

PRESS RELEASE

30 October 2018 : MOPEAD Symposium at Alzheimer Europe Conference

A Special Symposium was organised by MOPEAD (Models Of Patient Engagement for Alzheimer's Disease) at Alzheimer Europe's 28th conference, in Barcelona, on 30 October 2018. Over 75 conference delegates came to hear about these IMI-funded project strategies to identify individuals with mild cognitive impairment and prodromal Alzheimer in the community. The project preliminary findings were presented and discussed.

Mercè Boada (Fundació ACE and project Coordinator), presented MOPEAD's rationale: the need to change the paradigm in the disease continuum: Alzheimer's disease (AD) is still diagnosed too late, when the symptoms have appeared and become hard to manage. By evaluating four different patient engagement strategies (Citizen Science, Open House, Primary and Tertiary Care settings) in five European countries (Germany, Slovenia, Spain, Sweden and the Netherlands), the project will help understand the obstacles to early diagnosis, overcome the barriers to access symptomatic treatment and services, motivate citizens' participation in research and clinical trials.

The project is a two-stage process: a pre-screening is organised in the general population followed by a full diagnosis when a participant meets the diagnostic criteria. Patient pre-screening is in its mid-stage phase and already reveals challenges and opportunities. Octavio Rodríguez Gómez (Fundació ACE) showed that there are important differences in the recruitment efficiency across the strategies and countries. This is because the project operates in a modular way: the implementation of the patient engagement strategies did not start or finish at the same time. This is attributed to long Ethics Review Board review in some countries (Germany) and difficulties in reaching the required number of participants.

The Open House recruitment (in a Memory Clinic) is completed in three countries (Slovenia, Spain and Sweden). The success of this strategy can be explained by the fact that it is easy to implement from a logistic point of view (the MOPEAD investigators are in charge) and the participants are very motivated to participate (they have the opportunity to have their cognition checked and participate in research).

Although the Citizen Science strategy (on-line cognitive test and marketing campaign with an informative content) started late (July 2018), Adrián Rodrigo Salas (GMV) presented interesting results: already 15,000 people have visited the platform, over 600 citizens have completed the test and more than 120 citizens were referred to a memory clinic for further evaluation. Slovenia is the only country to have reached the required number of participants for pre-screening.

Recruitment in Primary Care and Tertiary Care settings (involving diabetologists) is running relatively slowly and shows differences between countries. Current results show that it is more difficult to engage PCPs. This is particularly the case in the Netherlands. Besides a possible negative PCP attitude towards early diagnosis of AD and limited time, the reasons are unclear. This is why a survey will be conducted among PCPs in Europe to identify the reasons for this low engagement. Equally, patient engagement in PCP setting also revealed that the general population seems to be

reluctant to undergo a diagnostic evaluation, even when the pre-screening shows possible cognitive impairment. The reason is that the person was not aware of memory problems prior to the pre-screening, and the fear to receive a diagnosis of AD when no effective treatment is available

Despite Type2 diabetes (T2D) patients having an almost two-fold higher risk of developing dementia than people without diabetes that have the same age, the Tertiary Care engagement strategy shows disappointing results. Besides Spain who has reached the required number of pre-screened participants, the other countries are lagging behind. Andreea Cuidin (Vall d'Hebron University Hospital) identified some of the challenges linked to this low engagement: the lack of engagement of the medical staff and patients who do not wish to proceed to neuropsychological explorations, due to the presence of comorbidities. She identified some solutions that could help redress the situation: better motivate the medical staff, better explain to the patients the importance of an early detection of cognitive impairment in order to better adapt their hypoglycemic treatment (as hypoglycemia (low blood sugar induced by insulin) increases the risk by 2-3 fold).

The two salient pre-screening findings show that the Citizen Science and Open House strategies, where individuals voluntarily engage in the pre-screening, lead to a higher rate of individuals willing to receive a formal diagnosis. In the PCP and Tertiary Care settings, where PCPs and diabetologists identify individuals with possible MCI or prodromal AD, these latter did not want to have a full examination in a memory clinic and dropped-out of the project.

Annette Dumas (ASDM Consulting) presented the communication material that has been produced to support the patient recruitment. A set of user-friendly infographics presenting the project and engaging citizens to participate, the value of a timely diagnosis, the risk factors to develop AD, the differences between normal ageing and dementia aim at educating the public about AD, redress misconceptions and break stigma. They include Calls to Action to citizens to mind their memory and visit a doctor or a memory clinic if they are worried about their memory. The infographics' messages are gathered in a more detailed 'Educational Leaflet', including more information about AD, commonly used terminology, a graph presenting the development of the disease and three persons with dementia testimonies about the value of diagnosis. The project video, a more dynamic and engaging presentation of MOPEAD, was presented at the beginning of the Symposium.

The Symposium ended with a Call to Action: it is paramount to engage citizens, healthcare professionals and patients organisations to raise awareness about the value of early diagnosis of AD.

Why MOPEAD?

MOPEAD will contribute to the imperative to find interventions to halt AD. Dementia affects over 35 million people globally, a figure set to rise to over 115 million by 2050 due to the ageing of the population. AD puts a huge and growing burden on health and social systems, and the families and carers of those affected. Despite decades of research, there is still no treatment nor cure for the disease. It is therefore crucial to develop new interventions that will help identify hidden cases of AD. MOPEAD will do this through evaluating four patient engagement strategies and providing new insights for therapeutic interventions in clearly identified populations.

MOPEAD will respond to the urgency of finding interventions to halt AD by stimulating a faster recruitment of patients into clinical trials.

MOPEAD partners are Fundació ACE Institut Català de Neurociències Aplicades, Eli Lilly and Company Ltd, ASDM Consulting, AstraZeneca AB, European Institute of Women's Health, GMV Soluciones Globales Internet S.A.U., Karolinska Institutet, Modus Research and Innovation Ltd, Spomincica—Alzheimer Slovenia, University Hospital of Cologne, University Medical Centre Ljubljana, Fundacio Hospital Universitari Vall D'Hebron—Institut de Recerca, Stichting VUmc, Alzheimer Europe.

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It does this by facilitating collaboration between the key players involved in healthcare research, including universities, pharmaceutical companies, other companies active in healthcare research, small and medium-sized enterprises (SMEs), patient organizations, and medicines regulators. This approach has proven highly successful, and IMI projects are delivering exciting results that are helping to advance the development of urgently needed new treatments in diverse areas.

IMI is a partnership between the European Union and the European pharmaceutical industry, represented by the European Federation of Pharmaceutical Industries and Associations (EFPIA).

Through the IMI 2 programme, IMI has a budget of €3.3 billion for the period 2014-2024. Half of this comes from the EU's research and innovation programme, Horizon 2020. The other half comes from large companies, mostly from the pharmaceutical sector; these do not receive any EU funding, but contribute to the projects 'in kind', for example by donating their researchers' time or providing access to research facilities or resources.

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