Work Packages (WPs) of PRIME. Members of the Scientific and Ethical Advisory Board also attended the meeting, with representation from Alzheimer Europe and the International Diabetes Federation-Europe. During the meeting, each WP lead provided an update on progress towards milestones and deliverables, also identifying areas with challenges that need to be addressed. All WPs are making good progress, despite the complexities of undertaking research during the COVID-19 pandemic. The PRIME clinical study has started recruiting participants with Romano-Ward syndrome, a condition linked to insulin resistance and type 2 diabetes. Academic groups in Hungary, Italy and Germany are studying stem cell and animal models of type 2 diabetes and AD, while researchers in Denmark are analysing large clinical datasets to decipher the genetic links between metabolic and brain disorders. PRIME has also been developing materials to increase engagement of patient communities with the project, including webinars and information packs, and has also created an internal mentoring scheme to support the career development of junior researchers working on PRIME.

1 June: The AMYPAD Prognostic and Natural History Study reaches milestone of 1.000 research participants

The members of the Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD) initiative reached a significant milestone with the enrolment of the 1.000th research participant in its Prognostic and Natural History Study (PNHS). In this clinical study, researchers aim at understanding the role of amyloid imaging in the earliest stages of Alzheimer's disease to increase the chances of successful secondary prevention trials. The study recruits individuals suspected of possible Alzheimer's disease from various ongoing European parent cohorts.

Recruitment started in late 2018 and is expected to continue until March 2022. By the end of May 2021, 1.471 participants have been informed about the study, 1.001 consented, and 835 already underwent their amyloid PET scan. At this moment, the

PNHS has 17 active sites and 7 cohorts have been actively enrolling into the study (EPAD LCS, EMIF-AD, ALFA+, FACEHBI, FPACK, UCL-2020-412, Microbiota), with two other confirmed to begin enrolment soon. It has also been very rewarding, since a new cohort (Microbiota) has joined the AMYPAD PNHS study and started recruitment. Finally, the data integration process (from all data sources) and quality check of data has been initiated and the team has also conducted the first exploratory analyses of PNHS data.

9 June: The PRODEMOS project publishes its protocol paper

On 9 June, members from the Prevention of Dementia using Mobile phone Applications (PRODEMOS) project published a

paper in the journal BMJ Open, explaining the design of their international randomised controlled trial.
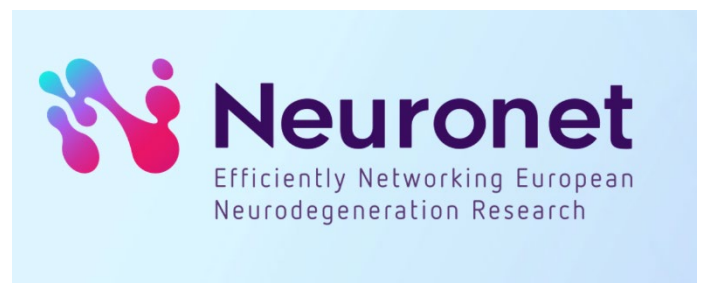
The PRODEMOS study is investigating the effectiveness and implementation of a coach-supported mHealth intervention on dementia risk in older people at increased risk of dementia from a low socioeconomic population in the UK and from the general population in Beijing, China.

People aged between 55 and 75 who own a smartphone and have at least two dementia risk factors are able to take part in the study. The intervention and follow-up period are 18 months.

The paper also includes the results of the 6-week pilot study conducted in the UK, aiming to test the mHealth platform functionality and study logistics. The pilot study was evaluated with the participants and coaches. A similar pilot study has been conducted in China. The full trial started in March in the UK and in June in China.

Further information on the PRODEMOS project can be found here: https://www.prodemos-project.eu

11-17 June: NEURONET hosts meetings of its Patient Privacy & Ethics and Data Sharing working groups

Neuronet is an Innovative Medicines Initiative (IMI)-funded coordination and support action, designed to support and enhance collaboration between the diverse projects in the IMI neurodegeneration portfolio. In 2019, Neuronet launched four Working Groups (WGs), cross-project spaces for experts to discuss common issues, priorities and opportunities for synergy and collaboration. Each Neuronet WG is focused on a particular

area of concern for IMI Neurodegeneration projects: data sharing, ethics & patient privacy, sustainability and regulatory/HTA interactions.

In June, Neuronet convened online meetings of its WGs on data sharing and ethics & patient privacy. On 11 June, Jean Georges (Executive Director of Alzheimer Europe) moderated a meeting of the ethics & patient privacy WG, which was attended by ethics and data protection experts working on the EPAD, AMYPAD, RADAR-AD, MOPEAD, EMIF and AETIONOMY projects, among others. Discussions were focused on the ways in which ethical, legal and social issues are identified and addressed in public-private partnership projects, and how to enhance collaborations between industry and academic partners.

On 17 June, Lennert Steukers (Neuronet project leader) and Michaela Rinaldi co-moderated a meeting of the data sharing WG, attended by data experts from EMIF, EPAD, Mobilise-D, IDEA-FAST and RADAR-AD along other IMI projects. Recent efforts of the data sharing WG have focused on collating information on the barriers to data sharing in the public-private partnership setting, and outlining recommendations to overcome some of these obstacles. During the WG meeting, experts described some of the complexities involved in negotiating data sharing agreements and frameworks that comply with data protection regulations and intellectual property requirements.

The WGs will meet again in September, working towards the development of deliverable reports that compile and share learnings on their respective focus areas.

https://www.imi-neuronet.org/

15 June: The AI-Mind project invites healthcare professionals to participate in a survey on clinical practices related to mild cognitive impairment

The EU-funded AI-Mind project has launched a survey regarding the current clinical practices related to the diagnosis of mild cognitive impairment (MCI) and the needs for diagnostic tools to predict, at an early stage, who is likely to develop dementia.

The purpose of this survey is to capture information related to existing clinical guidelines, reimbursement schemes and challenges, as well as to identify the state-of-the-art tools used in European hospitals for screening, diagnosing, monitoring and collecting information on met and unmet needs for the early diagnosis of people with MCI.

The survey is opened to all healthcare professionals (e.g. clinicians, nurses, psychologists) working in the field of dementia and MCI across all European countries. The survey is available online and planned to run until 1 August. If you are interested in taking part, please click here: https://nettskjema.no/a/aimindsurvey

If you have any questions, please contact contact@ai-mind.eu

17 June: The VirtualBrainCloud project convenes an online General Assembly meeting

On 17 June, the H2020-funded VirtualBrainCloud project (TVB_Cloud) held its General Assembly meeting online, summarising recent project developments and discussing upcoming plans. Chaired by Prof. Petra Ritter of Charité University Hospital Berlin, the meeting was attended by over 50 project participants, including representatives from the 17 institutions and organisations that make up the TVB_Cloud consortium. Angela Bradshaw (Project Officer) represented Alzheimer Europe at the meeting.

The main goal of TVB_Cloud is to facilitate the personalised prevention and treatment of dementia, by creating a decision support system for clinicians. Based around a cloud platform for personalised brain simulations, this system will integrate data from multiple sources (e.g. brain scans, genetic screens and neuropsychological tests) in a secure online environment.

During the 17 June General Assembly (GA) meeting, TVB_Cloud Work Package leaders provided brief summaries of ongoing activities on data processing, disease progression models, computational brain simulations, and the software development that underlies these activities. The majority of the GA meeting was focused on describing sustainability options for the project, during which follow-up scenarios were outlined and key exploitable outputs were discussed. The next GA will be hosted in the autumn.

https://virtualbraincloud-2020.eu/tvb-cloud-main.html

21 June: EU-FINGERS and LETHE launch survey to collect views on early diagnosis and prevention of Alzheimer's disease

The EU-FINGERS and LETHE projects have launched a survey examining the perspectives of European memory clinic clinicians who are involved in the diagnostic work-up for dementia.

The survey is opened to physicians (e.g. neurologists, geriatricians, psychiatrists) and other health care professionals (e.g. nurses, psychologists, dietitians) working in memory clinics across all European countries, willing to share their thoughts and experiences on communicating about early diagnosis of Alzheimer's disease, biomarkers, dementia risk and prevention.

The survey is available online and planned to run until 20 August. If you are interested in taking part, please click here:

https://vumc.datacoll.nl/ogyvcwhbpj?l=en