

Report

JPI HDHL workshop Data sharing & Data stewardship

Monday 13th of February 2017 - Vienna (Austria)



1. Aim & Background

On the 13th of February 2017, the Joint Programming Initiative Healthy Diet for a Healthy Life (JPI HDHL) organised a workshop to explore the scope of the new ambitious Joint Action focusing on Data sharing & Data stewardship.

The aim of this workshop was to identify the next steps that JPI HDHL should take to further stimulate open science and improve the circulation and reuse of scientific data in the field of nutrition and health. The JPI HDHL coordinates research on the impact of diet and lifestyles on health. This research significantly contributes to the construction of a fully operational European Research Area for the prevention of diet-related diseases. In this context, the sharing of knowledge, research output and data is of high importance for the JPI HDHL to address its aims.

2. Participants

Representatives from related Research Infrastructures (RI's) and initiatives, JPI HDHL Management Board members, funders, scientists and a few representatives from industry attended the workshop (see annex I), which resulted in the presence of a wide range of expertise and different perspectives.

As there are already several initiatives working on this topic, it is important that the outcome of the workshop will connect as much as possible with existing infrastructures and policy developments. Therefore, the representatives from related Research Infrastructures drafted a 2-pager about their initiative/ Research Infrastructure, which were published on the workshop webpage in advance.

3. Group Decision Room

JPI HDHL used the Group Decision Room method to host an interactive workshop session. In this method, small discussion groups (3-4 persons per group) discussed together a number of questions. The responses of each group were submitted on a laptop and subsequently plenary discussed.

During the group decision room the role of the JPI HDHL, the needs and gaps of the field and the next steps that JPI HDHL could take, were discussed. Below, the main outcomes of this session will be described.

3.1 Role of JPI HDHL

The domain of Nutrition and Health is complex and investment in data sharing and data stewardship is needed to interconnect different research areas and to make data widely accessible. Data sharing enables better exploitation of existing research (data), fosters collaboration and stimulates the development and testing of innovative ideas. JPI HDHL funded already many different projects, which makes it possible to interconnect different research areas within the field and encourage collaboration between researchers of different countries.

JPI HDHL aims to connect research with the needs of end users and to transfer research results to the end users. JPI HDHL should invest in data sharing and stewardship with this mind set. Another aspect that was discussed is the necessary funding to keep RI's running and up to date and to enable researchers to use the RI facilities. It was discussed if the role and responsibility of the JPI HDHL – and

connected funding agencies – is to support RIs in such way or that (in the end) this should be paid through institutional funding or the projects that make use of RI facilities.

3.2 Needs, gaps & impact

Marketing and education to raise awareness

Marketing and education could be essential to stimulate researchers to increase the usage and visibility of RI's. It is important to make researchers more aware of the benefits and possibilities of using RI's. Ideas to increase awareness and knowledge of researchers are:

- To fund a case study (project) that uses data from merged datasets in order to show what can be achieved with such an approach;
- To use case studies in education and training to show the added value of merged datasets.

Another way to stimulate researchers is to think of incentives to make the use of shared/FAIR data and RI's more attractive. An example of such incentive could be an index to describe the impact of data sharing of an individual researcher.

Besides raising awareness of researchers, it is also important to get more attention for this topic on a policy level and to explain to policy makers the importance of data standardization and data sharing.

Harmonization of data

Another need that was identified is the harmonization of data. It was indicated that harmonization of data is often difficult due to a lack of standardization (for example in the used definitions and the used methods) and due to the quality of the available data. To really create impact, the primary data should be of better quality.

ENPADASI published common methodological definitions and sampling methods that should allow researchers to reproduce the conducted research. These definitions are however subject of change and have to be updated; furthermore the developed definitions do not cover the whole scope of JPI HDHL like qualitative social science data.

Training on harmonization and standardization of research data and describing the data is crucial to improve the reusability of data. Creating a language that everyone understands across Europe is not only important for the food domain but broader and not only for researchers but also for policy.

Stimulate the use of ENPADASI and link existing RI's

It is important to stimulate the use of existing RI's in the field. Participants indicated that strengthen and linking existing initiatives on national and international level will create support and awareness. The connection of the nutrition and health field with the food production and sustainability area should be taken into account. Currently this connection is insufficient and even absent in some countries. A good interplay between ESFRI, existing Infrastructures and JPI HDHL is important to move forward. Existing RIs should help to design the needed RI(s) for nutrition and health. Supporting the use and out role of products developed by ENPADASI and implementation/further development could be a starting point. The general question of suitable business models for research infrastructures and related tools/services should also be addressed.

3.3 Concrete actions for JPI HDHL

The last part of the workshop focused on concrete next steps that JPI HDHL could take to further strengthen open science and stimulate the reuse of data. Suggestions for both funded and non/low funded actions were included. The following suggestions received the most votes:

1. Funding action: Training on harmonization/standardisation of data to enable and stimulate data sharing in close collaboration with existing RIs. More ambitious would be to develop (ISO) standards for data in the area of Nutrition and Health to ensure that the basis is strong enough to truly benefit from investments to combine datasets.
2. Small investment: Knowledge hub that focusses on existing standards and initiatives on data standardisation/ harmonization relevant for research in nutrition and health. The development of an overview of initiatives and standards of collecting data and applying methods that relate

to the research area of nutrition and health and the promotion of the use of these initiatives and standards. Follow up investment should be on the development of standards that are lacking.

3. Formal collaboration of the JPI HDHL with ESFRI to get food and nutrition on the agenda. A note made by the participants is that this will not bring the funding needed on the table, but will support in getting the nutrition & health RI higher on the agenda within the EU member states as well as on the level of the EC.
4. A call or funding of pilot studies where the research question will be answered with existing data/ a combined dataset. Publication of case studies should show the added value of data sharing.

Based on the suggestions of the participants and the discussions during the workshop it can be concluded that harmonisation and standardisation of data is an important next step to stimulate data sharing and open science.

3.4 Initiatives & stakeholders to connect with

- WHO, FAO, EC (DG RTD, DG Santé, JRC)
- ESFRI
- ESFRI biomedical infrastructures: ECRIN, BBMRI, EATRIS, ELIXIR and MIRRI
- Connect to Codex Alimentarius (harmonized global food standards)
- ISO (organisations that set up standards)

ANNEX 1

List of participants

Name	Surname	Organization/ Research Initiative
Peter	Abuja	Medical University of Graz, Austria
Andreas	Aeschlimann	Management Board JPI HDHL Switzerland
Wolfgang	Ahrens	Scientific Advisory Board member JPI HDHL
Maud	Alligier	European Clinical Research Infrastructures Network (ECRIN)/ European Nutritional Phenotype Assessment Data Sharing Initiative (ENPADASI)
Rafael	Andrés, De	Management Board JPI HDHL Spain
Wilke	Ansem, van	Organisation for Health Research and Development (ZonMw), The Netherlands
Erika	Ax	Management Board JPI HDHL Sweden
Martijntje	Bakker	Vice chair management Board JPI HDHL, The Netherlands
Martine	Batoux	The French National Research Agency (ANR), France
Serena	Battaglia	European Clinical Research Infrastructures Network (ECRIN)
Nastasia	Belc	Management Board JPI HDHL Romania/Metrofood RI
Johannes	Bender	Federal Office for Agriculture and Food (BLE), Germany
Chris	Birt	Stakeholder Advisory Board member JPI HDHL
Jildau	Bouwman	European Nutritional Phenotype Assessment Data Sharing Initiative (ENPADASI)
Pamela	Byrne	Chair Management Board JPI HDHL Ireland
Steve	Canham	European Clinical Research Infrastructures Network (ECRIN)
Kristina	Foterek	National Aeronautics and Space Research Centre (DLR), Germany
Sanne	Geel, van	Organisation for Health Research and Development (ZonMw), The Netherlands
Petra	Goyens	European Commission
Rob	Hooft	ELIXIR, infrastructure for Data in the Life Sciences
Minna	Huttunen	Management Board JPI HDHL Finland
Monika	Kocmanová	Management Board JPI HDHL Czech Republic
Rosario	Lombardo	The Microsoft Research - University of Trento Centre for Computational and Systems Biology (COSBI)
Mary-Jo	Makarchuk	Management Board JPI HDHL Canada
Annamaria	Marzetti	Ministry of Agricultural, Food and Forestry Policies (MIPAAF), Italy
Oliver	Mayer	Management Board JPI HDHL Austria
Bruce	McCallum	Management Board JPI HDHL New Zealand
Katheryn	McPherson	Management Board JPI HDHL New Zealand
Jean Michell	Oppert	Scientific Advisory Board member JPI HDHL
Giuditta	Perozzi	CREA-NUT, Food & Nutrition Research Centre, Italy
Giovina	Ruberti	Management Board JPI HDHL Italy
Christophe	Sauce	Danone Nutricia Research
Nadia	Slimani	International Agency for Research on Cancer (IARC)
Pieter	Veer, van 't	Food, Nutrition and Health Research Infrastructure (FNH-RI)
Jolien	Wenink	Project Manager JPI HDHL Netherlands
Kurt	Zatloukal	Biobanking Biomolecular Resources Research Infrastructure (BBMRI)
Karin L.	Zimmerman	Food, Nutrition and Health Research Infrastructure (FNH-RI)
Peter	Zock	Unilever Foods Research & Development