EBRAINS

ean
european academy of neurology

EAN-EBRAINS JOINT WORKSHOP
THE FUTURE OF MEDICAL DATA SHARING IN CLINICAL NEUROSCIENCES

9–11 DECEMBER 2021
HYBRID EVENT

REGISTRATION DEADLINE:
25 NOVEMBER 2021

FINAL PROGRAMME

Human Brain Project

Co-funded by
the European Union

ABOUT THE EVENT

Data sharing stimulates science in all scientific disciplines, including the Clinical Neurosciences. Promotion of data sharing and the implementation of standardized harmonization rules among a global research community reduces the burden of unexploited research and plays a critical role in mitigating the problems of reduced sample sizes. Today, medical and research activities in clinical neuroscience produces a massive amount of data that could leverage our knowledge and understanding of brain diseases. Unfortunately, despite growing incentives for open data, most of it remains currently locked in hospitals or labs, either for regulatory or cultural reasons.

The Medical Informatics Platform (MIP) was developed in the framework of the Human Brain Project (HBP) as an innovative tool to investigate, compare and analyse large patient datasets distributed across centers without requiring the data to be transferred and stored outside their site of origin. The platform is integrated in EBRAINS, the sustainable European Research Infrastructure for brain-related research and legacy of the HBP.

Recently, the HBP has started a pilot project with the **European Academy of Neurology** (EAN) with the idea to use the MIP to promote clinical data sharing using a federated approach. EAN is the primary scientific and educational European organisation in the field of Clinical Neurosciences, including more than 45,000 members, as well as 47 European National Societies. EAN is committed to scientific progress and aims to keep Europe at the forefront of neurological research and to maintain its position as one of the world's scientific hotpots in neurology.

CALL FOR REGISTRATIONS

HBP and EBRAINS together with the EAN invite the entire scientific community to join the forthcoming workshop on the Future of Medical Data Sharing in Clinical Neurosciences. This event aims at exposing and openly discussing all issues and challenges associated with data sharing in Europe, from ethics to data safety and privacy, including those specific to data federation, such as the development and validation of federated algorithms. We propose a platform to disclose the preliminary results of these use-cases, four brainstorming sessions involving EAN Scientific Panels, demonstrations and a hands-on session, which will highlight important aspects and issues of medical data sharing and offer participants the possibility to understand how to use the MIP for their own applications.

Registration deadline: 25 November 2021
Please note that registration for the workshop is mandatory.

Scientific chairs:

Prof. Philippe Ryvlin │ Centre hospitalier universitaire Vaudois, Switzerland
Prof. Thomas Berger │ Medical University Vienna, Austria

Contact:
workshop.edu@humanbrainproject.eu

Further information & registration:
www.humanbrainproject.eu/education/ebrains-workshops/medicaldata

Organised by:

Human Brain Project
Education Programme

In cooperation with:

ean
european academy of neurology

Sponsored by:

ADDI
Alzheimer's Disease
Data Initiative

THURSDAY 9 DECEMBER 2021

*The HBP and the EAN Scientific Committee have co-developed this programme.
The time zone of the event is CET (UTC/GMT+1).

Plenary Sessions (on-site & virtual)

13:30	Registration

14:00 – 15:45	Plenary Sessions

14:00 – 14:15	**Introduction** Thomas Berger │ Medical University Vienna Philippe Ryvlin │ Centre hospitalier universitaire vaudois
14:15 – 14:45	**The Human Brain Project: An overview** Katrin Amunts │ Forschungszentrum Jülich
14:45 – 15:15	**EBRAINS: The future of the Human Brain Project** Paweł Świeboda │ EBRAINS AISBL
15:15 – 15:45	**EAN: Achievements and Ambitions** Paul Boon │ University of Ghent

15:45 – 16:15	Coffee Break

16:15 – 17:45	Plenary Sessions

16:15– 16:45	**EHDS: The future of data sharing in Europe** Maria-Ioana Gligor │ European Comission - European Reference Networks and Digital Health
16:45 – 17:15	**MIP: Why federating data in Medicine** Philippe Ryvlin │ Centre hospitalier universitaire vaudois
17:15 – 17:45	**EAN: Why sharing data in clinical neuroscience** Thomas Berger │ Medical University Vienna

17:45	End of the Day

FRIDAY 10 DECEMBER 2021

Track 1 (on-site & virtual)

FEDERATION USE CASES

8:30 – 10:00

Parallel session 1: Dementia
Chair: Jean-François Demonet | Université de Lausanne & Gilles Allali | CHUV

8:30 – 9:00	The spectrum of data sharing in Dementia	PJ Visser (Amsterdam Univ. Med. Centers)
9:00 – 9:30	The MIP federation in Dementia	Melanie Leroy (Université de Lille)
9:30 – 10:00	EAN scientific panel on dementia	Kristian Steen Frederiksen (Danish Dementia Research Centre - Rigshospitalet - Copenhagen University Hospital)

10:00 – 10:30 — Coffee Break

10:30 – 12:00

Parallel session 3: Traumatic Brain Injury
Chair: Matthew Abrams | Karolinska Institutet & Stefano Finazzi

10:30 – 11:00	The international initiative for TBI research	Hester Lingsma (Erasmus University Medical Center)
11:00 – 11:30	The MIP federation in TBI	Stefano Finazzi (Mario Negri Institute for Pharmacological Research IRCCS)
11:30 – 12:00	EAN Scientific Panel on neurotraumatology	Dafin Muresanu (Foundation of the Society for the Study of Neuroprotection and Neuroplasticity (SSNN))

12:00 – 13:30 — Lunch Break

13:30 – 15:15

Parallel session 5: Stroke
Chair: Anna Bersado & Charlotte Cordonnier | Université de Lille

13:30 – 13:55	The impact of data sharing in stroke	Valeria Caso (University of Perugia)
13:55 – 14:20	The spectrum of national and European stroke registries	Georgios Tsivgoulis (National and Kapodistrian University of Athens)
14:20 – 14:45	Why federating stroke registries	Maurizio Leone (IRCCS Casa Sollievo della Sofferenza)
14:45 – 14:55	EAN scientific panel on stroke	Anna Bersano (Fondazione IRCCS Istituto Carlo Besta)

15:15 – 15:45 — Coffee Break

15:45 – 17:15

Parallel session 7: Epilepsy
Chair: Reetta Kalviainen | Kuopio University Hospital & Tim von Oertzen

15:45 – 16:15	Data sharing in epilepsy	Helen Cross (University College London)
16:15 – 16:45	The MIP federation in epilepsy	Philippe Ryvlin (Centre hospitalier universitaire vaudois)
16:45 – 17:15	EAN Scientific Panel on epilepsy	Tim von Oertzen (Kepler Universitätsklinikum)

17:15 – 18:45

Parallel session 9: Other/future use-cases
Chair: Thomas Berger | Medical University Vienna & Arseny Sokolov | CHUV

17:15 – 17:45	European Database on Narcolepsy and related hypersomnia	Yves Dauvilliers (University of Montpellier) & Ramin Khatami (Klinik Barmelweid)
17:45 – 18:15	Neurorehabilitation	Letizia Leocani (IRCCS Ospedale San Raffaele)
18:15 – 18:45	NeuroCOVID	Elena Moro (Grenoble Alpes University)

18:45 — End of Workshop Day

PARALLEL SESSIONS

Track 2 (virtual only)

FEDERATION CHALLENGES

Parallel session 2: Ethics
Chair: Bernd Stahl | De Montfort University

8:30 – 9:00	Re-use of clinical data for research	Michaela Th. Mayerhofer (BBMRI-ERIC)
9:00 – 9:30	How to make data public	Ida Aasebø (University of Oslo)
9:30 – 10:00	Ethics requirements for MIP usage	Erika Borcel (Centre hospitalier universitaire vaudois)

10:00 – 10:30 — Coffee Break

Parallel session 4: Data safety
Chair: Oksana Kulyk | IT University of Copenhagen

10:30 – 11:00	The challenge of protecting hospital data	Franck Calcavecchia (Hopitaux Universitaires de Genève)
11:00 – 11:30	Data safety on EBRAINS	Stefano Gorini & Alex Upton (CSCS)
11:30 – 12:00	How to secure MIP networks across hospitals	Emrah Kavun (Centre hospitalier universitaire vaudois)

12:00 – 13:30 — Lunch Break

Parallel session 6: Data privacy
Chair: Jean-Louis Raisaro | École polytechnique fédérale de Lausanne & Yannis Ioannidis

13:30 – 13:55	State-of-the art cryptography approach to data privacy	Barbara Carminati (Università degli studi dell'Insubria)
13:55 – 14:20	Risk-based data anonymization for medical research	Fabian Prasser (Charité Berlin)
14:20 – 14:45	Differential privacy	Minos Garofalakis (Technical University of Crete)
14:45 – 14:55	The present and future model of MIP data privacy	Yannis Ioannidis (University of Athens, Athena Research Center)

15:15 – 15:45 — Coffee Break

Parallel session 8: Federated analytics
Chair: Jan Bjaalie | University of Oslo & Yannis Ioannidis

15:45 – 16:15	What is federated analysis	Yannis Ioannidis (University of Athens, Athena RC)
16:15 – 16:45	How to build and validate a federated algorithm	Jason Sakellariou (University of Athens)
16:45 – 17:15	The MIP federated analytics	Giorgos Papanikos (University of Athens)

Parallel session 10: Ontologies and knowledge graph
Chair: Jan Bjaalie & Yannis Ioannidis

17:15 – 17:45	Ontologies for clinical neurosciences	Martin Hoffman-Apitius (University of Bonn/Fraunhofer-Institut für Algorithmen und Wissenschaftliches Rechnen SCAI)
17:45 – 18:15	The power of EBRAINS Knowledge Graph	Jan Bjaalie (University of Oslo)
18:15 – 18:45	Using knowledge graph in hospitals	Christophe Gaudet-Blavignac (University of Geneva)

End of Workshop Day

SATURDAY 11 DECEMBER 2021

Track 1 (virtual only)

9:00 – 10:30
Brainstorming from EAN panels on data sharing
(This session is upon invitation only)

Group 1 (Chair: Maurizio Leone | IRCCS Casa Sollievo della Sofferenza)

- **Neuroepidemiology** | Ettore Beghi (Mario Negri Institute for Pharmacological Research)
- **Pain** | Martin Rakusa (University Medical Centre Maribor)
- **Muscle & NMJ disorders** | Maria Judit Molnar (Semmelweis University Medical School)
- **Movement disorders** | Angelo Antonini (University of Padua)

Group 2 (Chair: Eavan McGovern | Beaumont Hospital & Mara Rocca | IRCCS Ospedale San Raffaele)

- **Child Neurology** | Sarah Bürki (University Children's Hospital Zurich)
- **Neurocritical care** | Serefnur Ozturk (Selçuk University)
- **Neurogenetics** | Sylvia Boesch (Medical University Innsbruck)
- **Coma & Disorders of consciousness** | Rita Formisano (Fondazione Santa Lucia)
- **Clinical Neurophysiology** | Hatice Tankisi (Aarhus University Hospital)
- **Neuroophthalmology & -otology** | Nese Celebisoy (Ege University)

Group 3 (Chair: Romana Höftberger | Medical University Vienna)

- **Multiple Sclerosis & Neuroimmunology** | Celia Oreja-Guevara (Hospital Clínico San Carlos de Madrid)
- **Infectious diseases** | Pille Taba (University of Tartu)
- **Neurooncology** | Anette Storstein (Haukeland University Hospital)
- **Neuropathies** | Christian Krarup (University of Copenhagen)
- **Neuroimaging** | Federica Agosta (Vita-Salute San Raffaele University / IRCCS Ospedale)

Group 4 (Chair: Femke Bouwman | Amsterdam University Medical Centers)

- **Autonomic nervous system disorders** | Alexandra Fanciulli (Medical University Innsbruck)
- **Headache** | Pablo Irimia (Universidad de Navarra)
- **Neurosonology** | David Skoloudik (University of Ostrava)
- **Higher cortical functions** | Masud Husain (University of Oxford)
- **ALS & frontotemporal dementia** | Andrea Calvo (University of Turin)

10:30 – 10:45	Coffee Break

10:45	Plenary Session (open for everybody)

- **Report of the four groups**
  Maurizio Leone, Mara Rocca, Eavan McGovern, Romana Höftberger, Femke Bouwman

11:45	Concluding remarks

Thomas Berger & Philippe Ryvlin

12:15	End of the event

PARALLEL SESSIONS

Track 2 (virtual only)

9:00 – 11:45
MIP hands-on sessions

9:00 **MIP Installation**
Erika Borcel | Centre hospitalier universitaire vaudois

- Administrative & technical steps towards MIP Installation

9:20 **Data preparation**
Laith Abu-Nawwas | Centre hospitalier universitaire vaudois

- Delineating and implementing a data model in the MIP
- Harmonizing a dataset according to the data model
- Integrating anonymized data into the MIP

09:50 **Extracting regional brain volumes from the MIP MRI pipeline**
Laith Abu-Nawwas & Carolina Ciumas | Centre hospitalier universitaire vaudois

10:10 **Data Analytics**
Laith Abu-Nawwas | Centre hospitalier universitaire vaudois

- Data Governance principle
- Current and new algorithms

10:30 – 10:45	Coffee Break

10:45 **Dementia Use Case**
Mélanie Leroy | Université de Lille

- Selection of metadata and descriptive analysis
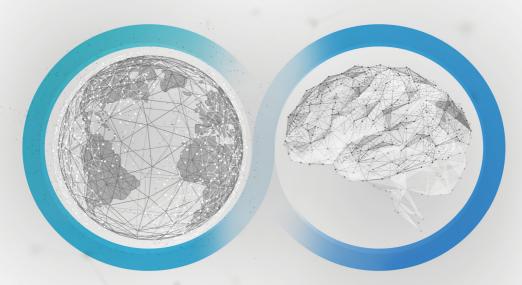- Developing a predictive model
- Clustering analyses

11:15 **TBI Use Case**
Stefano Finazzi | Mario Negri Institute for Pharmacological Research IRCCS

- Selection of metadata and descriptive analyses
- Validation of prognostic models

11:45	Concluding remarks

Thomas Berger & Philippe Ryvlin

12:15	End of the event

The AD Workbench is where collaboration drives innovation.

The Alzheimer's Disease Data Initiative is on a mission to fundamentally transform Alzheimer's disease research. Our AD Workbench is a secure, cloud-based platform where researchers can request, share, store, and analyze data, all at no cost. It streamlines data sharing so we collaborate more effectively and expand our collective knowledge. Together, we can find answers for the more than 55 million people worldwide living with Alzheimer's disease and related dementias.

Explore the AD Workbench.
Visit Alzheimersdata.org/ad-workbench

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