



## 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** 





## **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:**

Further information & registration:

workshop.edu@humanbrainproject.eu www.humanbrainproject.eu/education/ebrains-workshops/medicaldata

Organised by:



Human Brain Project Education Programme

#### In cooperation with:



#### Sponsored by:



## **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 (CHUV)
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



Track 1 (on-s	Track 1 (on-site & virtual)				
	FEDERATION USE CASES				
8:30 - 10:00	Parallel session 1: Dementia Chairs: Jean-François Demonet & Gilles Allali   Centre hospitalier universitaire vaudois				
8:30 - 9:00 9:00 - 9:30 9:30 - 10:00	The spectrum of data sharing in DementiaPJ Visser (Amsterdam Univ. Med. Centers)The MIP federation in DementiaMélanie Leroy (Université de Lille)EAN scientific panel on dementiaKristian Steen Frederiksen (Danish DementiaResearch Centre - Rigshospitalet - Copenhagen University Hospital)				
10:00 - 10:30	Coffee Break				
10:30 - 12:00	Parallel session 3: Traumatic Brain Injury Chairs: Matthew Abrams   Karolinska Institutet & Stefano Finazzi   Mario Negri Institute for Pharmacological Research IRCCS				
11:00 - 11:30	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				
12:00 - 13:30	Society for the Study of Neuroprotection and Neuroplasticity (SSNN)) Lunch Break				
<b>13:30 – 15:15</b> Chairs:	Parallel session 5: Stroke Anna Bersado   Fondazione IRCCS Istituto Carlo Besta & Charlotte Cordonnier   Université de Lille				
13:55 – 14:20 14:20 – 14:45	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				
<b>15:45 – 17:15</b> Cha	Parallel session 7: Epilepsy irs: Reetta Kalviainen   Kuopio University Hospital & Tim von Oertzen   Kepler Universitätsklinikum				
16:15 - 16:45	Data sharing in epilepsyHelen Cross (University College London)The MIP federation in epilepsyPhilippe Ryvlin (Centre hospitalier universitaire vaudois)EAN Scientific Panel on epilepsyTim von Oertzen (Kepler Universitätsklinikum)				
17:15 - 18:45	Parallel session 9: Other/future use-cases				
	Chairs: Thomas Berger   Medical University Vienna & Arseny Sokolov   CHUV				
17:45 - 18:15	European Database on Narcolepsy and related hypersomniaYves Dauvilliers(University of Montpellier) & Ramin Khatami (Klinik Barmelweid)NeurorehabilitationLetizia Leocani (IRCCS Ospedale San Raffaele)NeuroCOVIDElena 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 | Maaike van Swieten & Jan Bjaalie (University of Oslo)
- 9:30 10:00 Ethics requirements for MIP usage

Erika Borcel (Centre hospitalier universitaire vaudois)

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)		

#### Lunch Break

	Parallel session 6: Data privacy Chairs: Jean-Louis Raisaro   CHUV & Yannis Ioannidis   University of Athens, Athena RC
13:30 - 13:55	
13:55 - 14:20	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 Chairs: Jan Bjaalie   University of Oslo & Yannis Ioannidis   University of Athens, Athena RC
15:45 - 16:15 16:15 - 16:45 16:45 - 17:15	What is federated analysisYannis Ioannidis (University of Athens, Athena RC)How to build and validate a federated algorithmJason Sakellariou (University of Athens)The MIP federated analyticsGiorgos Papanikos (University of Athens)
	Parallel session 10: Ontologies and knowledge graph Chairs: Jan Bjaalie   University of Oslo & Yannis Ioannidis   University of Athens, Athena RC
17:15 – 17:45 17:45 – 18:15 18:15 – 18:45	Ontologies for clinical neurosciences   Martin Hofmann-Apitius (University of Bonr 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)
	Field of Markets David

End of Workshop Day

#### 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)

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#### Coffee Break

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

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

11	:4	5
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#### Concluding remarks

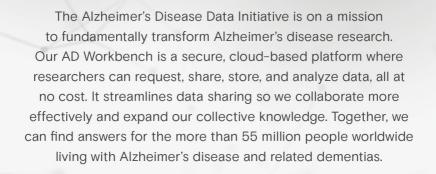
Thomas Berger & Philippe Ryvlin

## **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 09:50	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         Extracting regional brain volumes from the MIP MRI pipeline         Laith Abu-Nawwas & Carolina Ciumas				
10:10	<ul> <li>Data Analytics</li> <li>Laith Abu-Nawwas   Centre hospitalier universitaire vaudois</li> <li>Data Governance principle</li> <li>Current and new algorithms</li> </ul>				
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	<ul> <li>TBI Use Case</li> <li>Stefano Finazzi   Mario Negri Institute for Pharmacological Research IRCCS</li> <li>Selection of metadata and descriptive analyses</li> <li>Validation of prognostic models</li> </ul>				
11:45	Concluding remarks				
	Thomas Berger & Philippe Ryvlin				
12:15	End of the event				

# The AD Workbench is where collaboration drives innovation.



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







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# humanbrainproject.eu/education









