BBMRI.nl & Health-RI expert meeting 2021: The next step in making health data available for research.

#1 – Collecting FAIR data

Health-RI and BBMRI.nl organised a new serie of expert meetings to discuss the next step in making health data available for research. This expert meeting series is a continuation of the expert meetings series of 2020 that focussed on different practical approaches to make health data available for scientific use. On Thursday, September 9th, the first session took place. The meeting focused on the FAIR principles, the value of collecting FAIR data, and in particular various methods and standards how to achieve this. The meeting, chaired by Jan-Willem Boiten (Health-RI), was attended by forty-seven experts affiliated to public and private institutes, representing a broad spectrum of knowledge and expertise.

Prof. Wiro Niessen (CTO Health-RI, ErasmusMC) introduced the mission of Health-RI: Building an integrated health data research infrastructure accessible for researchers, citizens, and care providers. Facilitating and fostering the optimal use of knowledge, tools, facilities, health data and samples to enable a learning healthcare system and to accelerate sustainable and affordable personalized, data-driven, health. Health-RI aims to realise these goals through implementation of three overarching workflows implemented in a hub and nodes model:

1. Making health data available in a FAIR manner
2. Data discovery, access & governance
3. Data analysis & learning

The introduction was followed by a presentation of Rob Hooft (Health-RI, DTL) entitled 'Collecting Data FAIR: A Why and How'. Rob highlighted why making data FAIR is crucial to accelerate the benefits of research for patient care. "Data munging is proven to take 80% of the time, leaving only 20% for analytics." When FAIR is considered and implemented at the start of data collection, it will save considerable time and effort at a later stage when the data are used and shared. Standards are available to FAIRify (clinical) terminology, such as the globally acknowledged SNOMED-CT and ICD-10 standards. These and other standards as well as relevant literature how to FAIRify your data can be found below and more will follow during the next expert meetings. Rob's presentation concluded: "Starting the FAIR journey is doable!"

Margreet Bloemers (ZonMw) presented about 'FAIRifying your data from a funders' perspective. ZonMw is committed to increase the impact from research output by improved FAIRification of data and data management. ZonMw fulfils various roles in FAIR data management.

- First to set the requirements for grant proposals and awarded projects to deliver 'FAIR' data.

- Second, to support the development and community of specific FAIRification workflows, including the contribution to this expert meeting series.
- Third, as a consortium partner (for instance in a European Antibiotic Resistance Project) to implement the collected knowledge and insights from the FAIRification workflow into practice.

Importantly, the national Health-RI COVID-19 observational Data Portal was highlighted as a fundamental show case to prove the added value of FAIRification of data to allow for a nationwide response to an emerging health threat. Finally, Margreet called for 'more data stewards'.

The second expert meeting will be held on September 23rd. This meeting, chaired by Jeroen Beliën (Amsterdam UMC), will focus on Data Findability and Linkage. Sabine Siesling (IKNL) and Edwin Cuppen (Hartwig Medical Foundation) will present their experiences and the latest methods and standards how to enable findability and linkage of your data. Registration can be done here. If you have any questions or comments, please contact Robin Verjans (robin.verjans@lygature.org).

Literature:

1. G. Strawn, "75 Years of Astonishing Evolution of IT: 1946–2021," in IT Professional, vol. 23, no. 3, pp. 21-27, 1 May-June 2021
2. Peter Wittenburg; From Persistent Identifiers to Digital Objects to Make Data Science More Efficient. Data Intelligence 2019; 1 (1): 6–21.
3. Brodie, M.L. (2015). Understanding Data Science: An Emerging Discipline for Data Intensive Discovery. DAMDID/RCDL.
4. Data Scientist Report 2017.
5. Wilkinson (2016). The FAIR guiding principles for scientific datamanagement and stewardship.

Standards & templates:

a) SNOMED-CT: comprehensive clinical terminology standard mapped to international standards.
b) RDA DMP Common Standard for Machine-actionable Data Management Plans
c) FAIR Data Maturity Model: specification and guidelines, June 2020.