INFACT
Joint Action on Health Information

A sustainable network of networks
Deliverable 7.1

21 February 2020

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

Introduction to Deliverable 7.1

This is Deliverable 7.1 of the Joint Action on Health Information (hereinafter referred to as InfAct) with project number 801553. The major outcome expected of InfAct is a sustainable solid infrastructure on EU Health Information through improving the availability of comparable, robust and policy-relevant population health data and health system performance information. Through country collaboration, InfAct streamlines health information activities, reduces the data collection burden and works towards a sustainable and robust data collection in Europe that facilitates and supports country knowledge, health research and policy making.

This report, Deliverable 7.1, describes the concept behind a sustainable network of network in an EU health information infrastructure, which is composed of National Nodes and Research Networks. National Nodes, or National Consortia, bring together the key players in health information in Member States, and Research Networks, or Domain Specific Nodes, bring together experts in a specific health information field across European countries.

This deliverable (1) provides guidelines on setting up National Nodes within InfAct based on good practices and experiences of Member States, (2) provides criteria and procedures to judge the functioning of Research Networks and (3) defines the terms of reference for the functioning of a Network Committee in a future research infrastructure.

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Deliverable 7.1: Guidelines for setting up National Nodes

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1. National Nodes (NN) on health information

In many EU Member States (MSs) and other European countries, health information activities remain scattered over several institutes, without regular communication among these institutes. This sometimes leads to duplication of activities, limits interoperability of data between institutes, inhibits exchange of data or leads to lost opportunities for research or policy support. This document presents a first step in tackling these challenges: the establishment of National Nodes. The National Node (NN) on Health Information is a concept that emerged in the Joint Action (JA) on Health Information, called InfAct. Below, the concept is further explained in terms of aim and possible route to follow towards its establishment, within the time span of InfAct. It is aimed at all MS participating in InfAct.

A. What is a National Node (NN)?

The NN is an organisational entity, often linked to a national institution or governmental unit that functions as a national liaison and brings together relevant national stakeholders in the country in a systematic way. The relevant stakeholders may include, for example, the national statistical office, the national public health institutes, representatives from ministries of health, research and/or science, and others. In addition, the NN may function as a discussion and advisory forum in matters of health data and information both for national or international matters. Examples include aspects of the governance of data, indicators and health reporting at the international level and health information stakeholders at national level.

In some EU MSs, the NN function already exists in the form of a meeting organised by a coordinating institution or project. However, its function is often not clearly defined nor sustainably supported yet. For example, national stakeholders in some countries still discuss matters of health data and indicators as part of a consultation process set up under the umbrella of previous initiatives, e.g. Joint Action ECHIM on European Core Health Indicators. In the Annex you can find three examples of NN in Finland and Italy.

B. The aim of National Nodes (NN)

InfAct sees the NN as an opportunity to bring together regional/national stakeholders in health information in a more systematic manner. Setting up this NN will bring forth discussions on core issues in health information domains that are nationally and internationally relevant for the country. Bringing together the regional/national stakeholders makes it possible to:

- Share expertise at regional/national level
- Share ongoing activities at regional/national level
- Update on initiatives, meetings and expert groups at EU level

Within a future Distributed Infrastructure on Population Health (DIPoH), the NN can have an advisory role to DIPoH echoing the needs at national level using a bottom-up approach. Conversely, as described above, the NN can have a coordinating role for DIPoH bringing together the stakeholders at national level.

To function as a NN, it generally requires a broad knowledge and overview of the national health information system. The broader the health data situation, the often more numerous health data collecting organisations and their datasets, and the increasingly complex the national health data governance in general tends to be.

In many countries a NN is not always clearly developed yet, but the task is already carried out in a distributed way among more than one national organisation.

The NN competences with regards to international health information may involve:

- Having knowledge of and access to a regularly updated national ***overview of health related data collections and collecting organisations*** with a general sense of their ownership, timeliness, national coverage, quality and reporting.

- Being directly or indirectly involved in the national process of using health data analysis and integration for health policy support, i.e. ***national health reporting*** and/or a more general ***national advisory function on health policy*** setting.

- Having sufficient knowledge of and/or being involved in the national processes, with actors and priority setting in the area of ***national health data governance***, technical infrastructure (IT) development and related data protection and privacy issues.

- Having sufficient knowledge on ***legal constraints*** regarding data sharing, data linking and data usage for statistical analyses, including the national and EU legal framework.

- Having ***general knowledge of ongoing national health research*** in universities and national institutes and relevant data collections, outside the statistical realm or healthcare domain. This can involve knowledge of: larger longitudinal and/or national cohort studies, of government requested and funded national surveys (HIS and/or HES) or knowing the main research groups that perform outstanding comparative health research as part of ***international research networks***.

- Having been or often still ***working on international comparisons of health related issues*** is another useful competency for a NN. This could mean being partner in a comparative epidemiological research network or international health system research group or being involved in the international aspect of national population health monitoring or reporting. Assisting the Ministry of health in checking and validating the information in international health reports (WHO, OECD, EC) is another possible function.

Setting up a NN may benefit the country by bringing together national data collecting agents and optimise national data delivery. In the long term, the NN’s ‘spider in the web’ role would also help to involve the right experts to support national capacity building, improve working towards international quality standards, and optimising the secondary use of national (and international) health data for purposes of health research, public health monitoring and health system assessment. As a result, stronger national research capacity and stronger national health information systems will improve health, health care efficiency, well-being and economic prosperity.

C. The role of InfAct

One of the activities of InfAct, more specifically in WP7.1, is to assist Joint Action partners in setting up a NN. The aim is to reach out to all MSs and associated countries to support them in the process of the development of the NN. In practice, this means that InfAct assists by providing a stepwise approach on how to set up the NN.

2. Stepwise approach for setting up a National Node

The following stepwise approach provides guidelines for the MSs on how to set up, define, and organise a NN (See table 1). Being aware that responsibilities, organisations and procedures are different in each MS, this stepwise approach should be adjusted for the specific situation within each MS. Flexibility is necessary. Furthermore, the following steps are the ones expected to be achieved within the timeframe of the JA.

Steps for setting up first NN meeting:

1. Find a lead institute that could provide coordination for the National Node (Initially, this would be the InfAct partner). Describe its current role and the roles of other major partners.
2. The coordinating institute will identify relevant institutes, research networks, and experts in the domain of population health and health system performance in the country that could potentially be included in the National Node. Alternatively, describe what information exchange is already ongoing among these regional/national partners in health information.
3. The coordination institute initiate/schedule a first meeting among partners in September 2019 and decide internally on the format of the meetings, topics to be discussed, and expertise to be invited.
4. First NN meeting and plan second meeting.
5. The coordinating institute will report on the outcomes of a meeting that took place recently in which the participants (for example):
    - Agree on logistics of setting up National Node meetings (setting, agenda, coordinating further meetings,…),
    - Discuss issues experienced in health information in the country,
    - Report on updates from international meetings held at EU level and their conclusions,
    - Discuss the plans and role of the country in the future EU Health Information Research Infrastructure,
    - Other topics specific for national health information system.

3. Experiences from MSs in this process

A. InfAct NN survey

Within InfAct WP7, a survey was initiated end of November 2018 and sent out to InfAct partners (See survey questions and results in Annex I). The aim of the survey was to identify the current status of National Nodes in InfAct partner countries. More specifically, to identify whether regular meetings occur that bring together health information stakeholders, the topics discussed and frequency of meetings. Also, in case no such meetings occur, what are potential barriers and what are the benefits of bringing together health information stakeholders. This survey was also distributed during the European Public Health conference in Ljubljana (28/11/2018-02/12/2018), and encouraged during the InfAct panel session on 30/11/18.

Ten participants completed the entire survey. The following 9 countries were represented in the survey responses: Spain, Poland, Serbia, France, Finland, Italy, Slovenia, the Netherlands.

About half of the represented countries had an existing meeting which may be considered as a National Node, which occurs mainly as a face to face meeting either annually or informally and in accordance to ad hoc needs. The meetings are mainly organised by either the ministries (of health) or the national public health institutes. The topics discussed in these meetings included: health agendas, strategies and data related topics (i.e. sharing, linkage, harmonisation, interoperability, and others.

In countries where no meeting occur that bring together health information stakeholders, all countries see such a meeting feasible and clearly stated the benefits (i.e. better exchange of health information, more collaboration and shared discussions). However, the possible barriers described included mainly the lack of capacities and resources, and lack of a coordinating body an political will.

B. NN experiences in MSs

WP7 developed the guidelines based on previous experience from MSs with an existing national node. The following countries provided WP7 with a short description for the development of the NN guidelines: Finland, Italy and Netherlands. The descriptions are presented below. The guidelines (section I and II of this report) were distributed and discussed with InfAct partners during a teleconference on May 16th 2019. Fourteen countries participated in this teleconference.

1. The NN function in Finland

In Finland, the collection of national health and social welfare statistics has been centralised to THL National Institute for Health and Welfare (then: STAKES National Research and Development Centre for Health and Welfare) since the 1990s. At the same time a focal point for provision of international health and social welfare statistics was created and located at STAKES. Currently the Information Services Department at THL is in charge of proving health and social welfare statistics for the Nordic collaboration (NOMESCO Nordic Medico-Statistical

Committee and NOSOSCO Nordic Social Statistics Committee), EU, OECD, UN and WHO (Regional Office for Europe and the Headquarters).

For EUROSTAT Statistics Finland is in charge of the official relations, but the practical work is divided between three actors: Statistics Finland (statistics on causes-of-death, statistics on accidents at work, LFS Labour Force Survey, and EU-SILC Statistics on Income and Living Conditions), THL (EHIS European Health Interview Survey, health care statistics, health expenditure statistics, social expenditure statistics, and morbidity statistics) and Finnish Institute for Occupational Health (statistics on occupational diseases and other work-related health problems and illnesses).

A national coordination group was established with representatives from the Ministry of Social Affairs and Health, Statistics Finland and THL in the late 1990s. This group discusses and shares experiences on ongoing issues on health and welfare statistics and indicators. It also proposes all changes in the work division between institutions for the meeting of general directors of these three organisations. Finally, the group makes the final preparations for establishing the national opinion for the international meetings, especially for the Working Party of Public Health Statistics by EUROSTAT.

In addition, relevant projects have been presented and discussed in the national coordination group, such as those on health information (INFACT) health indicators (ECHIM), eHealth (PARENT) and health examination surveys (EHES). The main items for discussion and decisions are related to those projects that will lead to changes in data collection methods or to introduction of new infrastructures within the health information, statistics or indicators.

2. The set-up of NN in Italy

Starting from the involvement in the European BRIDGE Health project - BRidging Information and Data Generation for Evidence-Based Health Policy and Research, an Italian parallel project was launched by the National Center for Diseases Prevention and Control (CCM) of the Ministry of Health. As support to the BRIDGE Health: CCM-BRIDGE Project ‘Creation and development of the Italian network supporting the European BRIDGE-Health project aimed at structuring and providing sustainability to European activities in the field of Health Information (HI)’.

The aim of the project was to verify and improve the availability of health information to organize and develop an integrated, sustainable and standardized National Health

Information System (HI) to serve both as the Italian hub for a future European infrastructure and as a source of data, tools and methods for health research.

During the year of activity, HI experts were invited and involved in the project, including Ministry officials who had participated in the preparatory work of ERIC (European Research Infrastructure Consortium), responsible for the coordination of population registers, numerous in ISS, researchers of the ISTAT that collaborate in the European context to the collection and processing of health data with EUROSTAT and DG-Santè, experts from Universities, Public Health Units, and Medical Associations.

An Italian network of experts on HI was created with them and various integrated activities were carried out through the establishment of four working groups (WG): 'ECHI indicators', 'Communication, transmission, data dissemination', 'Governance', and 'Data interconnection'. The WGs worked in parallel, but in connection to each other, for a) the establishment of a network of HI experts; b) the verification of health data sources; c) the updating of ECHI short list indicators for Italy; d) the identification of information gaps due to problems in transmitting and communicating Italian data to international organizations; e) the identification of regulatory and ethical constraints on ethics and privacy, related to access, use and integration of health data through a proposal aimed at a sustainable organization and governance of the system; f) the implementation of a pilot project to interconnect and integrate current health and administrative data with data from longitudinal epidemiological studies carried out at the Istituto Superiore di Sanità (National Health Institute).

Some results of the project are described in the Report published on a dedicated page of the web site of the Progetto CUORE, and on the dedicated monography entitled "The Italian Hub of the European Health Information System BRIDGE - BRidging Information and Data Generation for Evidence-based Health Policy and Research" published on the Journal Epidemiology, Biostatistics and Public Health - EBPH. The main added value of the project lies in having put at the same table, with a common goal, some of the main institutions that collect, manage and provide health data, such as the Ministry of Health, the National Institute of Health, the National Institute of Statistics, the Universities. Certainly other institutions and associations will have to be involved, but this experience represents a first step towards the establishment of a national hub, in the form of an integrated network, that can be part of the future ERIC on Health Information (HIREP-ERIC).

The European Joint Action on Health Information ‘InfAct’ represents a unique opportunity to continue the process of creating a national node on HI consolidating the network among ISS, ISTAT, MoH, and Universities; and enlarging participation to Italian representative or coordinators of domains specific nodes (DSNs), medical associations, patient associations.

3. The NN function in the Netherlands

In the Netherlands, the RIVM (National Institute for Public Health and the Enviroment) integrates national health information from many sources into national health reports, foresight studies and websites. These information products also integrate international comparative information and indicators. The RIVM collects and integrates national data on healthcare expenditure from different healthcare sectors and settings from many different sources into studies on national health expenditure trends. This work by RIVM is on request from the Dutch Ministry of Health. To enable RIVM to regularly and systematically produce the reports on health and healthcare, RIVM manages an extensive network of national stakeholders in health information, including those collecting data and providing research evidence.

Close collaboration exists between the RIVM and Statistics Netherlands (CBS), which is the major player in the Netherlands that collects and hosts health-related data from many sources and delivers most of the data from the Netherlands to WHO, Eurostat and OECD. RIVM experts have initiated regular meetings with experts from Statistics Netherlands that cover several health information domains to discuss matters of interest, such as new developments and issues that regard the delivery and quality of Dutch data for use in the indicator sets from international organisations and the EC (Eurostat).

RIVM fulfils the spider in the web function on health information in the Netherlands by maintaining a web based overview of the major Dutch health data sets and their metadata. In addition, RIVM organises on request by the Ministry of Health a ‘Community of Data Experts’ that discusses issues of data interoperability, data strategy, harmonisation and standardisation and matters of common concern, i.e. data privacy. RIVM furthermore collects data on infectious diseases and executes, often in collaboration with other stakeholders, several national surveys in the areas of population health, nutrition, child health and environmental health issues.

In close collaboration with and often on request by the Ministry of Health RIVM-experts participate in international expert groups on health information that advise the EC, WHO and OECD in matters of indicator development, health reporting and international improvements in health information systems. Furthermore, RIVM-experts participate in several international health research networks and in projects that enable international comparisons and a better appreciation of the national health situation focusing on population health and health system performance. The potential National Node function, as described in this report, is therefore for the time being fulfilled by the RIVM.

C. NN update in MSs

The InfAct partner countries were subsequently asked to organise a national node in their countries. Thereafter, all the partners were invited to participate in the General Assembly meeting (24-25th of October 2019) and report on their experience with setting up the national node. In Table 1, an overview is given from the update that was provided by the partners of the set-up of national nodes in their country. Nineteen countries provided an update of which 6 were presented during the General Assembly. Upon request the slides are available of these presentation.

Table 1: current status of National Nodes (NN) reported by InfAct partners in October 2019.

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
1	Austria				First meeting expected to take place in December 2019/Jan 2020- Coordinated by Gesundheit Österreich GmbH
2	Belgium	Used to have a national focal point meeting organised by FPS health for joint questionnaire – was stopped.		A meeting coordinated by Sciensano took place on 07/06/2019. Meeting conclusion: focal point will be active again by Federal Public Service Health, and will co-coordinate further meetings with Sciensano.	
3	Croatia			Meeting held in October 2019. By Croatian Institute of Public Health (CIPH). Participating stakeholders: Ministry of Public Administration, Institute for Expert Evaluation, Professional Rehabilitation and Employment of People with Disabilities, Ministry of the Sea, Transport and Infrastructure, Ministry of Croatian Veterans' Affairs, Bureau of Statistics, Croatian Pension Insurance Institute, Ministry of Justice, Croatian Employment Service, Ministry of Healthcare. The meeting included InfAct presentation, introduction of concept of national node, stakeholders introduction, discussion about utility of national node, next steps, next meeting agenda.	

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
				Conclusions: Stakeholders very enthusiastic about the opportunity to liaise. There is a solid information exchange infrastructure, however not utilized well enough. Future plans - possibly include more stakeholders, exchange all of the health data available. Next steps: create a mailing list and exchange more detailed info about available information and potential to exchange them. Next meeting planned before end of 2019.	
4	Cyprus				No plans for a meeting. However Potential stakeholders and coordinators were identified. Health information centres in Cyprus: Health Monitoring Unit (HMU) at the Ministry of Health, and Cyprus Statistical Services (CySTAT) at the Ministry for Finance.
5	Czech Republic				Meeting planned for November 2019 by UZIS- The Institute of Health Information and statistics of the Czech Republic. Currently in the process of identification of relevant

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
					stakeholders at universities and research institutes.
6	Finland	The main actors meet regularly, but there has been no meeting regarding InfAct. Social and Health Data Permit Authority Findata starts operating at the beginning of 2020. Findata is a one-stop shop for the secondary use of social and health data.			
7	Germany	Committee for Health Reporting and Health Monitoring (GBEMON) at the RKI advises on the design and conceptual development of health monitoring and health reporting. It could be the nucleus for an enlarged national network on health information and advice on its development.	The InfAct National Nodes Concept could be discussed at the upcoming GBEMON meeting (Dec. 2019)		
8	Ireland	The Joint Health Data Liaison Group. This group will play an important role in assessing the needs of key users of health data and developing the statistical potential of data sources in this field. It will also	Potential to discuss InfAct activities and aims with one of the meetings.		

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		facilitate the effective exchange of information on all areas of health data between the main producers and users of such data. This is a joint venture between the Department of Health and the Central Statistics Office (NSI). It is jointly chaired by senior officials from both organisations. Plan to hold at least 2 meetings annually.			
9	Italy	A project was launched by the National Center for Diseases Prevention and Control (CCM) of the Ministry of Health as support to the BRIDGE Health: CCM-BRIDGE Project 'Creation and development of the Italian network supporting the European BRIDGE-Health project aimed at structuring and providing sustainability to European activities in the field of Health Information (HI)' with the aim of verifying and improving the availability of health information to organize		A comprehensive meeting has not been organised yet, but a preliminary meeting has been organised with the ISS President, the MoH representative in the JA AoM representative, and the ISS WP8 lead to discuss the necessary first steps to involve stakeholders to verify interest in a national hub, how to set up the national hub and which institute could coordinate the national hub.	

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		and develop an integrated, sustainable and standardized National Health Information System (HI) to serve both as the Italian hub for a future European infrastructure and as a source of data, tools and methods for health research (2016-2017) ISS, involving also its President, is contacting all stakeholders that could be involved in setting up a national hub on health information.			
10	Latvia			A meeting titled “a new opportunity for healthcare research” was coordinated by the Centre for Disease Control (CDPC is an institution of direct administration under subordination of the Minister for Health) and the University of Latvia. The participants included the Ministry of Health and additional stakeholders from health care institutions, researchers, and students. The meeting wold initiate discussion on new data usage options.Open to follow up meetings or collaboration.	
11	Netherlands			Meeting took place on 5th of November by RIVM.	

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
				The meeting included the following stakeholders: CBS, Erasmus MC, Health RI, Nictiz, Nivel, RIVM, Trimbos, VWS, ZonMw. The meeting presented InfAct activities and the concept of a NN for health information in the Netherlands. The expectations of a NN and what can be the aims of such meetings. To conclude the participants agreed for RIVM to set up an initial plan for the NN concept and take the lead to further elaborate based on this meeting and to take first practical steps.	
12	Norway	There is an already established node for data collection and curation, lead by the Directorate of health. Stakeholders include: Ministry, Directorate of Health, NIPH, Directorate of eHealth, Regional Health Trusts, Vendor. Annual meeting with all stakeholders occur every Autumn (Sep. 3-4, 2019). Emphasis of these meetings is on infrastructure, technical			In addition to the current node, Norway provided the idea for two additional potential NN based on InfAct priority: NN2 Health Data for Governance- lead by Directorate of Health. Currently not meetings take place or formalized group of key stakeholders exists. However, several formal and ad hoc groups based on specific issues (national and international).

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		quality and harmonized use of information models			NN3 Health Data for Research and Industry- lead by NIPH or eHealth. Currently no annual general meetings take place or formalized group of key stakeholder exists. However, there is a national program aiming to build a Health Data Analytics platform, led by Directorate of eHealth.
13	Portugal				Internal InfAct partners in Portugal are preparing for a NN meeting to include: DGS - Directorate-General of Health, ACSS - Central Agency for the Health System, INSA – National Health Institute, Infarmed - National Authority for medicines and health devices, SPMS - Shared Services of the Ministry of Health, INE-Portugal Statistics, and Academia - Faculty of Medicine of Lisbon, Institute of hygiene and tropical medicine -new university of Lisbon, and new university of Lisbon.

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
					Discussions were held with DGS, INSA and IHMT (INFACT Partner), additional informal conversations with ACSS was held with positive perspectives. Informal support from ESFRI Portugal was obtained. Formalization requires formal authorization from the Director-General of Health.
14	Romania			A meeting with all stakeholers took place after the InfAct peer review HIS assessment (WP5.1). Coordinating institute is NIPH. There is no second meeting planned yet. But stakeholders expressed there is room for collaboration in common projects.	
15	Serbia	Creation of NN announced during last meeting of IPH Network statistical representatives (October 10th).		Recent HIS assessment in Serbia (WP5.1) brought together stakeholders (TC, June 11th).	
16	Slovenia	There have been bi-annual meetings among stakeholders (National Institut of Public Health (NIJZ), Statistical Office of Republic of Slovenia (SURS),	InfAct was presented in the meeting 14 June 2019.		

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		Institut of Oncology, Ministry of Health, Health Insurance Institute of Slovenia, Institute for Macroeconomic Research, Institute for Economic Research) since 2004, jointly held by National Institut of Public Health and Statistical Office of Republic of Slovenia as major health information providers. Also, there are yearly national conferences "Statistical Days" with the aim of information exchange. The last meeting was held on 14 June 2019 in Ljubljana. InfAct was presented in that meeting.	The next meeting is planned in 2020, there is room for additions joint meetings.		
17	Spain	Multiple health research structures of which ISCIII is the main leading institution. CIBER: joint decentralized research centres networks with legal entity. CIBER is a consortia integrated by research groups selected to develop a forefront scientific programme on different			

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		strategic fields of interest for the National Health System. RETICS: a Cooperative Research Thematic Network. Composed of an association of Centres and/or Research Groups from different Institutions or Regions, from the public or private sectors, with common research agenda.			
18	Sweden	The PHAS leads the National Node for Health Statistics. The collaborating organisations include Statistics Sweden, the National Board of Health and Welfare, and SALAR. Meetings are held twice a year to discuss joint issues with international reporting of data and issues in lieu of international meetings in working groups. Hence the joint meeting is a forum for coordination and coherence at national level.	Potential to present InfAct in the next meeting.		

	Country name	Existing formation of a NN	Present InfAct in next existing meeting	Had a first NN meeting	NN first meeting is planned
		Last meeting was held 26th Sept 2019. Next meeting planned in spring 2020.			
19	Unite Kingdom	Creation of Health Data Research UK (HDRUK) in 2018, with the vision to work across the UK to exploit the extraordinary capability of informatics and to create a new type of research institute that leads the international agenda in health data science. By working in partnership with academia, NHS, Government, industry, charities and the public, the Institute will be a scientific driving force for new knowledge through data, bringing benefits to society by developing and apply cutting edge data science approaches in order to address the most pressing health research challenges facing the public.			

4. Annex I

WP7 National Nodes survey questions and results.

1. Are there any meetings occurring in your country that bring together health information stakeholders or partners at a national/regional level?

Country	Answer
Finland	Yes
France	Yes
Netherlands	Yes
Serbia	Yes
Slovenia	Yes
Czech Republic	No
Italy	No
Poland	No
Spain	No

a. How are the meetings organised? (Face-to-face or teleconference, frequency, formal invitation or informal gathering, etc.)

Country	Answer
Finland	F2F, at least once a year
France	F2F, formal annual congress and separate stakeholder meetings For example: EMOIS annual congress the national congress of the health information society and the French society of epidemiology
Netherlands	F2F, formal and informal meetings
Serbia	Not regular, the meetings are organised according to the specific emerging needs/topics. There are no regular meetings.
Slovenia	F2F, every 18 months, formal

b. Who attends these meetings? (Participating institutes and level of seniority, number of participants, etc.)

Country	Answer
Finland	THL, Statistics Finland, MoH.
France	Often the directors or assistant directors are invited to these meetings. For technical issues, other than directors, epidemiologists, statistician, clinicians, data scientists or data managers or biostatisticians are invited. Following institutes could be involved in these meetings: Ministry of health, Santé Publique France, French Data Hub, INSERM, National Health Insurance data department (CNAM), French Vital statistics department (INSEE). For strategic meetings, the number of participants may vary from 15-20 and the technical meetings may involve approx. 30 participants For EMOIS attendants include: National Insurance department French physician in information hospital departments French epidemiologist.
Netherlands	Varies between two technical people to any number of institutional directors.
Serbia	To discuss strategic issues, the main stakeholders are National statistical office of Serbia, Institute of Public Health of Serbia and Ministry of Health. Strong coordination of activities regarding development and improvement of HIS is needed. The meetings are usually organised between two parties (e.g. NSI and MoH, or NSI and IPHS). There is a need for all stakeholders to be around the table for many issues. Usually meetings are at the senior level.
Slovenia	NIPH, Health insurance fund, MoH, ministry of labour and social affairs, other health insurance companies, institute of Macroeconomic development, institutes of economic research; 20-25 participants; mid to top level.

c. What is usually discussed? (Please refer to any recurring topics and how the topics are selected)

Country	Answer
Finland	WG Public Health agenda, current reforms in each organization.
France	Topics for discussion are selected based on the need for certain projects. Following topics are discussed: sharing of data/info among different institutes, correct coding of data for epidemiological analysis, feedback from stakeholders to improve their services. For EMOIS all topics related to the administrative database and hospital-based cohorts.

Netherlands	Roles and tasks, problems, strategy, standardization, harmonization, privacy, data linkage, big data, interoperability, patient oriented information, new indicators, etc.
Serbia	Topics include: - improvement of data collection - requests for international reporting - implementing surveys - activities and tasks regarding accession of Serbia to the EU.
Slovenia	Topics include: - presentation of new data sources and new projects (e.g. presentation of on-going surveys, projects like Health in Municipalities, presentation of new classifications, etc.) - emerging issues (e.g. challenges with Healthy Life Years indicator) - development of new data sources and presentation of research in the fieldTopics are selected together with the Ministry of Health with the aim to cover all important issues in the country.

d. Who is the person organizing these meetings?

Country	Answer
Finland	Statistics Finland-Director of Social Statistics.
France	Mainly these meetings are organized by the different departments of Santé Publique France (SpF) and invite other institutes enlisted in Q2 and vice versa.
Netherlands	Varies. RIVM organizes a meeting called 'community of data experts' on behalf of the Ministry of Health.
Serbia	Depends on the topic. Usually senior level staff: Senior reperesentative, MOH (e.g. assistant Minister), Serbia Deputy Director (NSI), Serbia Head of Center of informatics and biostatistics (IPHS).
Slovenia	The National Institute of Public Health.

2. If no such meetings occur in your country:

a. Do you see this feasible in your country?

Country	Answer
Czech Republic	Yes
Italy	Yes, they have been organised from April 2016 to October 2017. Starting from the involvement in the European BRIDGE Health project - BRidging Information and Data Generation for Evidence-Based Health Policy and Research, an Italian, partially parallel, project was launched by the National Center for Diseases Prevention and Control (CCM) of the Ministry of Health as support to the BRIDGE Health: CCM-BRIDGE Project 'Creation and development of the Italian network supporting the European BRIDGE-Health project aimed at structuring and providing sustainability to European activities in the field of Health Information (HI). During the period of activity, HI experts were invited and involved in the project, including Ministry officials who had participated in the preparatory work of ERIC (European Research Infrastructure Consortium), responsible for the coordination of population registers, numerous in ISS, researchers of the ISTAT that collaborate in the European context to the collection and processing of health data with EUROSTAT and DG-Santè, experts from Universities, Public Health Units, and Medical Associations.
Poland	Probably yes
Spain	There is no structure / board gathering all regional authorities in charge of HI

b. What could be potential barriers?

Country	Answer
Czech Republic	lack of capacities of relevant institutions, absence of official background and assignment
Italy	1) Activities were implemented thanks to dedicated specific national funds, but in a limited period of time; 2) Experts tends to work in own specific thematics and find difficult to integrate experties and share knowledge; 3) A formal national broad aim of bulding, organising, and supporting a National Node on Health Information is still missing at political level, even though its importance is aknwoledged and agreed.

Poland	Lack of leading coordinator
Spain	Several boards regarding communicable diseases, but no non communicable diseases or HI. Structures not working

c. How could your country benefit from such meetings?

Country	Answer
Czech Republic	Dissemination of information, collaboration on projects, sharing the knowledge and experience. Coordination of activities on the routine basis.
Italy	During the experience described above, the Italian network of experts on HI focused on some topics such as 'ECHI indicators', 'Communication, transmission, data dissemination', 'Governance', 'Data interconnection' aiming at a) establishing a network of HI experts; b) verify health data sources; c) updating ECHI short list indicators for Italy; d) identify information gaps due to problems in transmitting and communicating Italian data to international organizations; e) identify regulatory and ethical constraints on ethics and privacy, related to access, use and integration of health data through a proposal aimed at a sustainable organization and governance of the system; f) implement a pilot project to interconnect and integrate current health and administrative data with data from longitudinal epidemiological studies carried out at the Istituto Superiore di Sanità (National Health Institute).
Poland	better exchange of health information between stakeholders
Spain	It would be an excellent platform to discuss at national level.

d. For further organization of our activities, could you provide contact details of a central contact person in your country that could organise such a meeting and we could interact with? (Please provide contact person name, email, institute and country)

Country	Answer
Czech Republic	Institute of Health Information and Statistics, Czech Republic
Italy	Istituto Superiore di Sanità, Rome, Italy The Italian Ministry of Health, Rome, Italy The National Institute of Statistics, Rome, Italy

Poland	Deputy Director of Department of Public Health in the Ministry of Health, Poland
Spain	/