19 October 2018 – buv/mc

Workshop of 15 August 2018 on

Longitudinal Studies - Data Interoperability

1. Background/Context

In line with the SNSF Open Research Data (ORD) policy, all longitudinal studies were mandated to establish a DMP, to make their data accessible to other researchers, and to actively search for collaborations. In view of the next multi-annual plan, the SNSF is looking into possibilities to strengthen the impact of cohorts on research of high public health relevance and to reduce the amount of funding for redundant infrastructures. In this context, the SNSF organized a workshop on 15 August 2018 on data interoperability. The aim of the workshop was to lay emphasis on the discussion on how SNSF funded longitudinal studies can assure data interoperability and data sharing, as well as on best practices for structuring and maintaining data archives and the question on whether cohort studies can profit from shared infrastructures.

2. Programme of workshop

In the workshop the participants were invited to reflect on future challenges for longitudinal studies regarding

•   Data harmonisation and interoperability
•   Shared data archives and infrastructures
•   Best practices for structuring and maintaining data archives

The following national and international keynote speakers contributed their view of the subject.

Part 1 Data sharing
Hugues Abriel, "Welcome address"
        Presented the history of the SNSF LS programme
Matthias Egger, "Past to future"
        Vision of the SNSF: a coherent national data platform for biomedical research
Ayşim Yılmaz, "Open research data policy of the SNSF"
        Presentation of the new SNSF ORD policy
Bruno Ledergerber (CH), "Longitudinal studies: from local to global data sharing"

Jens Lundgren (DK), "Precision medicine: need to construct datawarehouse/lake" (presentation not available)

Part 2: Data standardization:
Kari Hemminki (D/Sweden) "Practical examples of pros and cons of pooling large datasets"
Dipak Kalra (UK) "Scaling up the reuse of health data for research: learning from IMI projects"

Part 3: Data infrastructure:
Christian Lovis (CH, SPHN) "Health data interoperability: hopes and challenges in the Swiss context"
Michael Koller (CH) "The IDEAL project: IDentifier Linkage between patient-centered research and healthcare providers"

Part 4: Implications for SNSF funded longitudinal studies
The participants discussed in separate groups on Data sharing, data interoperability, shared infrastructure and the role of research institutions, SNSF, Swissuniversities/ETH, Academies, others.

The results from the workshop will be integrated in the preparation of the SNSF pluri-annual plan for 2021-2024.

Programme with list of keynote speakers and participants.