

participants and collected a wide range of cognitive, clinical, neuroimaging and biomarker data to help further our understanding of the early stages of Alzheimer’s disease. EPAD has made this database open access and publicly available to the research community through the EPAD LCS Research Access Process (ERAP).

On 10 March 2021, EPAD has released a report presenting an analysis of applications made to access the EPAD data and samples. This first bulletin covers applications made between May 2019 and January 2021.

A total of 125 applications was processed between the reporting period. 93% of applications was approved, while 5% was withdrawn and 2% was denied. Reasons for an application being denied include the identity of an applicant cannot be established or the applicant is named as a co-applicant on an already approved application.

There are three types of requests. “Data only” accounts for about 56% of the total applications received. About 31% of the researchers requested for the “MRI scans” whereas 13% of the researchers were interested in “biological samples”.

It is also interesting to note that about 65% of applications received came from researchers within EPAD partner organisations while 35% of the applications were from researchers outside of the EPAD partner organisations.

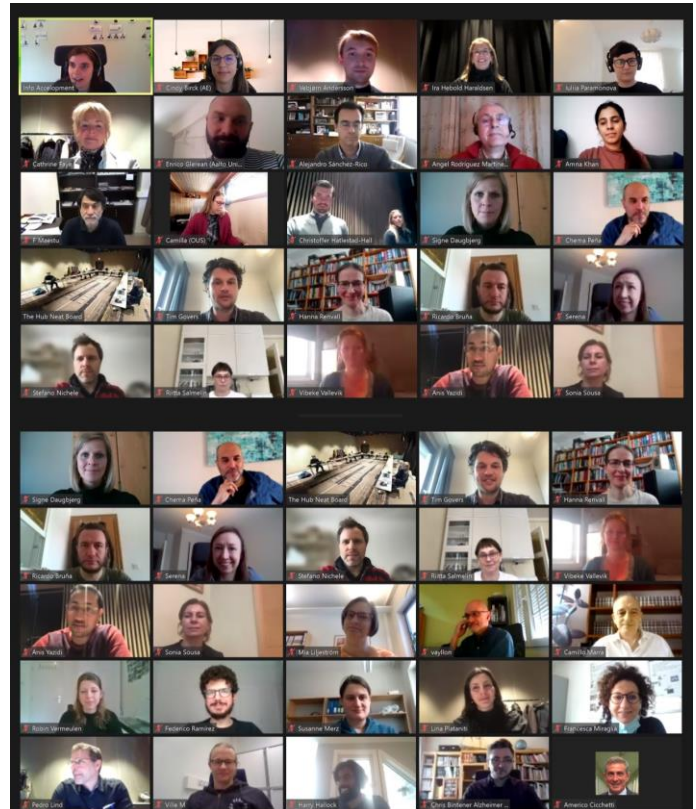
<http://ep-ad.org/2021/03/10/epad-releases-its-first-data-and-sample-access-bulletin/>

**11 March: AI-MIND convenes its kick-off meeting online**

On 11 March, the new H2020-funded project AI-Mind kicked off in an online meeting. AI-Mind aims to facilitating a paradigm shift in clinical practice. AI-Mind will create intelligent digital tools for screening of brain connectivity and dementia risk estimation in people affected by mild cognitive impairment.

During its lifecycle, two new artificial intelligence-based digital tools will be developed by AI-Mind. The AI-Mind Connector will identify dysfunctional brain networks, and the AI-Mind Predictor will assess dementia risk using data from the Connector, advanced cognitive tests, and genetic biomarkers. These two tools will be integrated into an intelligent diagnostics platform to identify both brain network disturbances and dementia risk, creating personalized patient reports for further intervention recommendations.

Ira Haraldsen (Oslo University Hospital, OUS, Norway) coordinator of the AI-Mind project, kicked off the meeting by welcoming almost 50 project contributors to the meeting. Following on from the introductory session, each work package lead had the opportunity to introduce its objectives and involvement in the project. All 15 partners of the consortium actively participated in the online meeting.



Alzheimer Europe will be involved in the ethics, Patient and Public Involvement (PPI) and communication activities of the project. Jean, Angela, Cindy and Chris took part in the meeting.

Visit the project’s website for more information:

<https://www.ai-mind.eu/>

**12 March: The World-Wide FINGERS Network organises an online meeting**

World-Wide FINGERS (WW-FINGERS) is an interdisciplinary network to share experiences, harmonise data and plan joint international initiatives to reduce risk of cognitive impairment or dementia.

On 12 March, Miia Kivipelto and Maria Carrillo welcomed almost 100 WW-FINGERS Network members to an online meeting. They provided insights into the network both internally as well as in the context of the global pandemic. They also highlighted that it is great to see how the WW-FINGERS Network has been growing reaching more than 30 countries, with the recent inclusion of two countries Luxembourg and Turkey.

The goal of the meeting was to continue the conversation on the SARS-CoV-2 survey within the WW-FINGERS network. Six members shared the progress surveying study participants in South-Korea, Singapore, Japan, Netherlands, Argentina and Cuba. They also shared their experiences on the survey including challenges, lessons learned, barriers and facilitators. These updates could be useful for countries, which have not yet launched the survey to address potential challenges and determine strategies.

Next, opportunities for dissemination such as presentations or special sessions at the Alzheimer’s Association International Conference (AAIC) and the Clinical Trials on Alzheimer’s Disease (CTAD) conference were mentioned.

Jean Georges, Executive Director, and Cindy Birck, Project Officer, of Alzheimer Europe attended the meeting.

**18 March: The final EPAD dataset is now available on the Alzheimer’s Disease Workbench**



The European Prevention of Alzheimer’s Dementia (EPAD) consortium, in their partnership with Aridhia, are proud to announce that the EPAD V.IMI

dataset has been incorporated into the Alzheimer’s Disease Workbench to provide even greater value to the global neuroscience research community.

The latest and final EPAD dataset went into open access to all researchers from over the world in November 2020 through the EPAD Research Access Process website. The final dataset is called Version.IMI (V.IMI) as it represents all the data collected and processed during the Innovative Medicines Initiative (IMI) funding period of EPAD. This contains the final longitudinal data including cognitive, clinical, biomarker and neuroimaging data sets from over 2,000 participants of the EPAD Longitudinal Cohort Study (LCS). Screening for the first participant in the LCS occurred in May 2016 and finished in early 2020. All 2,096 participants who consented and were included into the dataset are entered in this final V.IMI release.

EPAD is proud to partner with the Alzheimer’s Disease Data Initiative (ADDI) to help further the understanding of the early stages of Alzheimer’s disease (AD) and accelerate scientific progress. The V.IMI dataset has been incorporated into the Alzheimer’s Disease Workbench and is now available to ADDI researchers. This cloud-based platform has recently been launched to accelerate discoveries and innovations for AD and related dementias. The AD Workbench is guided by three main principles: increasing data sharing, easing data access, and developing new tools and analytics for researchers to use and share. It is open, inclusive, global and easy to use.

<http://ep-ad.org/2021/03/18/the-final-epad-dataset-is-now-available-on-the-alzheimers-disease-workbench/>

**22 March: New PARADIGM articles published**



In the last few months, two new articles have been published in peer-reviewed journals based on the work carried out by the Innovative Medicines Initiative (IMI) funded PARADIGM project.

The first article, entitled “Understanding multi-stakeholder needs, preferences and expectations to define effective practices and processes of patient engagement in medicine development: A mixed-methods study”, focuses on the needs

of different stakeholders when participating in Public Involvement activities in medicines development (i.e. in research priority setting, clinical trial design and early dialogues with Health Technology Assessment bodies).

The second article, entitled “Evaluation of patient engagement in medicine development: a multi-stakeholder framework with metrics”, describes how the PARADIGM monitoring and evaluation framework was developed and refined, and provides a few examples of how organisations in the project used the framework. Both articles were published in the Journal of Health Expectations and are available online (open access). Dianne Gove is a co-author of the first article, and Ana Diaz of both.

**22 March: Neuronet convenes 6<sup>th</sup> meeting of its Scientific Coordination Board**



On 22 March, the Innovative Medicines Initiative (IMI) funded Neuronet Coordination and Support Action convened the sixth Scientific Coordination Board meeting (SCB). The Board plays a central role in determining how Neuronet should direct its efforts. As leaders of IMI neurodegeneration projects, the SCB members bring wide-ranging scientific, clinical, R&D and computational expertise to the table, helping us to identify key challenges and priorities to address.

The meeting was attended by representatives of the AETIONOMY, ADAPTED, AMYPAD, EPAD, EMIF, IDEA-FAST, IMPRIND, Mobilise-D, MOPEAD, PHAGO, PD-MitoQUANT, PRISM2 and RADAR-AD projects along with members of the Neuronet consortium. Carlos Diaz, Coordinator of Neuronet, kicked off the SCB meeting by providing some general updates on Neuronet activities since the previous SCB meeting, which was held on 1 October 2020.

These activities include new updates and the public launch of the Knowledge Base & Asset Map, as well as our landscaping exercise of initiatives and gap analysis, collaborations between EPAD and PHAGO as well as IDEA-FAST and MOBILISE-D, among others.

Next, Pieter Jelle Visser introduced the European Platform for Neurodegenerative Diseases (EPND) consortium which is planned to be launched in the course of 2021.