiovascular disease epidemiology projects. Since 2000 she has worked on several EU-funded projects related to health examination surveys and related health information topics.

Currently she is leading a national project Projections of the burden of disease and disability in Finland - health policy prospects (2017-2021), being a work package leader and the member of the ethical board in the European Human Biomonitoring Initiative (HBM4EU), and partners in the Joint Action on Health Information (InfAct) and EU/H2020 project Science and Technology in childhood Obesity Policy (STOP). Her main areas of research are: survey methods especially challenges of survey non-response and harmonization of measurements.



Mariken Tijhuis

Dutch National Institute for Public Health and the Environment (RIVM), Dept of Health Knowledge Integration, The Netherlands

Mariken Tijhuis coordinates the Dutch contribution to InfAct for the Netherlands, at the National Institute for Public Health and the Environment (RIVM). At RIVM, she contributes to various national and international health information activities aiming to underpin evidence-informed health policies. This includes liaising with stakeholders on international health information issues and participating in expert groups.

Mariken holds a Master's degree in Health Sciences (Maastricht University), a PhD degree in Nutrition (Wageningen University) and is a board-certified post-doctoral epidemiologist.

She is interested in a great range of topics from cell to society and inspired by multidisciplinary teamwork. Integration of information and concepts from different scientific areas have been a recurring component of her work. Past and current topics include gene-environment interaction, benefit-risk analysis and health indicators. Her experience includes study design, data collection and management, statistical analysis, scenario analysis, systematic literature research, conceptual integration and project coordination.





Marieke Verschuuren

Public Health Consultant

Marieke Verschuuren (MD MSc PhD) is an independent public health consultant with a background in medicine, health services research and public health.

Marieke's fields of expertise include population health monitoring, health indicator development, health reporting, health information system assessment and evidence-informed policy making. Before starting as an independent consultant, Marieke worked at the Dutch Institute for Public Health and the Environment (RIVM), where, among other things, she was project leader of the Dutch Public Health Foresight Study 2018. She also worked at WHO Regional Office for Europe in Copenhagen, where she was the editor-in-chief of the European Health Report 2015. Marieke currently is member of the Executive Council of the European Public Health Association (EUPHA), and she was editor of the book 'Population Health Monitoring. Climbing the information pyramid', which was published earlier this year.



Isabel Noguer

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

Dr Isabel Noguer 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 Public Health from the Rey Juan Carlos University. Currently she is Leader of InfAct WP4

(Sustainability).

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 competitive 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.



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.



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.



Romana Haneef

Santé Publique France, France

Romana Haneef has a PhD in epidemiology and pharmacist by profession. She has been working as a public health researcher in the non-communicable department at Santé Publique France since June 2018. She joined Santé Publique France in Nov. 2017 to work on a European project focussed on the “Comparison of vaccination policies across

30 European Member States under VENICE initiative by ECDC at infectious disease department. She is specialized in developing new methods to answer various research questions and interpretation of scientific results. She has three years of field experience of public health activities (i.e., vaccination, rational use of medicines, health education, & etc.) in humanitarian action during various types of emergencies while working with World Health Organization in 2006 in Pakistan. Currently, she is involved in various research activities of the European project InfAct (i.e., Information for Action) and working as a coordinator of a work package focussed on the innovation in health information for public health policy development.



TECHNICAL DIALOGUE

Main outcomes from 1st Technical Dialogue

By this 1st TD InfAct partners provided 5 Fact-sheets to be presented and discussed with National Experts (NE) attendants.

A total of 15 countries gave inputs through National experts. Below are listed main factsheets provided by date and main recommendations from NE in terms of usefulness, feasibility, and EU-added value. (For more detailed information see TD minutes)

Main conclusions of the 1st Technical Dialogue

- General Data Protection Regulation (GDPR) versus interoperability was a major concern.
- There was a consensus about the added value of the proposals in terms of avoiding duplicates, promote MS mutual learning and cooperation.
- NE concluded the more countries providing data, the more strong results and public health impact.
- Feasibility to integrate InfAct outcomes into National/EU HIS was considered complex and depending on other national counterparts. More specific results were needed to properly discuss the subject.
- Some questions were raised about the level of commitment of the countries and differences in data quality among countries for comparability.





FACT SHEETS



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FACT SHEET

InfAct WP5: "Status of health information systems in European Union (EU) Member States (MS) and regions:

Two-Round Delphi Study of Methods for Prioritizing Health Information at the National Level (WP5.3)"

Key outputs

1. WP5 aims to outline the current state of health information collection among EU and associated countries. The results from WP5 form the foundation for a sustainable EU Health Information System (EU-HIS), which standardizes health information (e.g. indicators) collected by MS and facilitates cross-border dialogue to promote health in all policies. Within WP5, WP5.3 seeks to tackle inequalities in health information quality by outlining national health information prioritization processes.
2. Results from WP5's two-round, Delphi survey (executed by WP5.3) will be used to develop a best practices Framework for prioritization of health information (e.g. selection of indicators) at national level. This framework may also inform health information prioritization at European level for establishment of an EU-HIS.
3. We have developed a Delphi Survey (Methodology and tools) for pre-testing and survey among representatives from EU and associated countries.
4. A list of best practices of health information prioritization at the national level and Framework for prioritization will be submitted for publication in order to affect the working practices of those developing national health information systems. Through uptake of this framework in systematic establishment of national health information systems, we hope to establish a systematic process for information prioritization, which could be further applied at the European level, for example in the context of an EU-HIS.

Background and Rationale

Ideally, health information should serve as the foundation for the health-politics action cycle¹, however inequalities in collected health information exist across the EU and associated countries. Varying data quality can affect ability to collect the extended time trends necessary to form insights about population health needs, which are prerequisite for implementation of policies and programs accounting for those health needs across EU and associated countries². In order to continuously respond to population health needs using national policy (agenda-keeping), it is first necessary to understand how important determinants of health and traits of the health system impact population health and how to most effectively promote population health (agenda-setting). Thus, EU and associated countries must overcome existent inequalities in health information. Through efforts to promote comparable health data, InfAct strives to facilitate comparison of national information and data as well as synthesis of evidence and development of best practices in Europe. The goal for this exchange of knowledge across borders is promotion of health in all policies³ across the EU.

As the foundation for standardization of the health information (e.g. indicators), collected by MS, WP5 aims to outline the current state of health information collection among EU and associated countries. One method used to achieve this goal is a two-round Delphi study (executed by WP5.3), collecting information on current methods used to prioritize health information (e.g. selection of indicators)

¹ Rosenbrock R, Public Health als Soziale Innovation, Das Gesundheitswesen, Bd. 57, 3 (1995), S. 140-144

²Health Inequalities in Germany, an International Comparison:

https://www.rki.de/EN/Content/Health_Monitoring/Health_Reporting/GBEDownloads/Journal-of-Health-Monitoring_03S1_2018_Health_inequalities.pdf?__blob=publicationFile (accessed 18.07.2019)

³ World Health Organization, Health in all policies: Helsinki statement. Framework for country action; WHO, Geneva. 2014.



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collected at the national level. Results from the two-round Delphi study will be synthesized into a draft best-practice framework for health information prioritization across EU and associated countries.

Detailed, systematic description of national methods for prioritization of health information (e.g. indicators) are uncommon in the literature on prioritization of health information, while there are no EU-wide reviews of methods used for health information prioritization. Our Delphi study contributes to the literature in that it aims to document national methods for health information prioritization across the EU and associated countries, and also strives to synthesize documented methods into a framework providing guidance for best practices for prioritization of health information. A framework for prioritization of health information at the national level is a first step towards development of standards for prioritization of health information within an EU-HIS.

Proposal

WP5.3 employs a two-round Delphi survey which will be distributed to EU and associated countries' representatives participating in the InfAct joint action, and may include responses from representatives working in National Public Health Institutes, National Statistics Offices, National organizations involved in developing health targets, Policy making, or stakeholders involved in the production of national health reports.

After a literature review of methods for prioritization of national health information we developed the questionnaire for our two-round Delphi Survey. The first round Delphi survey collects the following information using 19 open-ended questions:

- Existence of structured or formal processes for health information development/prioritization in participating countries
- Any other informal processes to prioritize/develop health information
- Methodologies for structured processes (stakeholder involvement, criteria for HI prioritization)

Information from the first round will be presented in the second round as closed questions. Participants in the first round will rank methods, processes and criteria according to degree of "desirability", "feasibility", "importance" and "confidence", based on their own expert opinion.

Both rounds will be implemented online using the Voxco survey software. Voxco is the preferred survey software of the Robert Koch Institute based on its extensive provisions for data protection and security.

Following data protection clearance of the survey, a pre-test will be conducted among representatives from 3 EU-MS Partners from InfAct. Thereafter rounds one and two of the Delphi Study will be conducted with a field time of three weeks per round. After analysis of the two Delphi rounds, final feedback containing results and additional information regarding the next steps for the project, including the development of a draft framework for prioritization of health information at the national level, will be circulated to participants. Information circulated at this point likely includes plans for dissemination of results.

Recommendations for sustainability

A framework for prioritization of health information enhances comparability of health information systems across the EU and associated countries. The framework and best practices, as identified and ranked by survey participants, will be submitted for publication in a highly visible, internationally distributed journal, for reference by those working in development of health information, in an effort to influence their work. By developing a comprehensive framework for systematic health information prioritization we create a tool which has potential use at both national and international levels, versatility which supports sustainability of the tool.



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FACT SHEET

InfAct WP8: “Tools and methods for health information support: Questionnaire for MSs regarding health data collection methods and procedures (WP8.1)”

Key outputs

1. *Background:* WP8 aims at summarizing existing health data collection methods in EU by: i) reviewing and identifying standardized data collection methods and related quality assurance procedures; and ii) elaborating common procedures and guidelines for accessibility and availability of health information both for individual-based data and health indicators.
2. *Innovative tools to improve the current EU-HIS:* WP8.1 developed an ad hoc questionnaire to identify projects/studies which collect health data for population health monitoring (HM)/public health surveillance and health system performance assessment (HSPA) at national or regional level.
3. *Most relevant results:* the pilot phase of the survey addressing InfAct participating countries was useful in finalizing the survey tool and provided preliminary information on projects/studies implemented in 11 European countries.
4. *Feasibility of being integrated in HIS and translated into policies:* The results of study will facilitate researchers looking for standardized methods and procedure for collecting, processing and sharing health data, and policy makers in accessing comparable and re-usable health information.

Background and Rationale

Health-related data are collected from a variety of sources such as population-based registries, health interview and examination surveys, longitudinal studies, administrative healthcare records, e-health solutions, etc. Data is collected for different purposes, including population health monitoring (HM)/public health surveillance and health system performance assessment (HSPA). Health monitoring data provide the main information for the description of population health status, while performance measurement seeks to monitor, evaluate and communicate the extent to which various aspects of the health system meet the key objectives.

Most health data are not included in international databases such as WHO, OECD or Eurostat, limiting their use for research and for policy relevant international benchmarking and comparisons.

The objectives of this study are to identify methods of data collection (and the related harmonization and standardization procedures), data availability and accessibility for HM and HSPA in projects/studies carried out in EU/EEA Member States.



This project is funded
by the Health
Programme of the
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Proposal

WP8.1 elaborated the online survey aimed at identifying health data collection methods and procedures in Member States. The questionnaire addresses epidemiologists, researchers that have played leading roles in EU projects, health data managers working in national health and research institutions, and universities. In the pilot phase, the questionnaire was shared with EU and associated countries' representatives participating in the InfAct WP8 meeting held in Brussels in February 2019. The final version was distributed to all InfAct participants asking them to share the questionnaire with their colleagues (snowball recruitment).

The questionnaire is composed of four sections: i) source of information/data sources - project/study background information; ii) quality assurance procedures in data collection; iii) availability; and iv) accessibility. In addition, socio-demographic characteristics of the respondents were also collected. Overall, the questionnaire was composed of 29 multiple choice or open-ended questions.

In the pilot phase, 26 questionnaires were completed from 11 countries (Belgium, Czech Republic, Estonia, Finland, France, Italy, Latvia, Slovenia, Spain, The Netherlands, and United Kingdom). Ten projects/studies are representative at national level, 10 at regional level and 6 at both national and regional levels. Eight projects/studies are shared with European Research Networks (e.g., ECHO¹, EHIS², ECHIM³, EHES⁴), while three are under development (EHES, ECHIM). Thirteen projects/studies have public description of dataset purpose and content (metadata). Of these, only one project uses metadata reporting standards, in particular DDI-Data Documentation Initiative⁵.

Recommendations for sustainability

The survey will generate knowledge on standardized health data collections, methods and procedures for HM and HSPA in EU. It will also facilitate the identification of national or sub-national health data collected through standardized procedures but not included in international databases or research networks.

The results of the study will facilitate researchers looking for standardized methods and procedure for collecting, processing and sharing health data, and policy makers in accessing comparable and re-usable health information.

Sustainability is ensured by creating a guidance for good-practices in health data collection, and in facilitating health data availability and accessibility for research purposes and policy making.

Compliance with metadata standards can guarantee interoperability of different health information systems, which is the key to the successful implementation and sustainability of an evidence-based research infrastructure.

¹ ECHO-European Collaboration for Healthcare Optimization

² EHIS-European Health Interview Survey

³ ECHIM- European Community Health Indicators Monitoring

⁴ EHES-European Health Examination Survey

⁵ Data Documentation Initiative. <https://www.ddialliance.org/explore-documentation>



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

FACT SHEET FOR BURDEN OF DISEASE

WP 9 “Innovation in health information for public health policy development”

Key outputs

1. Background: Burden of disease approaches are not part of routine public health monitoring and reporting in Europe, and the policy development process across the Member States. Therefore, Member States need some guidance and training to adopt and integrate BoD approaches in their public health systems.
2. Innovative tools to improve the current EU-HIS: The Steering Group and the Cost Network will continue to work beyond the duration of InfAct project. PHE* has started storing GBD data in their data repositories to be used for analysis, and are investigating an API to link GBD data with other datasets.
3. Most relevant results: Three key areas of action are highlighted: 1. the need for methodological trainings to strengthen skills in calculating and in interpreting the BoD estimates across the Member States; 2. the encouragement of more collaborations across MSs to share or exchange good practices on BoD; and 3. the importance of the implications of BoD data to guide policies across MSs.
4. Feasibility of being integrated in HIS and translated into policies: A steering group and Cost network would provide guidance, support and recommendations to MSs to integrate burden of disease approaches into EU-HIS and policies.

*PHE: Public Health England

Background and Rationale

The burden of disease (BoD) methods quantify the comparative magnitude of health loss due to disease, injury and risk factors. These methods can add value to existing approaches. For example, in the UK, GBD 2016 data on mortality, causes of death, and disability have been used to analyse the burden of disease in the countries of the UK and within local authorities in England by deprivation quintile. It showed that improvements in mortality and life expectancy slowed notably after 2010, particularly in cardiovascular disease and cancer, and that targeted actions are needed if the rate of improvement is to recover. This applies as well to the increasing proportion of burden due to morbidity, such as musculoskeletal problems and depression.¹ Moreover, GBD methodology is also used to highlight causes and extent of the slowdown in improvements in life expectancy across European MS (on going work). Unfortunately, these practices are generally not part of routine public health monitoring and reporting in Europe, and the policy development process across Member States. The main reasons for this are varying levels of knowledge, experience, and capability to apply and use BoD methods. Therefore, Member States need some guidance and training to adopt and integrate BoD approaches in their public health systems. The Joint Action (Information for Action) project aims to establish a sustainable EU-HIS (Health Information System) to improve public health policy and health care (health surveillance and health system performance). Therefore, this Joint Action has emphasized the potential role of burden of disease measures to provide actionable population health information across Europe. In this context, a set of three workshops sponsored by Joint Action has been planned.

The overall objective of these workshops is to raise awareness, share knowledge and experience, and provide mutual support and to integrate BoD indicators in the public health policies across Europe. The first workshop was mainly focussed on the concept and methodology of BoD across the

¹ Changes in health in the countries of the UK and 150 English Local Authority areas 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016; Lancet 2018; 392: 1647–61 Published Online October 24, 2018 [http://dx.doi.org/10.1016/S0140-6736\(18\)32207-4](http://dx.doi.org/10.1016/S0140-6736(18)32207-4)



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Member States and the second one was about the use of BoD methodologies/data in public health policy and practice.

Proposal

There were 40 participants from 25 Member States to attend these workshops and only three Member States (Bulgaria, Ireland and Luxembourg) were not represented.

Two workshops on "Burden of Disease" focusing on concept and methodology of BoD and the implications of BoD estimates in public health policy were held. These workshops were supported by technical presentations describing the concepts and methods to estimate BoD measures and the use of BoD data in health policy using various case studies from Member States, followed by expert exchange with facilitated discussions and group work. The case studies included national BoD studies from Belgium, Germany, Netherlands, and Scotland. The challenges and opportunities to use BoD approaches alongside other approaches across the Member States were also explored. There were 16 participating BoD experts from Belgium, Germany, the Netherlands, Serbia, Sweden, United Kingdom and United States.

Two workshops were held at Santé Publique France and attended by 16 BoD experts and 40 participants from 25 MSs. The workshops were well received by the participants particularly with regards to the diversity of the group and the possibility to share knowledge and experience from various perspectives. These workshops highlighted three key areas of action: 1. the need for methodological trainings to strengthen skills in calculating and in interpreting the BoD estimates across the Member States; 2. the encouragement of more collaborations across MSs to share or exchange good practices on BoD; and 3. the importance of the implications of BoD data to guide policies across MSs.

Recommendations for sustainability

At the end of two BoD workshops, an informal group as a beginning of the "Steering Group" was proposed to plan and carry out various BoD activities across the Member States. In parallel another initiative called "Cost Network" was created with the same objective.

The main intention of these initiatives is to continue the BoD activities beyond the strict terms of the InfAct project itself, as a forum which can provide support, guidance and recommendations to MSs engaged to integrate burden of disease approaches into EU-HIS and policies.

There is a WHO manual for "Burden of Diseases" as a tool kit to calculate BoD estimates which is not yet available but would be provided to all Member States. This manual could be adopted according to the needs of each MSs to estimate their own BoD estimates.

The steering group will focus on following recommendations:

- Methodological trainings to calculate BoD estimates are needed to implement BoD approaches in routing public health monitoring and reporting in Europe.
- More collaborations among Member States on BoD activities especially on methodological guidance are needed in the future.
- Joint country studies on BoD are needed.
- Good practices or inspiring case studies on BoD should be shared among the Member States.
- Better approaches to translate BoD data for policy are required.
- A general session on "BoD estimates and health policy" would be effective for policy-makers to understand the usefulness of BoD estimates in health policy.



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FACT SHEET INDUSTRIAL POLLUTION AND CANCER

WP9 “Innovation in health information for public health policy development”

Case study: Use of information from non-health related UE databases for health surveillance: the inclusion of E-PRTR data into spatial mortality and morbidity analyses

Key outputs

1. The integration of non-health related UE databases is a feasible strategy to enrich and develop health surveillance. The design of ad-hoc instruments for this purpose can facilitate the use of these data as well as the comparability of the results among EU countries.
2. This case-study presents a practical example, focused on the use of the data included in the European Pollutant Release and Transfer Register (E-PRTR), which allows estimating industrial pollution exposure, for cancer surveillance.
3. “*En-risk*”, an easy-to-use java/web application tool, allows merging, at country level, a) the information of the location of industrial facilities included in the European Pollutant Release and Transfer Register (E-PRTR); and b) the municipal mortality or morbidity data. Afterwards, it performs an exploratory spatial analysis of association between them by type of exposure

Background and Rationale

Being able to combine health information with environmental health determinants is very important, both for surveillance or epidemiological monitoring and for risk studies in health. Within the European Union, there are many non-health data that can be used in this context. However, due to the heterogeneity in the availability and in the formats of this data, its integration with health data is difficult and represents an important challenge, which, in many cases, is complex and require specific expertise.

A good example of a potentially useful source of significant environmental data that might be relevant for health is the [European Pollutant Release and Transfer Register](#) (E-PRTR), which allows estimating exposure to industrial pollution, a very relevant environmental risk factor from a public health point of view (1). The register, maintained by the European Environmental Agency, contains annual data on more than 30,000 industrial facilities that reported emissions over a determined threshold of any of the selected 91 pollutants. The list of industries comprises 65 economic activities within 9 industrial sectors. For each facility, E-PRTR provides information on type of activity, geographical location and emissions of polluting substances. These data can be freely downloaded from the website of the registry. E-PRTR was established through Regulation (EC) No 166/2006, and covers 28 EU Member States as well as Iceland, Liechtenstein, Norway, Serbia and Switzerland

Proposal

In this case study, we are piloting “*En-risk*”, an easy-to-use java/web interactive application tool that merges, at country level, the information of The European Pollutant Release and Transfer



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Register (E-PRTR) and the municipal mortality or morbidity data to perform an exploratory spatial analysis of association between them by type of industrial facility. The application works in the user computer. It downloads the geographic coordinates for each facility from the official web of the E-PRTR, while health data can be directly loaded into “*En-risk*” by the user. This way, health information is always stored and managed in the computer of the user in order to guarantee data protection.

The application needs web connection (but could be optional) as well as the following minimum data:

- **Shapefile** (cartography) of the country (spatial unit = municipality)
- Annual **observed deaths** (for mortality) or **cases** (for morbidity) and **population figures broken down by age groups (18) and by sex** per municipality
- Optional information that could also be loaded by the users: social and economic environment information at municipal level.

With this information the application directly calculates

- a) The expected number of deaths or of cases of the selected disease, using as reference the rates by age group and sex for the whole country.
- b) The distance from the municipal centroids (information obtained from the shapefile) to the location of all the industrial facilities included in the E-PRTR. These distances allow classifying municipalities as exposed or not exposed to industrial pollution, according with the definitions included in the methodological annex.

With these elements, and thanks to the extended expertise of the research team in this field, *En-risk* performs a complex spatial association screening analysis that allows to evaluate whether there is any excess mortality/morbidity in those municipalities exposed to industrial pollution compared to those not exposed, globally and by industrial sectors. If the user has loaded additional information (social and economic environment information at municipal level), the analysis could be also performed considering them as possible confounding factors.

The final output of the application will include: 1) a table or forest plot of Relative Risk of mortality due to exposure to industrial pollution by industrial sector and disease analyzed; 2) a standard database adding the environmental exposure to the health data provided, that might be used for further analyses or allow looking to the spatial distribution of the exposure. However, other types of outputs can be developed. For example, ranking of municipalities with excess of risk, spatial cluster analysis, etc.

The use of the application does not require statistical knowledge, although the interpretation of the results clearly needs public health expertise. In addition, if this initial screening indicates the presence of any health problem linked to residential proximity to industrial pollution in any country, it should be followed by ad-hoc studies to deepen into it.



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Recommendations for sustainability

The formulation of the European Directive on Integrated Pollution Prevention and Control (IPPC) and the creation of the EPRTR enable Member States to incorporate information of industrial pollution sources from E-PRTR into health information system, which is homogeneous and comparable among European countries. *En-risk* facilitates the study of the relationship between pollutant groups, type of industrial sector and health effects such as cancer all around all Europe. It can be used by public health services to identify health problems and to point to key policy interventions to reduce the impact of industrial pollution on health. In addition, the same approach, handy and cheap, can be applied to other geographically-based European environmental databases. Finally, its sustainability is clear because is a normative tool that might improve interoperability of health information systems with non-health data, which would be included in machine learning algorithms in the future.

References

- (1) Fernández-Navarro, P.; García-Pérez, J.; Ramis, R.; Boldo, E.; López-Abente, G. Industrial pollution and cancer in Spain: An important public health issue. *Environ. Res.* 2017, 159, 555–563.



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FACT SHEET INTEROPERABILITY

WP10 “Assessing and piloting interoperability for public health policy”

Key outputs

1. Holistic European model and research infrastructure that can translate data, information and knowledge into support for policy making, using services based on data linkage, sharing and management, and knowledge development is needed. WP10 will pilot the methods and techniques required to reach this goal.
2. Overview of state-of-art in projects linking, sharing and managing health data in Europe shows great dispersion, limited duration and lack of communication and collaboration among themselves, with minority being on-going projects with sustainable governance structures.
3. Identification of enablers and barriers is a first step toward identification of key issues and good regulatory and organisational practices in order to deliver a practical tool for professionals in Europe and beyond working with data sharing, linking and management across borders.
4. A first version of the Data Model and the Event Log Builder and Process Mining Pipeline/ (EBL and PMP) scripts implementation for one out of the three case studies has been distributed to pilot the development of a federated data infrastructure.

Background and Rationale

BRIDGE-Health, a network of public health research networks and a predecessor to the InfAct project, posed the need of developing a holistic European model and research infrastructure that can translate data, information and knowledge into support for policy making, using services based on data linkage, sharing and management, and knowledge development. WP10 will pilot the methods and techniques required to reach this goal, developing upon the building blocks defined in the European Interoperability Framework (EIF) and EIF for e-Health. These documents describe four “vertical” interoperability layers – legal, organisational, semantic and technical as well as a “background” layer – interoperability governance. The objective of WP10 is twofold:

1. Map and analyse national and international inspirational case studies with the focus on public health surveillance and/or research, in the field of health status, health determinants and health systems performance, where interoperability, data linkage, data sharing and data management, data security and privacy issues play an important role;
2. Develop empirical work on interoperability, data linkage, data sharing and data management, using a number of case study pilots on a range of topics, applying a variety of data sources from different countries.

Proposal

In regards to the first objective, inspirational experiences were collected:



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1. by conducting a survey among the WP10 and InfAct project partners and the wider European health information community represented by informaticians, public health professionals, statisticians, health data stewards and health information systems governance bodies for which we knew or assumed might provide insights on inspirational experience tackling data interoperability issues in cross-country data sharing projects.

2. through desk research of projects that potentially fulfilled the inclusion criteria. For this, we mostly used publicly available information on the Health Data Navigator (HDN) site [1] and European Commission's Community Research and Development Information Service (CORDIS) database [2].

In total, we analysed 59 inspirational experiences collected through an online questionnaire (n=28) and desk research (n=31). Results were in no way meant to be exhaustive. Rather, they intended to give an overview of the state-of-art in projects linking, sharing and managing health data in Europe and beyond. Results show great dispersion and limited duration of these projects, with evidence of communication and collaboration among themselves, despite dealing with similar topics and data, being scarce. Furthermore, a minority of the efforts analysed here operate as on-going projects with sustainable governance structures. For further analysis, questionnaire for semi-structured interview with coordinators of these projects was constructed, and is now being piloted.

Regarding our second objective, 3 case studies have been selected:

1. Dementia - trying to understand the exposure of individuals to healthcare services,
2. Health Resilience - providing a composite indicator on the welfare and health of population and
3. Acute Ischemic Stroke - catching the whole pathway of care of individuals.

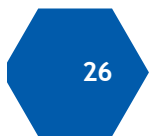
A questionnaire about the availability of sources of information in each country for an eventual use as to illustrate the development of a decentralised infrastructure was sent to partners. Replies from 6 countries have been compiled. Semantic interoperability issues were explored, and based on the results data model and specifications for the development of the federated infrastructure aimed at deploying the case study on stroke was made and disseminated for preparation among partners.

Recommendations for sustainability

Inspirational examples have been identified, and solutions they have developed to address interoperability issues and deliver FAIR data while ensuring security and data privacy will be analysed, and outcomes will be reported to public health stakeholders.

References:

1. <http://hdn.euhs-i.eu/international-home/eu-and-international-projects/103-share>
2. <https://cordis.europa.eu>





INFAC T 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



WP 4

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, evidence-based 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).

WP leads and co-leads

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



WP 5

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





WP 6

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 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





WP 7

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





WP 8

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





WP 9

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





WP 10

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.

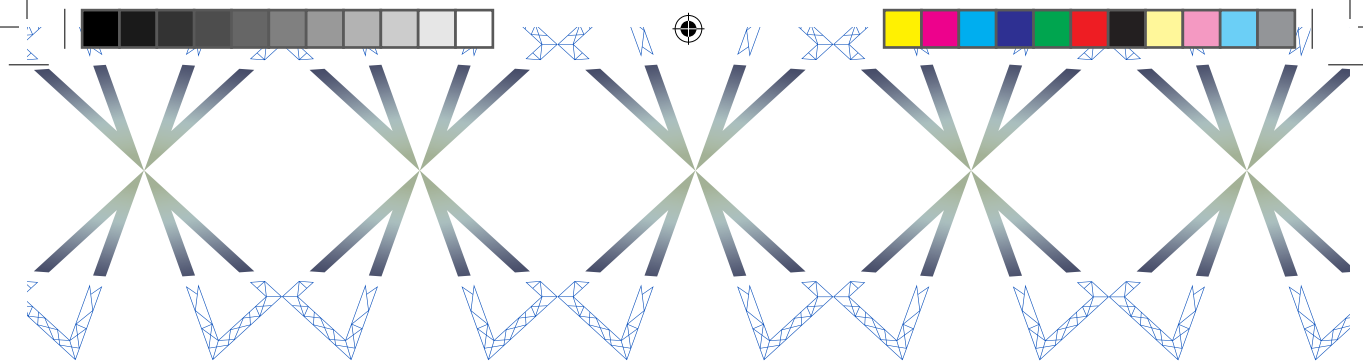
Tasks

- 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.

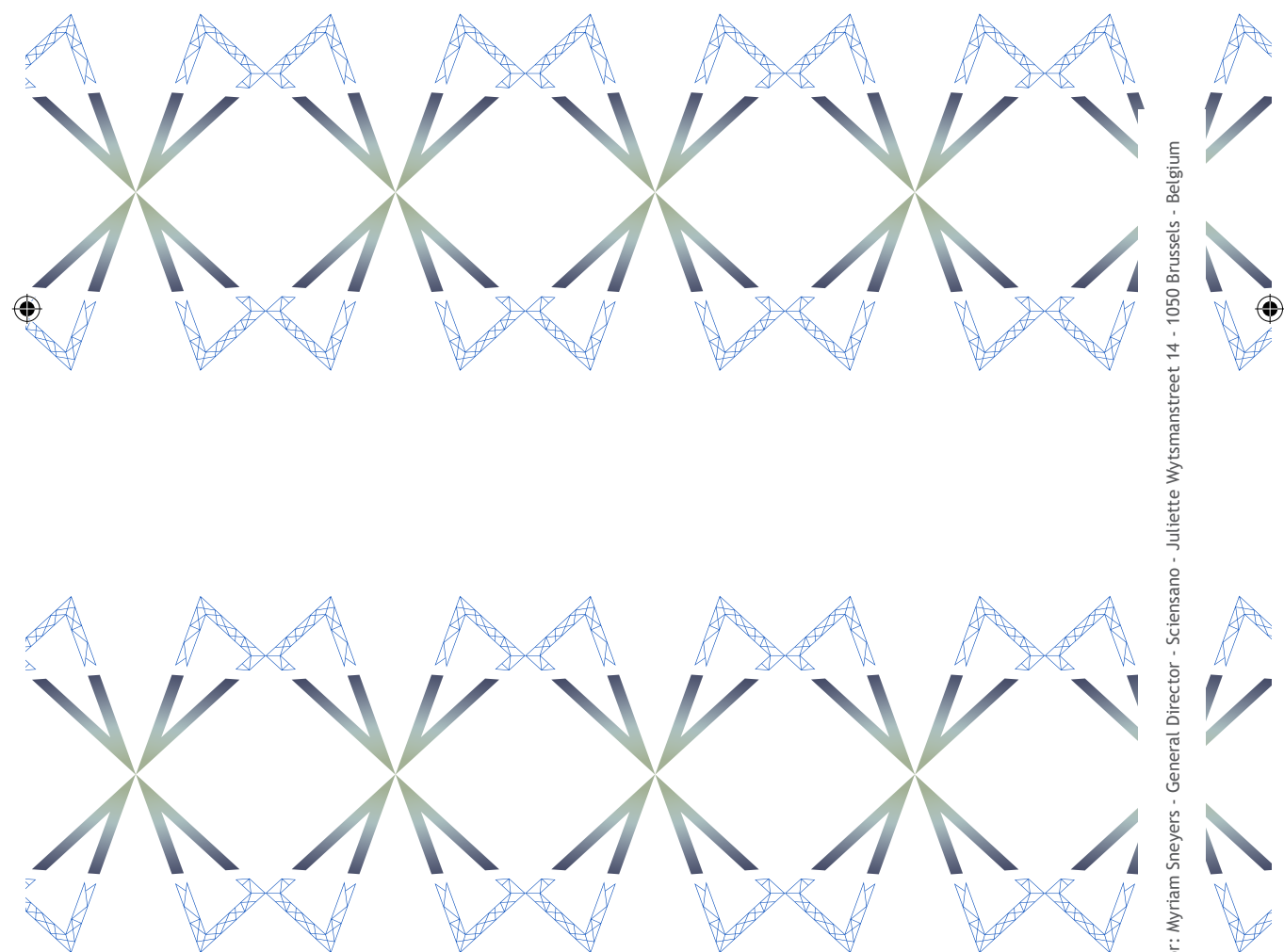
WP leads and co-leads

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- Instituto Aragonés de Ciencias de la Salud, Spain





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