MS26: European Health Information Web Based Platform

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Executive summary

This document is Milestone number 26 of the work package 7 (WP) 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 policymaking.

This document describes the web based platform which will developed within InfAct as a basis for the Health Information Research Infrastructure. The platform will be the gateway for potential users to make use of the services of the Research Infrastructure. These include the catalogue for population health data, tools, experts, and guidelines; capacity building and trainings information; Innovation in health information tools and methodologies; and decision-making support. A description of the different pages of the platform are provided, as well as, the different subsections in each page.

InfAct: European Health Information Web Based Platform

I. Task description

Within work package(WP)7, task 7.4 is to prepare a functional design and develop a website providing the support platform for a future Health Information Research Infrastructure (RI). The website will contain a repository function for:

- technical reports and scientific articles,
- data collection, processing, analysis and dissemination methods and tools,
- health information projects,
- indicators/data sets,
- compiled information on National Nodes (NNs) and Domain Specific Networks (DSNs),
- training programmes, and
- information on financial source.

Some of these elements are collected in the framework of InfAct. WP7 is responsible to prepare the backbone and launch the basis of the web based platform. The different WPs of InfAct, WP 5-10, provide the content for the web based platform using information from previous projects, national and international experiences.

The development makes use of standards as given by INSPIRE[1] and the FAIR principles (Findable, Accessible, Interoperable, and Reusable). The platform is built in a way that each network or project is responsible to update its information on the web based platform. For sustainability, possible automation using a scraping tool is evaluated.

The web based platform is designed in a way to respond to the needs of a future Health Information RI, but is in a first phase developed to host the documents produced by InfAct. It is also designed in a flexible way in order to respond to needs that may come up at a later stage.

II. Users of web based platform

The primary users of the web based platform are:

- Researchers in the public health sphere: researchers in public health and population sciences as well as epidemiologists, statisticians, pharmacist, health professionals, data scientists, ethicists, sociologists etc. Data providers and developers in various health information domains.
- Policy and decision-makers in national and international organisations.
- Other public active in the field of public health.

The secondary users of the web based platform are:

- Non-governmental organisations and civil societies in the public health and healthcare area.

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[1] https://inspire.ec.europa.eu/

- Media and journalists.
- Students and educational organisations of population health and health services.
- General population.
- Industry and private sector.

III. Structural representation of platform

The homepage is divided into six sections as represented in figure 1. On the homepage include a news section, announcements and job opportunities, and a general search function.
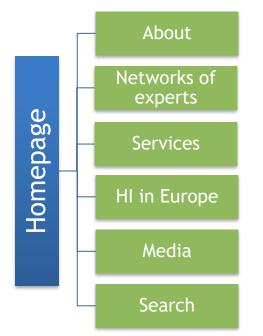

Figure 1: Structure of the homepage. HI = health information

A. About

The About section describes general information about the future Health Information RI including its mission, vision and objectives. It can be described as a "*who we are*" section. The governance structure of the Infrastructure is described and the partners (institutions) involved in the set-up of the Infrastructure are listed with their contact information. A summary describes the activities (figure 2).

Figure 2: Description of About section.

B.   Networks of experts

This section describes the various research networks that are involved in the Health Information RI.

The RI will operate through two types of nodes or networks (figure 3):

1. The national nodes. These are located in EU countries that are members of the RI. Each member of the RI will designate an institution that will provide national health information and interact with the different entities of the RI. The national node will thus have a dual role as a national health information provider and health information coordinator. The national nodes work on cross-cutting issues related both nationally and internationally. The number of national nodes is fixed (one node per MS). Information could be provided by national public health institutes, research institutes, or health organisations.

2. The domain specific research networks. These are specific to health topics and respond to current priorities and projects at EU level. The domain specific networks carry out deep analysis in areas for which capacity does not always lie at national level. They can liaise with national nodes providing guidance on how to collect and analyse data at national level, and through this, harmonise activities. In case of multiple networks within the same specific research domain, a node will be elected to take on the coordinating partner role with the RI representing that specific domain. The numbers of domain specific nodes are variable. Individual EU countries may opt to coordinate one or more domain specific nodes.

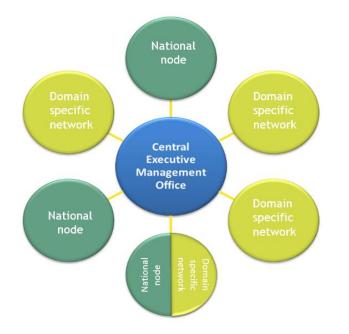Being an institute within a national node does not prevent from joining a domain specific research network.

Figure 3. Research Infrastructure organisational structure

The descriptions is organised in a systematic way in order to provide the same standardised information about each network (figures 4 and 5).

National nodes description and information will be available on the website in national language(s) and in English. In the national nodes, relevant information can be stored about the national representatives, include country reports and possibly a description of health information sources in this country. Research networks will provide more information including metadata, and contact information. WP 7.1 are developing the content for this section of the website. The development of the structure of national nodes and network of experts will be done in collaboration with WP8, namely T8.4. Further work on coordination of networks will later on be covered by T8.4. Possible information available on the platform regarding the National Nodes:

- Home: country of National Node with main contact person
- Partners in country:
    - List of institutions working on health information in the country (with links to their homepages)
    - List of responsible persons and experts within institutions / within domains
- Sources of health information
    - Links to results, data, information, relevant projects, etc.
    - Link to national health reports (or upload of the document)
    - Link to sub-national reports
    - Links to networks of experts where relevant
- News/events on health information in the country
- Get involved /join us section

Suggestion of the information regarding the domains specific research network or node on the platform:

- Description of the network (topic covered, aims, purpose, etc)
- Coordination and responsible institutions / experts
- Partners
  - List of institutions (with links to their homepages)
  - List of experts (with links to their contacts)
  - List of relevant international organisations (with links to their homepages)
  - Related projects (with links to their homepages)
- On-going work (links to work under development; possible to restrict the views of the content) with repository of documents (related to on-going work)
- Tools and publications
  - Results from different projects (from the same or overlapping domain)
  - Repository of documents (finished results)
  - Tools, data and information
  - Legislation (if relevant)
  - Guidelines
  - Presentations, infographics, video presentations etc
- Forum or site for discussion, exchange of views, etc.
- Links to other projects, network nodes, etc.
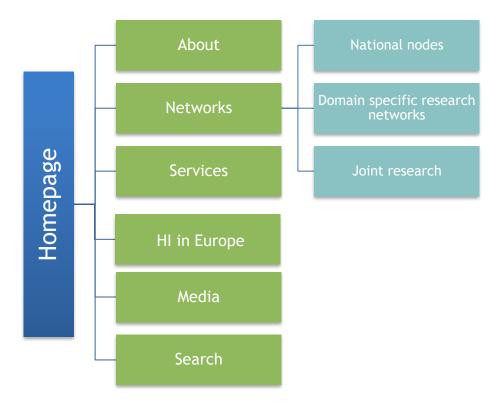- Event and news
- Get involved/join us section

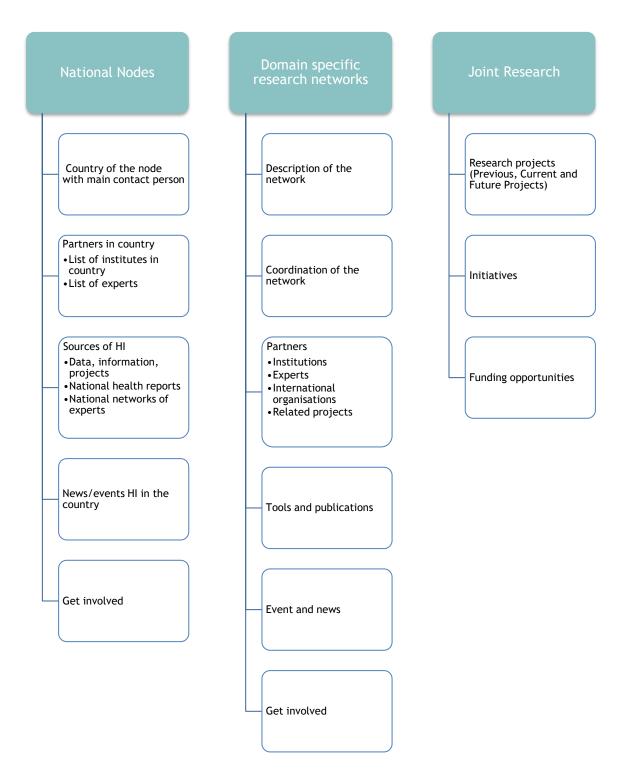Figure 4: Networks section from homepage

Figure 5: Networks section with national nodes and domain specific nodes.

C. Services

The RI will provide large-scale, integrated and sustainable services to population health sciences through four main services:

1. A **one-stop shop**: the RI will be a library providing the data catalogue on health and health care data and their meta-data as well as methods. It will facilitate access and (re-)use of European data for research on the health of populations and on health care systems.

2. Investing in **innovation** in health information development for population health research to support health researchers use pan-European data in a distributed way, link different data sources and make their research FAIR and ELSI compliant.

3. Providing **capacity building** to promote interoperability and tackle health information inequalities: learning about management of data on population health and health care starting from the phase of designing data collections to analysis, reporting and preservation. Training of the health research community involves both the data producers and data users.

4. Assisting the health research community in developing methods for **knowledge translation research** to support decision-making processes. This is the return of investment to society improving the health of the European citizens and increasing the efficiency of our health care systems.

In order to provide the services of the RI, the platform will take on specific activities and functions(figure 6).
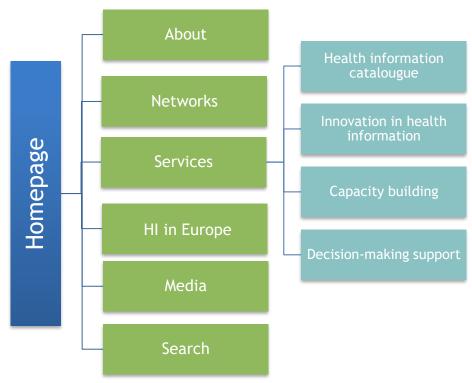

Figure 6. Overview of all services described in the web based platform.

1. Health information catalogue (WP5,7 and 8 outputs):

The first service provided by the RI is a one-stop shop for EU health information research. This is presented in the form of a catalogue of the networks (including the NN and the DSN), different experts in health information domains, links to different databases, and a list of tools and guidelines available on the web platform (figure 7).
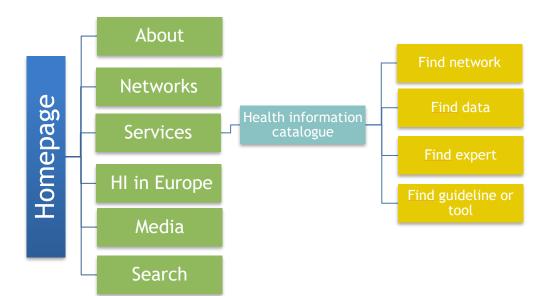

Figure 7. The catalogue includes information for all topics included in the services of the Research Infrastructure

2. Supporting actions for innovation in health information research

The second service, actions are set out to support innovation in health information research. These combine the as a first stage the outputs of InfAct WP9 and 10, from which various services can be deduced. The following aspects will be part of the service for innovation for health information as shown in figure 8:

a. Innovative use of data sources (road map)
b. Health indicators estimated from linked data/advanced statistics
c. Generic methods
d. Development of new methods
e. Best practices/Inspiring examples (impact in practices)
f. Computing services
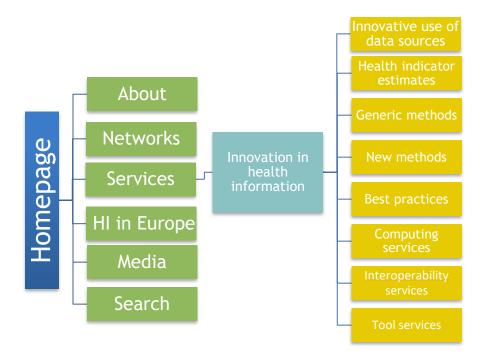g. Interoperability services
h. Tools services

Figure 8. Platform activities for the RI service regarding innovation in health information research.

3. Services related to capacity building

The services provided by training can be organised in a sub section under capacity building services as shown in figure 9.
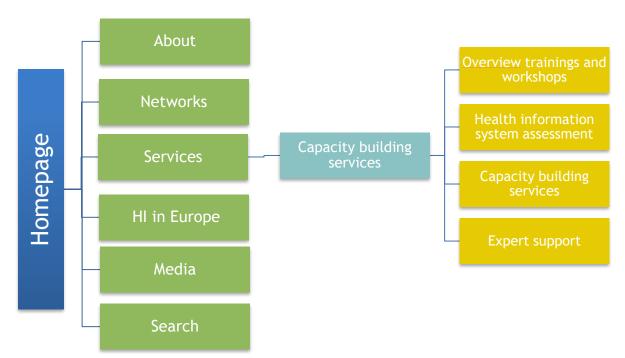

Figure 9. Capacity building services platform activities.

4. Decision-making based on evidence based research

The last services provided by the RI are related to decision-making. The section is divided into two sections: policy recourse and policy processes, as shown in figure 10.
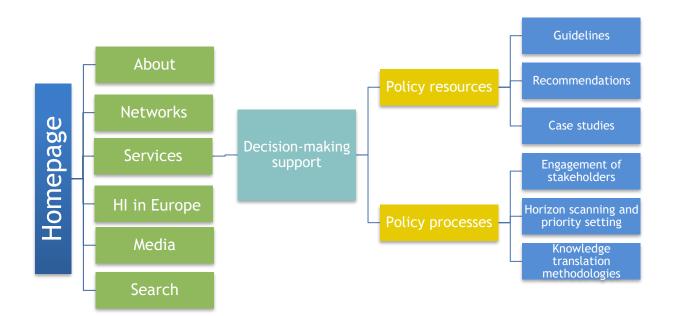

Figure 10. Policy support sections provided by the platform.

D. Health information in Europe

The section health information in Europe lists an overview of international organisations working in health information and provides hyperlinks to these organisations such as the organisations under the European Commission, the OECD, WHO Europe, etc. Also other relevant projects or initiatives could be reported here e.g. TO-REACH, the European Open Science Cloud, other RIs etc. Under this section a link to the networks section of the homepage (NN and DSN in figure 4) is also available.
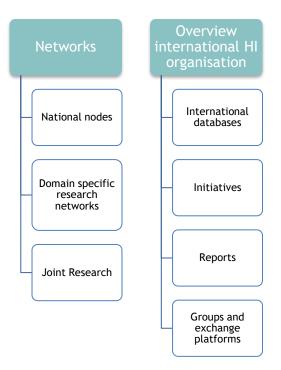
Figure 11: Health information in Europe section including networks and international organisations sections

E.   Media

This section provides information on news about the RI, contact forms, social media, layman reports for journalists, job opportunities and hyperlinks to possible communication between the partners of the RI.

F.   Search

This is general function on the homepage. Searching in this function provides links to all locations where the keywords appear.