

PHIRI

Population Health Information
Research Infrastructure

National Nodes - sustainability of the structure

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Executive summary

The National Node (NN) is an organizational entity, often linked to a national institution or governmental unit that functions as a national liaison and brings together relevant national stakeholders in the field of public health information 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 NNs may function as a discussion and advisory forum in matters of health data and information both for national and/or international matters.

Approaching the end of PHIRI project, analysis of national nodes structure is presented in this report. Four forerunners among NNs are described and analysed, the SWOT analysis of current situation was performed, and finally, the two-fold strategy for NN sustainability and step-by-step engagement of NNs is described.

Key points

- The majority of EU countries, in collaboration with PHIRI partners, has managed to establish a National Node in one of possible forms.
- National Nodes are important contact points to connect partners within countries and to enable exchange of knowledge and practices about health information systems between countries.
- Two-fold strategy for NNs sustainability based on Health Information Portal sustainability and national strategies is described.
- The key points how to engage countries and national health information actors to ensure sustainability of National Node structure, are described in the paper.

National Nodes – the sustainability of the structure

I. Background – what are National Nodes?

A National Node is an organizational 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, a National Nodes may function as a discussion and advisory forum in matters of health data and information both for national or international matters.

National Nodes are playing a key role in PHIRI (Population Health Information Research Infrastructure): they feed this Research Infrastructure and its online Health Information Portal with relevant sources, data, experts, tools and guidelines. Vice versa, they report relevant international information to their country. To support the development and the well-functioning of the National Nodes, PHIRI organizes regular meetings where representatives of each National Node present their main achievements since the last meeting and their planned activities to learn and be inspired by the other countries.

National Nodes have been regarded as an opportunity to bring together regional/national stakeholders in health information in a more systematic manner. Setting up this national node could 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 National Node (NN) coordinating function requires a broad knowledge and overview of the national health information system, the 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 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 three main information sources in international health reports (WHO, OECD, EC) is another possible function.

At the beginning of PHIRI, we recommended the following structure of National Node

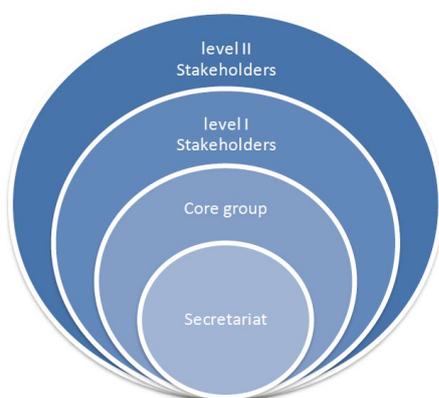


Figure 1: The proposed structure of National Node

Structure depends on national organisation of health information stakeholders. The core group are institutions mainly involved in population health information activities, level I stakeholders are those who work directly with data (e.g. research institutes), and level II stakeholders are those who use data for policy and decision making.

II. Development of National Node structure during the life cycle of PHIRI

PHIRI started in late 2020 with the heritage of Joint Action Health Information (JA InfAct, [1]) regarding National Nodes organisation / coordination and their role within the Health Information Portal. At the **beginning of 2021**:

- only 13 national nodes existed,
- 10 countries were “thinking about it” as collected by Mentimeter during one of the NNs coordinators’ meetings, with some initial national meetings and some basic negotiations with national stakeholders, and
- the rest had not even started to build the skeleton of the national node.
-

At the same time, only 20 countries filled in some basic information regarding their work at the Health Information Portal. Information on around 200 data sources was gathered, about 60 % of them were entered by eight forerunners (Austria, Belgium, Estonia, Finland, Germany, the Netherlands, Slovenia and Spain).

By the end of PHIRI project, almost all countries provided descriptions of their health information systems and activities of national nodes, and the number of data sources increased to 332. A few countries provided only a link to their national catalogues (e.g. France, Portugal). This is quite useful for the users of the Health Information Portal when one would like to explore the national data sources, however it does not allow to exploit the full capacity of the search function at the Portal. For example, if the researcher wants to find all data sources related to maternal mortality, the search engine of the Portal will not find anything for France and Portugal. Bearing in mind that all countries will develop their own national data catalogues during the next few years based on EHDS regulation proposal [4], where Article 37 describes the tasks of Health Data Access Bodies, among other tasks also providing public access to a national dataset catalogue that shall include details about the source and nature of electronic health data. Therefore, the separate development of the catalogues could be an important thread for data sources at the Health Information Portal and its search engine. Finland has also developed the national catalogue (<https://findata.fi/en/>), but still provides information on many data sources also at the Health Information Portal.

Description of current situation of National Nodes organisation is available in Annex 1.



Figure 2. Current representation of National Nodes at the Health Information Portal (<https://www.healthinformationportal.eu/search-countries/search-national-nodes>)

III. Forerunners among National Nodes

The selection of forerunners is done based on authors' judgement and according to potential lessons learnt from their cases.

1. Finland

Finland does not have a formal National Node, but national organizations such as Finnish Institute for Health and Welfare (THL), Statistics Finland, the Social Insurance Institution of Finland (KELA), and Social and Health Data Permit Authority (Findata) work closely together and organize joint meetings to discuss issues related to health data. Besides, the national catalogue of metadata has been created at Findata (<https://findata.fi/en/>) following the national regulation on secondary use of social and health data.

Lessons to learn: national metadata catalogue, close cooperation of institutions.

2. France

The Health Data Hub is a public structure whose objective is to enable project coordinators to easily access pseudonymized data hosted on a secure platform, in compliance with regulations and citizens' rights. The Hub was established by the Law on the organisation and transformation of the healthcare system (24 July 2019). Using the Health Data Hub platform, project leaders are able to cross-reference and analyse the data in order to improve the quality of care and patient support. The Health Data Hub is active within France, but unfortunately not active within PHIRI and also provides only link to the national metadata catalogue.

Lessons to learn: formally established National Node, national metadata catalogue.

3. The Netherlands

The Dutch National Node has been formally introduced with its own website <https://www.rivm.nl/en/national-node-health-information>.

The National Node on Health Information is formed by national institutions that generate and use data and information for international purposes. It has a core team consisting of the National Institute for Public Health and the Environment (RIVM, secretariat), Statistics Netherlands (CBS) and the Netherlands Institute for Health Services Research (NIVEL). The National Node further consists of stakeholders that do not directly generate data, but instead use it for various purposes (such as policy development) or conceive the right conditions for such use (such as standardisation).

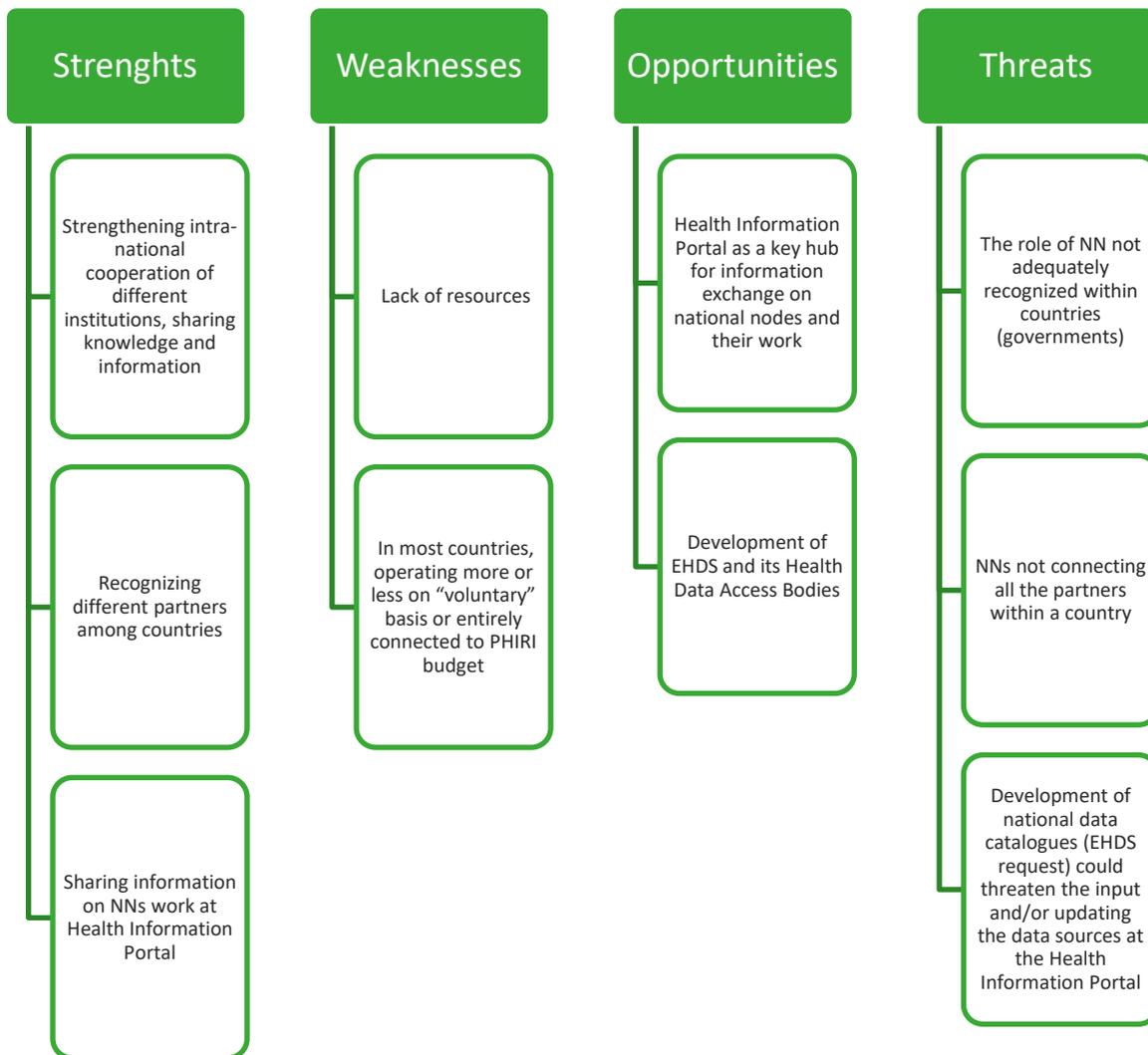
Lessons to learn: formally established National Node, National Node website.

4. Germany

The Committee for Health Reporting and Health Monitoring (GBEMON) advises the Department of Epidemiology and Health Monitoring of the Robert Koch Institute (RKI), Germany's National Public Health Institute, on the development of medium- and long-term goals and on the design and conceptual development of health monitoring and health reporting. The committee includes 19 stakeholders from different areas of the health system who are affiliated with health sciences/public health, the Public Health Service and autonomous governing bodies within the healthcare system. It meets twice a year under the content-related and organisational responsibility of the RKI. The Committee has agreed to take on the role of a National Node in December 2019.

Lessons to learn: formally established National Node, clear definition of common goals.

IV. SWOT analysis of National Nodes structure



V. National Nodes beyond PHIRI

A. Two-fold strategy to ensure sustainability of National Nodes

Sustainability of National Nodes depends mostly on national activities, but the presentation of NNs and the connectivity between them depends also on sustainability on Health Information Portal. Therefore, the further activities of National Nodes depend on two-fold strategy:

- **The Health Information Portal** is currently the main tool for National Nodes to provide information on their activities, the national data sources, health information dissemination, national projects and major players in the country (health information actors). As the current funding period of PHIRI through the European Union's Horizon 2020 research and innovation programme (grand agreement No 101018317) is ending in October 2023, the resources for maintaining and developing the Health Information Portal from that funding source are also coming to an end. Although Sciensano (Belgium) has committed for the time being to maintain the HIP on their server, their support will be limited to bug fixing and small updates. To obtain future funding for further development and updating of the materials on the Portal, several funding proposals have been prepared for open calls that will use the Health Information Portal for their purposes under EU Horizon Europe as well as EU4Health programmes. More on sustainability of the Health Information Portal is available in document A sustainability roadmap for the European Health Information Portal [5].
- **National strategies:** even though the Health Information Portal will still be maintained at minimum efforts, the further active work of National Nodes is prerequisite for up-to-date information at the Portal. From the overview of National Nodes' description, it is clear that some National Nodes were active even before PHIRI and will continue to do so due to their national commitments. On the other hand, there are some National Nodes not very active and there is serious concern that their activity will vanish beyond PHIRI. PHIRI working group estimated that effort of 0.5 PM per country per year would suffice for active coordination of National Node. The strategy how to maintain and update the NNs activity depends from country to country, but main points are listed below in subchapter B.

At the bottom line, the Health Information Portal is a tool and an enabler, but national commitments to maintain National Nodes themselves are the crucial point for further work.

B. How to engage countries and national health information actors to ensure sustainability of National Node structure?

For the sustainability of National Node structure, we prepared a set of recommendations to help National Node's coordinators to develop, upgrade and promote their National Node:

1. From examples of countries above, it is clear that national consensus of different health information actors is a good starting point for active National Node. It is great if this consensus is defined by law, but **a short written agreement among different actors** with their commitment would push activities forward. As mentioned above, for a basic National Node

coordination, 0,5 PM per year would suffice. This resources shall be planned within the agreement.

2. Within PHIRI, most countries appointed one person as a National Node Coordinator. We recommend that the coordinator prepares **a short action plan** for the period 2024-2026 on updating the information at the Health Information Portal. Depending on national plans and strategies, preparation of **national roadmap** for next ten years would be excellent step forward.
3. Taking into account the **development of EHDS** and setting up the National Health Data Access Bodies (HDAB), one shall be aware of some similar function of HDAB and National Node. Namely, HDAB is by draft EHDS regulation responsible (among many other tasks) for development and updating of national metadata catalogue, and cooperate with and supervise (national) data holders. These are all important National Node functions, besides others described at the beginning of this document. Parallel development of EHDS infrastructure for secondary use of data is an excellent opportunity for countries which have not developed the National Node in full functionality yet. Majority or all countries applied for the direct grants for setting up the infrastructure for secondary use of data. One of the obligatory tasks is development of national metadata catalogue, so one can conclude that countries will develop their own catalogues. On the contrary, Health Information Portal will implement the Health extension of the DCAT-AP metadata standard, that is currently being developed in the HealthData@EU project [3]. This will provide European member states with an advantage, as their metadata records that are on the Health Information Portal are already available in a format that matches the European requirements and can easily be harvested or simply displayed on their national portals using the Health Information Portal's API. This is important as Member States will be required by the EHDS regulation to have that national metadata catalogue available.
4. **Health Information Dissemination (Reports)** is not as widely and accurately reported at the Health Information Portal as data sources, but is very valuable source of information for researchers. We recommend to establish a mechanism to extract necessary information from national publication catalogue; the most interesting publications are those that cannot be found through PubMed, Web of Science, and other similar databases. This could be part of the action plan mentioned above.
5. One of the key elements for sustainability of the Health Information Portal is to ensure **visibility of the Portal** also after the PHIRI funding period ends by keeping PHIRI Newsletter and social media accounts active. This could also be done by help of National Nodes coordinators to spread the knowledge of rich information at the Health Information Portal.

References

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3. HealthData4EU. www.ehds2pilot.eu
4. The European Health Data Space - Proposal for a regulation: https://health.ec.europa.eu/publications/proposal-regulation-european-health-data-space_en

5. Hanna Tolonen, Miriam Saso, Csaba Kiss, Brigid Unim, Luigi Palmieri, Pascal Derycke, Mariana Peyretero, Luis Lapao, Nienke Schutte (2023): A sustainability roadmap for the European Health Information Portal. Zenodo, <https://doi.org/10.5281/zenodo.10021129>.

Disclaimer

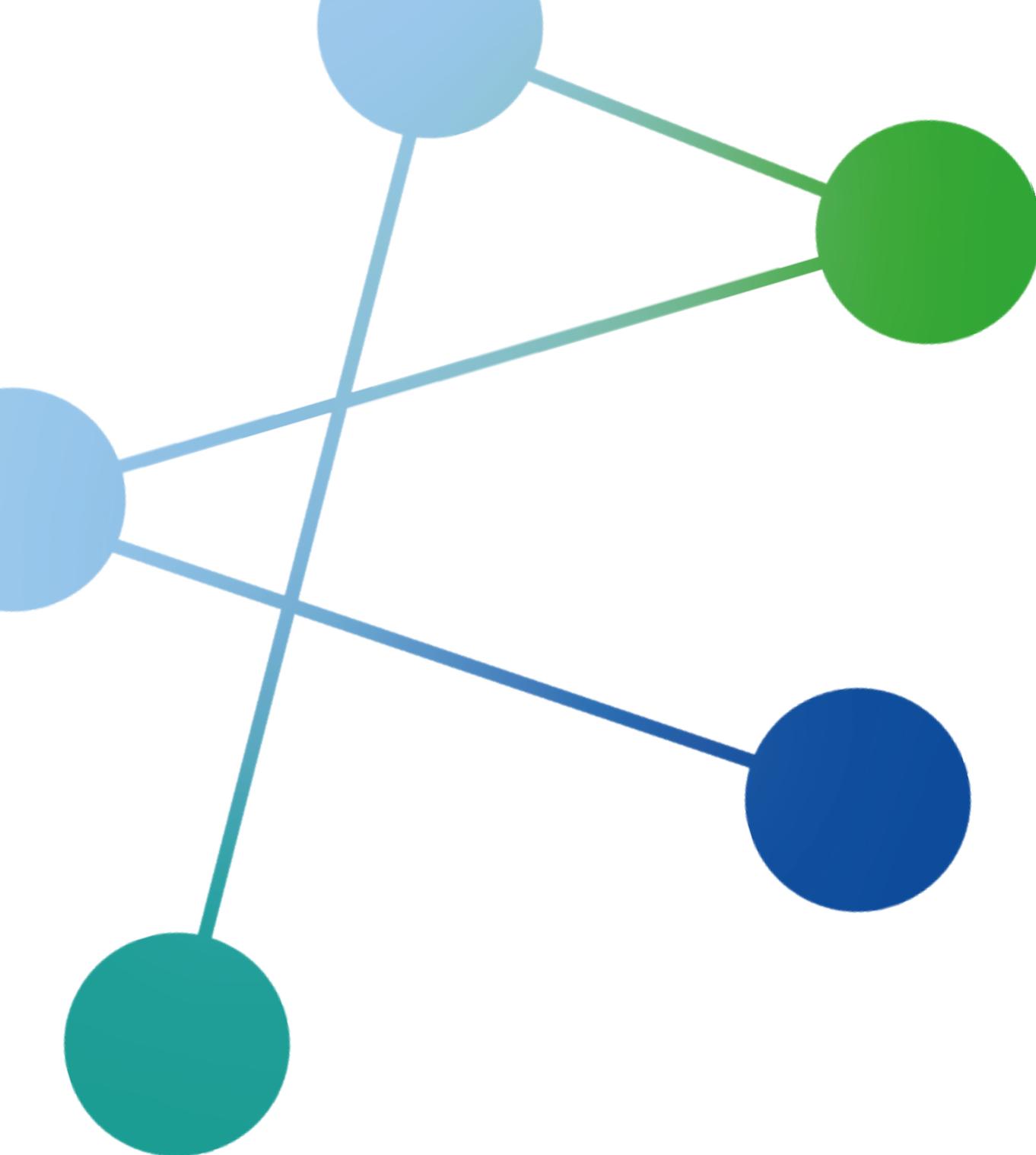
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Annex 1: Descriptions of National Nodes

Country	National Node Description
Albania	Coordinating Institution University of Vlora
Austria	<p>National Node Description The Austrian National Public Health Institute (Gesundheit Österreich GmbH, GÖG) is the institution responsible for researching and planning public healthcare in Austria, and also acts as the national competence and funding centre for the promotion of health. Set up by federal law on 1 August 2006, GÖG has the federal government as its sole shareholder, represented by the Ministry of Social Affairs, Health, Care and Consumer Protection. It is a public non-profit limited liability company fully owned by the Republic of Austria, organised in three business units.</p> <p>ÖBIG - Österreichisches Bundesinstitut für Gesundheitswesen: The Austrian National Institute for Health Services Research, founded in 1973. It analyses data, provides comprehensive information in the field of public health policy, and facilitates reform and innovation processes.</p> <p>BIQG - Bundesinstitut für Qualität im Gesundheitswesen: The Austrian National Institute for Quality in Health Care was founded in 2007 (Act on Healthcare Quality). It develops standards, maintains registries, evaluates the quality of healthcare interventions and provides information and decision support to promote high quality healthcare in Austria.</p> <p>FGÖ - Fonds Gesundes Österreich: The Austrian Health Promotion Fund was founded in 1998 (Health Promotion Act). It promotes health and support initiatives to establish and improve knowledge, competences, and networks by granting financial assistance and offering guidance.</p>
Belgium	No information, Sciensano working as a National Node
Bosnia and Herzegovina	No information, coordinating Institution ZAVOD ZA JAVNO ZDRAVSTVO FEDERACIJE BOSNE I HERCEGOVINE
Croatia	No information, Coordinating Institution HRVATSKI ZAVOD ZA JAVNO ZDRAVSTVO
Czech Republic	No information, USTAV ZDRAVOTNICKYCH INFORMACI A STATISTIKY CESKE REPUBLIKY coordinates the activities
Estonia	No information, Coordinating Institution TERVISE ARENGU INSTITUUT
Finland	Finland does not have a formal National Node but national organizations such as Finnish Institute for Health and Welfare (THL), Statistics Finland, the Social Insurance Institution of Finland (KELA), and Social and Health Data Permit Authority (Findata) work closely together and organize joint meetings to discuss issues related to health data.
France	Provided for by the 24 July 2019 Law on the organisation and transformation of the healthcare system , the Health Data Hub is a public structure whose objective is to enable project coordinators to easily access pseudonymized data hosted on a secure platform, in compliance with regulations and citizens' rights . Using the Health Data Hub platform, project leaders are able to cross-reference and analyse the data in order to improve the quality of care and patient support.
Germany	The Committee for Health Reporting and Health Monitoring (GBEMON) advises the Department of Epidemiology and Health Monitoring of the Robert Koch Institute (RKI), Germany's National Public Health Institute, on the development of medium- and long-term goals and on the design and conceptual development of health monitoring and health reporting. The committee includes 19

	<p>stakeholders from different areas of the health system who are affiliated with health sciences/public health, the Public Health Service and autonomous governing bodies within the healthcare system. It meets twice a year under the content-related and organisational responsibility of the RKI.</p> <p>The Committee has agreed to take on the role of a National Node in December 2019.</p>
Hungary	No information, Coordinating Institution National General Directorate for Hospitals
Ireland	No information
Italy	No information
Latvia	No information, coordinating Institution SLIMIBU PROFILAKSES UN KONTROLES CENTRS
Lituania	Lithuania has not created an official National Node. Health information institutions are communicating in working order.
Malta	Coordinating Institution Directorate for Health Information and Research – Ministry for Health – Government of Malta
Norway	Norway has been an early user of information and communications technology in the health sector. There are different types and categories of health data and personal health data filing systems in Norway as well as different types of records and registers such as patient medical records, local, regional or central personal health data filing systems, and data processed in medical and health research. The use of national ID numbers gives Norway a very good starting point for collecting knowledge of the health status and the health challenges of the population from health registries, patient records, and health studies.
Poland	Poland does not have a formal National Node appointed. Different national organizations such as the Ministry of Health (MZ), National Institute of Public Health (NIZP-PZH), Central Statistical Office (GUS), Chief Sanitary Inspectorate (GIS), Center for eHealth (CeZ) and other entities involved in the process of health data collection, monitoring and supervision, cooperate to discuss matters related to health data, also as regards data on COVID-19.
Poland	Poland does not have a formal National Node appointed. Different national organizations such as the Ministry of Health (MZ), National Institute of Public Health (NIZP-PZH), Central Statistical Office (GUS), Chief Sanitary Inspectorate (GIS), Center for eHealth (CeZ) and other entities involved in the process of health data collection, monitoring and supervision, cooperate to discuss matters related to health data, also as regards data on COVID-19.
Portugal	There is an installation team, including DGS and UNL. Soon a National Node in Portugal will be fully defined.
Romania	There is no formal national node in Romania. The National Institute of Public Health is acting as an informal national node for the scope of the PHIRI project. It provides the technical and methodological guidance of the network of public health, monitors the health of the population, communicable and non-communicable diseases to identify community health problems, develop the methodology, tools and indicators for monitoring and evaluating health services and programs, of public health promotion and health education and ensures the existence of a system information and integrated informatics for public health management.
Serbia	Coordinating Institution INSTITUT ZA JAVNO ZDRAVLJE SRBIJE "DR MILAN JOVANOVIC BATUT"
Slovakia	Slovakia does not have an official National Node. However, there are certain information nodes which could cover the expected functionalities in common. Placement in different entities is caused by different legal establishment of certain bodies of public governance.
Slovenia	National Node (NN) is coordinated by National Institute of Public Health. Till 2020, NN was organised under the auspices of National Statistical System; main national health data producers and users were involved. In 2021, the NN is

	expanded to the institutions outside national statistical system and reorganised as recommended by JA InfAct.
Spain	<p>There is no formal national node in Spain. In the meanwhile, the Instituto de Salud Carlos III (Institute of Health Carlos III), or ISCIII, will act as an informal national node for the PHIRI purposes. The mission of the ISCIII is to contribute to improving the health of all citizens and to fight diseases through the promotion of research and innovation in Health Sciences and Biomedicine and through the provision of ground-breaking scientific and technical services and educational programmes directed towards the National Health System.</p> <p>ISCIII depends from two ministries, the Ministry of Science and Ministry of Health.</p>
Sweden	Coordinating Institution Folkhälsomyndigheten
The Netherlands	<p>Formally introduced, with its own website</p> <p>The National Node on Health Information is formed by national institutions that generate and use data and information for international purposes. It has a core team consisting of the National Institute for Public Health and the Environment (RIVM, secretariat), Statistics Netherlands (CBS) and the Netherlands Institute for Health Services Research (NIVEL). The National Node further consists of stakeholders that do not directly generate data, but instead use it for various purposes (such as policy development) or conceive the right conditions for such use (such as standardisation).</p>
UK	<p>The Secure Anonymised Information Linkage (SAIL) Databank is a world-class internationally recognised privacy-protecting trusted research environment (TRE), enabling robust secure storage and use of anonymised individual-level linked data for research to improve health, well-being and services. The SAIL Databank holds anonymised data on the population of Wales. Backed and endorsed by the Government, the SAIL Databank receives core funding from the Welsh Government's Health and Care Research Wales.</p>



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