NIA IMPACT
COLLABORATORY
TRANSFORMING DEMENTIA CARE

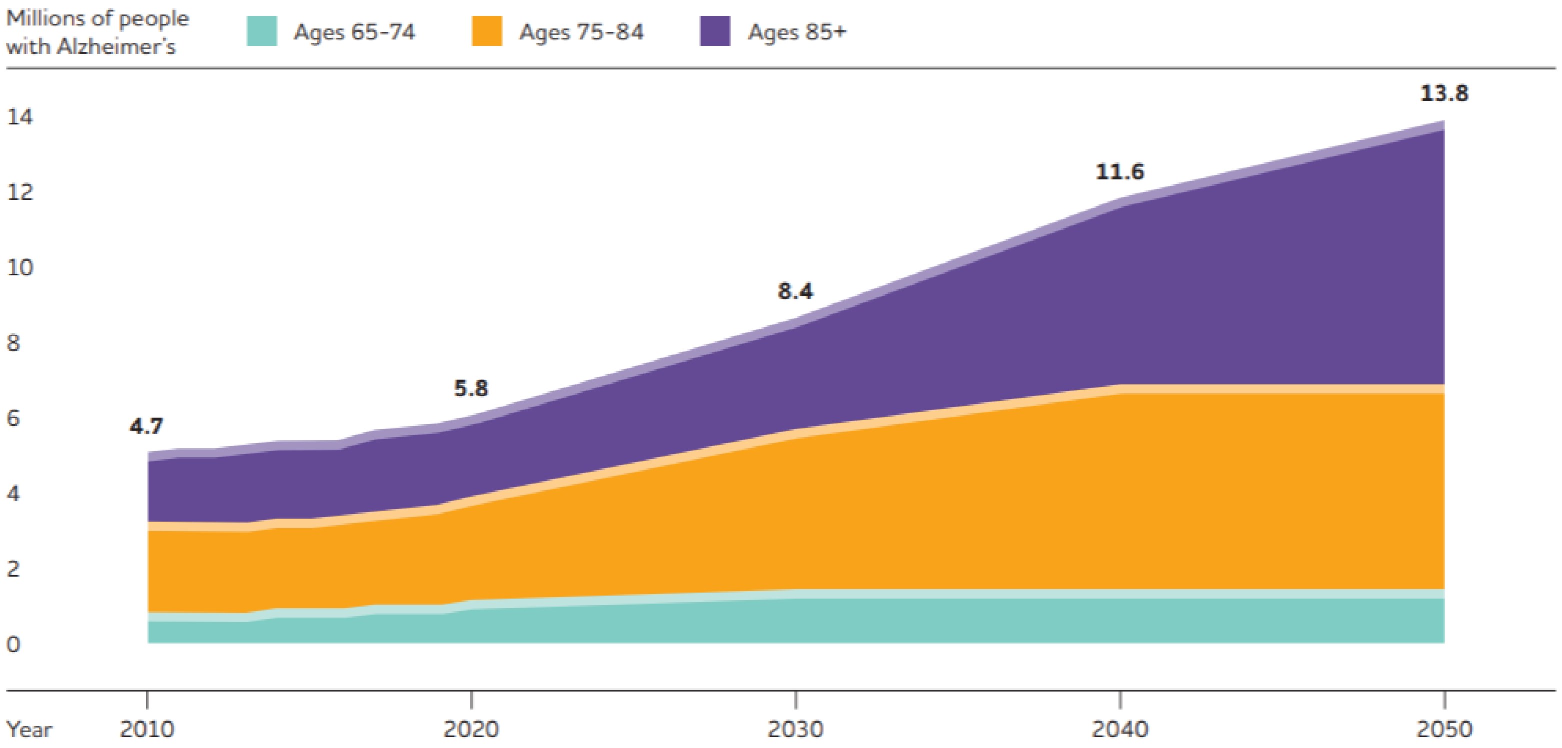
National Institute on Aging (NIA) IMbedded Pragmatic Alzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory (NIA U54AG063546)

BUILDING DATA CAPACITY FOR PATIENT-CENTERED OUTCOMES RESEARCH

PATIENT PERSPECTIVES ON DATA NEEDS

GARY EPSTEIN-LUBOW, MD

Background



Projected Number of People Age 65 and Older (Total and by Age) in the U.S. Population with Alzheimer's Dementia, 2010 to 2050

Created from data from Hebert et al.[A10,51]

- >5 million with AD/ADRD; increasing
- Urgent public health need to provide care to PLWD and care partners
- Non-pharmacological interventions have efficacy but limited adoption
- ePCTs potential to accelerate translation of interventions into clinical practice

ePCTs Bridge Research and Clinical Care

Designed with stakeholder input

Intervention integrated into routine clinical flow

Data from HCS EHR and administrative datasets

Diverse, representative study population

Outcomes important to decision makers

ePCTs in Dementia Require Special Focus

HEALTH CARE SYSTEMS

Nursing homes

Assisted living

Home health

Rehab

Hospice

Hospital

DATA SOURCES

Medicare

Minimum DataSet

EHRs

ETHICS/ REG

Vulnerable

Consent capacity

Federal-wide assurance

OUTCOMES

PWLD

Care partners

HCS

Ascertaining from datasets

DESIGN/ STATS

Cluster RCT

Dyadic

Loss to follow-up

IMPLEMENT

Complex interventions

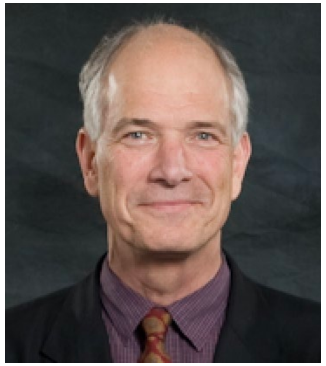
Challenging settings

Adherence

Leadership

Susan Mitchell, MD, MPH

Principal Investigator
Professor of Medicine, Harvard Medical School
Senior Scientist, Hebrew SeniorLife
Marcus Institute



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Cores

Patient/Caregiver Reported Outcomes

Develops and supports use of PCROs relevant to PLWD and their CPs in the design and conduct of ePCTs.

Laura Hanson, MD, MPH
Professor of Medicine
University of North Carolina

Executive Committee:

Antonia Bennet, PhD
Amy Kelley, MD, MSHS
Christine Ritchie, MD, MSPH
Debra Saliba, MD, MPH
Joan Teno, MD, MS
Sheryl Zimmerman, PhD

Teams

Stakeholder Engagement

Engaging stakeholders, including HCSs, in the conduct of ePCTs among PLWD and their CPs.

Gary Epstein-Lubow, MD
Associate Professor,
Brown University

Executive Committee:

Jill Harrison, PhD, Associate Lead
Katie Maslow, MSW
Ellen Tambor, MA
Laurie Herndon, MSN, GNP, BC
Brenda Nicholson, MD
Linda Elam, PhD

What are the main data needs for dementia?

- Information to improve person-centered care.
- Reporting on functional status.
- Linkage of data: people living with dementia (PLWD) and caregivers.
- Strategies for capturing information about lived experience.
- Methods for standardizing proxy reporting for people who lack capacity to report directly.

Implications of the statutory scope of PCOR

- Increases opportunities for learning about PCOs
- Creates risk for under-representing PCOs from under-represented groups
- Potential for added burdens or missed opportunities related to family members and caregivers
  - Collection of data about caregiving
  - Collection of data as proxy respondents for PLWD
  - Missing data from family caregivers

Unanswered questions & underserved populations by current PCOR data infrastructure

- There is not a standard measure set for people living with dementia
- There is not a standard measure set for family caregivers.
- Quality measures for dementia care are optional in most reporting systems
- There are challenges regarding collection of PCOs from people living with moderate or severe dementia
- Accommodations for data collection may be required for people with limited health literacy
- Linkage of data for caregivers

What new data sources could be incorporated into the PCOR data infrastructure?

- Five dementia measures in Merit-based Incentive Payment System (MIPS) could become required:
  - Dementia Associated Behavioral and Psychiatric Symptom Screening and Management
  - Dementia: Cognitive Assessment
  - Dementia: Education and Support of Caregivers for Patients with Dementia
  - Dementia: Functional Status Assessment
  - Dementia: Safety Concern Screening and Follow-up for Patients with Dementia

- Consumer Assessment of Healthcare Providers and Systems (CAHPS) Measures of Patient Experience:
  - Continue use and consider expand to include proxy report of dementia

What data capacity challenges is HHS best positioned to address?

- 2020 Recommendations of the Public Members of the HHS Advisory Council on Alzheimer’s Research, Care and Services, including:

- Clinical Care Recommendation 5: **Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.**
  - Use CMS definitions of care “value” and study models that enhance value
  - Rely on the CMS ”Meaningful Measures” initiative, including use of new care planning codes, the annual wellness visit, and MIPS dementia measures

https://aspe.hhs.gov/public-members-advisory-council-alzheimers-research-care-and-services-2020-recommendations#clinical

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Questions?

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