



MOPEAD newsletter

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This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under Grant Agreement No 115985. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations

LOOKING AHEAD, THREE YEARS OF MOPEAD JOURNEY



MOPEAD was born from the need that we, as neurologists, saw when it came to diagnosis. Times change and so do people who we diagnose. Everyday citizens are more aware of their memory and some can feel changes in it with ageing. We need to give an answer. We need to lead the way to a healthier ageing

in the near future. And there is where MOPEAD can bring hope.

All the learnings the project has given, the data and knowledge it has generated, will provide new paths for citizens, for researchers, for policy makers as well as for other stakeholders involved.

This is our legacy. This is what we want Europe to remember about the MOPEAD project. That we have opened new ways for citizens to be involved and for memory clinics to lead through cooperation.

Memory matters and it is a good that countries, in Europe and beyond, must protect.

Mercè Boada, MOPEAD project leader, Founder and Medical Director of Fundació ACE, Institut Català de Neurociències Aplicades

Passion, scientific method and a true spirit of collaboration have characterized MOPEAD for the past 3 years, since its kick off in 2016. What a journey.



Challenging yes, but also fantastic learnings bringing great value to both scientific and policy communities, with the ultimate goal to support who is impacted by Alzheimer's disease in Europe.

An earlier diagnosis can give people with Alzheimer's disease and their families 'more time' and the opportunity for intervention, including involvement in Clinical Trials. MOPEAD offered the opportunity to talk about the value of timely diagnosis in a compelling way, through constructive scientific, policy and cost efficacy evaluations. It explored innovative ways to approach early engagement in Alzheimer's disease,

through citizen's participation, in a diverse array of Health Care Systems.

A 3 years' journey that brought a breadth of knowledge that will serve Policy, Science and Research and we are honoured to have been part of it.

Laura Campo, MOPEAD project leader, International Corporate Affairs, Alzheimer's disease at Eli Lilly and Company

MOPEAD HELPED US TO GROW

At the University Hospital Cologne, we had very positive experiences with the MOPEAD project. In total, 321 participants carried out the pre-screening at our site. We received meaningful feedback from participants who were part of the project and their families. The interest in an easily accessible cognitive work-up became especially apparent in the Open House strategy and therefore, we aim to explore whether a similar procedure could be introduced at our clinic in the future. In contrast, we learned that there are still many challenges to an online approach, which would need to be faced if such a strategy were to be implemented in Cologne.



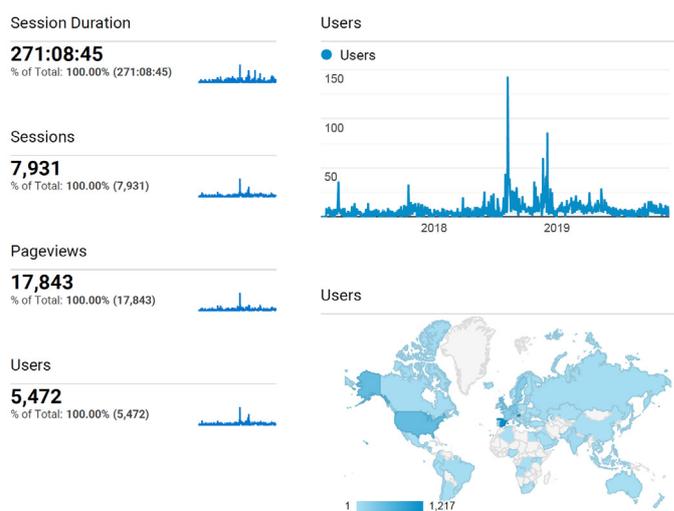
The project resulted in valuable cooperation with local general practitioners and dialectologists, some of which are very interested in further research activities. In addition, MOPEAD helped to raise visibility for the Cologne Alzheimer's Prevention Center, which was launched in the beginning of 2019. In the future, we want to build on this cooperation and continue working together to promote the value of timely diagnosis and prevention strategies for AD.

Working on MOPEAD was a great opportunity to learn more about patient engagement in different European countries. We want to build on the experiences and cooperation that were established within the project and continue to raise awareness about the benefits of timely diagnosis.

Frank Jessen

AWARENESS RAISING AND EDUCATION CAMPAIGN AND EXTENT OF PATIENT ENGAGEMENT

MOPEAD built its successful patient engagement strategies on top of awareness raising and education campaign. A variety of communication material have been produced to reach out to a wide audience through various communication channels: project website, social media, public meetings (conferences, meetings), publications, newsletters and press releases. The central communication channel was MOPEAD Project website (<https://www.mothead.eu/>). During the project 5520 website users from 90 different countries spent altogether 270 hours on the MOPEAD website, viewing 17,894 pages. All posted on MOPEAD's website: infographics (<https://www.mothead.eu/infographics>), a standalone page on the dementia symptoms has been added (<https://www.mothead.eu/symptoms>), as well as another page giving tips for coping with the disease (<https://www.mothead.eu/tips-for-coping>).



MOPEAD patient engagement strategies overview

The **Online Citizen Science Campaign** (sometimes called “Run 1”) was one of the most innovative patient engagement strategies developed by MOPEAD. In this strategy, an online test was developed and deployed in the area of each MOPEAD site and an online marketing campaign promoted the test to target users who may be searching the web for queries related to their memory health. By the end of the recruitment period over 1,400 citizens across all MOPEAD sites had taken the online test, suggesting the huge potential value of this sort of application for citizens in Europe.



1 Neuropsychological online test.

The **Open House Initiative** (sometimes called Run 2), was one of MOPEAD's most successful patient engagements strategies. In this strategy, the MOPEAD sites invited the general public to their centres to be screened by neurologists and neuropsychologists for mild cognitive impairments through advertisement campaigns on a local level. The initiative was very well received by citizens in all five countries, with over 600 citizens attending the Open House screenings across all MOPEAD sites. This strategy also proved the most effective in engaging citizens in further memory evaluations, as participants were motivated to take part in the project.



2 Neuropsychological test conducted at a memory clinic.

The **Primary Care Campaign** (sometimes called “Run 3”) proved to be an extremely informative study at all MOPEAD sites. This strategy set out to identify citizens with cognitive impairment in the primary care setting and to conduct training and awareness programmes among Primary Care Physicians (PCPs) at each MOPEAD site. Over 400 citizens were pre-screened by PCPs participating in the MOPEAD study across each site and almost 100 citizens who were screened positive for mild cognitive impairment agreed to further evaluation at the memory clinics. While the sites did not all reach their goals for recruitment, this strategy has proved to be a very valuable study and has led to a “spin-off” study conducted by the University Hospital of Cologne on GP attitudes towards timely diagnosis of mild cognitive impairment.



3 Neuropsychological test carried out by general practitioners.

The **Tertiary Care Campaign** (sometimes called “Run 4”) implemented cognitive pre-screening of patients with type 2 diabetes mellitus by endocrinologists. This strategy was challenging to implement as while diabetic patients in the tertiary care setting have a high risk of cognitive impairment, they are usually patients with other severe diseases and complications. Over 50 citizens took part in this

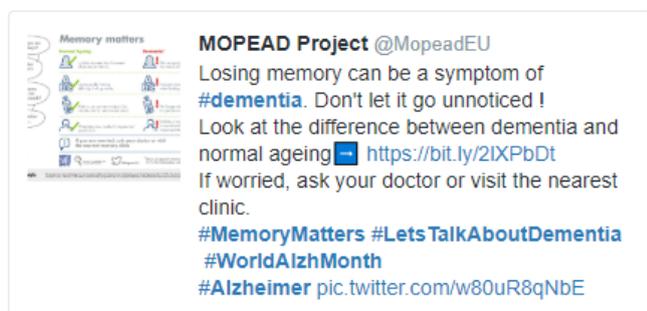


4 Neuropsychological test given to patients diagnosed with type 2 diabetes.

strategy across all sites, of which a high percentage presented high risk of cognitive impairment and were eligible for further study. Further education is needed for both patients and the diabetes care providers about cognitive impairment as a complication of type 2 diabetes, as early detection of AD in these patients is particularly important due to the great impact of the disease's symptoms on diabetes control.



MOPEAD Projects World Alzheimer's Month 2019 Campaign with key messages about the importance of timely diagnosis and about the importance of engaging the general population in their memory health. To support these campaign messages, the campaign would use communication materials developed by the project which are located on the project website. A high engagement rate was observed throughout the period, and MOPEAD content received collectively over 12,000 impressions on the Twitter platform ([@MopeadEU](https://twitter.com/MopeadEU)).



MOPEAD's Tweets frequently surpassed the industry benchmark in terms of engagement by using varied and engaging content such as videos, infographics and images related to the project. MOPEAD also successfully inserted itself into the conversation surround World Alzheimer's month by using appropriate hashtags and drawing attention to relevant articles.



MOPEAD PATIENT ENGAGEMENT STRATEGIES KEY WINS

Ethics MOPEAD raised a number of ethical and social issues that required particular attention: in seeking to identify novel approaches to patient engagement, MOPEAD explored a new territory, involving the development of procedures which include the use of well-established tests and approaches but which were applied in situations where participants were attracted in ways that are relatively new. This called for reflection about possible ethical issues, some of them being closely related to very specificity or uniqueness of the project design. The project's ethical challenges were discussed by the Consortium members and external ethics advisors. This led to a number of recommendations to guide the recruitment strategies. This work will be shared with the public in an article that will be published in 2020. (open access)

Cost-effectiveness of MOPEAD's patient engagement strategies An evaluation of the cost-effectiveness of MOPEAD's four patient engagement strategies was made. The project's methodological challenges implied that the cost effectiveness of MOPEAD needed to be considered from a broad view-point. It appeared that the most cost-effective patient engagement strategy identifying people with cognitive impairment was in the Tertiary Care setting, followed by Primary Care. However, these care settings have capacity problems for dementia diagnostics. The Citizen Science and Open House can be more cost effective after modifications and adjustment. The full evaluation and conclusions will be presented in an article to be published in 2020. (open access)

General practitioners survey During the course of the project, a survey was designed to assess GPs' attitude towards early and AD diagnosis and explore potential barriers to timely diagnosis. All sites were invited to participate by sharing the survey with the GPs locally. Overall, more than two thirds of GPs held the view that an early diagnosis at the very early dementia stage or before dementia at the stage of mild cognitive impairment (MCI) was of value. They also held the view that the benefits of an early diagnosis outweighed the risk (58% for patients vs 71% for caregivers). The barriers to timely diagnose the disease included the perception that currently available pharmacological treatment options presented no benefit or low benefit. Lack of time was another factor, with a country-specific difference though showing that a higher proportion of Swedish GPs indicated they have sufficient time.

The perception of reimbursement of diagnostic procedures differed between sites. In contrast to the other countries, reimbursement was indicated as insufficient by the majority of GPs in Slovenia and Germany, which might be explained by differences in the reimbursement procedures. For example, German GPs receive a fixed amount per patient and per quarter of the year, independent of the number of visits per quarter. Other barriers included the lack of confidence regarding diagnostic procedures. For instance, the number of GPs who felt less confident was higher in Germany compared to other sites and lower in the Netherlands. Non-pharmacological treatment options were widely accepted by GPs, with 85% considering them as beneficial. However, a high proportion of the respondents also indicated that they are not sufficiently available. In summary, this survey gave an overview on GPs' attitudes on early and pre-dementia diagnosis in five European countries and provided insight into the handling and perception of timely diagnosis.

Sex and Gender Policy Brief Women are at the epicentre of the Alzheimer's crisis as patients, caregivers and family members. Alzheimer's disease disproportionately impacts women as patients, caregivers and family members. Women are more likely than men to develop, live with and die from AD. Across all EU Member States, more women have AD than do men (Alzheimer Europe, 2017; OECD/EU, 2018; EIWH, 2019). Women also experience AD differently than do men. Both biological influences and social factors have been shown to affect brain health and AD risk (EIWH, 2019). Women comprise the majority of both formal and informal caregivers of those with AD (Alzheimer's Disease International, 2014; Alzheimer's Disease International & Karolinska Institute, 2018). Thus, women disproportionately experience the burden of AD. The MOPEAD Project is contributing to the inclusion of sex and gender in AD research and policy. Sex and gender integration in AD prevention, diagnosis treatment and care can help support people affected by the disease as well as their family and carers. MOPEAD is producing a Gender Policy Brief (D5.6) that recognises the impact of Alzheimer's disease on women as patients, carers and their families. The brief explores both the biological and social factors with regard to sex and gender that impacts the development, diagnosis, progression, treatment of Alzheimer's disease. The brief targets key stakeholders in particular policy makers, healthcare professionals and patient, and it includes concrete steps for action to reduce sex and gender inequities.

The brief will be available online and distributed to key stakeholders at the end of 2019.

At the end of the projects two documents complementary to each other were produced:

1) **public education and aware-raising strategies**

Models Of Patient Engagement for Alzheimer's Disease
Moving towards earlier diagnosis of Alzheimer's disease
PUBLIC EDUCATION/AWARENESS RAISING STRATEGIES



Alzheimer's disease (AD) is a societal challenge that will be exacerbated in the future. It is the most common form of dementia (70% of the cases). It is a major cause of disability and dependency. In 2018, it was estimated that 7% of the population over 60 were affected by dementia in the European Union (EU). Age being a risk factor, this number is expected to rise to 8% by 2040 due to the ageing of the population. The disease generates significant costs that are a challenge to the sustainability of the healthcare services. It is therefore imperative to find new interventions to halt the AD burden.

There are still too many undiagnosed cases of AD in Europe despite the fact that its early diagnosis is cost-effective¹.

AD has a preclinical stage when it is probably the best moment to intervene²: people with early AD (mild cognitive impairment (MCI) due to AD and mild AD dementia) remain outside of clinical settings and the diagnosis rates are low. The subjective cognitive decline paradigm can identify individuals at risk of developing cognitive impairment.

Dementia researchers are increasingly focusing their efforts on finding ways to prevent the onset of dementia symptoms in the first place. For this, they need to reach people who are still in the very earliest stages of the disease through raising awareness of general population, health care professionals and decision makers to design and implement the best preventive strategies.

Several modifiable risk factors have been identified, that can be used for preventive multi-domain strategies or to identify high risk populations.

The cultural and socio-economic diversity between countries (including the healthcare systems that are basically different) imply that the best patient engagement strategy could be distinct for each country.

Reaching out to the relevant stakeholders

The urgency to tackle AD shows us the need to raise awareness about AD and dementia among a large spectrum of stakeholders (citizens who may be developing the disease without being aware of the symptoms, the health professionals who are not equipped with sufficient knowledge to be able to detect the disease or feel confident about talking about the disease, the work-place, businesses, policy makers...). Specific attention must be paid to women as a population disproportionately affected by the disease (as patients, carers and professionals) and presenting higher risks of developing the disease³.

There is value in raising awareness and educating the public about dementia, its symptoms, risk factors and prevention. This should be an on-going strategy, with clear messages and definitions, in lay language.

The value of a timely diagnosis must be clearly promoted (increased quality of life for patients and carers, cost benefits to society) while taking into account the ethical issues related to the disclosure of such a diagnosis and the specificities of each EU Member State (differences in the availability and access to support and treatment, reimbursement schemes).

Awareness and public education campaigns such as World Alzheimer's Day/Month, National Carers Day, International Women's Day are key to raise attention towards the topic and therefore chances of being heard.

The material produced by leading AD associations (Alzheimer's Disease International) or the World Health Organization (WHO), EU projects like MOPEAD opens a novel space for raising awareness and educating the public. Peer-testimonies are also an essential pillar to awareness and education strategies.

Understanding the basics of AD - citizens

Definitions - Messages	Target population
<ul style="list-style-type: none"> What is dementia? What are the symptoms? How is it diagnosed? What are the treatments available? What kind of support is available? What is the value of an early diagnosis? Are there ethical issues? Is there a genetic influence? 	<ul style="list-style-type: none"> General public Health professionals Businesses Policy makers

2) **recommendations for policy makers and regulators.**

They are a legacy to the project and will serve to continue raising awareness about the need to move towards early diagnosis of AD.

Models Of Patient Engagement for Alzheimer's Disease
Moving towards earlier diagnosis of Alzheimer's disease
RECOMMENDATIONS FOR POLICY MAKERS AND REGULATORS



Halting dementia and Alzheimer's disease (AD) is an imperative that calls for relevant policy action in the context of societal and economic challenges faced by the EU (aging of the population, increase in the number of persons likely to be affected by AD and the consequent increase in healthcare and social costs putting to danger the sustainability of the healthcare services).

Balance shows that the disease pathological process starts many years before clinical symptoms appear. This calls for the importance of identifying a disease-modifying therapy targeted at early AD (before cognitive impairment) (MCI) due to AD and mild AD dementia). Research has also brought evidence about risk factors and prevention strategies that could potentially delay the onset of the disease.

Some studies have evidenced the economic and social value of early detection of AD. However, an important proportion of people with mild dementia due to AD symptoms in need of care and treatment still are a timely diagnosis.

The early detection strategies tested and evaluated by MOPEAD have shown that it is possible to identify AD at risk-early stage. Based on MOPEAD work, research, policy makers and governments should implement strategies that could modify the disease in a broad scale and be ready if these modifying therapies reach the market.

MOPEAD has been instrumental in the sense that it has tested patient engagement models that have used non-traditional information, cost-effective and ethical approaches. It has been identified that when the paradigm to earlier diagnosis of AD, tackle societal challenges and remove barriers to innovation. The models tested were also instrumental in raising awareness of AD, necessary complex and cognitive decline risk in the general population.

Dementia and AD have been recognised as a public health priority at national, European and international levels. The international community's work towards the 2025 dementia goal is articulated around four key areas: Finding a disease-modifying therapy, living well with dementia, better care, and reducing the impact of dementia. Despite many efforts having been made, research funding still needs to be significantly increased to meet these four goals.

Overall policy recommendations

The overarching policy recommendation is to improve the early diagnosis of people with MCI or early AD. Not only will this improve the quality of life of people with AD and their carers, it will also prepare an environment that will readily benefit from modifying therapies for early stage AD that reach the market. This calls for a concerted approach involving civil society, patients, health professionals, industries, policy makers and governments, regulatory bodies.

Raising awareness about the disease, its symptoms, diagnosis, treatment, risk factors and prevention is the cornerstone to the care and quality of life for patients and carers and a powerful means to reduce the impact of the disease. Without thorough knowledge and understanding about AD among society, governments and policy makers, scientists, health care professionals, there is no hope to take action.

Developing early diagnosis of AD: governments need to adapt their health systems to facilitate the early identification of people with early AD, before the symptoms are too advanced. This will help respond to the urgency to reduce the burden of the disease currently on society and citizens. It will also help prepare the environment to be ready if disease-modifying therapies for early AD eventually reach the market. Early diagnosis also benefits society, providing access to available treatment options and support for patients and families.

Engaging patients to participate in clinical trials: the misconception that dementia is a normal part of life is a barrier to individuals getting a diagnosis, getting the health care support they are entitled to and being in control of their own lives. Involving patients in research, care and professionals in national, European and global policy work supports can contribute to eliminate stigmas around the disease and create strategies tailored to their needs.

Healthcare: improve access to care therapies: finding effective ways to reach patients' need to get access to therapies as soon as they have been approved and regulatory increased pressure on health budgets requires multidisciplinary discussions. Patients are experts with their disease and can bring valuable insight into therapies development and health technology innovation (HTI). They should be considered as partners in decisions made about their health.

Healthcare: empowering citizens to take care of their brain health includes being aware about risk factors and disease their risk of dementia must be halved. The growing evidence showing great progress in understanding why individuals may be able to reduce their risk of dementia must be halved. Therefore, the following recommendations should be embraced by national and European policy makers, the international community and regulators. They are geared towards MOPEAD's goal to shift the paradigm to early diagnosis of AD, engaging patients and carers at early stages of the disease and improving patients participation in clinical trials.

MOPEAD has tested and evaluated four patient engagement strategies in the EU countries (Germany, the Netherlands, Slovenia, Spain and Sweden): two whereby citizens actively performed a cognitive test: Citizens Science (online pre-screening tool), Open House (pre-screening tests performed in a memory clinic without a physician's referral) and two strategies for patients at risk, in which their cognition was tested in two settings: Memory Care setting (patients were identified and tested by their General Practitioner (GP)), Tertiary Care setting (the identification and tests were performed by neurologists specialised in treating Type 2 diabetes, a risk factor for AD). The persons considered of being at risk were then offered a full diagnostic assessment in a memory clinic that they were free to accept or refuse.

MOPEAD has helped address by studying two strategies whereby citizens actively performed a cognitive test: Citizens Science (online pre-screening tool), Open House (pre-screening tests performed in a memory clinic without a physician's referral) and two strategies for patients at risk, in which their cognition was tested in two settings: Primary Care setting (patients were identified and tested by their General Practitioner (GP)), Tertiary Care setting (the identification and tests were performed by neurologists specialised in treating Type 2 diabetes, a risk factor for AD). The persons considered of being at risk were then offered a full diagnostic assessment in a memory clinic that they were free to accept or refuse.

Overall, the Citizens Science and Open House strategies were attractive to recruit subjects to participate in pre-screening, in the Tertiary Care setting, it appeared more difficult to engage healthcare professionals in recruiting participants. Also, in Primary Care, it was somewhat problematic to recruit participants. Once identified as possibly presenting cognitive impairment, many subjects were often reluctant to get a formal diagnosis.

The most cost-effective patient engagement strategy identifying people with cognitive impairment was in the Tertiary Care setting, followed by Primary Care. However, these care settings have capacity problems for dementia diagnosis. The Citizens Science and Open House can be more cost-effective after modifications and adjustment.

The results of the survey among GPs, conducted during the project to evaluate their engagement in the diagnosis of dementia, revealed that more than two thirds held the view that an early diagnosis was of value and the benefits of an early diagnosis outweighed the risk. The barriers to earlier diagnosis of the disease included the perception that currently available pharmaceutical treatment options presented no benefit or low benefit, lack of time, lack of confidence regarding diagnostic procedures. The perception of reimbursement of diagnostic procedures differed between sites. Non-pharmaceutical treatment options were widely accepted (GPs considering them as beneficial) despite a high proportion of the respondents indicating that they were not sufficiently available.



The MOPEAD Models Of Patient Engagement for Alzheimer's Disease project is the first that in clinical practice, the diagnosis of AD at early stages was done in a memory clinic, the creation of a barrier to access available treatments and support services, as well as the opportunity to enrol in clinical trials at early stages of the disease.

The project responds to the cultural shift towards early diagnosis of AD, at the initial symptomatic stage of the disease, an indication of early AD is the first step toward providing patients with optimal opportunities for intervention and involvement in clinical trials.

MOPEAD will also positively influence public education about AD, memory complaints and cognitive decline.



The project has received funding from the Innovative Health Union (IHU) under grant agreement No 101019742. The lead authoring member of the European Union Horizon 2020 research and innovation programme of the European Union of Pharmaceutical Innovation and Health (EUPHIA) is the European Union of Pharmaceutical Innovation and Health (EUPHIA).

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OUR EXTERNAL ENGAGEMENT - 2019 END OF PROJECT EVENTS



Now that we are approaching the end of our four-year journey, we were already able to share some of our preliminary findings. The new Coordination and Support Action for the Innovative Medicines Initiative's research projects on neurodegeneration (Neuronet) organised a series of four parallel sessions at the Alzheimer Europe Conference in The Hague (Netherlands). Here we were also able to showcase some of the well-established connections with other projects such as the AMYPAD, EPAD and RADAR-AD consortia and to explain nominal differences in the participation in our different models throughout the five participating countries. Video recordings and

presentations of the four sessions are available on the [Neuronet website](#). We're also especially proud that our Project Coordinator Mercè Boada represents our MOPEAD project on [Neuronet's Scientific Coordination Board](#), providing insights on gaps in research related to Alzheimer's disease and supporting cross-project collaboration.

Our partners also organised a closing event as part of [Alzheimer Europe's Lunch Debate in December 2019](#), showcasing the learnings and recommendations from MOPEAD. We were glad to be able to make sure that



the findings that came out of the research conducted as part of our project were communicated to policy makers, ensuring that these have some clear examples of what can be done to help communities towards creating environments in which people can receive a diagnosis earlier in their disease cause.



Last but not least, we also participated in Alzheimer Europe's Alzheimer Association Academy where we shared preliminary findings with representatives of local Alzheimer's Organisations. This included presentations on:

- Citizen science – the role of online cognitive tests for the detection of dementia
- Involving general practitioners in dementia diagnosis
- What role for diabetologists in the diagnosis of dementia
- Open house initiatives at memory clinics to improve MCI and dementia detection

Publications on our findings are underway and in the meanwhile, the scientific community can already read about the details of our framework in Alzheimer's & Dementia the journal of the Alzheimer's Association. The publication introducing our project is entitled "The MOPEAD project: Advancing patient engagement for the detection of "hidden" undiagnosed cases of Alzheimer's disease in the community" and can be downloaded here: [https://www.alzheimersanddementia.com/article/S1552-5260\(19\)30072-X/fulltext](https://www.alzheimersanddementia.com/article/S1552-5260(19)30072-X/fulltext)



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