



# MS23: Guidelines for National Nodes (NN): Connecting National Stakeholders in Health Information

A stepwise approach-June 2019

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## I. 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

The NN function generally requires a broad knowledge and overview of the national health information system, the broader health data situation, the often numerous health data collecting organisations and their datasets, and of national health data governance in general. That is the type of expertise what we would call the national coordinating function on health information. This national function is not always clearly developed yet and can be distributed among more than one national organisation.

The NN function on 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 the NN function. 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.

## II. 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.

**Table 1: steps for setting up first NN meeting**

#	Step	Timeline
1	Find a <b>lead institute</b> 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.	As soon as possible
2	The coordinating institute will <b>identify relevant institutes, research networks, and experts in the domain of population health and health system performance</b> in the country that could potentially be included in the National Node. Alternatively, describe what information exchange is	By June 2019

	already ongoing among these regional/national partners in health information.	
3	The coordination institute initiate/schedule a <b>first meeting</b> among partners in September 2019 and decide internally on the <b>format of the meetings, topics</b> to be discussed, and <b>expertise</b> to be invited.	By July 2019
4	First NN meeting and plan second meeting	Before September 26 <sup>th</sup> , 2019
5	The coordinating institute will <b>report on the outcomes</b> of a meeting that took place recently in which the participants (for example): <ul style="list-style-type: none"> <li>1. Agree on logistics of setting up National Node meetings (setting, agenda, coordinating further meetings,...),</li> <li>2. Discuss issues experienced in health information in the country,</li> <li>3. Report on updates from international meetings held at EU level and their conclusions,</li> <li>4. Discuss the plans and role of the country in the future EU Health Information Research Infrastructure,</li> <li>5. Other topics specific for national health information system.</li> </ul>	September 26 <sup>th</sup> , 2019
6	Second NN meeting	By January 2021

### III. Annex

#### 1. **Example of 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 providing 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. **Experience setting up 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.



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