

Assessing the impact of applications of digital health records on
Alzheimer's disease research - Washington, DC, 2015

Half a century of records linkage in the Rochester Epidemiology Project (REP)

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Outline

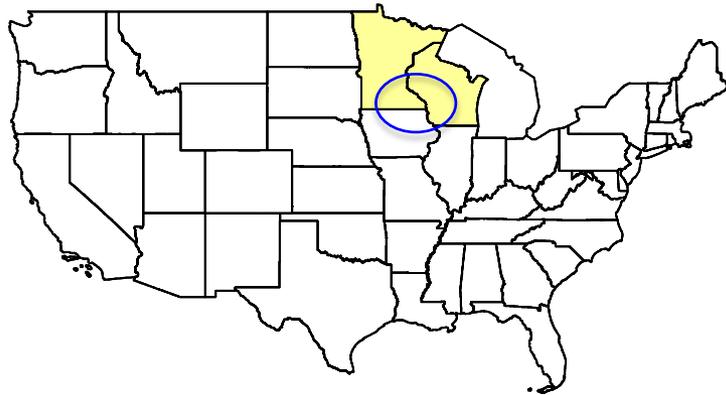
- Definition and key features of the REP
- Contributions to dementia research
- Possible uses in future clinical trials

I have nothing to disclose

Definition and key features

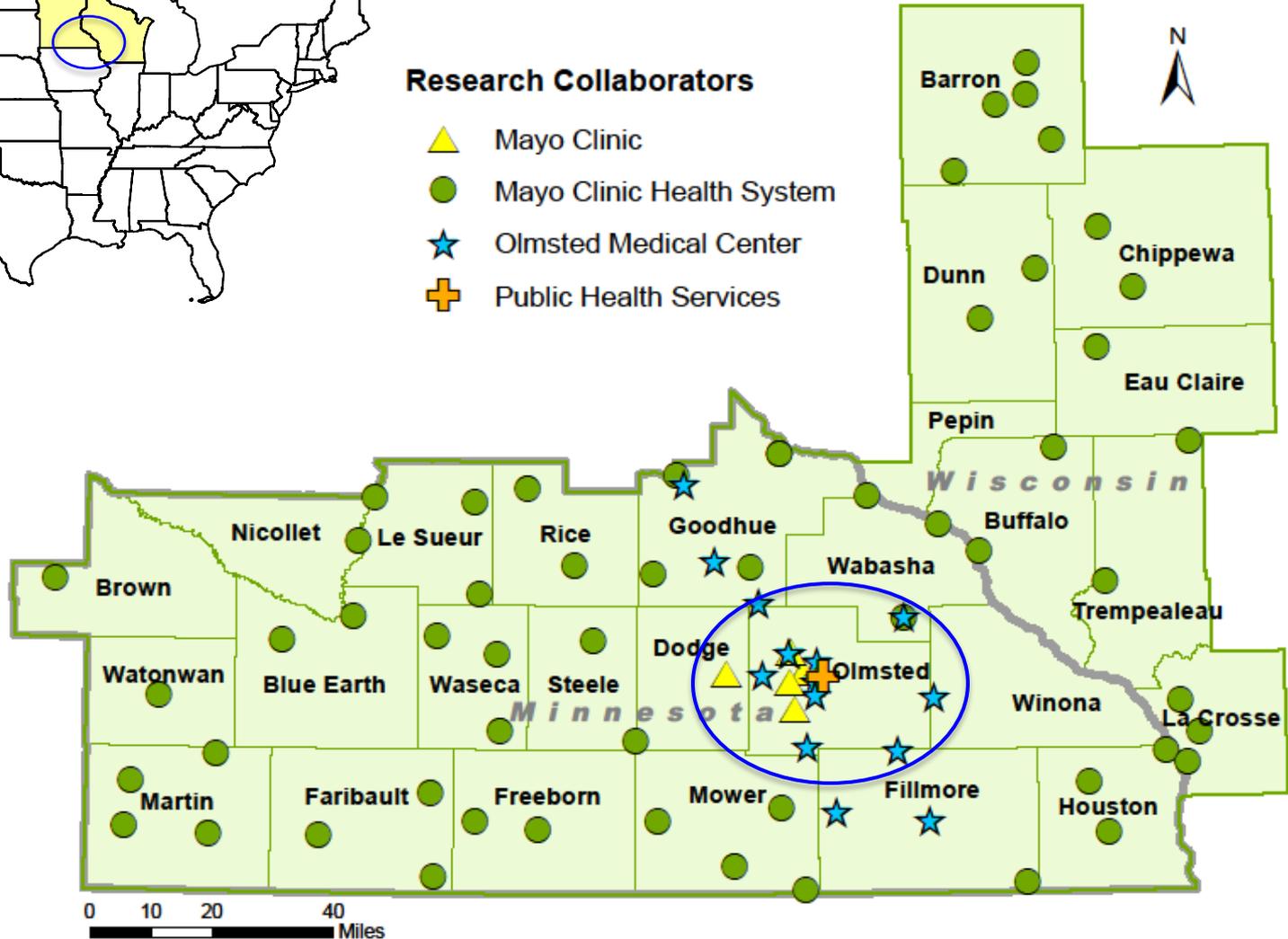
- Linkage of digital health records (DHRs) for research
 - Initially paper records, then electronic (digital)
 - Within and across care-providers
 - Population-based = defined geographic region
 - Identifiable data
 - Existed for almost 50 years, > 2,400 papers
 - Covers ~150,000 subjects, or ~ 1 million subjects
- Utility of DHRs data
 - **Size**: How many people?
 - **Depth**: For how many years?
 - **Type**: What data are stored and retrievable?

Size: geographically-defined population



Research Collaborators

- ▲ Mayo Clinic
- Mayo Clinic Health System
- ★ Olmsted Medical Center
- ✚ Public Health Services



Olmsted Co. ~ 150,000 → 27-county region ~ 1,000,000

Depth: medical records over life



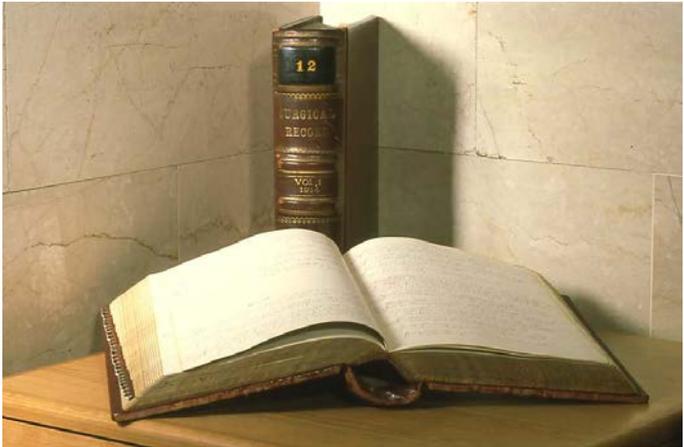
Adult life

Aging



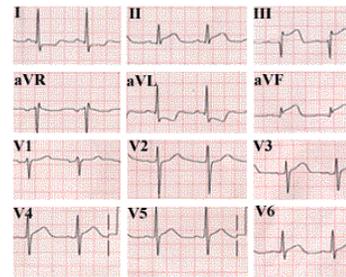
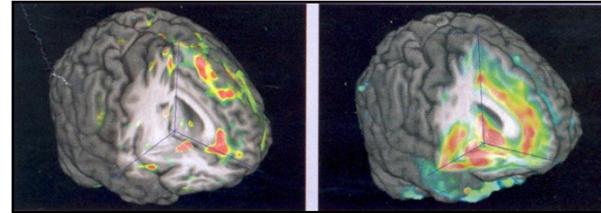
Birth

Intra-uterine life



Types of data

Laboratory tests



Prescriptions of drugs



Medical diagnoses and surgical procedures



Life habits

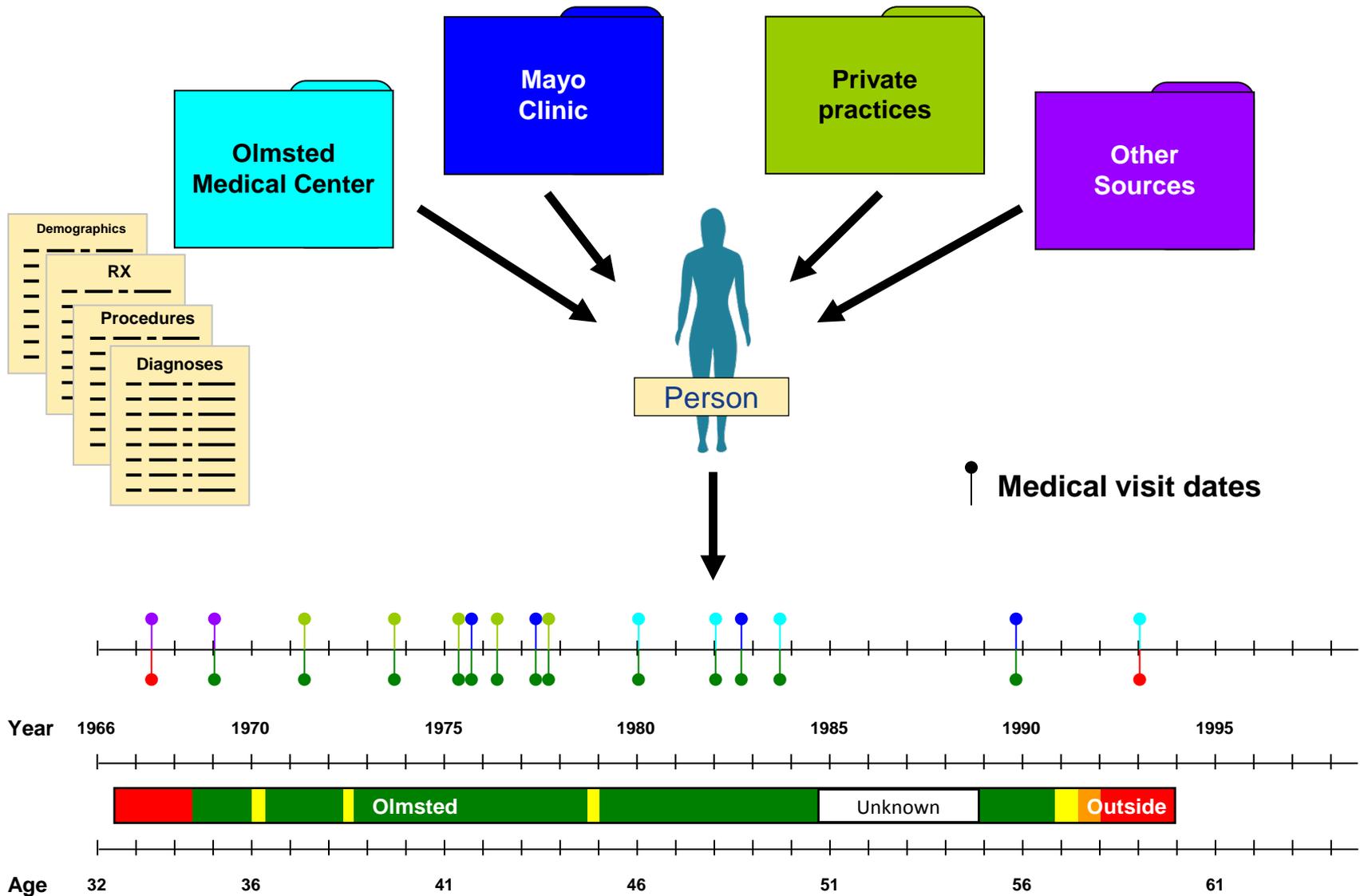


Immunizations

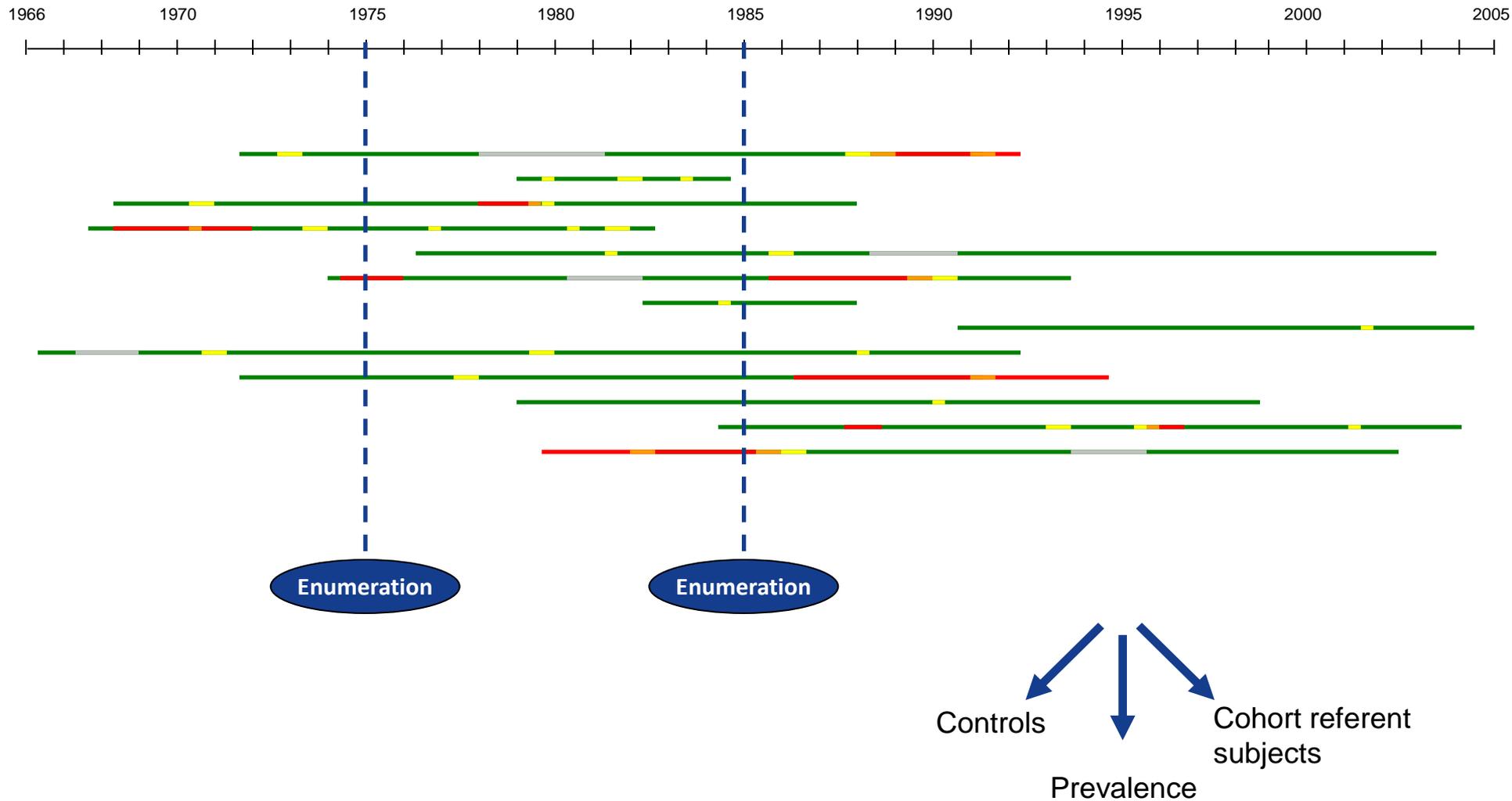
Services and procedures



Linkage of records



Uses of timelines and census

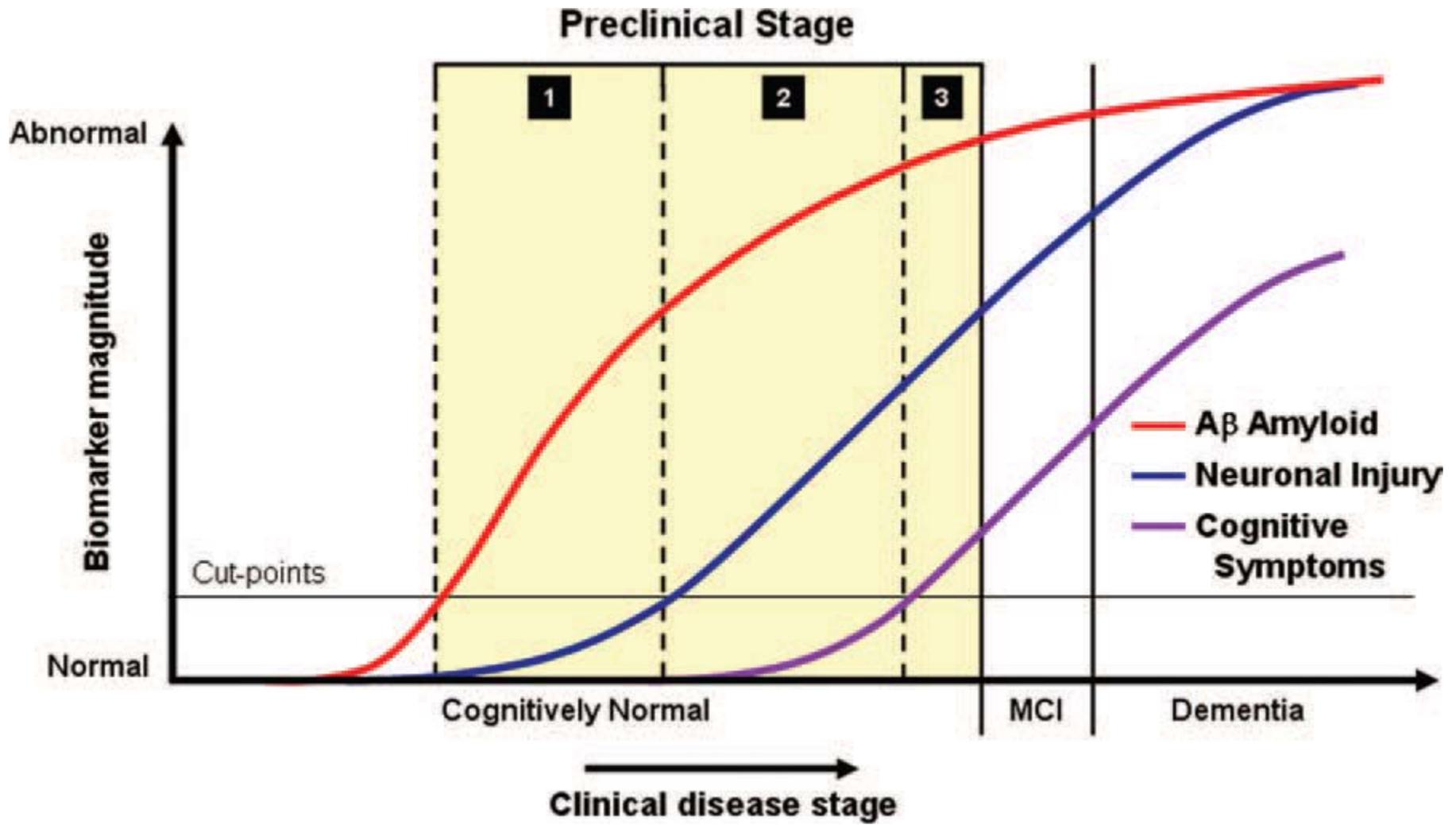


Time, place, and person

Studies of dementia

- Passive surveillance methods
 - Prevalence and incidence
 - Survival
 - Risk and protective factors
- Combined active contact and passive surveillance in the [Mayo Clinic Study of Aging](#)
 - Prevalence and incidence of [mild cognitive impairment](#)
 - Natural history, outcomes
 - Risk and protective factors
- Population-based studies of [biomarkers](#) (reduced bias)
 - Blood
 - Cerebrospinal fluid (CSF)
 - Imaging

Preclinical stages



Population-based biomarkers

- Biomarkers as predictors of dementia
- Brain amyloidosis
 - CSF amyloid
 - PET amyloid imaging
- Neuronal injury and degeneration
 - CSF tau
 - Tau imaging
 - FDG PET
 - Structural MRI

REP and future clinical trials

- To identify patients
 - In a geographically-defined community
 - Use address and telephone number to contact patients
- To obtain baseline data
 - Define medical co-morbidities and past drug use
 - Use laboratory tests preceding baseline
- To study long-term outcomes after the trial phase
 - Passive long-term follow-up for mortality and morbidity
 - Long-term side effects
- To study non-participants

Conclusions

- The Rochester Epidemiology Project (REP)
 - Linkage of identifiable data across care providers
 - Geographically-defined population
 - Existed for almost 50 years; > 2,400 papers
 - Covers ~150,000 subjects, or ~ 1 million subjects
- Contributions to dementia research
 - Registry of dementia: passive
 - Study of mild cognitive impairment: passive + active
 - Study of biomarkers: active
- Possible use in clinical trials

Thank you

The screenshot shows the website for the Rochester Epidemiology Project. At the top right, the title "Rochester Epidemiology Project" is displayed with the email "info@rochesterproject.org". A navigation menu includes links for HOME, ABOUT US, COMMUNITY, IN THE NEWS, PUBLICATION SEARCH, FOR RESEARCHERS, and CONTACT. The main banner features a photograph of a river with a canoe and the text "Improving health globally by studying health locally". On the left sidebar, there are logos for the Rochester Epidemiology Project (EST. 1966), Olmsted Medical Center, and Mayo Clinic Health System. Below the banner, there are three columns of content: "What is the Rochester Epidemiology Project?" (describing the research consortium), "In The News" (highlighting a study on skin cancer cases from February 2014), and "Videos" (with a video player thumbnail). The footer contains copyright information, funding logos for NIH and the National Institute on Aging, and the project's tagline and website URL.

Rochester Epidemiology Project
info@rochesterproject.org

HOME ABOUT US COMMUNITY IN THE NEWS PUBLICATION SEARCH FOR RESEARCHERS CONTACT

**Improving health globally by
studying health locally**

What is the Rochester Epidemiology Project?
The Rochester Epidemiology Project (REP) is a research consortium to collect, link, and store medical record information for people living in Olmsted County and southeastern Minnesota.

In The News
Rise in Skin Cancer Cases
February 2014
In a recent REP study, researchers found a large increase in new cases of skin cancer between 1979 to 2009, especially in middle-aged women. [more](#)

Videos

**Improving health globally by studying health locally
A Southeast Minnesota Collaboration**

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Funding:

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