



**EBRAINS**



# **EAN-EBRAINS JOINT WORKSHOP**

## **THE FUTURE OF MEDICAL DATA SHARING IN CLINICAL NEUROSCIENCES**

**9–11 DECEMBER 2021**  
**VIRTUAL EVENT**

**REGISTRATION DEADLINE:**  
**25 NOVEMBER 2021**

**PRELIMINARY 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 hotspots 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](mailto:workshop.edu@humanbrainproject.eu)

### Further information & registration:

[www.humanbrainproject.eu/education/ebrains-workshops/medicaldata](http://www.humanbrainproject.eu/education/ebrains-workshops/medicaldata)

### Organised by:



### In cooperation with:



## 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).

13:30	Registration
14:00 – 15:45	Plenary Session
14:00 – 14:15	<b>Introduction</b> Thomas Berger   Medical University Vienna Philippe Ryvlin   Centre hospitalier universitaire vaudois
14:15 – 14:45	<b>The Human Brain Project: An overview</b> Katrin Amunts   Forschungszentrum Jülich
14:45 – 15:15	<b>EBRAINS: The future of the Human Brain Project</b> Paweł Świeboda   EBRAINS AISBL
15:15 – 15:45	<b>EAN: Achievements and Ambitions</b> Paul Boon   University of Ghent
15:45 – 16:15	Coffee Break
16:15 – 17:45	Plenary Session
16:15 – 16:45	<b>EHDS: The future of data sharing in Europe</b> Maria-Ioana Gligor   European Commission - European Reference Networks and Digital Health
16:45 – 17:15	<b>MIP: Why federating data in Medicine</b> Philippe Ryvlin   Centre hospitalier universitaire vaudois
17:15 – 17:45	<b>EAN: Why sharing data in clinical neuroscience</b> Thomas Berger   Medical University Vienna
17:45	End of the Day

\*This programme is subject to change.

## FRIDAY 10 DECEMBER 2021

### Track 1

#### FEDERATION USE CASES

8:30 – 10:00

##### Parallel session 1: Dementia

Chair: Jean-François Demonet | Université de Lausanne

The spectrum of data sharing in Dementia | PJ Visser (Amsterdam University Medical Centers)

The MIP federation in Dementia | Melanie Leroy (Université de Lille)

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

The international initiative for TBI research | Hester Lingsma (Erasmus University Medical Center)

The MIP federation in TBI | Stefano Finazzi (Mario Negri Institute for Pharmacological Research IRCCS)

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: Charlotte Cordonnier | Université de Lille

The impact of data sharing in stroke | Valeria Caso (University of Perugia)

The spectrum of national and European stroke registries | Georgios Tsivgoulis (National and Kapodistrian University of Athens)

Why federating stroke registries | Maurizio Leone (IRCCS Casa Sollievo della Sofferenza)

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

Data sharing in epilepsy | Helen Cross (University College London)

The MIP federation in epilepsy | Philippe Ryvlin (Centre hospitalier universitaire vaudois)

EAN Scientific Panel on epilepsy | Tim von Oertzen (Kepler Universitätsklinikum)

17:15 – 18:45

##### Parallel session 9: Other/future use-cases

Chair: Paul Boon | University of Ghent

European Database on Narcolepsy and related hypersomnia | Yves Dauvilliers (University of Montpellier) & Ramin Kathami (Klinik Barmelweid)

Neurorehabilitation | Letizia Leocani (IRCCS Ospedale San Raffaele)

NeuroCOVID | Elena Moro (Grenoble Alpes University)

18:45

End of Workshop Day

## PARALLEL SESSIONS

### Track 2

#### FEDERATION CHALLENGES

##### Parallel session 2: Ethics

Chair: Bernd Stahl | De Montfort University

Re-use of clinical data for research | Michaela Th. Mayerhofer (BBMRI-ERIC)

How to make data public | Ida Aasebø (University of Oslo)

Ethics requirements for MIP usage | Erika Borcel (Centre hospitalier universitaire vadouis)

Coffee Break

##### Parallel session 4: Data safety

Chair: Oksana Kulyk | IT University of Copenhagen

The challenge of protecting hospital data | Frank Calcavecchia (Hopitaux Universitaires de Genève)

Data safety on EBRAINS | Stefano Gorini & Alex Upton (CSCS)

How to secure MIP networks across hospitals | Emrah Kavun (Centre hospitalier universitaire vadouis)

Lunch Break

##### Parallel session 6: Data privacy

Chair: Jean-Louis Raisaro | École polytechnique fédérale de Lausanne

State-of-the art cryptography approach to data privacy | Barbara Carminati (Università degli studi dell'Insubria)

Risk-based data anonymization for medical research | Fabian Prasser (Charité Berlin)

Differential privacy | Minos Garofalakis (Technical University of Crete)

The present and future model of MIP data privacy | Yannis Ioannidis (University of Athens, Athena Research Center)

Coffee Break

##### Parallel session 8: Federated analytics

Chair: Yannis Ioannidis | University of Athens, Athena Research Center

What is federated analysis | Yannis Ioannidis (University of Athens, Athena Research Center)

How to build and validate a federated algorithm | Jason Sakellariou (University of Athens)

The MIP federated analytics | Giorgos Papanikos (National and Kapodistrian University of Athens)

##### Parallel session 10: Ontologies and knowledge graph

Chair: Jan Bjaalie | University of Oslo

Ontologies for clinical neurosciences | Martin Hoffman-Apitius (University of Bonn/ Fraunhofer-Institut für Algorithmen und Wissenschaftliches Rechnen SCAI)

The power of EBRAINS Knowledge Graph | Jan Bjaalie (University of Oslo)

Using knowledge graph in hospitals | Christophe Gaudet-Blavignac (University of Geneva)

End of Workshop Day

## SATURDAY 11 DECEMBER 2021

### Track 1

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

**Group 1** (Chair: Mara Rocca | IRCCS Ospedale San Raffaele)

- **Neuroepidemiology** | Ettore Beghi (Mario Negri Institute for Pharmacological Research)
- **Neurocritical care** | Serefnur Ozturk (Selçuk University)
- **Coma & Disorders of consciousness** | Rita Formisano (Fondazione Santa Lucia)
- **Neuroimaging** | Federica Agosta (Vita-Salute San Raffaele University / IRCCS Ospedale San Raffaele)
- **Neurosonology** | David Skoloudik (University of Ostrava)

**Group 2** (Chair: Eavan McGovern | Beaumont Hospital)

- **Child Neurology** | tbd
- **Clinical Neurophysiology** | Hatice Tankisi (Aarhus University Hospital)
- **Neurogenetics** | Sylvia Boesch (Medical University Innsbruck)
- **Neuroophthalmology & -otology** | Nese Celebisoy (Ege University)
- **Pain** | Martin Rakusa (University Medical Centre Maribor)

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

- **Multiple Sclerosis & Neuroimmunology** | Celia Oreja-Guevara (Hospital Clínico San Carlos de Madrid)
- **Muscle & NMJ disorders** | Maria Judit Molnar (Sемmelweis University Medical School)
- **Infectious diseases** | Pille Taba (University of Tartu)
- **Neurooncology** | Anette Storstein (Haukeland University Hospital)
- **Neuropathies** | Christian Krarup (University of Copenhagen)

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

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

**10:30 – 10:45** Coffee Break

**10:45** Plenary Session (open for everybody)

- **Report of the four groups**  
Four chairs as above

**11:45** Concluding remarks

**12:15** End of the event

## PARALLEL SESSIONS

### Track 2

**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

**12:15** End of the event



This project has received funding from the European Union's Horizon 2020 Framework Programme for Research and Innovation under the Specific Grant Agreement No. 945539 (Human Brain Project SGA3).

**[humanbrainproject.eu/education](https://humanbrainproject.eu/education)**

