



# National Nodes - a short manual

March 2021



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## 1. What is a National Node (NN)?

The NN is an organisational entity, often linked to a core group of national institutions or governmental units that function as a national liaison and brings together relevant national stakeholders 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.

## 2. What is the purpose of this manual?

With this manual, we would like to present to you

- the technical part of entering the information to the portal (how to log in, how to use the application, etc.), and
- the methodological part (what information to enter and how).

## 3. To whom the manual is intended?

This manual is intended for people who are contact persons of NNs, and also to people who will prepare part of the data needed in the NN description, helping the contact person to complete the description.

## 4. How to start?

For the successful start, we recommend you to:

- make sure you have received the information of your account for HIP (user ID and password). If not, please contact Sciensano staff at [infact.coordination@sciensano.be](mailto:infact.coordination@sciensano.be) or [phiri.coordination@sciensano.be](mailto:phiri.coordination@sciensano.be).
- read the methodological part of the manual. Your work will be much easier if you prepare some information in advance.
- Please note that your session will be automatically ended after 1 hour of inactivity.

## 5. How to connect to the portal?

Open your browser (chrome, firefox,...).

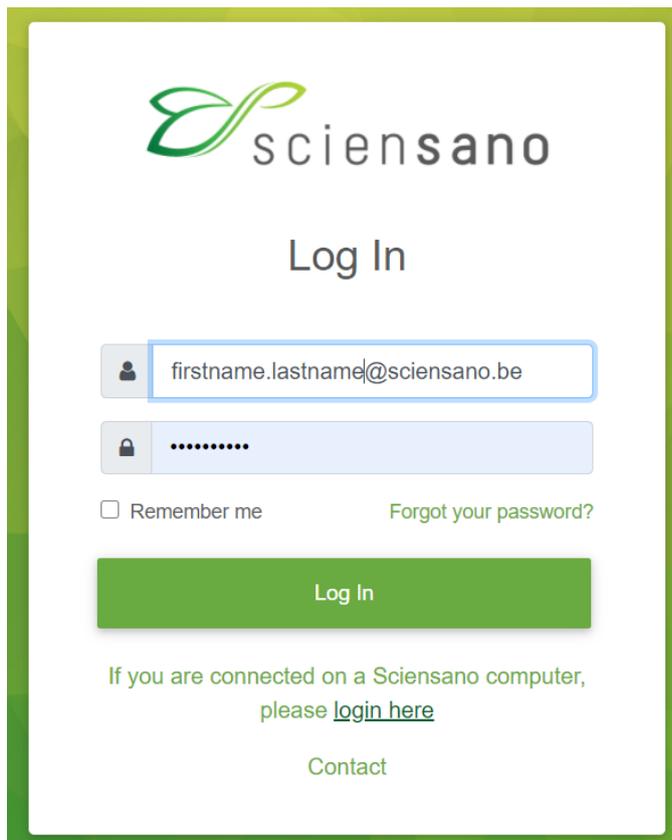
Go to <https://www.healthinformationportal.eu/user>

You see the screen below

Do not enter your username or password in the fields displayed here, but click on the

button 

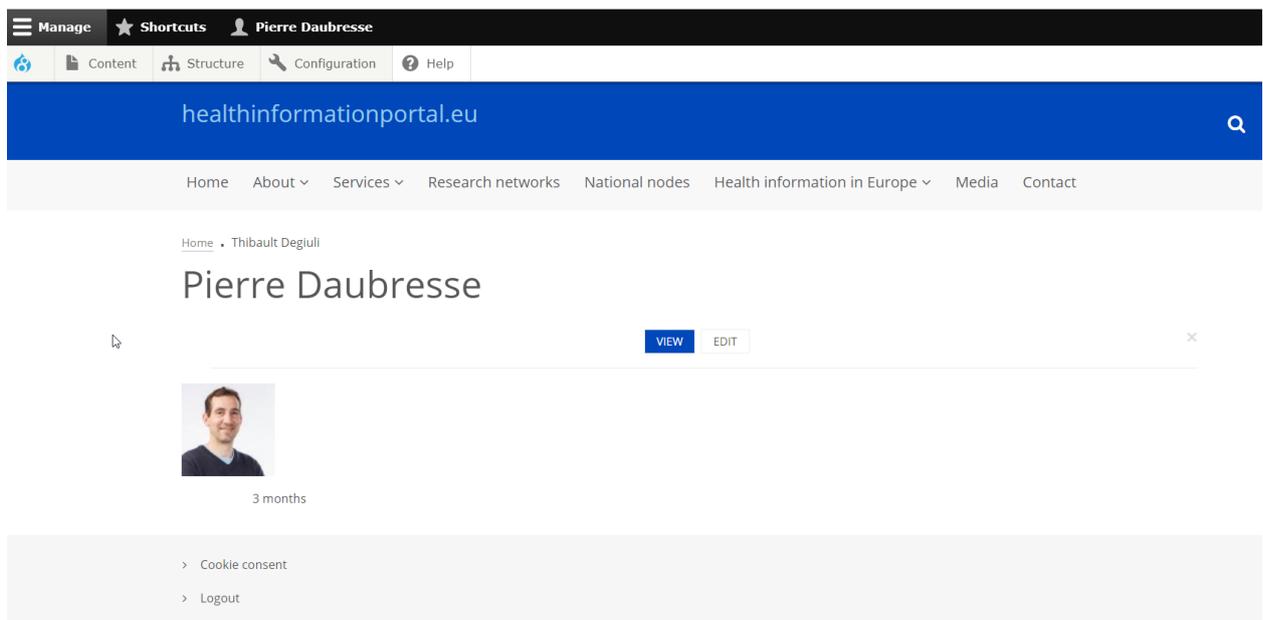
You'll be redirected to the Sciensano Authentication portal



The image shows the Sciensano authentication portal. At the top is the Sciensano logo, which consists of a green stylized leaf-like shape followed by the word "sciensano" in a lowercase, sans-serif font. Below the logo is the text "Log In" in a large, bold, sans-serif font. There are two input fields: the first is for the username, containing the text "firstname.lastname@sciensano.be", and the second is for the password, represented by a series of dots. Below the password field are two links: "Remember me" with an unchecked checkbox, and "Forgot your password?". A large green button with the text "Log In" is positioned below these links. At the bottom of the form, there is a message: "If you are connected on a Sciensano computer, please [login here](#)". Below this message is a link labeled "Contact".

Enter the username and password you have received from the HIP coordinators, and click on button Login

Once logged in, a new toolbar should appear at the top of the screen

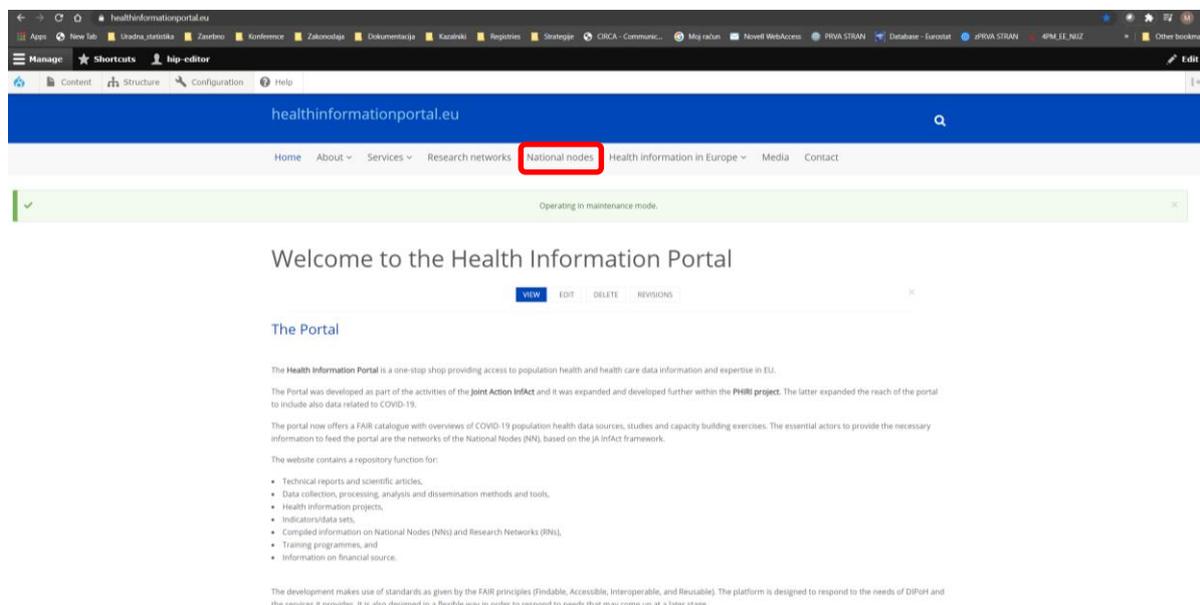


The screenshot shows the user interface of the healthinformationportal.eu website after a user has logged in. At the top, there is a dark navigation bar with a hamburger menu icon, the word "Manage", a star icon for "Shortcuts", and a user profile icon for "Pierre Daubresse". Below this is a lighter navigation bar with icons and labels for "Content", "Structure", "Configuration", and "Help". The main header is a blue bar with the text "healthinformationportal.eu" and a search icon. Below the header is a white navigation menu with links for "Home", "About", "Services", "Research networks", "National nodes", "Health information in Europe", "Media", and "Contact". The main content area shows a breadcrumb trail "Home > Thibault Degiuli" followed by the name "Pierre Daubresse" in a large font. Below the name is a profile picture of a man, with "3 months" written underneath it. To the right of the profile picture are "VIEW" and "EDIT" buttons. At the bottom of the page, there is a light gray footer area with links for "Cookie consent" and "Logout".

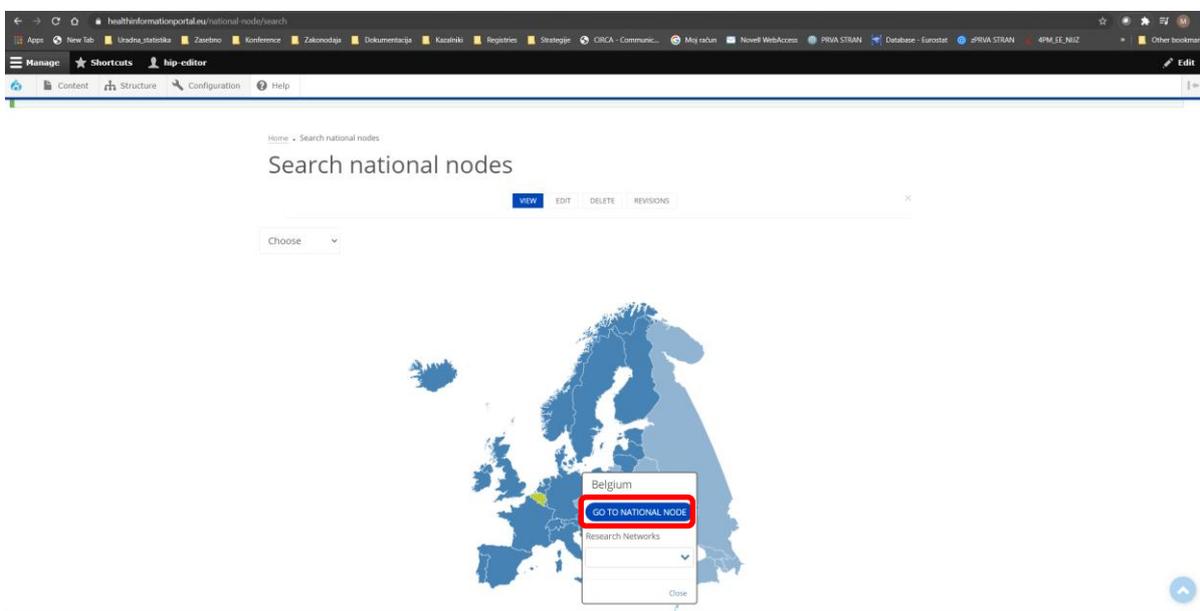
Actions you will be allowed to perform on the site depend on your role.

## 6. How to find your NN to edit and start editing?

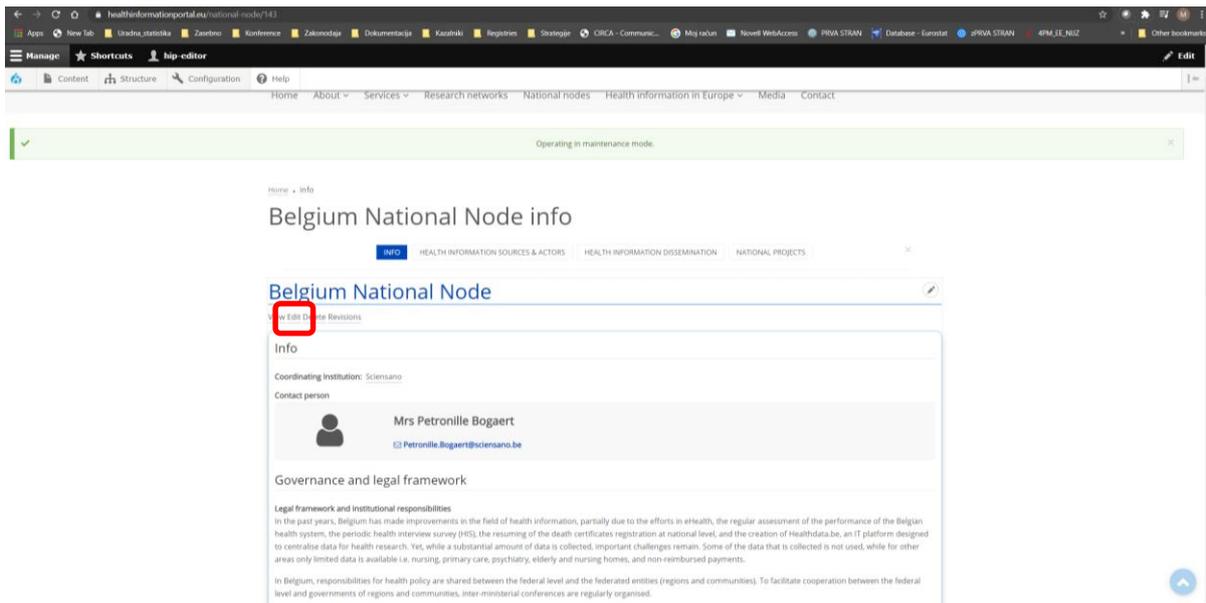
Once you logged in to the portal, you'll get the initial page



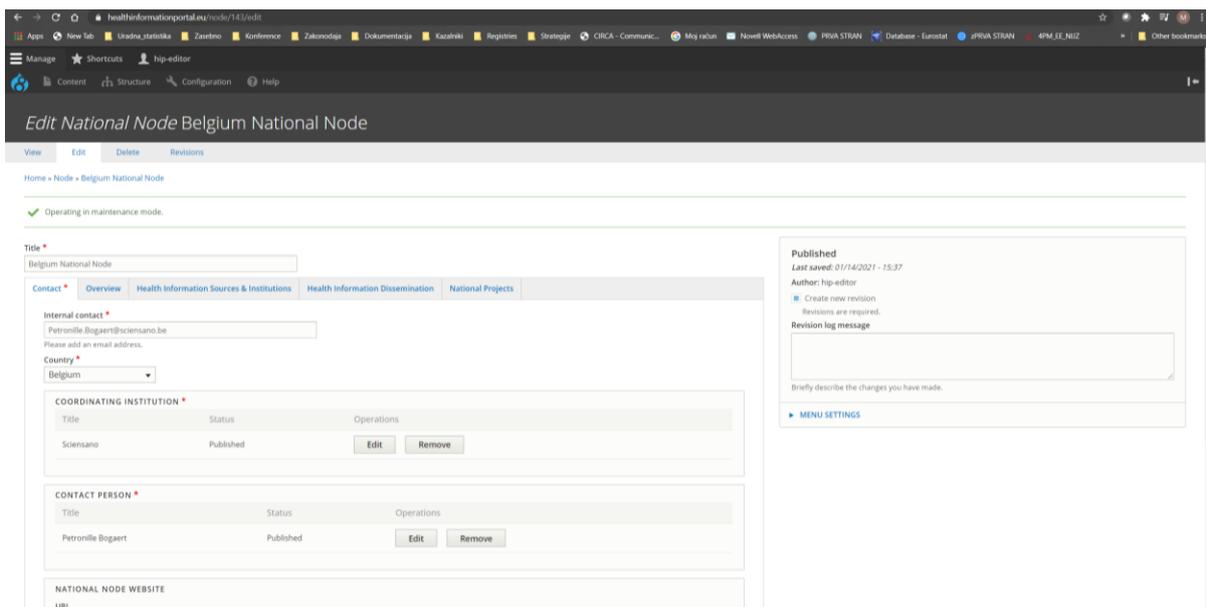
Then click at the National Node bar (red square above). You'll get the map of Europe.



Select your country and click on the map. You'll get a pop-up window, then you select "Go to national node" (red square above).



You click on a small EDIT button just below the name of NN (red square above). You'll be immediately switched to the editing mode which looks like the screen shot below:



Please note that all fields marked with \*, are obligatory.



Please note that there is  button at the bottom of each tab - please, use it every now and then to prevent losing any data.

There's possibility to consult immediate help in the format of Tool-tips, which is available when you click on small grey or blue question mark next to the field name, e.g.:

Internal contact  \*

Country \*

## 7. Topics - conceptual framework and keywords

The main advantage of HIP is search function and connectivity of different contents. This is possible only by proper tagging of the information at HIP. Therefore, there are two powerful tools used for tagging the information. Conceptual framework is four-layer framework developed to embrace the contents of health information at the aggregated levels. It is available also in the appendix to this document. It was built into the HIP in a way that when describing HI source or publication, you can select different levels. For example, when describing the mortality registry, you would select:

1<sup>st</sup> level: Health Status

2<sup>nd</sup> level: Mortality

3<sup>rd</sup> level: Age-and-cause-specific mortality

4<sup>th</sup> level: all causes

Since the same HI source is used also for estimation of e.g. maternal mortality, you would tag the same HI source also with

1<sup>st</sup> level: Health Status

2<sup>nd</sup> level: Mortality

3<sup>rd</sup> level: Maternal, perinatal and newborn mortality

4<sup>th</sup> level: Maternal mortality

In the same manner, you can add as many tags as you want. You could also stop at level two, so you would tag your source only as Health Status → Mortality. But in this case, when user will search for maternal mortality, your HI source will not be found. Therefore, we recommend to spend a little more time to properly tag HI sources and dissemination.

Please note that this framework will change over time since in the life course of PHIRI some additional items will be added to the framework.

Besides conceptual framework, “common” keywords as known from articles are also possible to use. In addition to above, you can also add free keywords. They will be used by search engine as well.

Later on in this documents, terms “Topics” and “Keywords” are used to distinguish between topics based on conceptual framework and free keywords.

## 8. What information is needed

The description of NN is organised in five tabs:

1. Contact - Basic information on NN
2. Overview - Overview of HI in the country
3. Health information sources & institutions
4. Health information dissemination
5. National projects - National health information projects

Please note that view in editing mode differs from that in viewing mode. In this manual, we're referring to editing mode.

The whole table of all necessary information is presented in the appendix to this manual at the end of document. In the following subchapters, the content of each tab is presented with instructions how to prepare and how to enter the information.

Some information has been already pre-filled

- List of institutions: long list of institutions dealing with health information has already been uploaded. We uploaded all partners of InfAct and PHIRI, and some partners of research networks. Please note that names of institutions are filled-in with their original names, with their acronyms and code of countries (e.g. Finland - TERVEYDEN JA HYVINVOINNIN LAITOS) and not with their English substitutes. You can search institutions by any part of text (e.g. entering THL will give you back the above mentioned example; our advice is to start search with country name to narrow down the selection).

## 8.1. Basic information on NN

There are following information to provide

Variable	Comment
Internal contact*	Please provide e-mail address of person who will enter majority of data and is able to reply to questions from the coordinators.
Country*	Already pre-filled in.
Institution, coordinating national node*	
Web page of coordinating institution	
Contact person	Name and surname of contact person
Contact details	e-mail address of contact person
Web page of national node	If exists

If the information on institution, coordinating national node, has not been pre-filled in, please follow this procedure:

- Try “Add existing institution”, then enter a few letters of the original name of the institution (like “Scien...” or “Belgium”). A list of all institution with part of the name corresponds to “Scien” will appear, then you select the right one.
- If you can’t find the right institution, then select “Add new institution”. In this case, you’ll create a new institution that will be uploaded to the system and will be available at all later stages. You will have to provide the web site of the institution and the country.

The same procedure needs to be followed also in case of HI sources and HI dissemination.

## 8.2. Overview of HI in the country

Overview of health information in the country is descriptive part of the NN. Here, some textual presentation of the HI organisation, strategic view and frameworks shall be presented. We'd like you to check before entering the information the following documents where all this information might already exist:

- Health Information System Assessment documents if this assessment has been conducted in your country
- Health in Transition at European Observatory on Health Systems and Policies web page (<https://www.hspm.org/mainpage.aspx>, go to Countries, select your country)
- OECD Health Care Quality and Outcomes Working Party (HCQO): Questionnaire on Health Data Development and Governance (countries filled in this questionnaire in 2019).

Variable	Description and remarks
Governance and legal framework	Short description of legal framework (list of relevant acts, regulations, etc., with links if possible), together with description of division of institutional responsibilities (e.g. which institution is responsible for communicable disease surveillance, for major health system performance indicators, etc.). Include the description of centralisation or decentralisation of the HI system.
Health Information Strategy	Short overview of existing health information strategies and links to the documents.
Main players (institutions)	Short overview of major institutions managing health information (data collection, data management, dissemination,

	translation into policies,...) and short description of their responsibilities.
National data/privacy protection regulation and specific data access policies	Short overview of national data/privacy protection regulation/legislation and short overview of data access policies (e.g. if there's necessary to get approval from national or institutional ethical committee, are there any other bodies that approve data access; or data are freely available for secondary use).
Health Information Infrastructure and Management*	Short description of HI infrastructure and management, including the existence of centralized database (or several databases)
Existence of a unique patient identifier or general person identifier	Yes/no (do not overlook this at the bottom of the page)
Name of the identifier	Provide the name of the identifier.

### 8.3. Health information sources and managing institutions

The purpose of this tab is to provide exhaustive list of health information sources with information of managing institution, web site that more information on the HI source is available and information on access to data.

The following variables are used to describe the HI source:

Variable	Description and remarks
Name of HI source*	Short descriptive name of HI source in English. For the HI sources that are managed in all countries, we provide list of names (see below the table). Please, use these names to enable search.
Type of HI source*	Drop-down list: Survey/interview data, administrative data, population data, registry data, biobank/sample/specimen data, customer record data, observational study data, other. See examples at the next page.
Institution*	Managing institution (or data owner). Please follow the same procedure as described in section 8.1.
Topics (conceptual framework)	Insert as many key words defined by conceptual framework as you like. You can use any number of levels (1-4), but preferably 4.
Key words (free)	In case that you feel that conceptual framework is not describing well your HI source, please feel free to enter up to 10 keywords.
Website	Website where more information on HI source could be found. Please use specific data source

	website if exists and not general page of the data owner.
Access information	Short description how users can access data for research or some other purposes. You can describe this in a few sentences or simply provide a link where more information is available.

Type of data	Examples
Survey/interview data	For example: health surveys, interview surveys, online panels
Administrative data	For example: (electronic) health care records, hospital discharge data, reimbursement data etc.
Population data	For example: mortality, population structure etc.
Registry data	For example: patient registries for cancer, diabetes, HIV etc.
Biobank/sample/specimen data	For example: 'omics'-data, saliva, urine, blood etc.
Customer record data	For example: mobility data, food consumption etc.
Observational study data	For example: cohorts, examination surveys etc.
Other	

When you enter all requested data, click on “Create HI Source & Institution” to create and save this data source.

To avoid a lot of manual work, there’s function of duplicating the existing HI source. When you enter one source, you can simply duplicate it (with button Duplicate, see picture below); then you edit the duplicated version. This is very handy if the next HI source could be described by similar topics / conceptual framework.

HI SOURCES & INSTITUTIONS			Show row weights		
Title	Status	Operations			
+ Health Interview Survey	Unpublished	Edit	Duplicate	Remove	
+ Hospital discharge database	Unpublished	Edit	Duplicate	Remove	
+ Perinatal registry	Unpublished	Edit	Duplicate	Remove	

Short list of recommended names for most common HI sources

Hospital discharge database

Mental hospital discharge database

Emergency health care data

Primary care data

Prescribed medicines database

Cancer registry data

Diabetes registry data

Cardio-vascular disease registry data

Mortality data

Formal long-term care data

Patient experiences survey data

Perinatal registry

Health Interview Survey

Survey on Income and Living Conditions

Population registry

Census of population and/or households

## 8.4. Health information dissemination

The purpose of this tab is to provide exhaustive list of different dissemination channels with information on title, scope, type, key words, web page and language. You're invited to insert different publications: scientific peer-reviewed publication, scientific report, policy briefs, fact sheet or leaflet, publications for professional communities, publications for general public, newsletter, web portals with open data, etc. You can provide general, thematic, regional publications.

The following variables are used to describe the HI:

Variable	Description and remarks
Title	Copy the title of your publication, article, name of web portal, etc.
Type of publication	Dropdown list: Scientific peer-reviewed publication, report, policy briefs, fact sheet or leaflet, newsletter, tools, guidelines, portal or web site, presentations, infographics, video presentations etc., meetings - reports and other documents, other
Scope of publication	Dropdown list: general, thematic, regional, other
Topics - conceptual framework	Conceptual framework as described earlier
Keywords	Free keywords
Link	URL address of publication
Language	Dropdown list of languages. You can enter several languages.

## 8.5. National health information projects

The purpose of this tab is to provide an overview of existing national health information project that are important for the development of HI sources, innovative use of data, providing new data to users, etc. Please do not fill in the international projects that you participate in or coordinate them. Information on various international projects and research networks will be provided separately within Research Networks tab and then automatically connected to countries that are participating in.

The information on national HI project are as follows:

Variable	Description and remarks
Project title	Title of project (in original language)
Project acronym	
Short description	Brief description of the project (aims, results, etc)
Link to project home page	Link
Keywords	Free set of keywords to enable search function

## 9. When you finish your work

- Please make sure that you **saved** your work. At that time, the NN will not be visible to the outer world since the content will not be published yet.
- You can come back at any time and edit your NN again.
- Editors will publish your NN to be visible at the web.

## 10. Appendices

### 10.1. The whole list of variables

Q	Item	Item subheading
0	Internal contact	e-mail address
1	Contact	
	Country	Dropdown list
	Institution, coordinating national node:	Text
	Web page of coordinating institution	URL address
	Contact person	Text
	Contact details	e-mail address
	Web page of national node	URL address
2	Overview	
	Governance and legal framework	Text
	Health Information Strategy	Text
	Main players (institutions)	Text
	National data/privacy protection regulation and specific data access policies	Text
	Health information infrastructure and management	Text
	Existence of a unique patient identifier	Yes/no
	Name of the identifier	Text
3	Health information sources and institutions	
	Name of HI source	Text
	Type of HI source	Dropdown list
	Institution	Text
	Topics - conceptual framework	Dropdown list
	Key words - free	
	Website	URL address
	Access information	text
4	Health information dissemination	
	Title	
	Type of publication	Dropdown list
	Scope of publication	Dropdown list
	Topics - conceptual framework	Dropdown list
	Key words	
	Link	URL address
	Language	Dropdown list
5	National Health Information Projects	
	Project (title, acronym)	Text
	Short description	Text
	Link to project home page	URL address
	Key words	

## 10.2. Conceptual framework

Level 1	Level 2	Level 3	Level 4	
Determinants of health	Individual characteristics and behaviours	Behaviours	Alcohol consumption Food consumption Physical activity Reproductive and maternal Tobacco use Use of psychoactive substances	
		Individual characteristics	Birth weight Blood pressure Cholesterol Overweight/obesity	
	Physical and social environment	Physical environment	Housing and sanitation Pollution	
		Social environment	Social network Work-related	
	Socioeconomic and demographic factors	Demographic factors	Demographic factors	
		Socioeconomic factors	Education Employment/occupation Income/poverty	
	Health status	Morbidity/disability	Accidents & injuries	Home/leisure Self-injury Traffic Work
			Communicable diseases	Airborne and/or vaccine-preventable diseases Covid-19 Food and water borne Sexually transmissible and/or blood borne Zoonotic
Disability			Disability	
Non-communicable diseases			Cancer Cardiovascular diseases Dental diseases Diabetes Mental diseases Reproductive, maternal and newborn health Respiratory diseases	

		Self-reported health status	Self-perceived health/morbidity
	Mortality	Age- and cause-specific mortality	All causes Cancer External causes Infectious diseases Non-communicable diseases (excluding cancer)
		Life expectancies	Health expectancy Life expectancy Reduction of life expectancy (PYLL)
		Maternal, perinatal and newborn mortality	Infant mortality Maternal mortality
	Wellbeing	NA (Wellbeing)	Wellbeing
Health systems	Health resources and activities	Care utilisation	Consultations Diagnostic exams Hospital utilisation Long-term care Reproductive, maternal and newborn health Surgical procedures
		Health employment and education	Education Health workforce migration Nurses and/or midwives Physicians Remuneration Workforce other
		Pharmaceutical sales & consumption	Generic market Pharmaceutical consumption Pharmaceutical sales
		Physical and technical resources	Hospitals and beds Medical technology Other care units/beds
	Health system performance	Access	(Un)met needs or their causes Health care coverage
		Costs/expenditure	Assets Financing scheme Function Provider Provision factors Revenues
		Quality	Autopsy Cancer screening Cancer survival rates

