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

Olmsted Co. ~ 150,000

27-county region ~ 1,000,000
Depth: medical records over life

Intra-uterine life

Birth

Adult life

Aging
Types of data

Medical diagnoses and surgical procedures

Prescriptions of drugs

Laboratory tests

Life habits

Immunizations

Services and procedures
Linkage of records

- Olmsted Medical Center
- Mayo Clinic
- Private practices
- Other Sources

Demographics
Medical visit dates
RX
Procedures
Diagnoses

Year
1966
1970
1975
1980
1985
1990
1995

Age
32
36
41
46
51
56
61

Uses of timelines and census

Time, place, and person

- Enumeration
  - Controls
  - Prevalence
- Cohort referent subjects
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

Jack et al., Ann Neurol 2012
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