

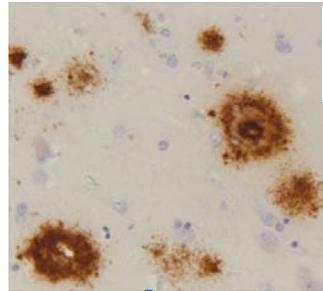


# EMIF: European Medical Information Framework

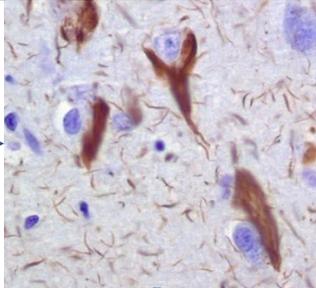
Pieter Jelle Visser, MD, PhD

Alzheimer center Limburg, Maastricht University  
Alzheimer center Amsterdam, Amsterdam UMC, location VUmc  
Karolinska Institutet, Stockholm

# Development of Alzheimer's disease



Amyloid plaques



Tau tangles



Atrophy



5 year

5 year

5 year

Normal memory

Mild memory impairment

Dementia

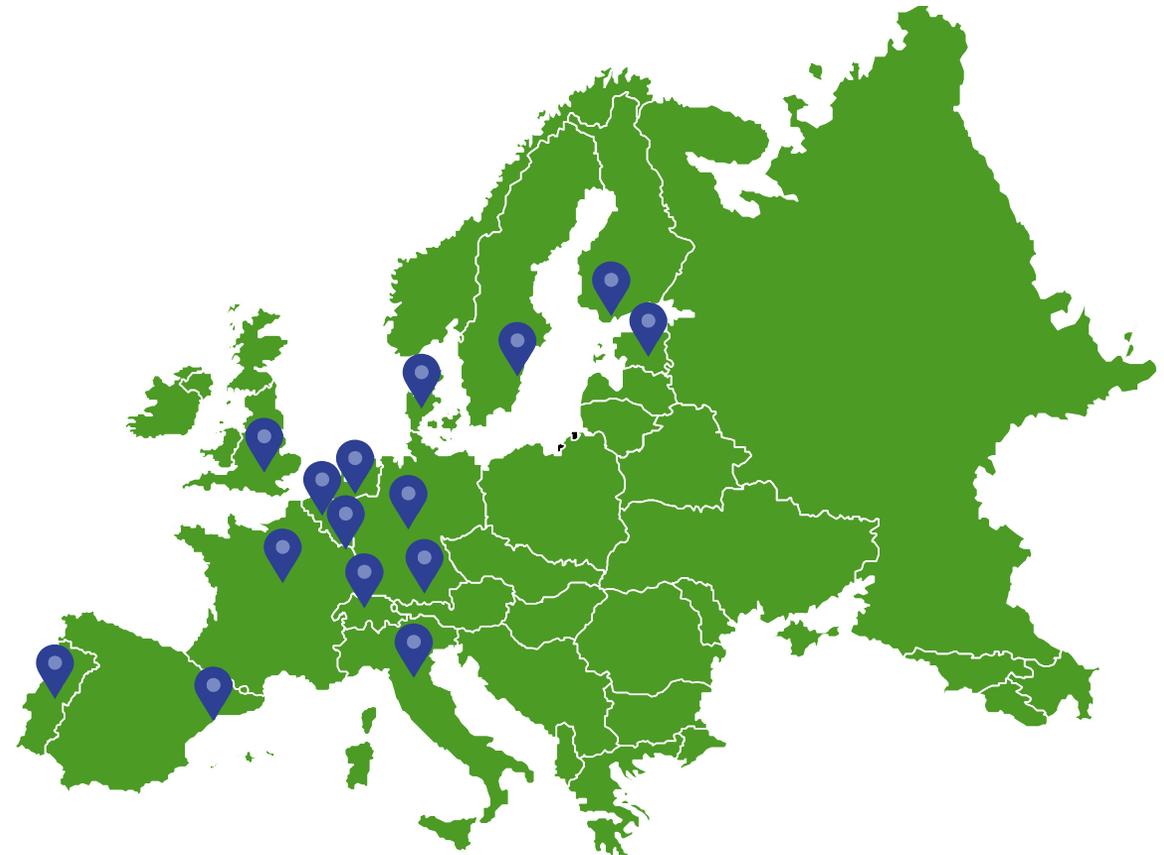
Dementia is end stage of long disease process

# EMIF-AD

- Project duration: 2013-2018
- Aims:
  - Increase understanding cause of the disease
  - Estimate prevalence and outcome of predementia AD
  - Discovery biomarkers and risk factors for predementia AD before the onset of dementia
  - Improving access to existing data

# EMIF

- Vision:
  - European hub for health care data intelligence, enabling new insights into diseases and treatments
- Three subprojects:
  - EMIF-Platform
  - EMIF-Metabolic
  - EMIF-AD
- 56 partners from countries



# EMIF: Partners



## ACADEMIC PARTNERS



## SME PARTNERS EFPIA PARTNERS



## PATIENT ORGANISATION



# Main outcomes: infrastructure

- EMIF-AD catalogue
  - Find existing data/samples/scans
  
- EMIF-AD tranSMART data platform
  - Sharing data

# EMIF-AD catalogue: search for cohorts

  
 pj visser

- HOME
- EMIF AD
- All
- Search
- Custom view
- Documentation
- Study Requests
- Taska
- PSTVST
- Map
- Dashboard
- New Entry
- Personal

EMIF CATALOGUE / EMIF AD

?

EMIF AD / All

Compare
Export
Print

Selected databases: 0

	Name	Institution name	Location	Age Ran...	T...	Last update	Select
	<input type="text" value="Filter"/>	<input type="text" value="Filter"/>	<input type="text" value="Filter"/>	<input type="text" value="Filter"/>	<input type="text" value="Filter"/>	<input type="text" value="Filter"/>	<input style="border: none; background: none;" type="button" value="?"/>
95+	<b>DRAFT</b> 95+ cohort – Sweden	University of Gothenburg	Sweden	95,109		2018-05-31	<input type="checkbox"/>
<a href="#">Actifcare</a>	ACces to Timely Formal Care	Maastricht University	Gemeente Maastricht, Provincie Limburg, Netherlands		451	2018-07-06	<input type="checkbox"/>
<a href="#">ADC</a>	Amsterdam Dementia Cohort	VU University Medical Center	Gemeente Amsterdam, Provincie Noord-Holland, Netherlands	30,100		2018-05-31	<input type="checkbox"/>
<a href="#">AddNeuroMed</a>	AddNeuroMed, Innovative Medicines for Europe (Innomed)	Institute of Psychiatry, King's College London	City of London, Greater London, England, United Kingdom	65,101	771	2018-02-06	<input type="checkbox"/>
<a href="#">AD &amp; FTDMDB</a>	<b>DRAFT</b> Alzheimer Disease & Frontotemporal Dementia Mutation Database	VIB Center for Molecular Neurology, University of Antwerp	Belgium			2018-05-18	<input type="checkbox"/>
<a href="#">ADGEN</a>	Kuopio-ADGEN	University of Eastern Finland	Kuopio, Kuopio, Pohjois-Savo, Finland	43, 89	650	2017-09-28	<input type="checkbox"/>

# EMIF-AD catalogue: search for cohorts

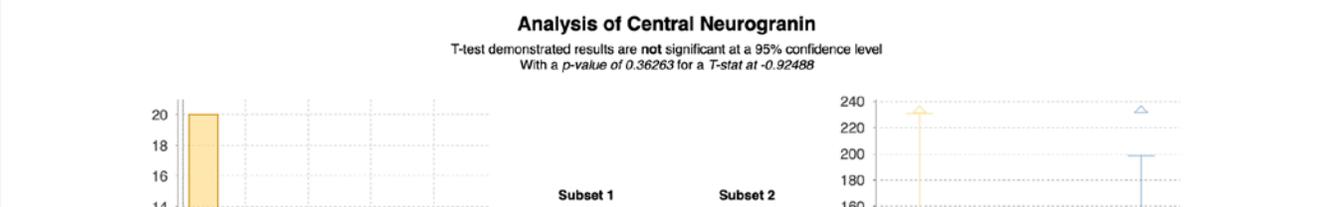
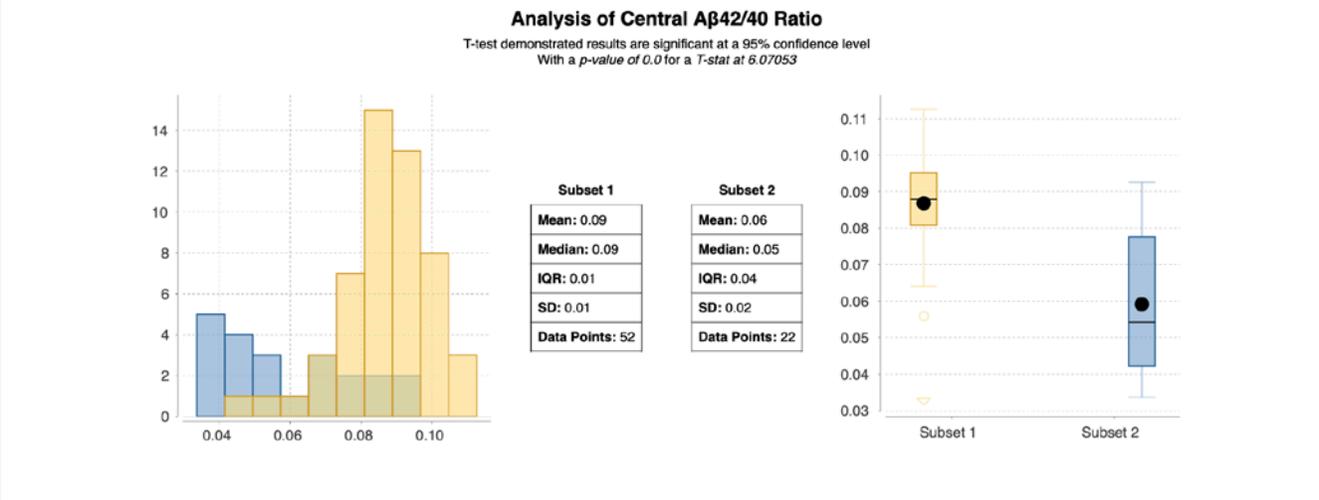
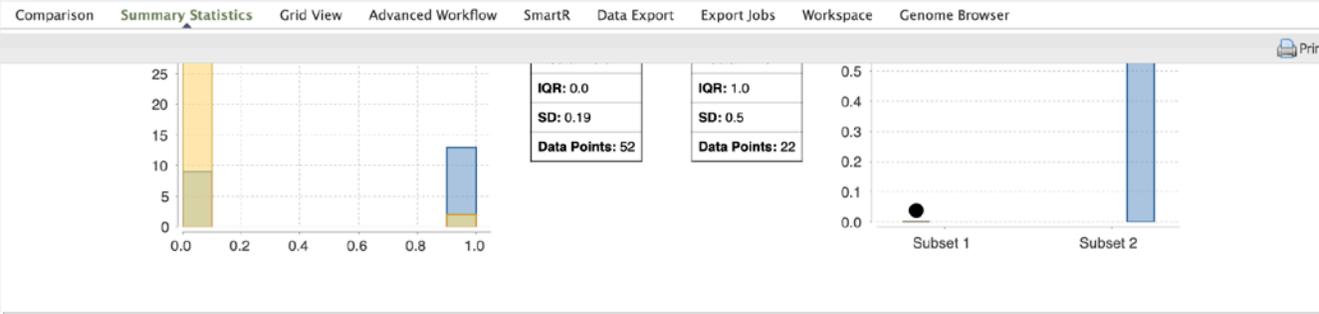
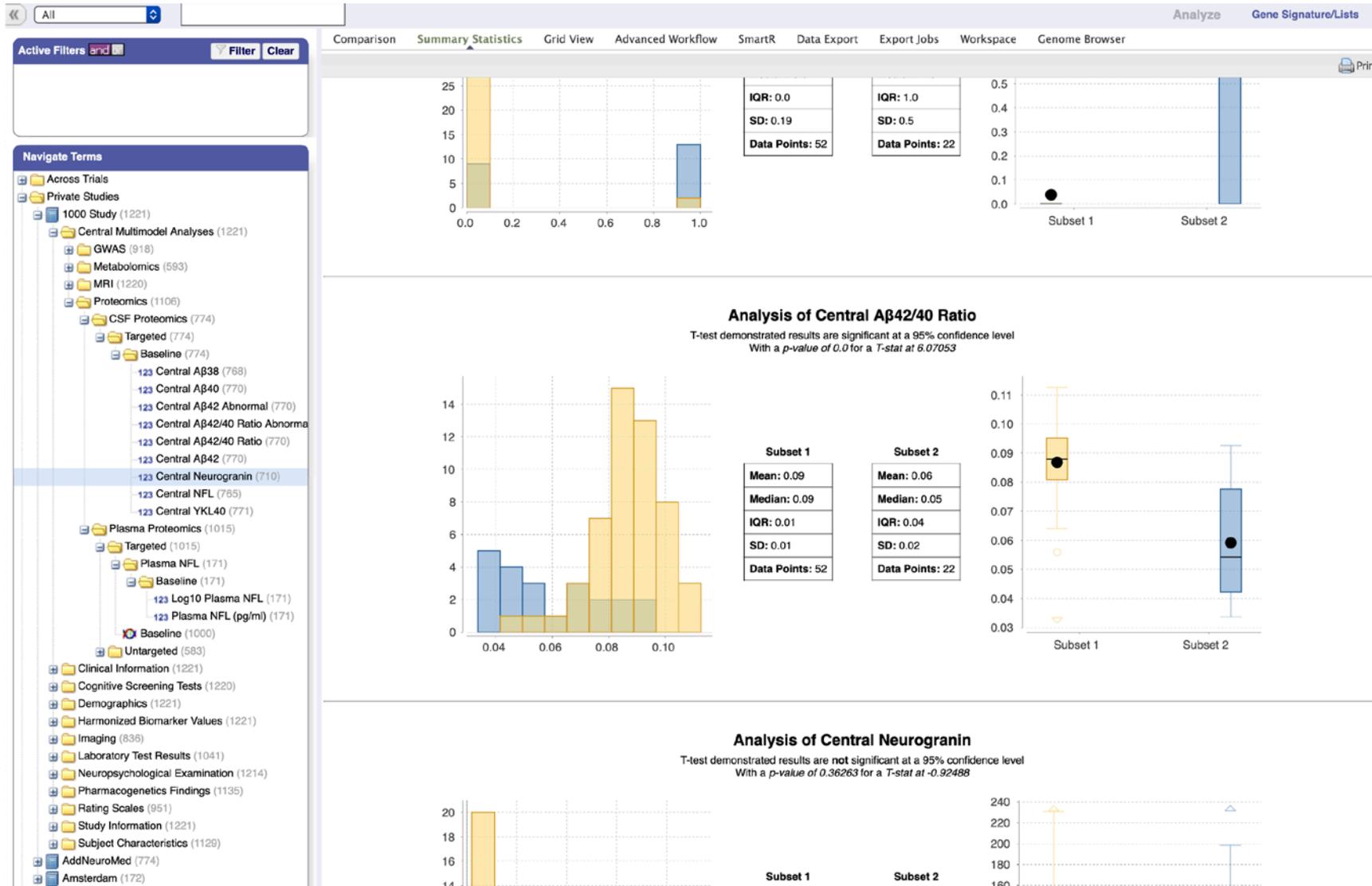
## DATABASE GENERAL INFORMATION

Provide general information about a database, such as the name, acronym, institution details and main responsables

1.01. Acronym	<input type="text" value="ADC"/>	✓
1.02. Name	<input type="text" value="Amsterdam Dementia Cohort"/>	✓
1.03. Institution name	<input type="text" value="VU University Medical Center"/>	✓
1.04. Department name	<input type="text" value="Neurology"/>	✓
1.05. URL of the database website (if available)	<input type="text"/>	👉
1.06. Unit/centre website(if available)	<input type="text" value="http://www.alzheimercentrum.nl"/>	✓
1.07. Principal Investigator (PI): Name	<input type="text" value="Philip Scheltens"/>	✓
1.07.01. PI: Address	<input type="text"/>	👉

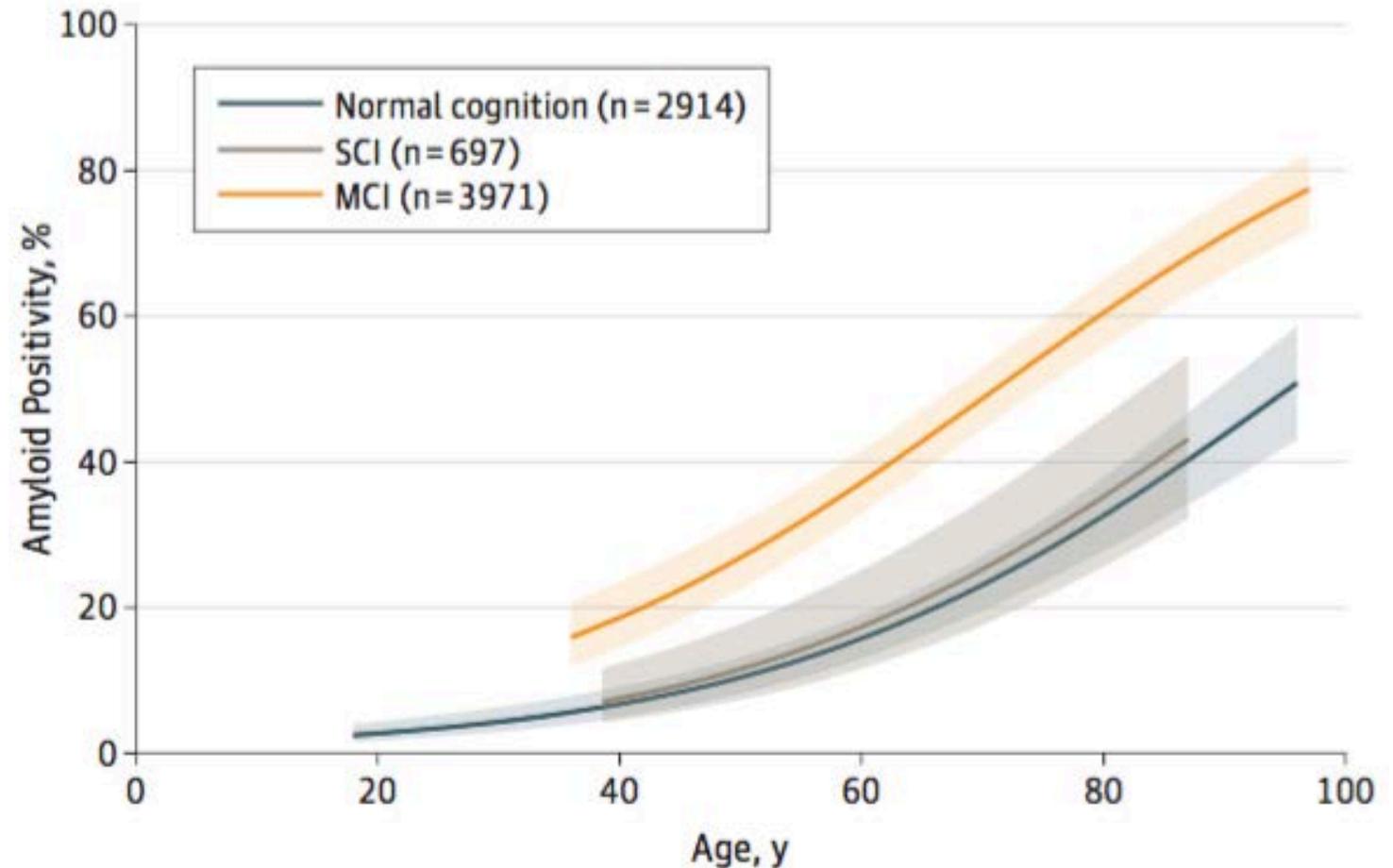
1. Database General Inform...	70%
2. Key Publications (1/1)	100%
3. Data Access (31/31)	100%
4. Study Characteristics (18...	90%
5. Inclusion / Exclusion Crit...	62%
6. Number of subjects (11/19)	57%
7. Clinical Information (11/12)	91%
8. Dementia and functional ...	41%
9. Subjective Cognitive Imp...	100%
10. Neuropsychiatric Scales...	25%
11. Quality of Life (1/1)	100%
12. Caregiver (1/1)	100%
13. Health Resource Utilisat...	0%
14. Remote Monitoring Tec...	100%
15. Cognitive screening test...	85%
16. Neuropsychological Tes...	82%
17. Physical Examination (8...	88%
18. Lifestyle Factors (3/8)	37%
19. Blood Collection (19/30)	63%
20. CSF collection (13/22)	59%
21. Urine Collection (1/1)	100%
22. MRI (7/31)	22%
23. PET (4/9)	44%
24. CT Scans (1/1)	100%
25. SPECT Scans (1/1)	100%
26. Electrophysiology (3/7)	42%
27. Neuropathology (1/1)	100%

# EMIF-AD Dataplatform for storage and analysis



# Prevalence amyloid pathology in non-demented individuals

- 50 cohorts worldwide
- N=8000



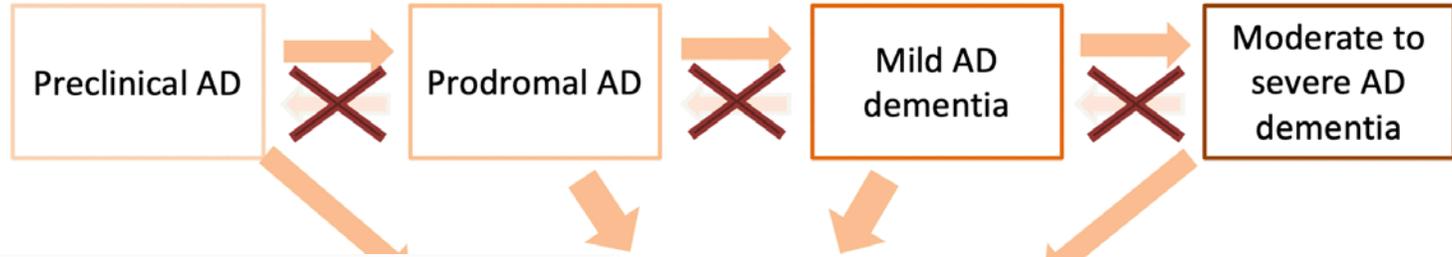
# Prevalence AD pathology and AD dementia

20 year predementia stage

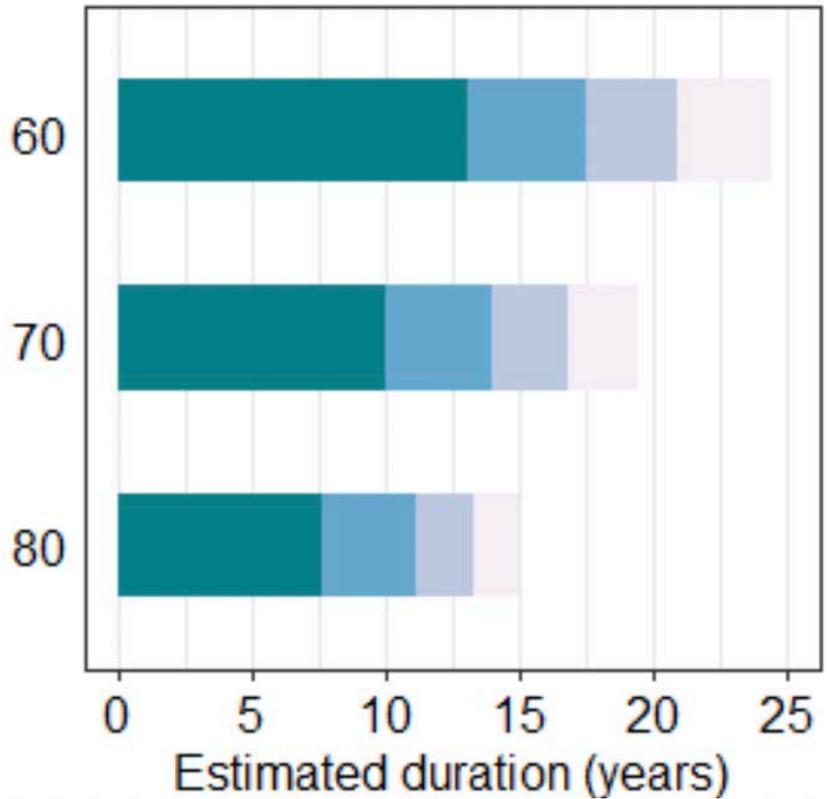
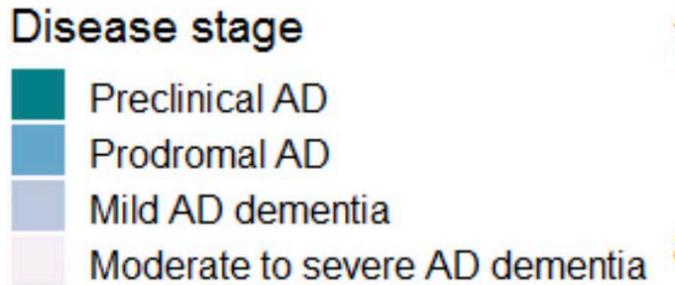


# Course of AD: from preclinical AD to death

- 6 cohorts worldwide
- N=3200



Age at start



Death

Total duration 24 years

Total duration 18 years

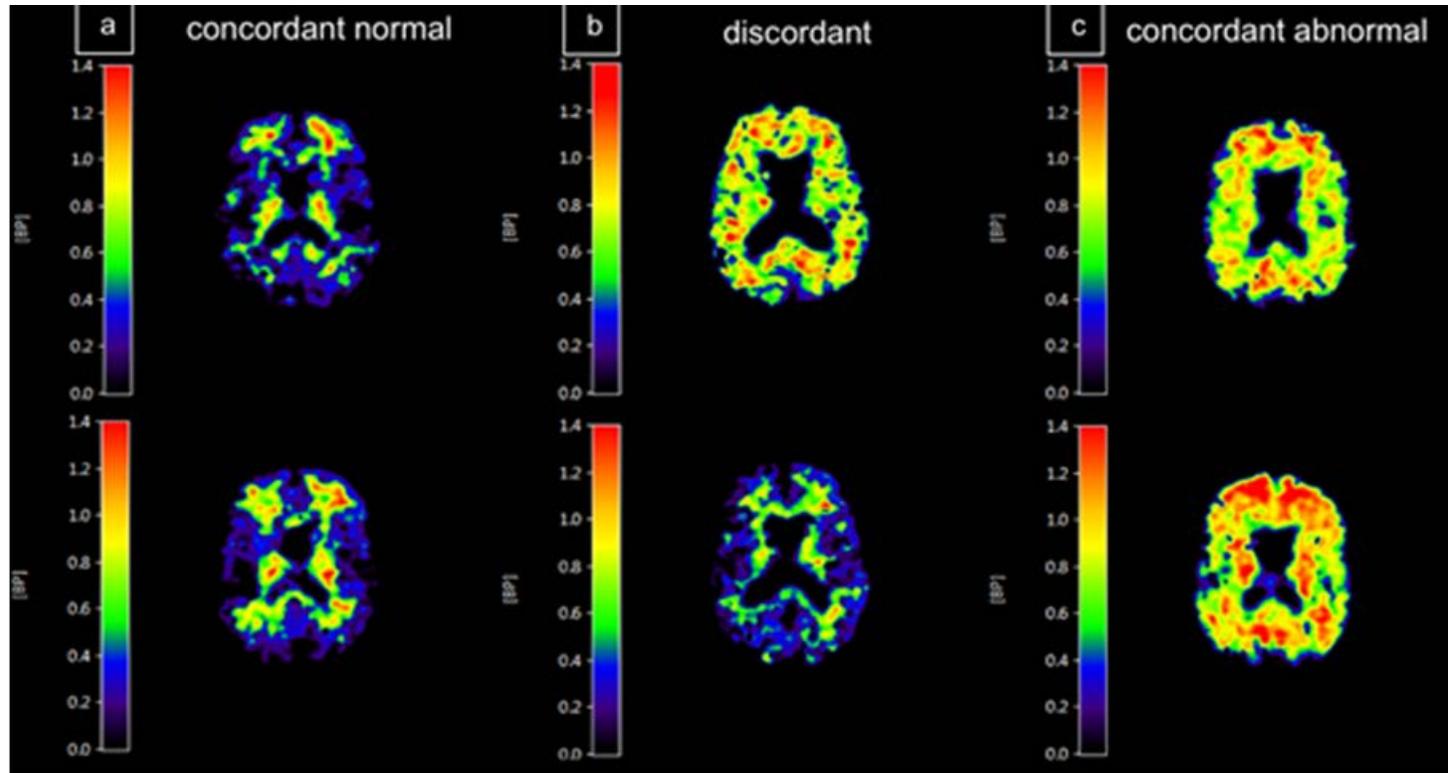
Total duration 15 years

# Pathophysiology- monozygotic twins



PreclinAD Twin study: 100 monozygotic twin pairs older than 60

# Pathophysiology- monozygotic twins



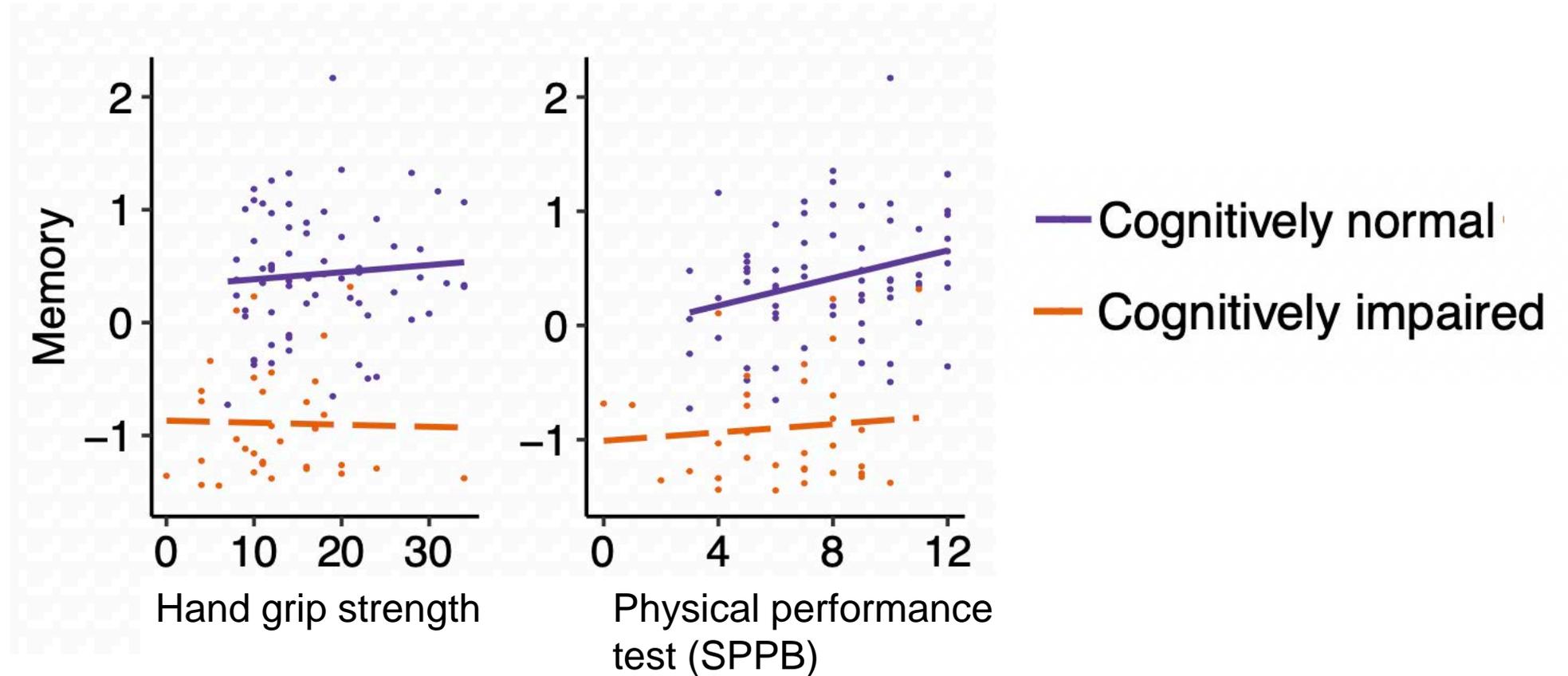
Amyloid concordance in cognitively normal monozygotic  
Twin correlation 0.55

# Protective factors for cognitive impairment in nonagenarians



EMIF-AD 90+ study (n=120)

# Protective factors for memory impairment in nonagenarians

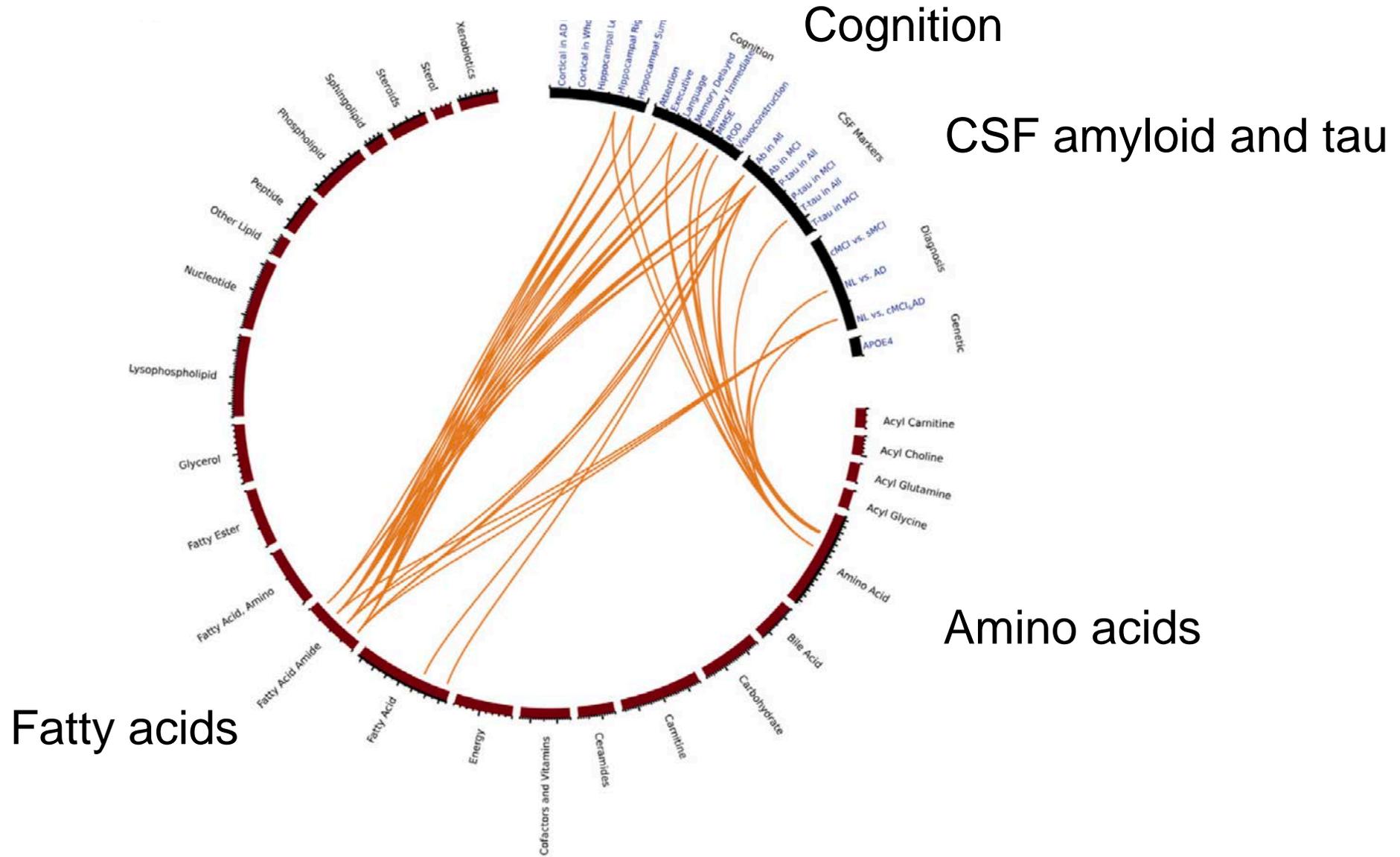


EMIF-AD 90+ study

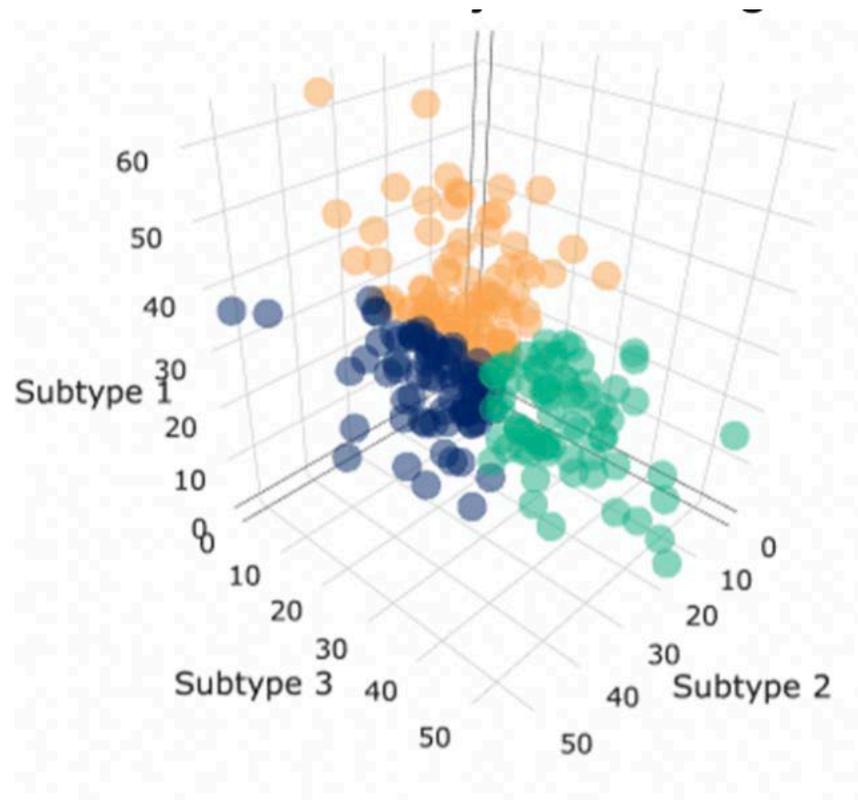
# EMIF-AD Multimodality biomarker discovery study

- Aim
  - Find diagnostic and prognostic markers for predementia AD
- 1200 subjects across AD spectrum selected from existing cohorts
- Analysis
  - MRI volumetry
  - CSF targeted and untargeted proteomics
  - Plasma proteomics and metabolomics
  - GWAS, exome sequencing, DNA methylation
  - ❖ Amsterdam Dementia Cohort
  - ❖ Antwerp cohort
  - ❖ Lausanne
  - ❖ San Sebastian – GAP
  - ❖ EDAR
  - ❖ DESCRIPA
  - ❖ PharmaCog

# Plasma metabolites and AD



# AD subtypes based on CSF proteomics



3 subtypes in amyloid positive individuals

# EMIF-AD team

- Stephanie Vos, Isabelle Bos, Karl Herholz, Stephan Carter, Rainer Hinz, Elles Konijnenberg, Anouk Den Braber, Jori Tomassen
- Gerald Novak, Mark Gordon, Sebastiaan Engelborghs, Jana Podhorna, Gayan Perera, Rob Stewart, Elizabeth Baker, Alejo Nevado-Holgado, Wenbo Tang, Preciosa Coloma, Lisa Ford, Nienke Legdeur, Maryam Badissi, Christian Schultheis, Rosemary Abbot, Hilikka Liedes
- Simon Lovestone, Johannes Streffer. Alison Baird, Cristina Legido-Quigley, Richard Dobson, Stephen Newhouse, Sarah Westwood, Anna Myers, Stuart Snowden, Malcom Ward, Lars Bertram, Kristel Slegers, Katie Lunnon, Henrik Zetterberg, Frederik Barkhof, Mara Ten Kate, Giovanni Frisoni, Alberto Redolfi,
  - Piotr Lewczuk, Hilikka Soininen, Henrik Zetterberg, Kina Höglund, Maria Pikkarainen
  - PI's data-cohorts: Philip Scheltens, Sebastiaan Engelborghs, Giovanni Frisoni, Rik Vandenberghe, José Luis Molinuevo, Anders Wallin, Alberto Lléo, Julius Popp, Pablo Martinez-Lage

# Acknowledgements

## ❖ EMIF Platform partners

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- Tony Brooks
- Jose Luis Oliveira
- Michel van Speybroeck
- Nigel Hughes
- Rudi Verbeek



[www.emif.eu](http://www.emif.eu)

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