Research Network (RN) – a short manual

26th of April 2021

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1. What is a Research Network (RN)?

A Research Network (RN) is an active network of national and/or regional experts from several countries that perform comparative research in a specific health area (information domain).

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 the contact persons of RNs and for people who will prepare part of the data needed in the RN description, helping the contact person to complete the description.

4. How to start?

For a successful start, we recommend you to:

- Request access to the HIP using the this link or by emailing phiri.coordination@sciensano.be with the following information: email and date of birth.
- 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**. You will, after refreshing the page, get the message "website under maintenance". Close your tab and log in again.

5. How to connect to the portal?

- Open your browser. Please make sure to use Google Chrome.
- Go to https://www.healthinformationportal.eu/user
  You will see the screen below

Log in

| LOG IN | RESET YOUR PASSWORD |

LOG IN WITH SCIENSANO IDP

Username

Enter your healthinformationportal.eu username.

Password

Enter the password that accompanies your username.

▼ CAPTCHA

This question is for testing whether or not you are a human visitor and to prevent automated spam submissions.
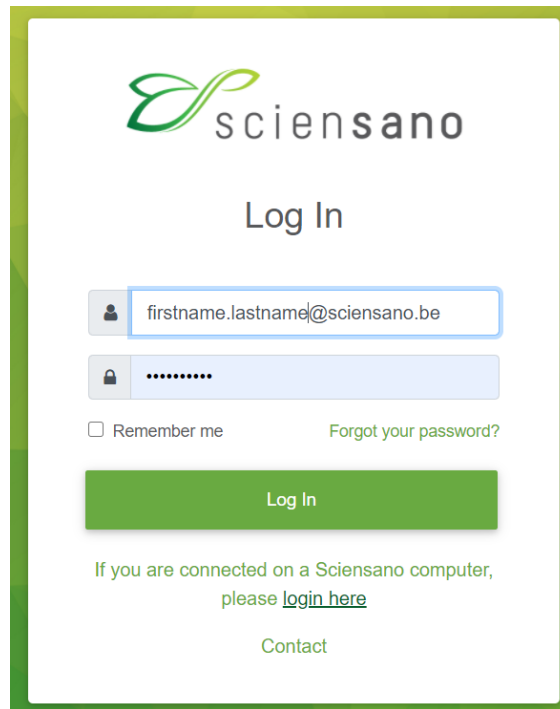
I'm not a robot
reCAPTCHA
Privacy - Terms

LOG IN

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

LOG IN WITH SCIENSANO IDP

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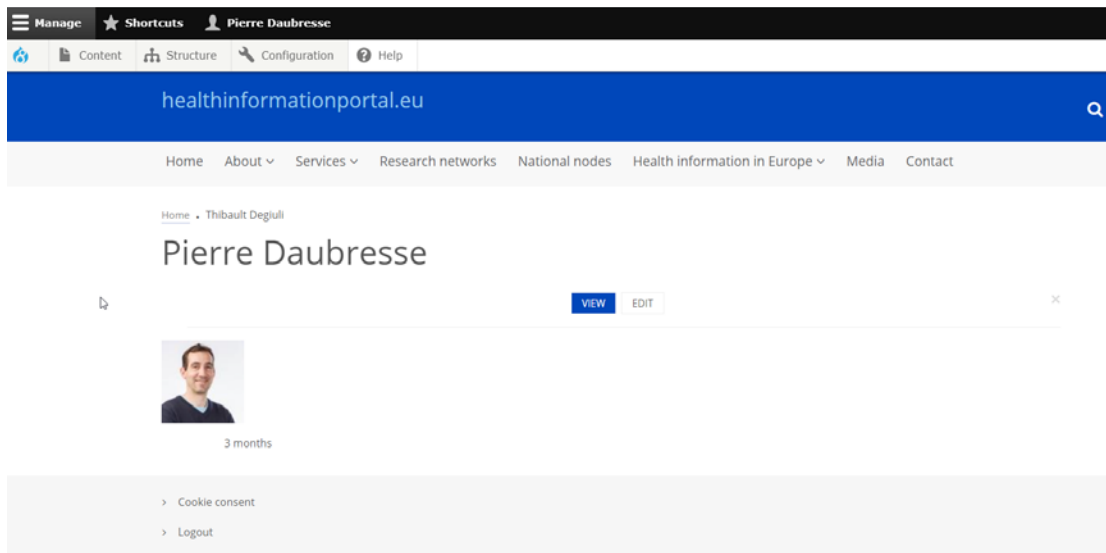
- You'll be redirected to the Sciensano Authentication portal.

- Enter the username and password you have received from the HIP coordinators, and click on button Login. They are the same ones you use for the PHIRI SharePoint.

- Once logged in, a new toolbar should appear at the top of the screen. The actions you will be allowed to perform in the Portal will depend on your role.

6. How to find your RN to edit and start editing?

Once you logged into the portal, you should see the homepage of the portal.
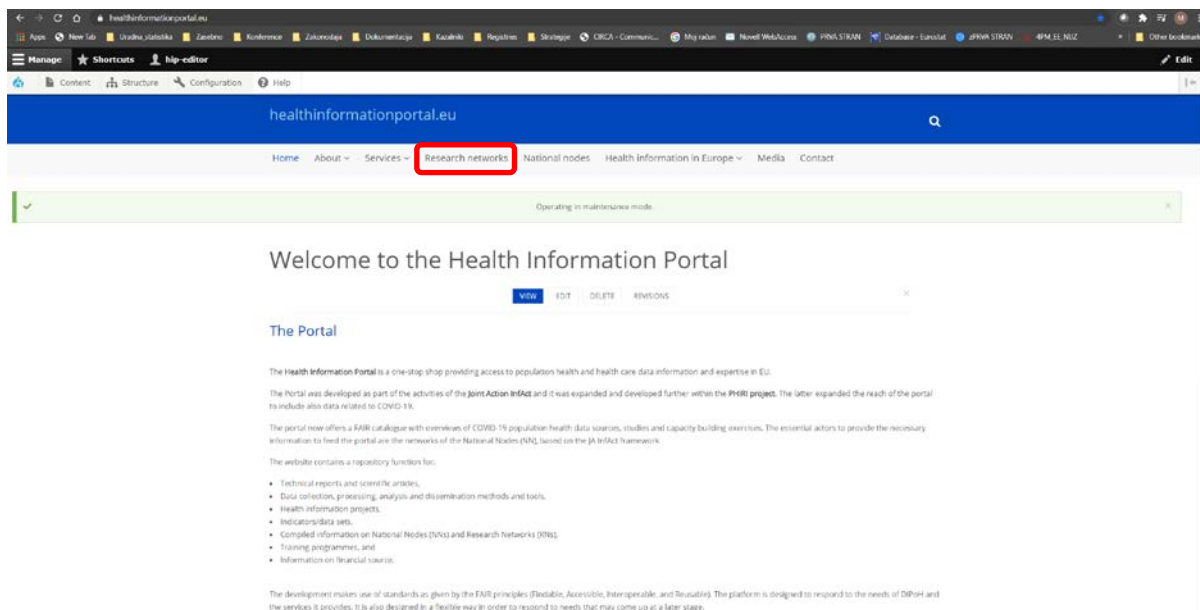
Click on the Research Network tab (red square above). You'll see the following screen.
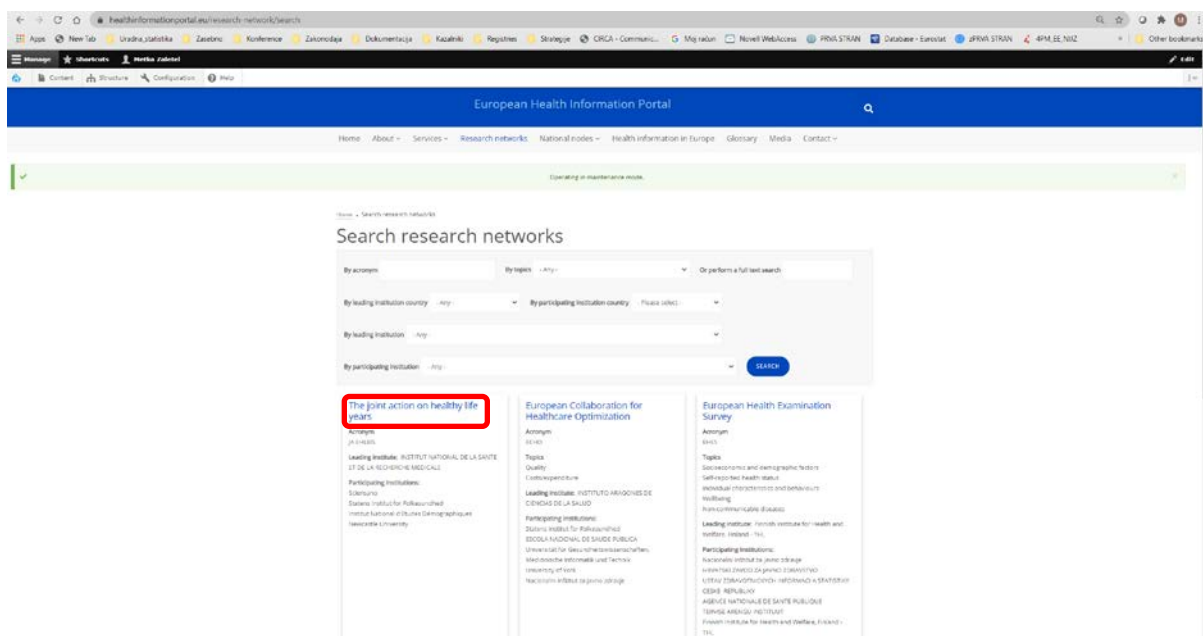
Select your research network and click on the name of the RN. You'll get a new screen with details on your RN. Please note that the coordinators might have already entered some basic information related to your RN into the system.
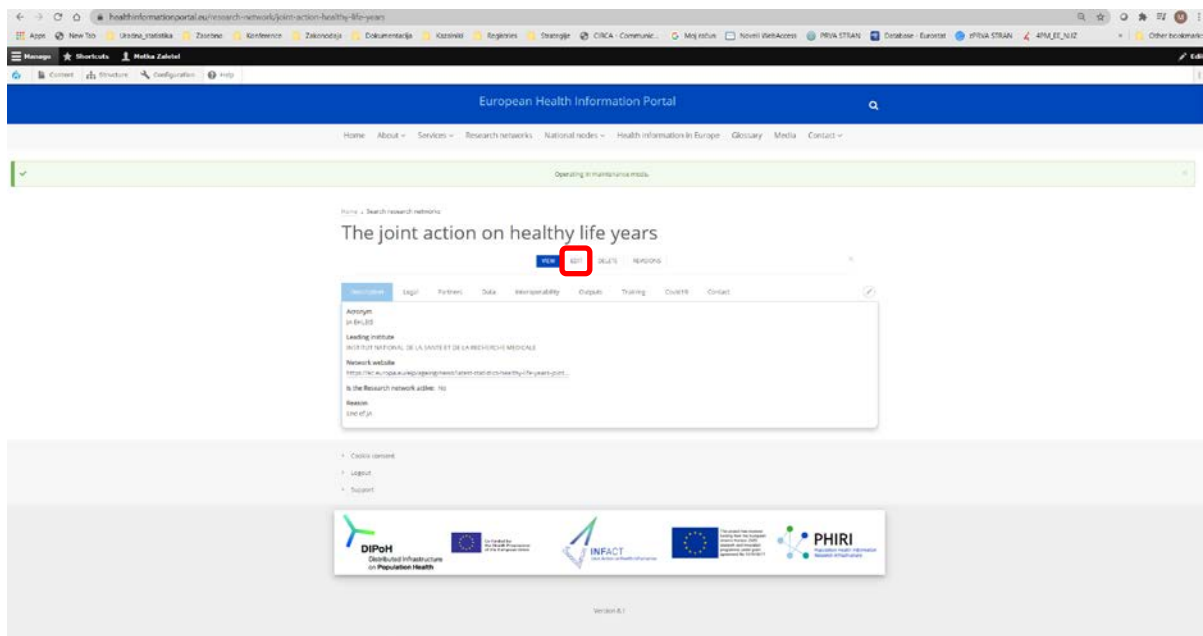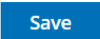
To add or edit the information, click on the small EDIT button, just below the name of the RN (red square above). You'll be immediately switched to the editing mode which looks like the screenshot below:
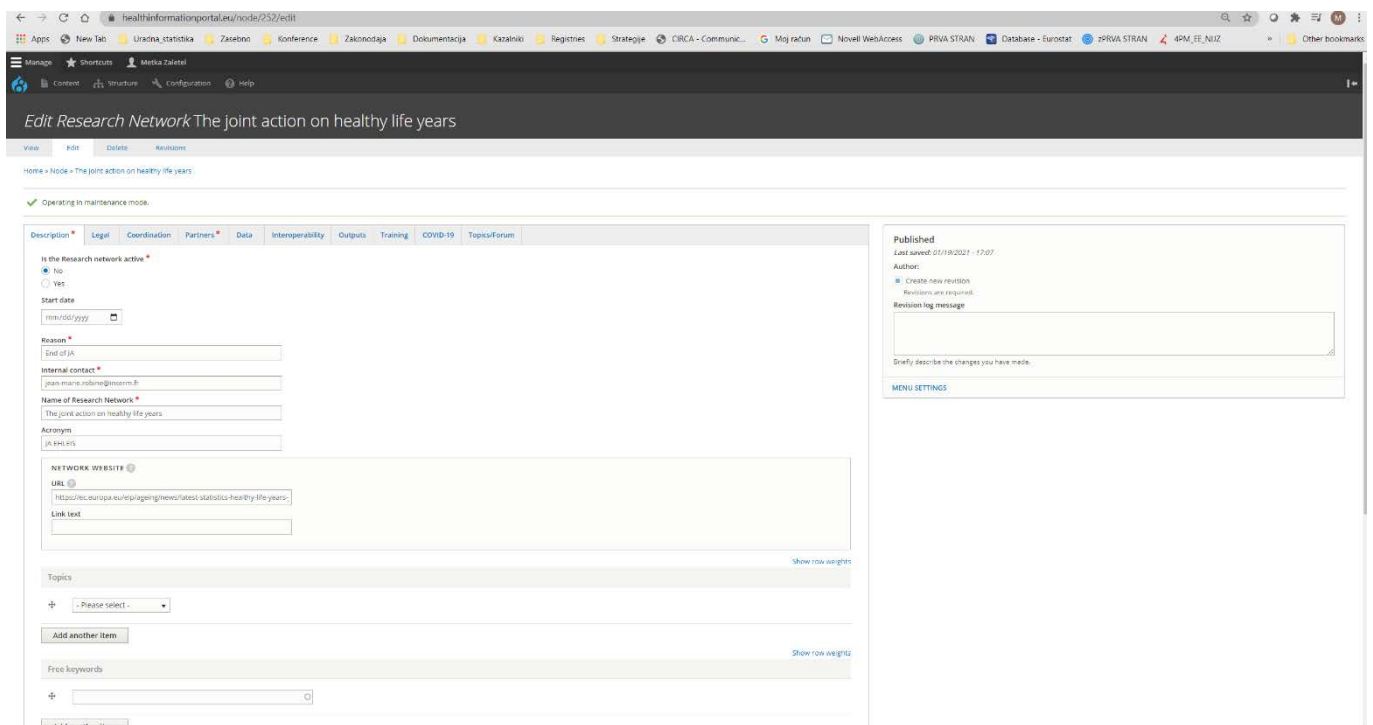
All the fields marked with *, are obligatory.

Please note that there is **Save** button at the bottom of each tab. Make sure to use it every now and then to prevent losing any data. The expiration time of the page is of one hour.

For your convenience, you can hover over the blue or grey question mark next to the different "field names" to have more explanation on the type of information that is requested.

Internal contact ? *

7. Topics - conceptual framework and keywords

The main advantage of the HIP is the search function and connectivity of the different content. This is possible only by proper tagging of the information in the HIP. Therefore, there are two powerful tools used for tagging the information.

1. <u>By using predefined Topics.</u> During InfAct, a conceptual framework consisting of a four-layers framework was developed to embrace the different topics related to health information at the aggregated level (see appendix). The Conceptual framework is now included into the HIP.

<u>Example:</u> When you are adding information related to a mortality registry, you will see the topic field.

You would then select:

- 1st level: Health Status
- 2nd level: Mortality
- 3rd level: Age-and-cause-specific mortality
- 4th 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

- 1st level: Health Status
- 2nd level: Mortality
- 3rd level: Maternal, perinatal and newborn mortality
- 4th 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 you to spend a little more time to properly tag your RN.

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.

2. Besides the conceptual framework, you will be able to tag the health information sources you are adding by using "common" keywords. The different material on the Portal will be searchable also by typing free key words in the search function of the Portal. If the key words connected to the e.g. health information source, match the ones written in the search tab, the health information source will be identified.

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 the RN is organised in ten tabs:

1. **Description** - Basic information on RN
2. **Legal** – legal aspects of RN activities
3. **Coordination** – information on leading institute and principal investigator
4. **Partners** – information on participating institutions, experts and contributors
5. **Data** – information on data collected by RN
6. **Interoperability** – basic information on IO
7. **Outputs** – list of outputs of RN provided elsewhere
8. **Training** – list of existing trainings (recordings, materials, etc) and trainings that could be offered by RN
9. **COVID-19** – information on activities related to COVID-19
10. **Topics/Forum** – any other information

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

The table with all the necessary information for a research network 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 on how to prepare and how to enter the information.

Some information might have been already pre-filled by the project coordinators:

- 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 the research networks. Please note that the names of the institutions are filled-in with their original names together with their country name (e.g. Finland - TERVEYDEN JA HYVINVOINNIN LAITOS) and not with their English substitutes. You can search institutions by any part of text, but our advice is to start search with the country name to narrow down the selection.

8.1.   Description of a RN

The table below shows the information required to complete the description of a Research Network.

Variable	Comment
Is the RN active? *	Yes/no. This information has been prefilled-in, but feel free to correct it.
Start date	Date when the activities of the RN first started.
Reason *	If the RN is not active, please provide the reason why the activities have stopped.
Internal contact *	Please provide the e-mail address of the person who will enter the majority of data and is able to reply to the questions from the coordinators.
Name of RN *	Already pre-filled in.
Acronym *	Acronym of the RN name.
RN website and link text	
Topics	Insert as many topics defined by the conceptual framework as you like. You can use any number of levels (1-4), but preferably 4. These topics will also be used for the data collected and the RN outputs.
Free keywords	These keywords will be also used for the data collected and the RN outputs.

Aim of the RN*	Brief description of the aims of the RN.

8.2. Legal

Short description of the legal aspects of the RN's activities.

Variable	Description and remarks
EU regulations	List of relevant EU regulations
GDPR/national binding regulations	List of national regulations binding the RN activities regarding personal data protection.
Legal status of network	Please provide any relevant information regarding the legal status of the RN.

8.3.   Coordination

The following variables are used to describe the HI sources:

Variable	Description and remarks
Leading institute	Leading institution of the RN
Principal investigator	Enter the name of the principal investigator. Please check first, if the person has already been entered into the system (try "Add existing person" and then type in the surname). If you haven't found the corresponding person, then go back (press Cancel) and click on "Add new person". You will have to provide first name, last name, e-mail address and institution.

If the information on leading institution has not been prefilled 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 institutions matching the search "Scien" will appear, then you select the right one.
- If you can't find the right institution, 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 partners (see next section).

8.4.   Partners

Variable	Description and remarks
Participating institutions*	Add as many institutions as you need. Press "Add existing institute" to check whether the institution has already been entered into the system. If you don't find it, then use "Add new institute".
Experts and contributors	Add as many experts as you need. Follow the same procedure as it is described for the Principal investigator.
Organisation of participation	Dropdown list: one representative from each country, several representatives from each country, other (and describe).
Related projects, network nodes	Add related projects (like: BridgeHealth is related to JA InfAct, etc).

8.5.   Data

The purpose of this tab is to provide an overview of the data collected in different ways by the RN. You can create as many data nodes as necessary. For each data node click on "Add new node". For each data node, you will have to enter the following variables:

Variable	Description and remarks
Accessibility of data – URL	Provide the address where data (or information on data) is available.
Procedure to access the data	Short description of how users can access the data (or simply provide link where the procedure is described)
Topics	Insert as many topics defined by the conceptual framework as you like. You can use any number of levels (1-4), but preferably 4.
Free keywords	Provide additional keywords.
Codebook(s)	Provide URL address where codebooks are provided (if any).
International classifications	If your datasets are using any international classifications, select it.
Type of data	Drop-down list: Survey/interview data, administrative data, population data, registry data, biobank/sample/specimen data, customer record data, observational study data, other.
Indicators	Please provide URL address where indicators are disseminated.
Aggregation level of data	For the datasets collected within RN, you can define what is the aggregation level of the data. You can select among - Centralized aggregated data - De-centralized aggregated data - Centralized microdata - De-centralized microdata
Link to data	For each aggregation level of data (see above) you can provide link where the data is available.

8.6.   Interoperability

The purpose of this tab is to provide basic information on interoperability.

Variable	Description and remarks
How is the data gathered from the partners?	Drop-down list: Data is not collected from partners, Partners send data in a certain format (e.g. CSV, xml),
How often do you collect data from partners?	Drop-down list: biannual monthly quarterly yearly Data is not collected from partners
How is the data transferred from partners to RN?	Drop-down list: Via mail, Via upload on secure system, Not applicable
How do you ensure data security for data transfer?	Drop-down list: digital certification data encryption Not applicable
How do you ensure data security for data access?	Drop-down list: digital certification data encryption Not applicable

8.7. Outputs

The purpose of this tab is to provide information on outputs of RN in all formats (reports, scientific publications, web portals, etc.). You can add as many different RN outputs as you want (simply click on "Add new output"). For each output, you have to fill in the following variables:

Variable	Description and remarks
Type of output	Dropdown list: scientific journal scientific peer-reviewed journal scientific peer-reviewed publication, report, country 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 (if you select "other", there is another field to describe)
Description	Brief description of the output
Link	URL address of the output
Topic	Insert as many topics as defined by the conceptual framework as you like. You can use any number of levels (1-4), but preferably 4.
Keywords	Free keywords

8.8. Training

The purpose of this tab is to provide information on already existing trainings and trainings that could be offered to interested groups. You can add several trainings (by clicking the button "Add new item"), and for each you have to fill in the variables in the table below, except for the possible trainings ("trainings that could be offered").

Variable	Description and remarks
Trainings already available	
Title	Name of the training
URL	URL address where the training or information on the training is available
Topics	Insert as many topics as defined by the conceptual framework as you like. You can use any number of levels (1-4), but preferably 4.
Free keywords	Free keywords
Training that could be offered	Short description of the content, conditions, length, … of the training that could be offered to different groups e.g. groups of experts, national nodes, other research networks, general public, etc.

8.9. COVID-19

The purpose of this tab is to provide information on relevance of work of the RN to Covid-19 related issues.

Variable	Description and remarks
Is the data collection relevant to Covid-19?	Mark the little square if the data collection is relevant.
Is the analysis relevant to Covid-19?	Mark the little square if the data analysis is relevant.
Is the capacity building relevant to Covid-19?	Mark the little square if the capacity building is relevant.
Is the interaction with policy makers / knowledge translation relevant to Covid-19?	Mark the little square if the interactions are relevant.

8.10.   Topics/Forum

The purpose of this tab is to provide any other information that has not been covered in previous tabs and to report whether there are platforms (forum, blog, etc) for communication among members.

Variable	Description and remarks
Are there any topics covered by the research network, but that could not be reported in the previous sections?	Dropdown list: Scientific peer-reviewed publication, report, country 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 (if you select "other", there is another field to describe)
If a forum or discussion platform is dedicated to the research network, please enter link here	URL address

9. When you finish your work

- Please make sure to save your work frequently.
- The information related to the RN will not be visible to the outer world immediately since the content might be reviewed first.
- You can come back at any time and edit your RN again.
- Editors will publish the information related to your RN which will then become visible on the Portal.

10. Appendices

10.1. The whole list of variables

Q	Item	Type of data
1	Contact	
	Is the RN active? *	Yes/no
	Start date	Date
	Reason*	Text
	Internal contact*	URL address
	Name of RN*	e-mail address
	Acronym*	Text
	RN website and link text	URL address
	Topics	Dropdown list
	Free keywords	Text
	Aim of the RN*	Text
2	Legal	
	EU regulations	Text
	GDPR/national binding regulations	Text
	Legal status of network	Text
3	Coordination	
	Leading institute	Text
	Principal investigator	Text
4	Partners	
	Participating institutions*	Text
	Experts and contributors	Text
	Organisation of participation	Dropdown list
	Related projects, network nodes	Text
5	Data	
	Accessibility of data	URL address
	Procedure to access the data	Dropdown list
	Free keywords	Text
	Codebook(s)	URL address
	International classifications	Dropdown list
	Type of data	Dropdown list
	Indicators	URL address
	Aggregation level of data	Dropdown list
6	Interoperability	
	How is the data gathered from the partners?	Dropdown list
	How often do you collect data from partners?	Dropdown list
	How is the data transferred from partners to RN?	Dropdown list
	How do you ensure data security for data transfer?	Dropdown list
	How do you ensure data security for data access?	Dropdown list
7	Outputs	
	Type of output	Dropdown list
	Description	Text
	Link	URL address
	Topic	Dropdown list

		Keywords	Text
8		Training	
		Title	Text
		URL	URL address
		Topics	Dropdown list
		Free keywords	Text
		Training that could be offered	Text
9		Covid-19	
		Is the data collection relevant to Covid-19?	Yes/no
		Is the analysis relevant to Covid-19?	Yes/no
		Is the capacity building relevant to Covid-19?	Yes/no
		Is the interaction with policy makers / knowledge translation relevant to Covid-19?	Yes/no
10		Covid-19	
		Are there any topics covered by the research network, but that could not be reported in the previous sections?	Text
		If a forum or discussion platform is dedicated to the research network, please enter link here	URL address

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

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			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

			Care
			Patient experience
			Patient safety
			Premature/avoidable mortality
			Reproductive, maternal and newborn health
			Vaccination coverage