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Contents

1. Introduction.....	3
2. Promote the link to the European Research Infrastructure via the Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project	3
2.1. Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project.....	3
2.2. The European Research Infrastructure Consortium (ERIC) Forum.....	4
3. Promote the link to other relevant infrastructures within EBRA consortium.....	5
3.1. ERA-Net NEURON	5
3.2. EU-Joint Programme – Neurodegenerative Disease Research (JPND).....	6
3.3. EBRA workshop “Everything you always wanted to know about data-sharing’, March 17th, 2021, online7	
3.4. EBRA cluster RI liaison activities coordinated by the European Brain Council.....	9
3.4.1. EPICLUSTER.....	10
3.4.2. Prevention of Severe Mental Disorders (PSMD) cluster.....	11
3.4.3. TRISOMY21 cluster	11
3.4.4. Predictive Model Systems (PREMOS) cluster	14
3.4.5. European Cluster for Imaging Biomarkers.....	15
3. Conclusions.....	17

1. Introduction

Within the Work package 4: ‘Accelerate excellence, innovation and translation, and foster exchange by promoting Open Science’ six tasks addressed the relevant areas.

Specifically, task 4.5 ‘Promote the links to and use of infrastructures among researchers’ comprised the subtask 4.5.1 ‘Promote the link to the European Research Infrastructure via the Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project’. The motivation for this task is that strengthening the links between existing infrastructures is of major importance in terms of infrastructure tools and services, and that ensuring access to Europe’s best research infrastructures for all the community is fundamental.

In the subtask “4.5.2 Promote the link to other relevant infrastructures within EBRA consortium”, the EBRA partners also facilitated access to other relevant research infrastructures within its Network engagement opportunities with the research community and patient groups.

An overview of the activities can be found below.

2. Promote the link to the European Research Infrastructure via the Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project

2.1. Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project



CORBEL is an initiative of eleven new biological and medical research infrastructures (BMS RIs), who together created a platform for harmonised user access to biological and medical technologies, biological samples and data services required by cutting-edge biomedical research. CORBEL will boost the efficiency, productivity, and impact of European biomedical research. The CORBEL consortium brought together eleven major new Biological and Medical Research Infrastructures (BMS RI) in Europe. Their resources include biological data, physical biobank samples, imaging facilities and molecular screening centers:

- ELIXIR— European Distributed Infrastructure for life-science information
- BBMRI— Biobanking and BioMolecular resources Research Infrastructure
- EATRIS— European Infrastructure for Translational Medicine
- ECRIN— European Clinical Research Infrastructure Network
- EU-OPENSREEN— European Infrastructure of Open Screening Platforms for Chemical Biology
- EMBRC— European Marine Biological Resource Centre
- Euro-BioImaging— European Research Infrastructure for Biological Imaging
- Infrafrontier— Infrastructure for mouse disease models and phenotype data
- Instruct— Integrated Structural Biology unlocking the Secrets of Life
- ISBE— Infrastructure for Systems Biology Europe
- MIRRI— Microbial Resource Research Infrastructure

CORBEL aimed to:

- Establish and improve effective partnerships with user communities. The BMS RIs need to effectively interface with the scientists and projects within large and diverse user communities and science funding bodies. CORBEL will set up simplified access points and joined-up service catalogues to support outreach to these users across medicine and biology
- Develop unique solutions to user needs. Each of the participating BMS RIs provides pan-European access to specialised research services, instruments, data, samples and facilities that collectively cover life-science research, from basic biology to medical translation. CORBEL focuses on the integration of these capabilities into the scientific workflow of advanced users, ensuring that they respond directly to the needs of cutting-edge European science.
- Implement a portfolio of seamless, shared research infrastructure services. These services will facilitate user access to data, samples and instrumentation through common access policies and a shared resource portal and enable users to manage data across infrastructure boundaries. CORBEL will set up a training programme for RI operators and key users to drive the rapid implementation of shared services into the operation.
- CORBEL follows BioMedBridges—the first cluster project bringing the biomedical sciences research infrastructures together—and will build on its achievements.

The implementation of a match-making strategy with the CORBEL project and catalogue of ESFRI services was hampered by the fact that CORBEL ended in 2019. With the ERIC Forum (successor of CORBEL) the exchange was re-established. EBRA and CORBEL did plan to organize at least two face-to-face workshops dedicated to the EBRA clusters and institutional multipliers to highlight tools and services available, and to foster the development of use cases. After the end of CORBEL, this plan was accordingly modified and a number of tailored events designed, e.g., workshops, for the neuroscientific community and specifically the EBRA clusters.

The CORBEL annual (and final) conference took place with a reduced program (due to Corona pandemic travel restrictions) on March 3rd, 2020.

2.2. The European Research Infrastructure Consortium (ERIC) Forum

With the ERIC Forum (successor of CORBEL) the exchange was re-established. The ERIC Forum Implementation Project is a Horizon2020 project that brings together the ERIC community to strengthen its coordination and enhance collaborations between the partners. One of its major outcomes is to frame the necessary knowledge to support RIs interested to explore the ERIC legal framework and ERICs in preparation with various aspects.

The major objectives of the ERIC Forum Implementation Project are to:

- Strengthen coordination and networking reinforcing the informal ERIC network or its successor framework,
- Support the organisation of specific meetings, targeted thematic workshops focusing on shared challenges such as the development of internal procurement rules, harmonised reporting, VAT exemption practices, insurances and pensions policies and training of governance bodies representatives
- Support ERICs in preparation, based on best practices
- Support common communication and outreach activities and strengthen external representation of ERICs' as a stakeholder in consultations and other policy actions that could affect them.

DLR-PT presented at the ERIC Forum Policy Seminar on September 14th, 2020, by explaining EBRA and NEURON efforts to make the relevant Research Infrastructures better known to the scientific community. The specific

needs of the EBRA-funded 'clusters' (projects aiming at networking activities under a common topic and disease area) were discussed on a Policy Seminar on September 14th, 2020.

3. Promote the link to other relevant infrastructures within EBRA consortium

Within the EBRA consortium, the partners liaised with the following relevant infrastructures. In particular, the EBRA partners promoted access to and use of platforms such as the Human Brain Project (HBP) Neuroinformatics and Medical Informatics Platforms and the platform GridSAM through the JPND.

3.1. ERA-Net NEURON

2nd ESFRI – RIs – EOSC workshop, October 6th and 7th, 2020, online

The 2nd ESFRI – RIs – EOSC workshop took place on October 6th and 7th, 2020 as virtual event, and NEURON informed the community by placing this event prominently on its website and e-mail circular to NEURON funded researchers and cluster heads.

The European Strategy Forum on Research Infrastructures (ESFRI) is a strategic instrument to develop the scientific integration of Europe and to strengthen its international outreach. The competitive and open access to high quality Research Infrastructures supports and benchmarks the quality of the activities of European scientists and attracts the best researchers from around the world. ESFRI operates at the forefront of European and global science policy and contributes to its development translating political objectives into concrete advice for RI in Europe.

European Open Science Cloud- Life (EOSC-Life) brings together the 13 Life Science 'ESFRI' research infrastructures (LS RIs) to create an open, digital and collaborative space for biological and medical research. The project will publish 'FAIR' data and a catalogue of services provided by participating RIs for the management, storage and reuse of data in the European Open Science Cloud (EOSC). This space will be accessible to European research communities.

NEURON symposium, January 27th, 2021, online

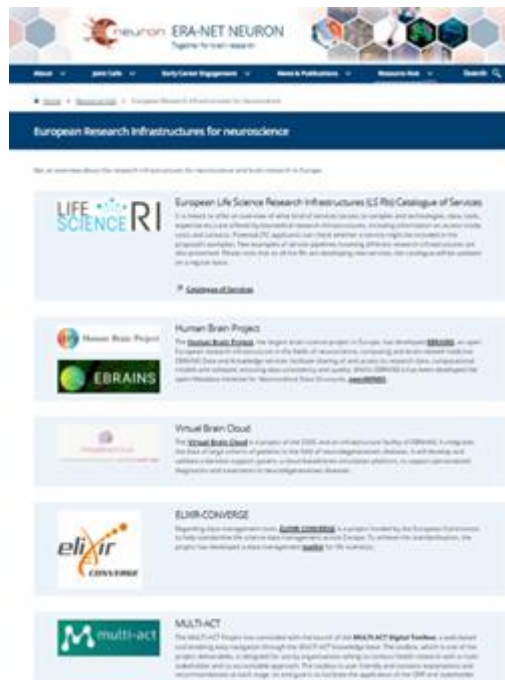
At the NEURON symposium on January 27th, 2021, the panel discussion on '[Data sharing, legal and ethical aspects in brain research](#)', was organized and talk/discussion videos and the booklet are available.

European Biomedical Research Infrastructures' resources for Researchers in Neurosciences, February 1st and 3rd, 2022, online

A specific webinar was organised by NEURON on February 1st, and February 3rd, 2022, termed European Biomedical Research Infrastructures' resources for Researchers in Neurosciences. The webinar addressed the different resources that several European Biomedical Research Infrastructures, such as ELIXIR, EBRAINS and INFRAFRONTIER, can offer to the researchers in Neurosciences. This webinar was prominently announced on NEURON's website, and an announcement was published on the EBRA landing page. The [webinar](#) is listed on NEURON's event calendar and the talks were recorded so that the content and speakers descriptions are available to any interested user.

NEURON website

Besides the practical events, the relevant RIs are constantly presented on a specific NEURON website.



3.2. EU-Joint Programme – Neurodegenerative Disease Research (JPND)

Within JPND, there is a dedicated task on “Innovative strategies for the creation and alignment of infrastructures and tools”. The leader of this task is Prof. Etienne Hirsch (INSERM). The aim of this task is to increase harmonization and standardization of imaging in the field of neurodegenerative diseases at the European level by reducing fragmentation of research activities and duplication of scarce resources.

The following actions have been undertaken within JPND.

Encourage researchers to involve ESFRI in project proposals

In 2019, JPND call texts explicitly encourage applicants to involve ESFRI in their project proposals.

Synthesis of working groups activities (JPND-sponsored meeting December 6th, 2019, Paris)

7 working groups supported by JPND came together with EU infrastructures EATRIS, ECRIN, as well as the Canadian Dementia Imaging Protocol (CDIP) and the HBP. The aim of the meeting was for the working groups to discuss the alignment, the future developments and issues of brain imaging they identified, and to share their recommendation in the framework of future JPND actions. There are needs for standardized definitions and protocols, for harmonisation of efforts and for increased dissemination to promote adoption by the neuroscience community. The field of brain imaging is committed to improve standardization and alignment of imaging methods, protocols and databases and the imaging community is eager to contribute to EU-sponsored endeavours in this direction. It was suggested to develop infrastructures designed with and for researchers that could support existing imaging data repositories, issue recommendation and help with ethical and legal questions. Existing infrastructures, such as ECRIN and the EOSC (European Open Science Cloud) EU consortium, together with CDIP and HBP are likely to be key partners for such actions.

Creation of an EBRA-funded cluster on Imaging biomarkers (ECIB)

The JPND-funded imaging working groups¹ were mobilized together to apply to the European Brain Research Area call for cluster. The resulting endeavor called ECIB (European Cluster for Imaging Biomarkers) and led by Pr. Thilo Van Eimeren and Pr. Stefano Cappa was successful and funded by EBRA. This cluster gathers 6 JPND brain imaging consortia, 1 JPND cohort, 1 IMI consortium and 2 H2020 consortia. Five associated partners were also implicated: CATI (Multicenter Neuroimaging Platform), BioFINDER (Swedish Multicenter Biomarker Study), DZNE NNN (German Neuroimaging Network), RIN (Italian Multicenter Neuroimaging Platform) and JPND board. The cluster also involved partners from ERA-Net so this endeavor initiated in the specific context of neurodegenerative disorders ultimately benefits imaging for other brain diseases such as neuropsychiatric and neurodevelopmental disorders. EBRA funding facilitated actions that advance the alignment and harmonization of imaging in neurodegenerative disorders. These actions incorporate networking events where members of the cluster are able to tackle different issues that currently limit the standardization and alignment of imaging in neurodegenerative disorders. Specific topics to be addressed include data handling (anonymity, GDPR compliance, storage, sharing), standardization of image processing and analysis (including big data approaches), availability of tools and resources, as well as the establishment of consensus criteria for the evaluation of imaging biomarkers utility for each neurodegenerative disorder.

Meeting with EBRAINS' French representative Philippe Vernier, November 15th, 2021

A meeting with EBRAINS' French representative Philippe Vernier took place on November 15, 2021, to present JPND missions toward alignment and harmonization on imaging in neurodegenerative diseases and discuss the potential contribution of EBRAINS to this endeavour based on the expertise of this ERIC in analytical tools development for imaging, big data handling and storage. They pursue these efforts with Eurobioimaging and Elixir which also have a recognized expertise in medical imaging, data handling and storage

JP-cofuND 2 intermediate symposium in Brussels on April 29th, 2022

Presentations of EOSC-life and EBRAINS at the JP-cofuND 2 intermediate symposium in Brussels on April 29th

Next actions

The next actions for JPND in 2022 are to see the involvement of ESFRI in JPND-funded projects by:

- Performing a survey on the use of ESFRI in JPND-funded projects
- Calls concerned: 2018 (last call without explicit mention of ESFRI) and following

The objectives: are to measure, inform, and leverage:

- To provide quantitative data on the use of ESFRI in JPND-funded projects since 2018
- To identify scientific domains/calls with differential involvement of ESFRI
- To assess how knowledgeable researchers are regarding ESFRI and their added value to their projects
- To identify further actions to increase awareness on ESFRI and leverage their involvement with JPND

3.3. EBRA workshop "Everything you always wanted to know about data-sharing", March 17th, 2021, online

ERA- Net NEURON, HBP/EBRAINS and EBC co-organised the EBRA workshop "Everything You Always Wanted to Know About Data Sharing" which took place on March 17th, 2021, from 9:00 to 13:00. The workshop was specifically designed for EBRA's clusters to discuss overarching matters related to data-sharing and combined – among others - the issues Data-sharing in brain research (pre-clinical & clinical data), Data Governance: legal and

¹ In 2016, JPND launched the call "Working Groups for Harmonisation and Alignment in Brain Imaging Methods for Neurodegeneration". As part of JPcofuND, 7 working groups were supported by JPND.

ethical considerations, and Leveraging Medical Data-Sharing through federated analytics: the Medical Informatics Platforms (MIP) besides two presentations of the EBRAINS platform. The agenda can be found here below.

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
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

The outcome of this meeting was written down in a meeting report (see below).

"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 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.
- 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."

3.4. EBRA cluster RI liaison activities coordinated by the European Brain Council

The EBRA consortium promoted links to and use of infrastructures in the selection of the last 2 clusters: PREMOS and ECIB. In addition, EBC linked the EBRA clusters to infrastructures by inviting relevant EU-research infrastructure representatives to their activities and ensured that they addressed the topic of research infrastructures in their meetings.

3.4.1. EPICLUSTER

EPICLUSTER Consensus meeting, June 17th, 2020, online.

Representatives from the research infrastructure EBRAINS joined the consensus meeting of the EPICLUSTER and shared their perspectives. During this meeting, the research and coordinating objectives and priorities of EPICLUSTER and the invited stakeholders were discussed before and during the meeting. These include (1) facilitating infrastructure, data and bio sample sharing, (2) increasing translation of basic to clinical science, (3) joint funding initiatives of scale and (4) supporting the longer-term vision of a multi-stakeholder epilepsy research community. Here below, the infrastructure specific part of the consensus document can be found.

Infrastructures The different epilepsy projects have created unique bio sample and data resources. These remain largely siloed, however, and are not yet community resources. There is now an opportunity to create a European Epilepsy Data Ecosystem to harmonize resources and establishing efficient mechanisms to share and exchange preclinical and clinical data between groups and projects and access expertise outside the epilepsy field. Further opportunities exist for data science analytics of multi-omics data to identify novel targets for therapy. Establishment of cooperating preclinical laboratories could provide a network for drug validation to de-risk new drug development pipelines. The recently established ERNs offer a unique opportunity of a high expertise network of hospitals, to perform academic trials with innovative therapies, and share data, which were acquired during routine clinical work for data analytic sciences. Now, EPI-CLUSTER should maximize opportunities to collaborate with infrastructures outside the field (e.g., Human Brain Project (HBP), ELIXIR, European Pediatric Translational Research Infrastructure, EpiCARE etc).

EPICLUSTER General Conference, December 2nd, 2020, online.

The meeting brought together various FP7 and Horizon 2020 epilepsy projects with stakeholders to review progress and future directions in key research areas including genetics, biomarkers, therapeutics, co-morbidities and biobanks/resources. There were 91 attendees at the workshop. This included the complete EPICLUSTER leadership group, several of the affiliated members from other projects and patient representatives, members of EBRA and the invited speakers. Here below, the infrastructure specific part of the agenda can be found.

11:10 Thematic session II: Biobanks and databases

Chairs: S. Sisodiya (UCL, UK), K. Kobow (Friedrich-Alexander-Universität Erlangen-Nürnberg, Germany)

Short overview of the current status of research, impact and gaps to be filled – Session chairs

DESIRE – Isabella Brambilla (European Dravet Syndrome Foundation) *“The Dravet syndrome European Registry”*

EpiRNA – Morten Venø (Omics, Denmark) *“Every microRNA and their targets in human Temporal Lobe Epilepsy: the EpiRNA iCLIP database and more”*

EpiPGX – Roland Krause (U Luxembourg) *“Infrastructures from EpiPGX: now and the future”*

EPISTOP – Eleonora Aronica (U Amsterdam, Netherlands) *“Biobanking in Tuberous Sclerosis Complex: challenges and opportunities for understanding epilepsy and cognitive and behavioral comorbidities”*

EpiTarget – Albert Becker (U Bonn, Germany) *“Integrated human epilepsy biopsy bank – key precondition for biomarker characterization”*

EpiCARE – Davide Mei/Renzo Guerrini (U Florence, Italy) *“Genetic discovery platform <https://epicare.discoverynexus.org/>”*

Q&A – 15 mins

Shaping the future of epilepsy research in Europe, September 29th, 2022, hybrid (Brussels and online)

This meeting focused on the sustainability and the future of the EPICLUSTER and the European epilepsy researchers. What do they need/want next? One of the sessions focused on the “sustainability of projects, networks and infrastructures.” In total, 138 meeting participants signed up to join the meeting. The infrastructure specific part of the agenda can be found here below.

Session 4 Sustainability of projects, networks and infrastructures

15:05 – 15:15:	EBRAINS, a sustained European Research Infrastructure with direct impact on epilepsy research <i>Philippe Ryvlin, University of Lausanne/CHUV, CH</i>
15:15 – 15:55	Roundtable with EPICLUSTER leadership <i>Moderator: Frédéric Destrebecq, European Brain Council, BE</i>
15:55 – 16:00	Final comments and Close <i>David Henshall, RCSI/FutureNeuro, IE</i>
16:00 – 17:30:	Networking coffee

The meeting outcomes will be published as a meeting report:

Henshall et al. (under preparation): Shaping the future of European epilepsy research: final meeting report from EPICLUSTER.

3.4.2. Prevention of Severe Mental Disorders (PSMD) cluster

Implementing precision and preventive psychiatry in Europe, September 21st, 2022, hybrid (Brussels and online)

This event was designed to highlight the urgent need to address the lack of parity between mental and physical health in European funding and to aid navigation of barriers to implementation of precision psychiatry. 45 participants signed up to join the meeting. EBRAINS representative, Damian Okaibedi Eke, was invited to speak about “How to navigate the current and existing legal and data protection frameworks to implement precision psychiatry?” (see the infrastructure specific part of the agenda here below).

SESSION 2: Implementation of precision and preventive psychiatry

Chair: Paolo Fusar-Poli

15:20 - 15:35:	How to navigate the current and existing legal and data protection frameworks to implement precision psychiatry? <i>Damian Okaibedi Eke, The Montfort University, Leicester</i>
15:35 - 15:50:	Regulator perspective on precision psychiatry: Guideline development, stratification and regulation of biomarker qualification <i>Interview with Florence Butlen, European Medicine Agency</i>
15:50 - 16:00:	Questions from the audience

3.4.3. TRISOMY21 cluster

Thematic Workgroup on Down syndrome research priorities: Research infrastructures and biocollections, November 29th, 2021, hybrid (Barcelona and online)

On November 29th, 2021, the TRISOMY21-cluster came together in Barcelona (Spain) with representatives from EU research infrastructures, networks, cohorts, repositories, biobanks, patient associations, and relevant stakeholders, from funding agencies to industry. They discussed European infrastructures for DS research and biocollections.

In the morning, several EU Cohorts and Registries presented their work including Horizon 21 Consortium, the independent cohorts/bio sampling initiatives la Princesa Madrid, PoliClinico Gemelli Rome, French DS cohort Lyon, Defeating Dementia in Down Syndrome(DIDS) Cambridge, Down Alzheimer Barcelona Neuroimaging

Initiative (DABNI), Genetic Forms of Intellectual Disability and Autism Spectrum Disorders (GENIDA), and the European network of population-based registries for the epidemiological surveillance of congenital anomalies (EUROCAT). This was followed by presentation from the EU Biobanks: BioJEL Jerome Lejeune Foundation, LonDowns, European Bank for induced pluripotent stem cells (EBiSC), Telethon and Askion. Finally, they discussed together 1. How to structure registries/repositories/biollections for DS research; 2. How to incorporate all existing cohorts/samples in large efforts such as Horizon 21; 3. Issues with regards to collection and storage of relevant samples for DS research and 4. The need for harmonization and guidelines for biobanking in DS research.

In the afternoon, similar initiatives in the US (i.e., Alzheimer's biomarker consortium for Down syndrome (ABC-DS), The Alzheimer's Clinical Trial Consortium-Down Syndrome (ACTC-DS), the INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Project and the Data Management and Portal for INCLUDE (DAPI) project shared their knowledge and experience on how to set up, contribute to and use registries/repositories/biobanks. Then, the European Strategy Forum on Research Infrastructures (ESFRI) and Biobanking and BioMolecular Resources Research Infrastructure-European Research Infrastructure Consortium (BBMRI-ERIC) presented services and support they can offer to the Down Syndrome research community. The day finished with a round table open to all participants.

The meeting provided a clear view on the European landscape of research infrastructures in Europe. A lot of work has already been done but there is still too much fragmentation and the accompanying challenges. A roadmap has been created on how to move forward but we can capitalize on what has already been done for Down Syndrome research in the US. We need to start building Down Syndrome Research Infrastructures across the borders and coordinate the work in Europe and globally. The TRISOMY21 cluster will play a very important umbrella role in this effort.

41 in-person and online participants joined the meeting.

The agenda can be found here below.

10:00 – 10:05: Welcome – *M. Dierssen*, Chair of the EBRA TRISOMY 21 cluster; *K. Aarts*, Project Manager at EBRA

SESSION 1: State of the art: EU cohorts/repositories/biobanks for DS research

Moderators: *Mara Dierssen, Marzia Perluigi, Marie-Claude Potier, Eugenio Barone*

10:05 – 10:10 Introduction – *Marie-Claude Potier*

10:10-11:25 **EU Cohorts and Registries**

10:10-10:20 **Horizon 21 Consortium** *Anne-Sophie Rebillat (TriAL21)*

10:20-11:15 **Other independent cohorts/biosampling:** *Diego Real de Asua, Angelo Carfi, Damien Sanlaville, Rafa de la Torre, Johannes Levin, Shahid Zaman, Isabel Barroeta, Pauline Burger*

11:15-11:25 **Eurocat:** *Joan Morris*

Coffee break: 11:25 – 11:45

11:45 – 12:15 **EU Biobanks**

BioJEL Jerome Lejeune Foundation *Sophie Durand*
LonDowns *Andre Strydom*
EBiSC *Julia Neubauer*
Telethon: *Luca Sangiorgi*
Askion *Stefan Chabierski*

12:15 – 13:15 **Round Table open to participants**

Chairs: *Marie-Claude Potier & Andre Strydom*

Ségolène Aymé, Angelo Carfi, Sophie Durand, Joan Morris, Anne-Sophie Rebillat, Luca Sangiorgi,

- ♦ How to *structure* registries/repositories/biollections for DS research? How to incorporate all existing cohorts/samples in large efforts such as Horizon 21?
- ♦ Issues with regards to *collection and storage* of relevant samples for DS research
- ♦ The need for *harmonization and guidelines* for biobanking in DS research

13:15 – 14:30: *Lunch*

SESSION 2:How to set up, contribute to and use registries/repositories/biobanks.

Learning from existing infrastructures

Moderators: *Mara Dierssen, Marzia Perluigi, Marie-Claude Potier, Eugenio Barone*

14:30-14:35 **Introduction** - *Eugenio Barone*

14:35-15:15 **The USA experience**

14:35-14:45 **ABC-DS** *Laurie Ryan*

14:45-14:55 **The Alzheimer's Clinical Trial Consortium-Down Syndrome (ACTC-DS)** *Lotta Granholm*

14:55-15:05 **The INCLUDE Project** (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE). *Melissa Parisi*

15:05-15:15 **The DAPI Project** (Data Management and Portal for INCLUDE (DAPI)) *Joaquin M Espinosa*

15:15- 15:35 **European Infrastructures**

15:15- 15:25 **ESFRI** *Radislav Sedlacek*

15:25- 15:35 **BBMRI-ERIC:** *Jens K. Habermann*

15:35 – 16:35 **Round Table open to participants**

Chairs *Marzia Perluigi and Juan Fortea*

Moderators *Pat Clark, Melissa Parisi, Tim Raemaekers, Hella Lichtenberg, Sylianos Antonorakis, Andre Strydom, Stephanie Sherman, Philippe Amouyel*

16:35 *Closing remarks*

The outcomes of this meeting have been written down in a meeting minutes report.

4th TRISOMY21 cluster event: Patient Involvement in European Down Syndrome research, October 10th, 2022, hybrid (Brussels and online)

During the final meeting of the TRISOMY21 cluster, the newest advances on data sharing, registries and bio samples in Down syndrome research were discussed as well as the engagement of people with Down syndrome and their families in research. The aim was to share the news on science and to better understand the needs people with Down syndrome that should drive further projects. 30 participants joined the meeting of which EBRAINS CEO Paweł Świeboda.

The agenda can be found here below.

11:30 – 11:35:	Welcome and introduction <i>Mara Dierssen, Centre for Genomic Regulation (CRG), Barcelona, Spain</i>
11:35 – 11:45:	Recent Advances in Down Syndrome and European Health Data Space <i>Mara Dierssen, Centre for Genomic Regulation (CRG), Barcelona, Spain</i>
11:45 – 11:55:	Data Sharing: The Federated European Genome-Phenome Archive <i>Babita Singh, Centre for Genomic Regulation (CRG), Barcelona, Spain</i>
11:55 – 12:10:	Patient Involvement in Brain Research <i>Joke Jaarsma, European Federation for Neurological Associations</i>
12:10 – 12:20	A central European Registry for Neurology <i>Joke Jaarsma, European Federation for Neurological Associations</i>

Open Discussion: What can patients do and how?
With patient representatives and TRISOMY21 cluster members

12:20 – 12:25:	Advancing brain health: cognitive activation with non-pharmacological methods <i>Jo Lebeer, University of Antwerp, Belgium</i>
12:25 – 12:30:	Registries: what are the problems, and opportunities. <i>Andre Strydom, Kings College London, UK</i>
12:30 – 12:35:	Bio samples: opportunities and benefits. Are we yet there? <i>Eugenio Barone, Sapienza University of Rome, Italy</i>
12:35 – 12:40:	Patient involvement. Advocacy groups, guidelines <i>Pat Clarke, European Down Syndrome Association</i>
12:40 – 13:15:	Roundtable
13:15 – 13:30:	Next steps and actions <i>Mara Dierssen, Centre for Genomic Regulation (CRG), Barcelona, Spain</i>
13:30 – 14:30:	Networking finger lunch

The outcomes of this meeting will be published in a high level peer review journal:

Potier et al. (submitted). Improving research for advancing treatments in Down syndrome. *Lancet Neurology*.

3.4.4. Predictive Model Systems (PREMOS) cluster

The PREMOS cluster is formed based on several large networks and current EU funded consortia, which join forces to propel disease modelling capacities and expertise for neuroscience research in Europe and beyond. One of those networks is the INFRAFRONTIER Research Infrastructure (www.infrafrontier.eu).

INFRAFRONTIER is the European Research Infrastructure (RI) for the generation, phenotyping, archiving and distribution of model mammalian genomes. The INFRAFRONTIER RI provides access to first-class tools and data for biomedical research, and thereby contributes to improving the understanding of gene function in human health and disease using the mouse model. The core services of INFRAFRONTIER comprise the harmonised systemic phenotyping of mouse mutants in the participating mouse clinics, and the archiving and distribution of mouse mutant lines by the European Mouse Mutant Archive (EMMA). In addition, INFRAFRONTIER provides specialised services such as the generation of germ-free mice (axenic service) and training in state-of-the-art cryopreservation and phenotyping technologies. The INFRAFRONTIER GmbH coordinates as a non-profit organisation the transnational activities of the national partners that together form the European INFRAFRONTIER

RI. Thus, the INFRAFRONTIER GmbH coordinates the Horizon2020 funded project INFRAFRONTIER2020, which comprises 29 partners across the EU and Canada including three SMEs. The INFRAFRONTIER GmbH currently evolves towards a European Research Infrastructure Consortium (ERIC) strongly supporting the sustained operation of the RI. INFRAFRONTIER is an ESFRI prioritized Research Infrastructure Landmark project4.

INFRAFRONTIER representatives took actively part in each PREMOS meeting.

1. 1st PREMOS cluster event: 3 working groups on the translational Models of Animal Models
 - Working Group 1, March 19th, 2021, online
 - Working Group 2, July 1st, 2021, online
 - Working Group 3, October 11th, 2021, in-person (Brussels)
2. Stakeholder meeting on translational value of animal models, April 1st, 2022, online
3. Policy meeting, September 22nd, 2022, hybrid (Brussels and online)

3.4.5. European Cluster for Imaging Biomarkers

The European Cluster for Imaging Biomarkers (ECIB) forges a complementary and synergetic harmonization alliance across major European consortia, networks and platforms engaged in multicentric collection, curation, transfer, and analysis of “big-imaging-data”. The ECIB ambition is to achieve transformative leaps in the translation of “big-imaging-data”-research into scientific and medical innovations by creating critical synergies between neuroimaging projects at both European and global level. In the big picture, we aspire to become instrumental in unlocking the full potential of new tools, technologies, and digital solutions for a healthy society.

ECIB has formed a highly inclusive Cluster of “big-imaging-data” projects from JPND, Horizon2020, and IMI. These projects are supplemented by National Neuroimaging Platforms of France, Italy and Germany and one of the largest national multicentric imaging biomarker consortium, the Swedish BioFINDER Study. This Cluster will weave together large European projects of different entities (Consortia, Networks, and Platforms) for a common greater goal: deploying latest advances in data science, computing, and imaging technologies to develop imaging biomarkers supporting personalized diagnostics and treatments in brain disorders.

Several cluster members are actively involved in the European research infrastructures (e.g., EBRAINS).

The 2 activities organised by the ECIB were focused on the sharing of brain imaging data:

1. Leadership meeting to develop a survey on the sharing of brain imaging data, May 10th, 2021, online
2. Consensus meeting, April 7-8, 2022, hybrid (Brussels and online)

Here below, the agenda of the consensus meeting is shown.

Day 1, 7 April 2022, 12:00 - 17:30 CET

12:00 - 13:00	Lunch
13:00 - 13:05	Welcome by the European Brain Council (EBC) <i>Prof. Wolfgang Oertel, EBC president</i>
13:05 - 13:10	Welcome by the European Cluster for Imaging Biomarkers <i>Prof. Thilo van Eimeren, MD, University of Cologne, Germany</i> <i>Prof. Stefano Cappa, MD, University Institute for Advanced Studies and IRCCS Mondino Foundation, Pavia, Italy</i>
13:10 - 13:15	Introduction to the European Brain Research Area (EBRA)

Kristien Aarts, PhD, European Brain Council

13:15 - 13:25

Introduction to ECIB cluster

Prof. Stefano Cappa, MD, University Institute for Advanced Studies and IRCCS Mondino Foundation, Pavia, Italy

13:25 - 13:30

Q & A

13:30- 13:50

Open science in future funding calls

Konstantinos Repanas, Policy officer at the Open Science Unit, EC Directorate-General Research and Innovation (DG RTD)

13:50 - 14:00

Q & A

14:00 - 14:20

Presentation of the ECIB survey: Aim, methodology and results

Kathrin Giehl, PhD, University of Cologne, Germany

14:20 – 15:00

Discussion of the survey results

All

15:00 – 15:30

Coffee break

15:30 – 15:40

Why should I share my data with everyone? The need for a new scientific currency

Prof. Thilo van Eimeren, MD, University of Cologne, Germany

15:40 – 16:10

Discussion and positions around the need for incentives

All

16:10-16:20

How can I share my data with others? Current challenges and options for sharing brain imaging data

Prof. Stefano Cappa, MD, University Institute for Advanced Studies and IRCCS Mondino Foundation, Pavia, Italy

16:20-16:50

Discussion and positions around data sharing

All

16:50-17:00

Summary and wrap up

19:00 – 22:00

Dinner

Day 2, 8 April 2022, 9:00 - 12:00 CET

09:00- 10:00

Consensus 1: Main obstacles of sharing brain imaging data

10:00-10:40

Coffee break

10:40-12:00

Consensus 2: Recommendations for the future

12:00-13:00

Lunch break

13:00 – 15:00

Writing of the final report on positions and recommendations regarding sharing brain imaging data in online repositories report with a smaller group

Prof. Thilo van Eimeren, Prof. Stefano Cappa, Kathrin Giehl, PhD

And others who are interested to help

The outcomes of this meeting will be published in a high-level peer review journal: Kathrin Giehl, Henk Mutsaerts, Kristien Aarts, Frederik Barkhof, Svenja Caspers, Gaëlle Chetelat, Marie-Elisabeth Colin, Emrah Düzel, Giovanni Frisoni, Arfan Ikram, Jorge Jovicich, Silvia Morbelli, Wolfgang Oertel, Christian Paret, Daniela Perani, Konstantinos Repanas, Petra Ritter, Bàrbara Segura, Laura Wisse, Elke de Witte, Stefano Cappa, Thilo van Eimeren (under preparation). Sharing brain imaging data in the Open Science era. How and why?

3. Conclusions

In conclusion, utilization of Research Infrastructures (Ris, see Table 1) still needs support from all sides, e.g. from the ERIC Forum by providing comprehensive information on all available RIs including procedural, technical and financial aspects, and also from funding organisations by promoting the knowledge of RIs. The feedback by participants at the interactive events was very positive, but often also they were surprised on the opportunities and available tools and technology. A continuous effort is thus required to bring the RIs to the researchers' attention and *vice versa*.

Table 1. List of European Research Infrastructures that were involved in the EBRA activities

Coordinated Research Infrastructures Building Enduring Life-science Services (CORBEL) project
Human Brain Project (HBP) Neuroinformatics Platform, Medical Informatics Platforms, Virtual Brain Cloud, Human Intracerebral EEG Platform
Platform GridSAM
European Distributed Infrastructure for life--- science information (ELIXIR)
Biobanking and BioMolecular resources Research Infrastructure (BBMRI)
European Infrastructure for Translational Medicine (EATRIS)
European Clinical Research Infrastructure Network (ECRIN)
Infrastructure for mouse disease models and phenotype data (INFRAFRONTIER)
European Research Infrastructure Consortium (ERIC) Forum
European Strategy Forum on Research Infrastructures (ESFRI)
European Open Science Cloud- Life (EOSC-Life)
EBRAINS
Multicenter Neuroimaging Platform - CATI
German Neuroimaging Network - DZNE NNN
Italian Multicenter Neuroimaging Platform - RIN
Canadian Dementia Imaging Protocol (CDIP)

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