EMIF-AD

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EMIF-AD

• EMIF = European Medical Information Framework

• AD = Alzheimer’s disease
EMIF family

EMIF-platform

EMIF-AD
EMIF-Metabolic
EMIF-Vaccine
EMIF-......
Why EMIF?

• Improve access to clinical data

  - Research data are scattered among many small cohort studies

  - Electronic health registry data are not easily accessible
    - Health insurance data
    - Hospital data
    - General practitioner registries
    - Pharmacy registries
Why an EMIF for AD?

- Alzheimer’s disease is a major clinical burden

Number of patients in millions

Ferri et al 2005
Why an EMIF for AD?

- Alzheimer’s disease is a major societal burden

![Bar chart showing annual societal costs in billion Euro from 2002 to 2040. The costs increase significantly by 2040. Chart source: Wimo et al 2007.](chart.png)
Why an EMIF for AD?

- Current diagnosis and treatment are too late
AD diagnosis

Severity amyloid pathology

0%
20%
40%
60%
80%
100%
AD diagnosis

Severity amyloid pathology

Onset of dementia
AD diagnosis

Severity amyloid pathology

Onset of dementia
Time of diagnosis
Start of treatment
AD diagnosis

Severity amyloid pathology

- Onset of dementia
- Time of diagnosis
- Start of treatment

15 years
AD diagnosis

Severity
amyloid
pathology

Onset of dementia

Diagnosis
Treatment

15 years

0% 20% 40% 60% 80% 100%
Needs

• EMIF
  - Platform that allows pooling cohort studies
  - Platform that allows access to Electronic Health Registry data

• AD
  - Tools for diagnosis of predementia AD
  - Tools for prognosis of predementia AD
  - Insight in early development of AD
Research challenge EMIF

Diagram showing the interaction between data access modules, common ontologies, and TTPs across sites. The diagram includes connections for data access and cataloging, as well as interactions with remote users and administrators. The diagram also indicates a transactional environment, local EMIF solution, and cloud-based EMIF solution with security infrastructure.
Research challenge AD

Amyloid PET scan
Research challenge AD

Amyloid PET scan

Cognitively normal

Demented
Research challenge AD

Amyloid PET scan

- Cognitively normal
- Cognitively normal
- Demented
Research challenge AD

Amyloid PET scan

1. Cognitively normal
2. Cognitively normal
3. Demented
The need for a PPP

• EFPIA partners
  - Data cohorts from AD trials
  - Expertise on statistics, ICT, and trial design

• Academic partners
  - Electronic health registries
  - Research cohorts
  - Biomarker discovery experience
  - Access to trial sites
Expected outcomes EMIF

• Catalogue of data from research cohorts and electronic health registries

• Workflows for accessing and pooling datasets
EMIF-AD has access to:

1. **Cohorts of cognitively normal subjects.**
   - 75000 subject of which 800 have CSF data, 6000 MRI scans, 70 FDG-PET scans, 200 amyloid PET scans, 40000 plasma samples, 40000 DNA samples, and 350 RNA samples

2. **Clinical cohorts of subjects with MCI or subjective complaints.**
   - 6500 subjects with MCI of which 2500 have CSF data, 3500 MR scans, 500 FDG-PET scans, 500 amyloid PET scans, 3000 plasma samples, 4000 DNA samples, and 450 RNA samples

3. **Electronic health registries**
   - >10 million patients; >30,000 samples, >10 years follow up
Expected outcomes AD

• Development:
  – New genetic markers for AD pathology

• Diagnosis:
  – Blood markers for diagnosis of AD in predementia stage

• Prognosis:
  – Cerebrospinal fluid, blood, imaging, and cognitive markers for prognosis
What next?

- **EMIF**
  - Continuous update with new data

- **AD**
  - Large (>1000 subjects) long-term (>10 years) follow-up studies of cognitively normal elderly subjects with repeated biomarker assessment
Thank you

http://www.imi.europa.eu/content/emif

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  - EFPIA leads: Mike Krams, Johannes Streffer
- **EMIF-platform:**
  - Academic lead: Johan van der Lei
  - EFPIA lead: Bart Vanieuwenhuysen