



EBRA Data Sharing Workshop Report

“Everything You Always Wanted To Know About Data Sharing”

On the 17th of March 2021, the European Brain Research Area (EBRA) workshop “Everything You Always Wanted to Know About Data Sharing” took place virtually from 9 am to 1 pm.

The day started with an introduction of the EBRA project (Frédéric Destrebecq, Executive Director, European Brain Council - EBC) and of EBRA’s clusters (EPICLUSTER, PSMD-CLUSTER, TRISOMY21-CLUSTER, PREMOS-CLUSTER and ECIB-CLUSTER). Dr. Hella Lichtenberg (project manager, ERA-NET Network of European Funding for Neuroscience Research - NEURON, German Aerospace Center - DLR Project Management Agency – PT, Germany) and Dr. Martin Telefont (Head of the Human Brain Project - HBP - Partnering environment, École Polytechnique Fédérale de Lausanne - EPFL) then addressed data sharing issues in brain research. They highlighted that brain research is conducted across different sites and institutions, and relies on the exchange of complex protocols, materials, and expensive machinery to generate data. That requires data sharing, also for future utilization of data and results, and solid ethical and legal instrumentation. Dr. Damian Okaibedi Eke (Research fellow, De Montfort University) closed this first part by providing deeper insight into the legal and ethical considerations in data governance.

During the second part of the workshop, examples of data sharing services were presented by representatives from the HBP and EBRAINS. Prof. Jan Bjaalie (Institute of Basic Medical Sciences, University of Oslo, and Infrastructure Development Director and leader of the Neuroinformatics Platform of the HBP) spoke about reproducible and transparent neuroscience, and how EBRAINS services can be used for publishing research data. Prof. Philippe Ryvlin (Head of the Department of Clinical Neurosciences, Centre Hospitalier Universitaire Vaudois; Lead of HBP Medical Informatics Platform - MIP; co-lead of HBP Human Intracerebral EEG Platform - HIP) introduced the clusters to the Medical Informatics Platform (MIP). The virtual brain was presented by Prof. Petra Ritter (Charité University Medicine Berlin; Director Brain Simulation Section, Charité and Berlin Institute of Health; Lead Virtual Brain Cloud EBRAINS Facility Hub; Lead Co-Design Project The Virtual Brain in SGA2) as an example of brain Simulation as a Service. This 2nd session was closed by Dr. Viktor Jirsa (senior researcher at the Centre National de la Recherche Scientifique – CNRS - in France and Director of the INSERM Institut de Neurosciences des Systèmes - UMR1106 Inserm - at Aix-Marseille University) who presented a simulation-based method targeting Epilepsy as an example of running simulation on top of clinical data.

During the workshop, two roundtable discussions - moderated by Steven Vermeulen (CIIO EBRAINS) - took place. During these discussions, the EBRA clusters had the opportunity to provide feedback and ask questions, to share their experience in data sharing and to address any further issues on the subject.

In general, the EBRA clusters found it interesting to see that solutions like EBRAINS are being developed. However, they did highlight that there are currently more important issues to solve than the technical ones. The main data sharing issues raised by participants were:

- Data sharing is a complicated issue in terms of the legal and regulatory aspects.
- There are **different perspectives on the feasibility of data sharing**: Data sharing means a large increase in administrative work for researchers. However, from the funders’ perspective, it helps clarifying the roles, secure the researchers and protect confidentiality of data.



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- A set of easy-to-follow data sharing guidelines should be created.
- **Researchers need to know WHY they should share their data:** Currently, there is a lack of motivation to share data. Therefore, a change in the culture around data sharing is generally needed. The value of sharing data needs to be better identified and differences in practices between neuroscience fields (e.g., between preclinical and clinical data) need to be addressed. Incentivising data sharing within the open science concept has also been raised.
- **Researchers need to know HOW they can share THEIR DATA:** Nowadays, researchers find it difficult to navigate existing platforms and use the data. In addition, there is a conflict between data sharing and the concept of open science vs. GDPR and the guarantee to process and share data anonymously and ideally, a baseline and/or standard procedure would need to be developed.
- **Researchers need to know WHICH data they should/can share:** There are different perspectives on this which do not just fall into the pre-clinical - clinical space but are based on research traditions based on sampling techniques and community membership.
- **Researchers need to know HOW they can re-use old data available on existing platforms:** Researchers find it difficult to navigate existing platforms and re-use existing data. To re-use existing data, the quality of the shared data needs to be assured and the scientific validity needs to be guaranteed.
- **Researchers need to know HOW they can be supported during the data sharing process:** The number of people that need to be involved in data sharing within institutions is increasing. This sometimes creates more problems than solutions and results in a diffusion of responsibility. To make data sharing happen, we should provide researchers and research institutions with enough money/funding and other resources (e.g., dedicated staff). Also, clear leadership is needed to drive data sharing in research.
- **Researchers need to know WITH WHOM they will/can share their data:** Data sharing needs to happen not only at EU level but also at national and international level. Initiatives at all geographical levels need to be created.

Based on the input of the final discussion, Dr. Martin Telefont closed the meeting by concluding that data sharing is not a one-solution-for-all requirements issue, but rather, needs different platforms and approaches for various scientific areas and applications. For instance, the pre-clinical vs clinical research addresses different challenges. Thus, a broader discussion is often necessary, taking into account local/area specific constraints and opportunities. A central issue is the quality of data/results and their maintenance. Furthermore, it was concluded that guidance, rather than more guidelines, is called for, which requires experienced people and accessibility to reduce entry barriers.