

Data sharing in clinical research: the EMIF-AD experience

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- ❖ Large clinical datasets needed for:
 - Studies on etiology
 - Studies on prevalence and course disease
 - Monitoring treatment effects
 - Selection of subjects for other studies

- ❖ Type of data
 - EHR
 - Research cohorts
 - Population-based
 - Clinical based

Incentives and barriers (researcher perspective)



❖ Incentives

- Access to data
- Access to patients
- Publication
- Funding

❖ Barriers

- No ethical approval
- No valid scientific question
- No acknowledgement

Involvement patients



- ❖ More than willing to advance medical research
- ❖ In research in clinical or epidemiological setting:
 - Ask consent for reuse data/samples
 - Ask consent for obtaining additional data from national registries

Technical needs



- ❖ Common data model
 - EMIF-AD Minimal dataset definition

- ❖ Search for cohorts
 - EMIF catalogue

- ❖ Search for patients
 - EMIF subject finder/EPAD prePAD
 - Searches within minimal datasets of local databases

- ❖ Central datastorage
 - EMIF tranSMART

EMIF catalogue



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ADGEN	Kuopio-ADGEN	University of Eastern Finland	Kuopio, Kuopio, Pohjois-Savo, Finland			2015-11-06	<input type="checkbox"/>
ADNI-1	Alzheimer's Disease Neuroimaging Initiative	University of California	San Francisco County, California, United States			2015-11-06	<input type="checkbox"/>
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ADNI-GO	Alzheimer's Disease Neuroimaging Initiative	University of California	San Diego County, California, United States			2015-11-05	<input type="checkbox"/>
AgeCoDe	German Study on Ageing, Cognition, and Dementia in	University of Bonn	Germany	2003	1.338	2015-11-05	<input type="checkbox"/>

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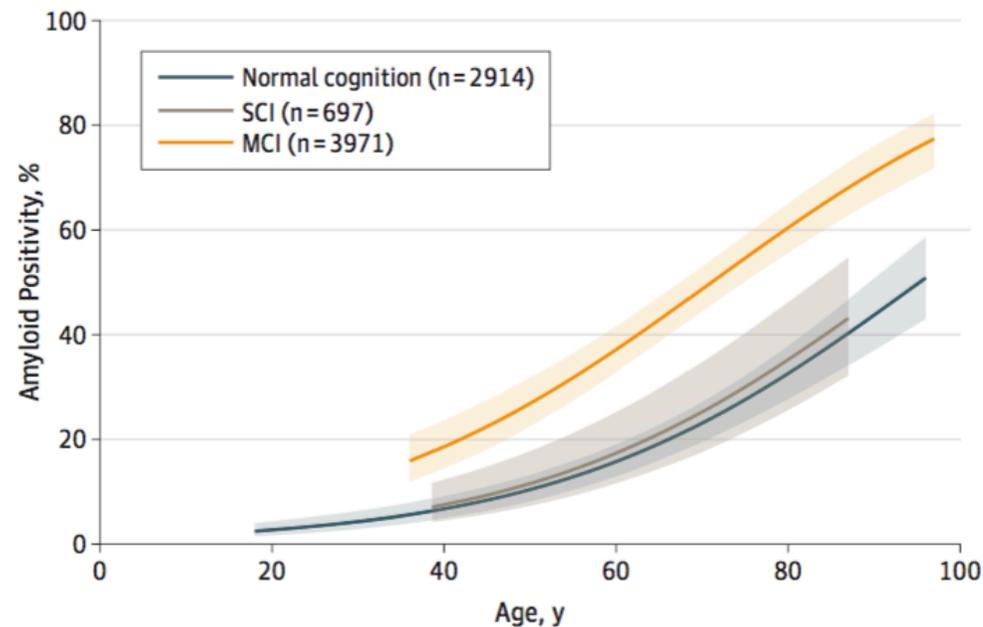
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Example: Prevalence predementia AD



- ❖ Subject level meta analysis of 8000 subjects from 51 cohorts

Figure 2. Association of Age With Prevalence Estimates of Amyloid Positivity According to Cognitive Status



The prevalence estimates were generated from generalized estimating equations. The model included age and cognitive status as predictors. Shading indicates 95% CIs; SCI, subjective cognitive impairment; MCI, mild cognitive impairment.

Jansen et al JAMA 2015

More Information



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