

Models of Patient Engagement for Alzheimer's Disease (MOPEAD): a European project to move Alzheimer's disease towards an early diagnosis



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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



What is its reason for MOPEAD being?

To better understand the obstacles to engagement patients for early diagnosis and treatment.

To establish successful strategies to overcome them.

To propose recommendations and guidelines

Our aim: develop a path towards remaining normal

Improving **timely diagnosis** through citizens' participation

Raising awareness of **HIDDEN** persons with cognitive decline

Provide strategies to plan actions aimed at **early detection**

MOPEAD: Generate data & share knowledge

Optimal phenotype diagnosis of AD

Optimal etiological diagnosis of AD

Journal of Alzheimer's Disease 34 (2013) 769–780
DOI: 10.1002/alz.12292
IOS Press

769

A Longitudinal Follow-Up of 550 Mild Cognitive Impairment Patients: Evidence for Large Conversion to Dementia Rates and Detection of Major Risk Factors Involved

Ana Espinosa^a, Montserrat Alegret^{a,*}, Sergi Valero^{b,c}, Georgina Vinyes-Junqué^a, Isabel Hernández^a, Ana Mauleón^a, Maitte Rosende-Roca^a, Agustín Ruiz^a, Oscar López^{d,e,f}, Lluís Tàrraga^a and Mercè Boada^{a,1}

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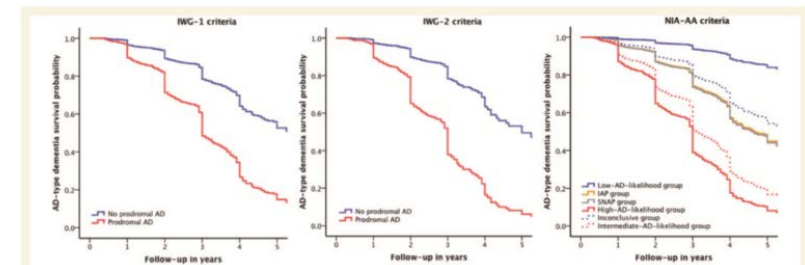
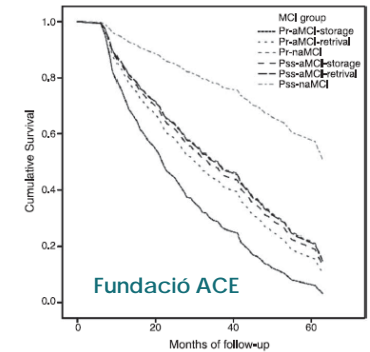


Figure 1 Alzheimer's disease-type dementia survival probability by the IWG-1, IWG-2 and NIA-AA criteria. The graphs represent the Alzheimer's disease-type dementia survival probability according to the IWG-1 (left), IWG-2 (middle), and NIA-AA (right) criteria, adjusted for age, gender, education and centre. IWG-1: The group without prodromal Alzheimer's disease represents subjects without memory

1330 | BRAIN 2015; 138; 1327–1338

S. J. B. Vos et al.

Using three new criteria



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MOPEAD consortium members

Partner	Country	Type of institution	Leader	Activities
Fundació ACE	Spain	Academic and clinical center	Mercè Boada	Management, clinical core, analysis, and dissemination
Eli Lilly and Company Ltd	UK	Pharmaceutical company	Laura Campo	Management, clinical core, analysis, and dissemination (H)
ASDM Consulting	Belgium	SME	Annette Dumas	Dissemination
Astra Zeneca	USA	Pharmaceutical company	Craig Shering	Clinical core (GMW)
European Institute of Women's Health	Ireland	NGO	Peggy Maguire	Dissemination
GMV Soluciones Globales Internet S.A.U.	Spain	IT company	Adrián Rodrigo	Clinical core and analysis
Karolinska Institutet	Sweden	Academic and clinical center	Bengt Winblad	Clinical core and analysis
Modus Research and Innovation Ltd	UK	Not-for-profit SME research organization	Neil Stewart	Management
Spomincica	Slovenia	Patient association	David Krivec	Dissemination
University of Cologne Medical Center	Germany	Academic and clinical center	Frank Jessen	Clinical core
University Medical Centre Ljubljana	Slovenia	Academic and clinical center	Milica Kramberger	Clinical core (L)
Vall d'Hebron Research Institute	Spain	Academic and clinical center	Rafael Simó	Clinical core (Run 4)
VU Medical Center	The Netherlands	Academic and clinical center	Pieter Jelle Visser	Clinical core
Alzheimer Europe	Luxembourg	Patient organization	Jean Georges	Management and dissemination



Alzheimer Europe (AE)

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MOPEAD SCHEMATIC ZOOM

4 different scenarios to engage citizens at risk of Alzheimer's disease (*pre-screening*)

Kick-off: October 2016
End: December 2019



Neuropsychological
online test



Neuropsychological test
conducted at a **memory clinic**

 3 years



Neuropsychological test
carried out by a **general practitioner**



Neuropsychological test
given to patients
diagnosed with type 2
diabetes by a **specialist**

 2.000
participants
(65-85 years old)

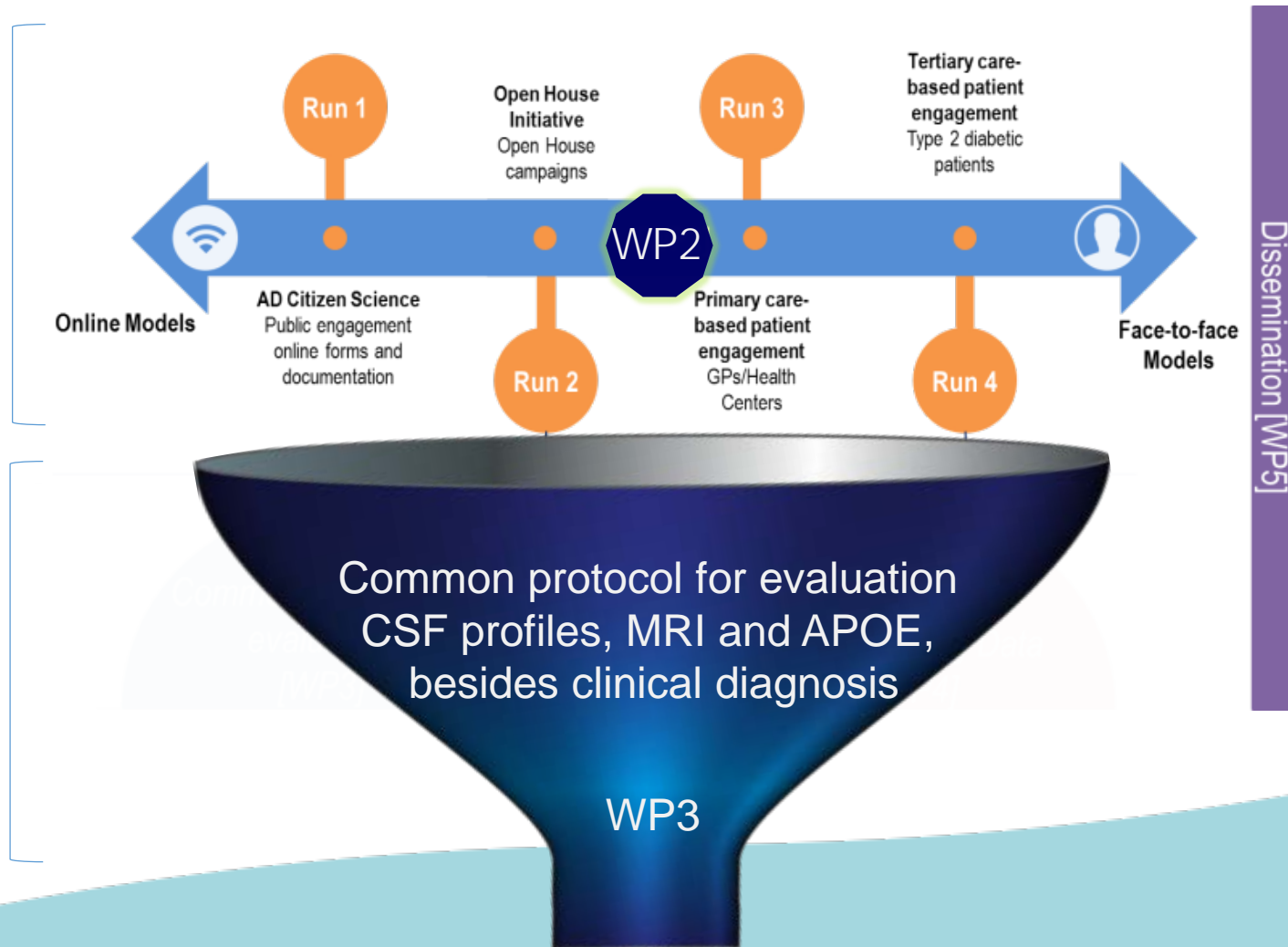
MOPEAD works like a funnel

PRE-SCREENING

2000 participants

SCREENING

660 participants



Screening models for recruitment

- Online citizen science platform
- Open house initiative @ memory clinics
- Primary care physician
- Diabetologist clinic

Common diagnostic protocol

- Establish diagnosis according to international criteria and validate previous screening stage

Data analysis

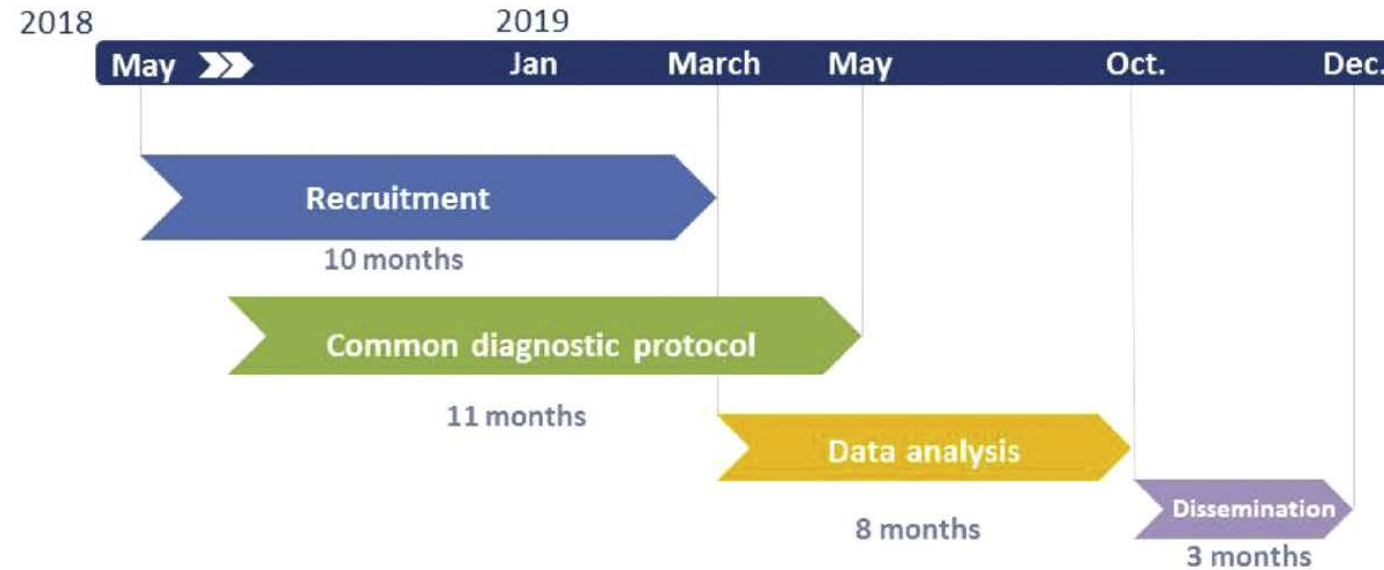
- Build models of effectiveness and cost efficiency of each patient engagement strategy and compare across centres and countries

Dissemination

- Distribute and advocate patient engagement models for their broader application

IMI-EFPIA MOPEAD

Cronogram & Activities



WP2: Pre-screening process (2000 participants)

Four different protocols. Each Run has its own specific protocol

AD Citizen Science

Inform consent
Demographics,
CANTAB-sub test

Total: 500 subjects
100 per country

Open House Initiative

Inform consent
Demographics,
MMSE,
SCD/ 3 Questions
FCSRT
HAD scale

Total: 500 subjects
100 per country

Primary Care Campaign

Inform consent
Demographics,
Clinical anamnesis
MMSE,
SCD/ 3 Questions
CAIDE Risk Score

Total: 500 subjects
100 per country

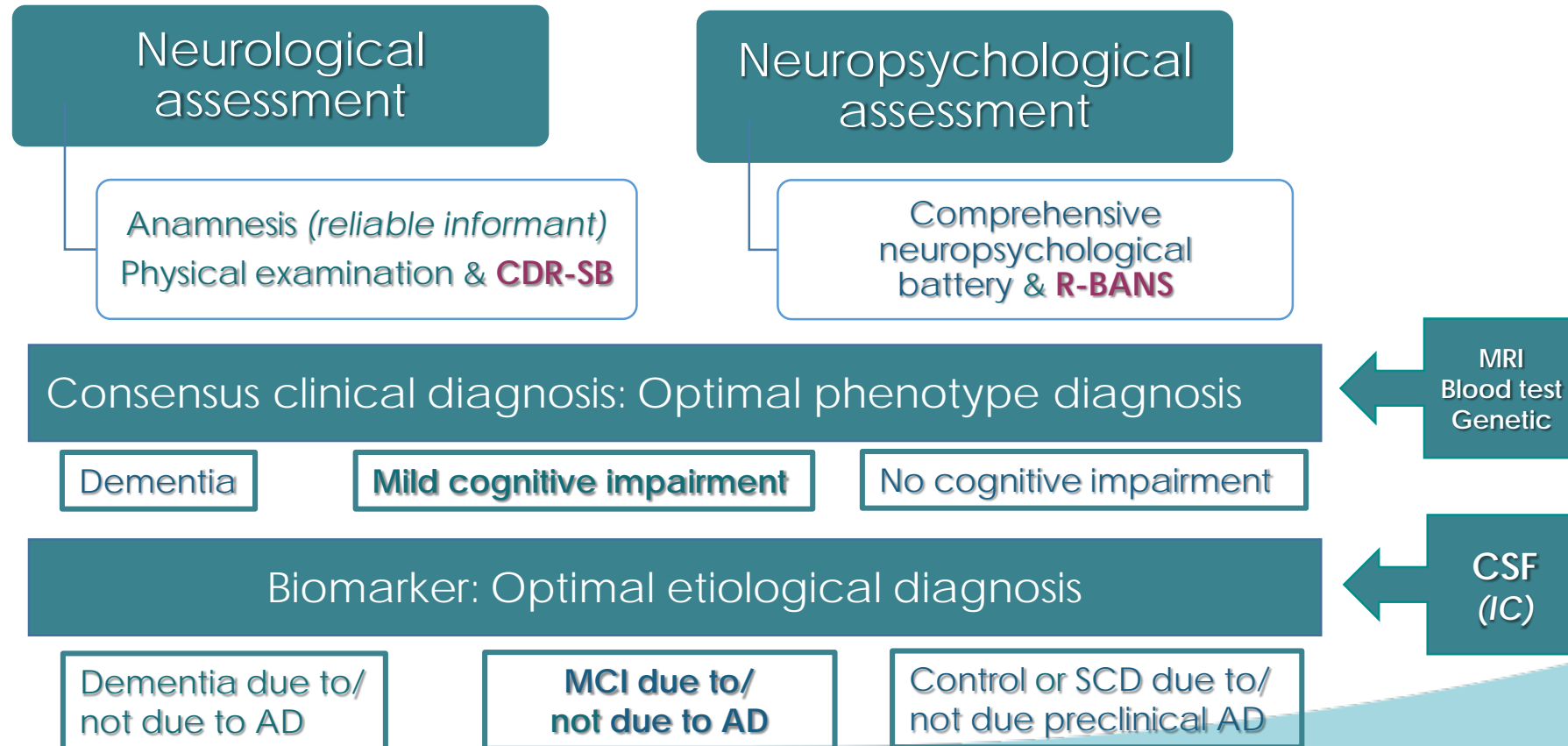
T2DM Campaign

Inform consent
Demographics
Clinical anamnesis
MMSE,
SCD/ 3 Questions
**Diabetes-specific
Dementia Risk
Score (DSDRS)**

Total: 500 subjects
100 per country

WP3: Screening process (660 participants)

Using established full diagnostic protocol to detect patients at risk of AD

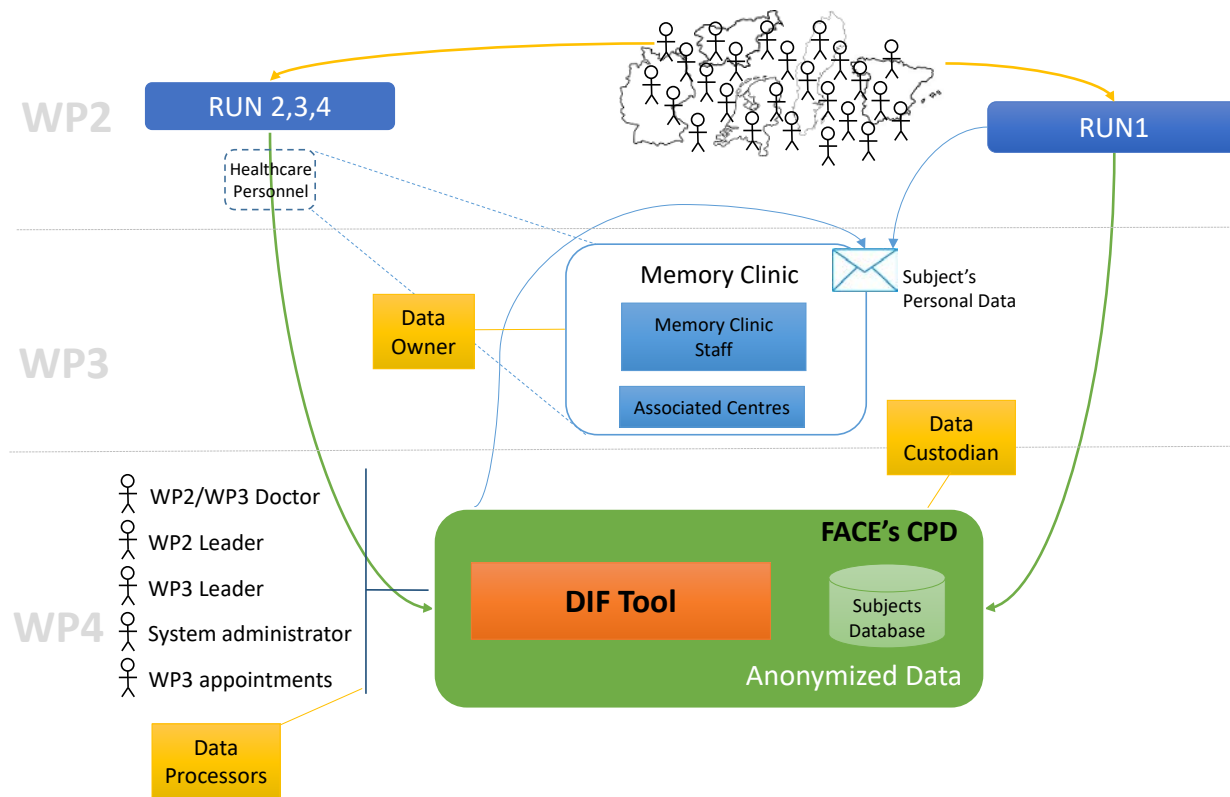


Strategies to evaluate efficiency of MOPEAD (WP4)

Data Management Plan Overview

- Input:
data from individuals

- Output:
results of the project



- Data Owner
- Data Custodian
- Data Processors
- Purpose of data collection

- ✓ Data transfer
- ✓ Data access
- ✓ Data storage and preservation

Roles, responsibilities and purpose of data collection

Subjects included up to today

	Total WP2	Total WP3	
RUN1	1487	87	
RUN2	661	155	+
RUN 3	435	94	+
RUN 4	264	56	+
Total	2,847	392 (+8)	29%

MRI final status

	MRI: Expected (660) and Performed (400/60%)					
	Germany	Netherlands	Slovenia	Spain	Sweden	ALL SITES
RUN1	5	6	30	31	19	91
RUN2	34	22	36	33	28	153
RUN 3	5	32	14	32	18	101
RUN 4	2	1	15	33	4	55
Total	46	61	95	129	69	400

CSF final status

CSF: Expected (396/660/60%) and performed (144/660/22%)

RUN	Germany	Netherlands	Slovenia	Spain	Sweden	ALL SITES
RUN1	1 (16.67%)	1 (6%)	23 (64.71%)	3 (9.7%)	12 (60%)	40
RUN2	4 (11.76%)	14 (45%)	18 (51.43%)	11 (33.3%)	18 (64.3%)	65
RUN 3	0 (0%)	6 (23%)	6 (35.30%)	6 (18.7%)	9 (47.4%)	27
RUN 4	0 (0%)	1 (100%)	8 (44.44%)	3 (9.1%)	0 (0%)	12
Total	5	22	55	23	39	144

MOPEAD Participation RUN 1

Country	Pre-screened	Pre-screened Positive	Pre-screened Positive/%	Evaluated WP3	Evaluated WP3/%	Evaluated vs positive/%
Germany	41	12	29,27%	6	14,63%	50,00%
Spain	528	161	30,49%	31	5,87%	19,25%
The Netherlands	140	63	45,00%	6	4,29%	9,52%
Slovenia	125	40	32,00%	13	10,40%	32,50%
Sweden	653	140	21,44%	31	4,75%	22,14%
Total	1487	416	27,98%	87	5,85%	20,91%

MOPEAD Participation RUN 2

Country	Pre screened	Pre-screened Positive	% Pre-screened Positive	Evaluated WP3	% Evaluated WP3	% evaluated vs positive
Germany	178	48	26,97%	34	19,10%	70,83%
Spain	101	39	38,61%	33	32,67%	84,62%
The Netherlands	181	54	29,83%	33	18,23%	61,11%
Slovenia	118	30	25,42%	22	18,64%	73,33%
Sweden	83	47	56,63%	33	39,76%	70,21%
Total	661	218	32,98%	155	23,45%	71,10%

MOPEAD Participation RUN 3

Country	Pre-screened	Pre-screened Positive	% Pre-screened Positive	Evaluated WP3	% Evaluated WP3	% evaluated vs positive
Germany	89	22	24,72%	5	5,62%	22,73%
Spain	105	56	53,33%	32	30,48%	57,14%
The Netherlands	77	40	51,95%	23	29,87%	57,50%
Slovenia	99	34	34,34%	19	19,19%	55,88%
Sweden	65	36	55,38%	15	23,08%	41,67%
Total	435	188	43,22%	94	21,61%	50,00%

MOPEAD Participation RUN 4

Country	Pre-screened	Pre-screened Positive	% Pre-screened Positive	Evaluated WP3	% Evaluated WP3	% evaluated vs positive
Germany	13	6	46,15%	2	15,38%	33,33%
Spain	109	75	68,81%	33	30,28%	44,00%
The Netherlands	12	4	33,33%	1	8,33%	25,00%
Slovenia	39	17	43,59%	4	10,26%	23,53%
Sweden	91	48	52,75%	16	17,58%	33,33%
Total	264	150	56,82%	56	21,21%	37,33%

MOPEAD Closing remarks

RUN 1

Global statement: Less harmonic run among the sites. Highly variable between countries. Ethic committees delayed their approval in some countries due to the complexity of citizen science keeping confidentiality of the personal data. The NPS tool seems to be appropriate to reach the clinical objective.

MOPEAD Closing remarks

Run 2

Global statement: run 2 was the easiest to implement and to deal with. The advertising campaign was useful to attract motivated participants. In our experience little effort was enough to attract participants.

Feedback by the patients: The majority of participants classified as positive in the pre-screening were willing to complete the diagnosis in WP3.

Feedback from the memory unit professionals: methodology and logistics were easy to understand and fits quickly into daily practice. They could adapt it at their specific logistics in each site's facilities.

MOPEAD Closing remarks

RUN 3

Global statement: Differences were established by different public health systems, different cultures and the memory clinics organization.

Feedback from the patients: Diagnostic procedures such as cognitive testing, MRI or LP are rejected by a part of this population. They find this test too long or invasive.

Feedback by the PCP/GP: No time, no treatment available and are not interested in training

MOPEAD Closing remarks

Run 4

Global statement: Different approaches to patients with T2DM and complex and diverse relations between memory clinics and tertiary endocrinology units.

Feedback by the patients: Pluripathologic patients with severe diseases, not wanting to be diagnosed with more diseases. They refuse lumbar punctions.

Feedback from the endocrinologists: lack of information and training about cognitive decline, low motivation to manage both entities as a unique public health issue.

MOPEAD Closing remarks

- ✓ MOPEAD has been created to be an open access study to use its data bank for academics, researchers, stakeholders, patients associations and pharma industry.
- ✓ MOPEAD has as its fundamental objective to build synergies with other IMI projects in order to reduce time and cost for professionals and institutions.
- ✓ As a **proof concept** study
 - ✓ it is a reproducible model through European countries.
 - ✓ it has the flexibility to be applied and adapted to the specific characteristics of the public health system.
 - ✓ it is a model that could settle educational plans adressed at health professionals and civil society.



See you in BCN-PIT 2020!

RUN2-Open House

RUN2	Pre-screened	Positive	%	Evaluated in WP3	%
Jessen	178	48	26,97%	34	19,10%
Boada	101	39	38,61%	33	32,67%
Visier	181	54	29,83%	33	18,23%
Kramberger	118	30	25,42%	22	18,64%
Winblad	83	47	56,63%	33	39,76%
Total	661	218	32,98%	155	23,45%

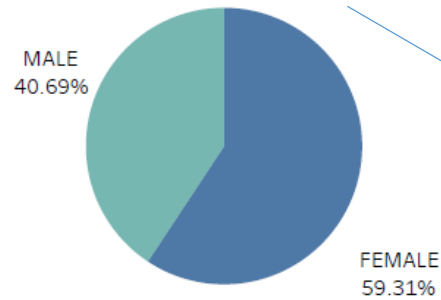
RUN2- Open House

RUN2		% evaluated vs positive	Diagnosed with MCI or Dementia	%	% Diagnosed with MCI or Dementia Vs Evaluated
DE	34	70,83%	19	10,67%	55,88%
ES	33	84,62%	32	31,68%	96,97%
NL	33	61,11%	1	0,55%	3,03%
SE	22	73,33%	17	14,41%	77,27%
SI	33	70,21%	13	15,66%	39,39%
Total	155	71,10%	82	12,41%	52,90%

Demographics Information

Participation by gender and age RUN 1 - Global

Participation

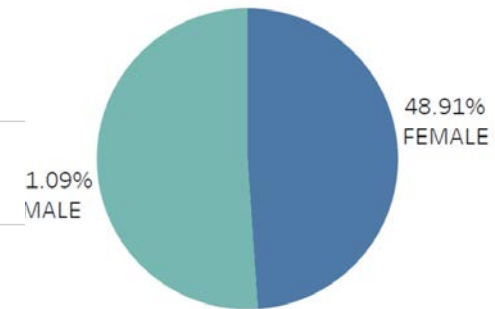
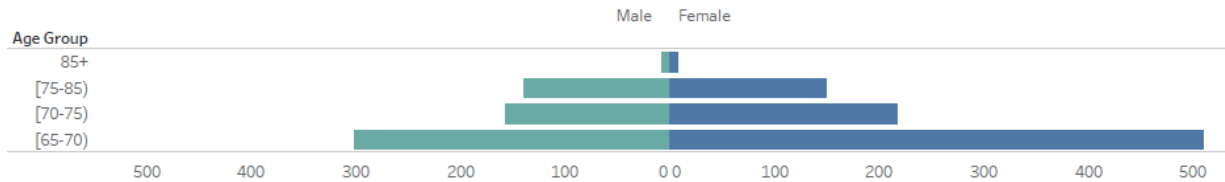


Participants evaluated



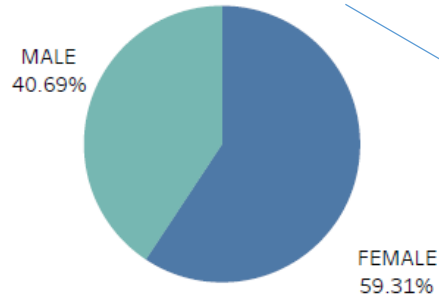
Total pre-screened: 1487

Total evaluated: 87



Participation by gender and age RUN 1 - Global

Participation

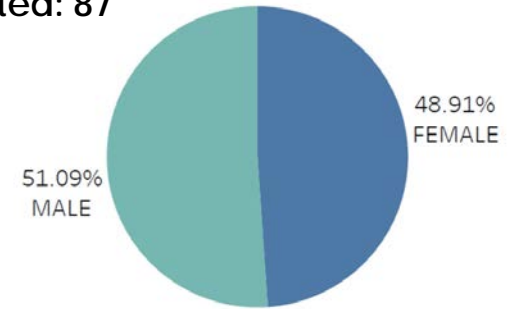
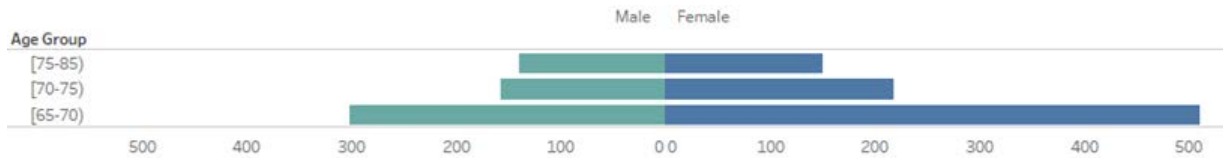


Participants evaluated



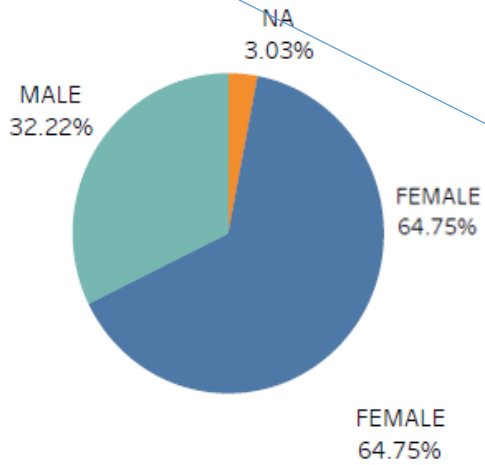
Total pre-screened: 1487

Total evaluated: 87



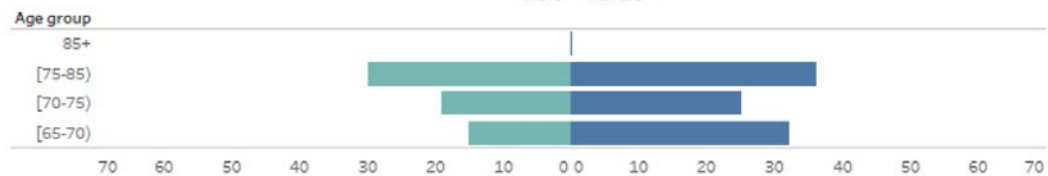
Participation by gender and age RUN 2 - Global

Participation

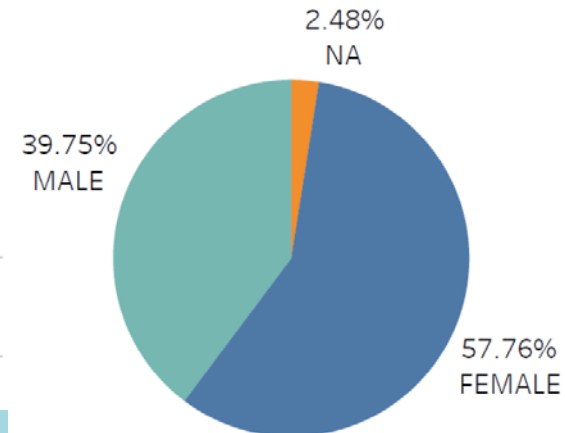
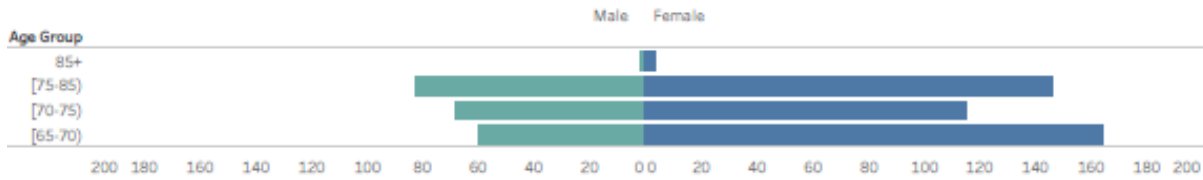


Total pre-screened: 661

Participants evaluated



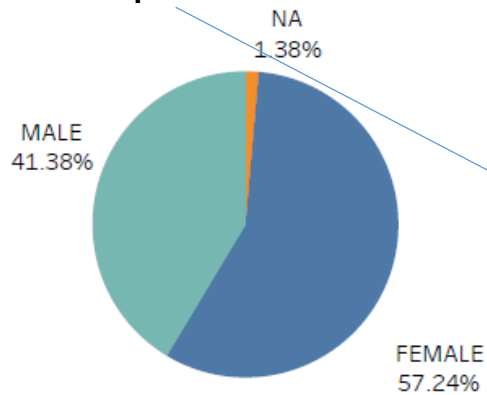
Total evaluated: 155



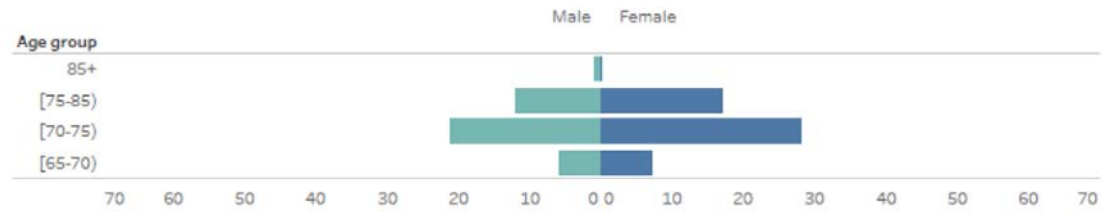
Note: age of people with unknown gender was not taken into account.

Participation by gender and age RUN 3 - Global

Participation

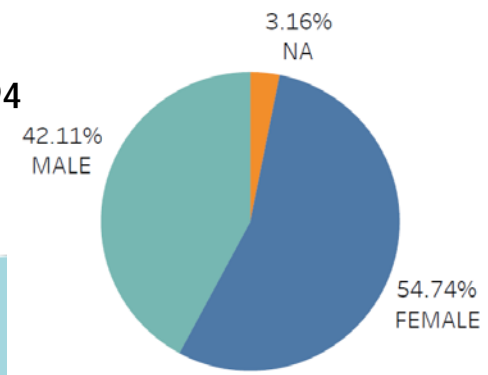
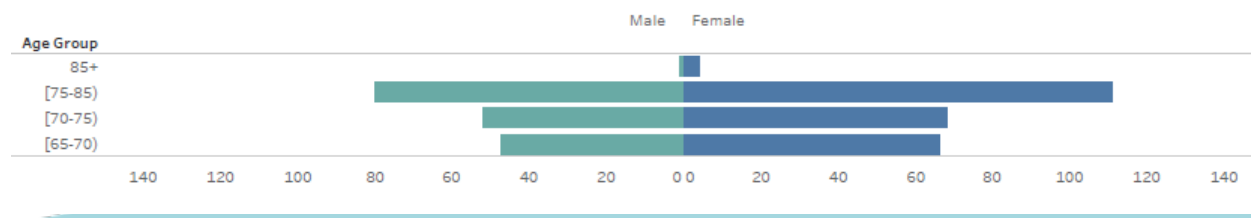


Participants evaluated



Total pre-screened: 435

Total evaluated: 94



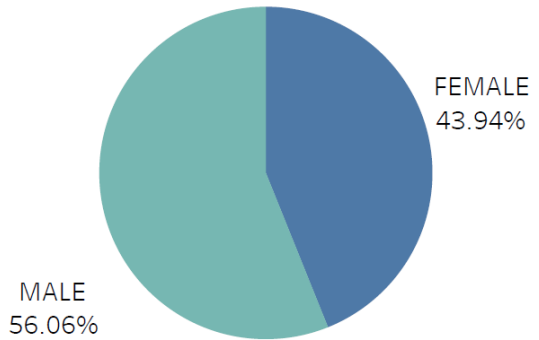
Note: age of people with unknown gender was not taken into account.

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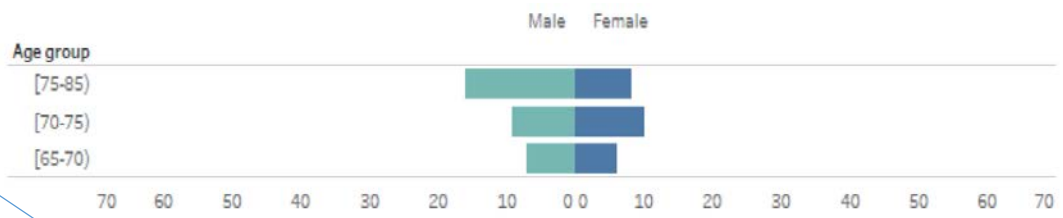


Participation by gender and age RUN 4 - Global

Participation

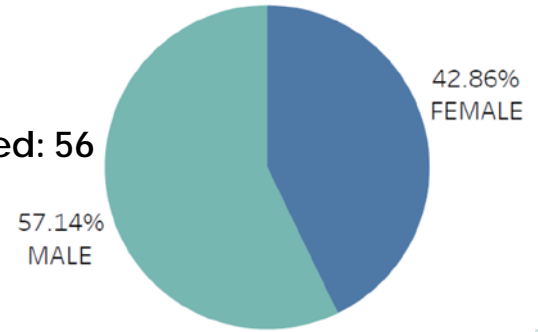
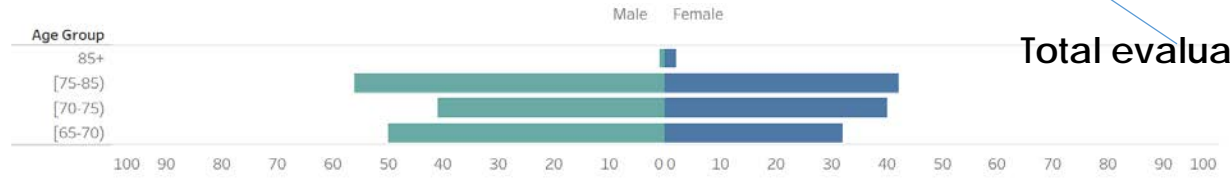


Participants evaluated



Total pre-screened: 264

Total evaluated: 56





Alzheimer's & Dementia ■ (2019) 1-12

Alzheimer's
&
Dementia

Review Article

The MOPEAD project: Advancing patient engagement for the detection of “hidden” undiagnosed cases of Alzheimer’s disease in the community

Octavio Rodríguez-Gómez^{a,b,*}, Adrián Rodrigo^c, Fátima Iradier^d, Miguel A. Santos-Santos^a, Hans Hundemer^e, Andreea Ciudin^f, Lena Sannemann^g, Marissa Zwan^h, Bridget Glaysherⁱ, Anders Wimo^j, Jaka Bonn^k, Gunilla Johansson^j, Isabel Rodriguez^a, Montse Alegret^{a,b}, Dianne Gove^l, Susana Pinó^a, Paloma Trigueros^c, Miia Kivipelto^{m,n}, Brandy Mathews^o, Antonio Ciudad^d, Daniel Ferreira^m, Christophe Bintener^l, Miren Gurruchaga^a, Eric Westman^{m,p}, Mark Belger^q, Sergi Valero^{a,b}, Peggy Maguire^r, David Krivec^s, Milica Kramberger^k, Rafael Simó^f, Inmaculada Pérez Garro^c, Pieter Jelle Visser^{h,t}, Annette Dumas^u, Jean Georges^l, Frank Jessen^{g,v}, Bengt Winblad^{j,w}, Craig Shering^x, Neil Stewartⁱ, Laura Campo^y, Mercè Boada^{a,b}, on behalf of the MOPEAD Consortium



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Preliminary Conclusions I

- Delays in inclusions were as consequence of IRB's approval focus on ethics issues in RUN1
- RUN2 in Spain has fulfilled the expectations due to F.ACE's previous experience in conducting Open House pre-screenings. It seems to be the most efficient
- RUN3 works very low as a consequence of poor GP's implications
- RUN4 seems to be efficient depending on public health systems

Preliminary Conclusions II

- Different inclusion rates in all RUNs and countries observed
- Once WP3 is finished, the correlation between pre-screening and screening will be assessed to check quality.
- Dissemination actions have been successfully