

EBRA workshop
**“Everything you always
wanted to know about
data-sharing”**

March 17th, 9 am - 1 pm



I. THE EUROPEAN BRAIN RESEARCH AREA (EBRA)

The EBRA consortium including the European Brain Council (EBC), the Human Brain Project (HBP), the Network of European funding for Neuroscience research (NEURON) and the Joint Programme – Neurodegenerative Disease Research (JPND), was created to respond to the H2020 call entitled “Coordinating European brain research and developing global initiatives”. The project aims at:

- Facilitating efficient collaboration, communication and operational synergies.
- Fostering alignment and better coordination of research strategies across European and global brain initiatives.
- Facilitating the emergence of research projects in specific areas in active clusters (i.e., research communities), and provide them with support for effective collaboration, including enabling sharing of data and access to research infrastructures; and increasing the visibility of the brain research portfolio as a whole and promoting the uptake of EBRA results to key stakeholders. A series of calls launched since 2019 resulted in the creation of 6 EBRA clusters.

In this context, EBC, NEURON and HBP are co-organising this workshop, specifically designed for EBRA’s clusters to discuss overarching matters related to data-sharing.

II. DATA-SHARING IN EUROPE

Over the years, data-sharing has become a major facet of the production of knowledge in all scientific domains. The European Commission (EC) is a key player in the take up of the Open Science movement and policy. With the General Data Protection Regulation (GDPR), it has set up the legal framework to manage and control data. The EC is also promoting data-sharing with new initiatives such as the [Open Research Europe](#) to ease open access publication and develop European Partnerships to promote the Findable, Accessible, Interoperable and Reusable (FAIR) principle with the [European Open Science Cloud](#) (EOSC) or developing an [European Data Strategy](#). Besides, funders, at European as well as national level, are increasingly requesting research projects to develop, implement and maintain data management plans. Many research infrastructures at different maturity levels exist and provide communities with services of different types (High Performance Computing (HPC), analytics, storage, data resources, software, training, etc) to support users active in a range of different research domains and settings (e.g., neuroscience, biobanking, genomics, clinical trials).

In neuroscience, standardisation efforts have led to the establishment of organisations like the International Neuroinformatics Coordinating Facility ([INCF](#)). The HBP, kicked off in 2013, has worked on establishing an ecosystem of applications that are the foundation of a new type of European Research Infrastructure ([EBRAINS](#)) to ease usage, analysis and data-sharing and worked with a range of different organisations (e.g., the International Brain Initiative) to support global adoption of good and best practices with respect to data-usage and management.

The ERA-NET NEURON [symposium](#) organised in January 2021 had a specific session on “Data-sharing, legal and ethical aspects in brain research” and was summarized by Elena Becker-Barroso, Editor-in-Chief of ‘The Lancet Neurology’ journal, as follows:

“the lack of reproducibility and research waste (particularly in pre-clinical research) indicative of problems with our academic culture of incentives and rewards”.



Challenges and measures are: "...data-sharing and open data for which methods and infrastructure are needed, training and know-how particularly on regulatory practices, and that transparency – as in clinical trials with registration and reporting – is key".

Change in research practice and culture is often an uneven process. So naturally, questions arise such as "What next?", "What are the priorities?", "What is missing or already exists and works well?", "What resources are needed?".

III. AIMS OF THE WORKSHOP

This workshop was conceived and designed to support the EBRA clusters regarding data-related challenges. It creates a forum for the clusters to share their needs and questions and to hear about trends and solutions with regard to the use and reuse, access and sharing of data. The intention of this workshop is to get a better understanding of how the different research communities work with data; and to identify the key roadblocks as well as opportunities.

During this workshop, an overview will be provided on current European best practices on one hand, and examples of how HBP produced solutions address data-management, data-sharing, and data-publishing challenges are faced by researchers. The discussion aims to identify areas where consensus already exists as well as to raise awareness on issues and challenges where more discussion with the broader brain research community is needed.

A significant outcome of this workshop will be the first version of a document that captures the essence of the data-sharing needs and challenges of the EBRA clusters, the overarching questions or issues that need to be addressed as well as possible action items that can be taken to accelerate the solution-finding process (e.g., further discussions; an opinion or white paper publication). This will facilitate the development of recommendations and instruments aimed at facilitating the sharing of and access to data amongst researchers.

IV. AGENDA

| Time | Description |
|--------------|--|
| 9:00 - 9:05 | Welcome and housekeeping Dr. Martin Telefont, EPFL, Head of the HBP Partnering environment, EBRA Partner |
| 9:05 - 9:10 | Short introduction to the European Brain Research Area (EBRA) project Frédéric Destrebecq, Executive director, EBC, EBRA coordinator |
| 9:10 - 9:30 | Introduction to EBRA's clusters: EPICLUSTER, PSMD-CLUSTER, TRISOMY21-CLUSTER, PREMOS-CLUSTER and ECIB-CLUSTER |
| 9:30 - 9:40 | Data-sharing in brain research (pre-clinical & clinical data) - Dr. Hella Lichtenberg, NEURON, DLR-PT, EBRA partner and Dr. Martin Telefont, EPFL, EBRA Partner |
| 9:40 - 9:50 | Data Governance: legal and ethical considerations Dr. Damian Okaibedi Eke, Research fellow, De Montfort University |
| 9:50 - 10:15 | Round table discussion Moderator: Steven Vermeulen, Chief Infrastructure and Information Officer, EBRAINS AISBL |



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| 10:15 - 10:25 | Break |
| 10:25 - 10:35 | Reproducible and transparent neuroscience: EBRAINS services for publishing research data Prof. Jan Bjaalie, Oslo University, HBP Infrastructure Development Director |
| 10:35 - 10:45 | Leveraging Medical Data-Sharing through federated analytics: the Medical Informatics Platforms (MIP) Prof. Philippe Ryvlin, Centre Hospitalier Universitaire Vaudois, Head of the HBP MIP |
| 10:45 - 10:55 | Brain Simulation as a Service: The Virtual Brain on EBRAINS Prof. Petra Ritter, Charité – Universitätsmedizin Berlin, Lead Virtual Brain Cloud EBRAINS Facility Hub, Lead Co-Design Project The Virtual Brain in SGA2 |
| 10:55 - 11:05 | Running simulation on top of clinical data: Simulation-based method targeting Epilepsy Dr. Viktor Jirsa, Aix-Marseille Université, HBP WP leader “The human multiscale brain connectome and its variability” |
| 11:05 - 11:15 | Break |
| 11:15 - 12:35 | Round table discussion Moderator: Steven Vermeulen, Chief Infrastructure and Information Officer, EBRAINS AISBL |
| 12:45 - 13:00 | Conclusion and next steps Dr. Martin Telefont, EPFL, Head of the HBP Partnering environment, EBRA Partner |

V. SPEAKERS' BIOGRAPHIES



Jan Bjaalie, M.D., Ph.D., is professor at the Institute of Basic Medical Sciences, University of Oslo, and Infrastructure Development Director and leader of the Neuroinformatics Platform of the EU Human Brain Project. He was founding Executive Director of the International Neuroinformatics Coordinating Facility (INCF) and is currently head of the INCF Norwegian Node and member of the INCF Council for Training, Science and Infrastructure as well as Co-chair of the International Brain Initiative. His research group has studied wiring patterns in the brain and developed data systems for organising and managing heterogeneous neuroscience research data by use of a new generation of digital brain atlases. The group develops software and workflows for analysis of data integrated in the atlases ("Google maps of the brain"). Jan Bjaalie is Chief Editor of *Frontiers in Neuroinformatics* and Section editor of *Brain Structure and Function*.





Frédéric Destrebecq is the Executive Director of the European Brain Council since October 2014. In this capacity, he is responsible for providing strategic direction and leadership while managing the day to day operations of EBC and its ongoing relationships with its member associations and other stakeholders, as well as representing the organisation in various European and national forums.

Prior to this position, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs. Fred holds a Master Degree in Political Science and International Relations from the Université Catholique de Louvain (Belgium). He also studied at the Institut d'Etudes Politiques (Paris) and University of Wales College (Cardiff), in the framework of the former EU Socrates exchange programme.



Damian Okaibedi Eke, Research fellow, De Montfort University

Damian's academic and research background is in Ethics of Emerging Technologies. His research interests and work currently include Data Ethics and Data governance.

In EBRAINS/HBP, he is the [data governance](#) coordinator.

Currently leads the International Brain Initiative's Data Standards and Sharing Working Group's Taskforce on Data governance.



Viktor Jirsa is 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. He has pioneered the field of connectome-based brain modeling and contributed for over 25 years to computational neuroscience at the interface with brain imaging data. Dr. Jirsa has published more than 160 articles and 6 patents with a total of over 14 000 citations and has been awarded international and national research awards including the Francois Erbsmann Prize for biomedical imaging in 2001, the Early Career Distinguished Scholar Award in 2004, and the Grand Prix de Recherche by Provence (PACA, Inserm) in 2018. Dr Jirsa is Scientific Director of the French large-scale multi-site clinical trial [EPINOV](#) testing Virtual Brain technologies in Epilepsy surgery with 400 prospective patients. In the [Human Brain Project](#), he leads the workpackage Human multiscale brain connectome, pioneering the European efforts in the use of brain network models for health and personalised medicine. Dr. Jirsa is a member of EBRA EPICLUSTER leadership.



Hella Lichtenberg, ERA-NET NEURON, German Aerospace Center (DLR) Project Management Agency (PT), Germany.

She is a trained geneticist with a habilitation in microbiology. Since 2007 she is responsible for NEURON's, since 2015 also for ERA-CVD's (Cardiovascular Diseases) coordination office, and since 2018 actively engaged in EBRA. The involvement in the international measures necessitates all areas of conceptualizing and executing research funding programmes including overarching topics like PPI, quality assurance in biomedical research, and ethical issues.



Petra Ritter, Univ.-Prof. Dr. med., 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, Member in European Cluster for Imaging Biomarkers (ECIB)

Petra Ritter serves in the leadership of several national and international neuroinformatics consortia. Her research focus lies on computational and clinical neuroscience; integration of multimodal radiologic imaging data and associated data through multi-scale brain network modelling, identification of the causal hidden processes underlying brain function and dysfunction.

Head of the Virtual Brain Cloud Facility Hub of EBRAINS: RI <http://virtualbraincloud-2020.eu/> and <https://arxiv.org/abs/2102.05888>.



Prof Philippe Ryvlin, Head of the Department of Clinical Neurosciences, Centre Hospitalier Universitaire Vaudois. Lead of HBP MIP (Medical Informatics Platform), co-lead of HBP HIP (Human Intracerebral EEG platform).

Philippe Ryvlin is a Neurologist specialized in Epilepsy, including presurgical evaluation and intracerebral EEG recordings. His research focuses on neurotechnologies in epilepsy and beyond, with specific interest in the prevention of premature mortality in epilepsy. He is a member of EBRA EPICLUSTER leadership.

The MIP is a unique, privacy aware and GDPR compliant platform that federates datasets distributed across institutions and their analysis. It is currently installed in over 30 EU hospitals. The HIP is a platform dedicated to sharing and analyzing Human intracerebral EEG (iEEG) data, to which more than 90% of EU and Asian-Oceanian iEEG centers have agreed to contribute.



Martin Telefont, PhD, is the Head of the HBP Partnering Environment at the Ecole Polytechnique Fédérale de Lausanne

Martin is a trained Neuroscientist with extensive experience in data integration and analytics. He serves as a member of the EBRA Project Steering Committee.

In EBRAINS/HBP, he contributes to Management and Coordination and the [Partnering Environment](#), a community of users and collaborators of HBP.



Steven Vermeulen, CIO, EBRAINS AISBL

Steven is a seasoned executive with more than 25y of experience in different sectors. Worked in telecoms, space, media, advertising, logistics and healthcare.

Throughout a career that started as a scientist and evolved into technical (software), management and even marketing and sales roles, the common thread has been introducing and applying new technologies in the market. Steven has taken leading roles in several internal start-ups in large companies and has done a MBO of a company in France. Recently he has been involved in applying his experience in digital transformation and data projects in several SME's.

In EBRAINS, Steven aims at matching the research infrastructure to the needs. Ebrains.eu

VI. EBRA CLUSTERS



EPICLUSTER was funded by EBRA in late 2019 as a 2,5-year networking action. The primary objective of EPICLUSTER is to establish a collaborative framework for the coordinated actions of epilepsy research in Europe, based around shared partnerships and research priorities.

Coordinator: David Henshall, Prof., RCSI/FutureNeuro Research Centre, Ireland



The Prevention of Severe Mental Disorders (PSMD) cluster was funded by EBRA in early 2020 as a 2,5-year networking action. The overarching aims of the cluster include fostering collaboration and gathering of experts on a determinate topic, organising and promoting several Network meetings, providing administrative support, facilitating dialogue with the stakeholders, supporting grant applications and dissemination of the results of funded projects.

Co-chair: Paolo Fusar-Poli, Prof., King's College, London, UK and University of Pavia, Italy; Co-chair: Ole Andreassen, Prof., Institute of Clinical Medicine, Oslo, Norway.



The **TRISOMY21-cluster** was funded in mid-2020 as a 2-year networking action. Through EBRA cluster, it intends to expand existing European networks to promote coordination and collaboration among European scientists belonging to these research networks and share common projects with the goal of understanding disorders of the developing brain leading to intellectual disabilities such as DS.

Coordinator: Mara Dierssen, Dr., Centre for Genomic Regulation, Barcelona (CRG), Spain; Co-coordinator: Marie-Claude Potier, Dr., Hôpital de la Pitié-Salpêtrière, Paris, France





The **BRAINFOOD cluster** was funded by EBRA in mid-2020 as a 2-year networking action. The overarching objective of the BRAINFOOD cluster is ultimately to positively impact on brain health by improving nutrition of European citizens based upon fundamental insights in the bidirectional links between brain health and nutrition.

Coordinator: Roger Adan, Prof., University Medical School Utrecht, The Netherlands; Co-coordinator: Suzanne Dickson, Prof., University of Gothenburg, Sweden



The **Predictive Model Systems (PREMOS) cluster** was funded in early 2021 as a 1,5-year networking action. The primary objective of the PREMOS cluster is to enhance the alignment of EU disease model development resources and preclinical research expertise with clinical and brain research community needs across academia and industry.

Coordinator: Sabine Hölter-Koch, Dr., Helmholtz Zentrum München, Germany

Co-Coordinator: Dr. Yann Hérault, Institut de Génétique, Biologie Moléculaire et Cellulaire (IGBMC), Université de Strasbourg, CNRS, INSERM



The **European Cluster for Imaging Biomarkers (ECIB)** was funded in early 2021 as a 1,5-year networking action. The European Cluster for Imaging Biomarkers (ECIB) forges a complimentary and synergetic harmonization alliance across major European consortia, networks and platforms engaged in multicentric collection, curation, transfer, and analysis of “big-imaging-data”.

Coordinator: Thilo van Eimeren, MD, University of Cologne, Germany
Co-Coordinator: Stefano Cappa, MD, University of Pavia, Italy

VII. FOOD FOR THE THOUGHTS: QUESTIONS

Below are some questions for you to reflect on as the workshop approaches.

- Did you have to provide a Data Management Plan for your 2020 or current project(s) to national or international funding? Did you encounter any problems, and if yes, which one?
 - Yes, and it was super easy.
 - Yes, and it was a pain, so HELP PLEASE!
 - No, but we think we will need to for the next project so HELP PLEASE!
 - No, because our area doesn't have that requirement yet.
- What data related changes did you make into the last year or are planning to make in the next year?
 - We are moving from local storage to a shared server for the lab, it's been painful.
 - We are working on a process to publish some of our data to a community site.
- Are you already using infrastructure-based data or analysis services? If so, which ones and what is your experience?
 - Yes are using ELIXIR to access and share molecular data.



The EBRA project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 825348.

- *Yes services, it's painful because we are trying to get TB of data to the data processing people.*
- *Yes, Dropbox.*

- How are you sharing data with collaborators outside of your organisation?
 - *Dropbox.*
 - *USB sticks in a suitcase.*
 - *Hospital/university/lab server.*

- Are you sharing your raw or processed data with the community? If so, how?
 - *Yes, with the service the publishers are providing.*
 - *Yes, as figures in the publications.*
 - *We are not sharing data.*

- Are you using publicly accessible data, and what's your experience with that?
 - *It's a lot of work to find good data aside from the five datasets everybody is using, most datasets are not usable because they are too small and the capture setup and formats make them unusable.*

- What type of instruments or guidelines are lacking to facilitate the sharing of data among projects, or countries?
 - *I can't get a copy of data from my collaborators in country x because it can't cross national borders.*
 - *National restrictions on data storage makes it impossible to keep primary data for a long time. So there is a lot of duplication of efforts and "one-off" work going on.*

VIII. FOOD FOR THE THOUGHTS: POINTERS TO INFORMATION ABOUT KEY CONCEPTS

Good Research Practice in Non-Clinical Pharmacology and Biomedicine, ISBN 978-3-030-33655-4 ISBN 978-3-030-33656-1 (eBook), <https://doi.org/10.1007/978-3-030-33656-1>

Open science – towards reproducible research, Jomier, Information Services & Use 37 (2017) 361–367 DOI 10.3233/ISU-170846

Resolving the Tension Between Exploration and Confirmation in Preclinical Biomedical Research, Dirnagl, 2019, Handbook of Experimental Pharmacology, https://doi.org/10.1007/164_2019_278

The bench is closer to the bedside than we think: Uncovering the ethical ties between preclinical researchers in translational neuroscience and patients in clinical trials, Yarborough et al., 2018, <https://doi.org/10.1371/journal.pbio.2006343>

Turning FAIR into reality, Final Report and Action Plan from the European Commission Expert Group on FAIR Data, European Commission Directorate General for Research and Innovation, 2018, <https://op.europa.eu/en/publication-detail/-/publication/7769a148-f1f6-11e8-9982-01aa75ed71a1>

OECD Principles and Guidelines for Access to Research Data from Public Funding, Organisation for Economic Co-operation and development, https://www.oecd-ilibrary.org/science-and-technology/oecd-principles-and-guidelines-for-access-to-research-data-from-public-funding_9789264034020-en-fr, 2007



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The organising committee of this workshop is composed of Kristien Aarts (Project Manager, European Brain Council); Elke De Witte (Head of project development, European Brain Council); Frédéric Destrebecq (Executive Director, European Brain Council); Hella Lichtenberg (Scientific Officer; DLR), Martin Telefont (Head of HBP Partnering Environment, EPFL, Human Brain Project); Marie-Elisabeth Colin (Scientific Project Manager, EPFL, Human Brain Project).

“Governance of research data ought to be ethically responsible, socially acceptable and legally compliant”

Damian Okaibedi Eke

“Integration is the foundation of actionable data. Looking deeper, integration is not just a collection of software tools on a fancy website, but starts with concepts and deep understanding, and is only then followed by the organisation of tools and good practices.”

Viktor Jirsa

“Research is conducted across different sites and institutions, and relying 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.”

Hella Lichtenberg

“This workshop shall offer an opportunity for EBRA clusters to understand the potential for HBP MIP and HIP to contribute to their scientific objectives, in particular through enhanced data-sharing.”

Philippe Ryvlin

“World-wide exchange of data is crucial. Data privacy is also crucial. There is no simple solution to simultaneously and efficiently meet both these needs. The solution proposed by Virtual Brain Cloud is to use encryption, sandboxing and access control as technical means to protect personal data.”

Petra Ritter

“To solve complex problems we need data that can be compared and used to draw a more complete picture of our state of knowledge.”

Martin Telefont

“I’ve worked on data in many forms, but all can be traced back to making data actionable. I strongly believe sharing increase the value even further.”

Steven Vermeulen