The National Academies of
SCIENCES·ENGINEERING·MEDICINE

Assessing the Impact of Applications of Digital Health Records on Alzheimer's Disease Research

Presented at the Alzheimer's Association International Conference on Alzheimer's Disease
Washington, DC | July 20, 2015

8:00 a.m. **Session Overview**

DANIEL BURCH
Global Therapeutic Area Head & Vice President for CNS
Pharmaceutical Product Development

8:05 a.m. **Clinical Trial Design: DHR Collaborative Efforts in Europe**
- Examine how electronic medical records (EMRs), research, and epidemiology cohorts have been used in the UK and Europe to identify biomarkers, recruit study participants, and model future clinical trials.
- Discuss the European Information Framework progress towards an integrated platform for data aggregation.

SIMON LOVESTONE
Professor of Translational Neuroscience
Oxford University

8:20 a.m. **Infrastructure Needs**

Half a Century of Medical Records Linkage in the Rochester Epidemiology Project
- Explore how passive record-linkage systems can be combined with active contacts to strengthen research to discover risk and protective factors for Alzheimer's disease.
- Review lessons learned, limits and gaps of EMR linkage systems, and how they can be used as practical tools.

WALTER A. ROCCA
Director, Rochester Epidemiology Project
Professor of Epidemiology and Neurology
College of Medicine, Mayo Clinic

Lessons Learned from Medicare Claims-Based Methods of Studying DHRs
- Review the current state of research and diagnostic methodologies based on administrative data and DHRs.
- Examine reverse translations and limitations of DHRs and identify other necessary data sources.

JULIE BYNUM
Associate Professor of Medicine
The Dartmouth Institute for Health Policy & Clinical Practice
The Geisel School of Medicine at Dartmouth

8:45 a.m.   **Ethical, Societal, and Legal Considerations**
- Examine what kinds of ethical, societal and legal issues must be considered in applying DHRs on Alzheimer's disease research.

  TIA POWELL
  Director, Montefiore Einstein Center for Bioethics
  Professor of Clinical Epidemiology and Clinical Psychiatry
  Albert Einstein College of Medicine

9:00 a.m.   **Opportunities for Alzheimer's Disease Research: Facilitated Panel Discussion**
- Identify a set of core principles that can be used to support innovative clinical trial design as well as infrastructure and cloud computing needs for Alzheimer's disease.
- Discuss how information contained within DHRs holds the potential to identify novel surrogate markers and modify clinical trial design.
- Identify the data sharing and management strategies and infrastructure necessary to identify potential surrogate outcomes.
- Discuss next steps and strategies for moving forward.

  SIMON LOVESTONE
  Professor of Translational Neuroscience
  Oxford University

  WALTER A. ROCCA
  Director, Rochester Epidemiology Project
  Professor of Epidemiology and Neurology
  College of Medicine, Mayo Clinic

  JULIE BYNUM
  Associate Professor of Medicine
  The Dartmouth Institute for Health Policy & Clinical Practice
  The Geisel School of Medicine at Dartmouth

  IYA KHALIL
  Executive Vice President and Co-Founder
  GNS Healthcare

  TIA POWELL
  Director, Montefiore Einstein Center for Bioethics
  Professor of Clinical Epidemiology and Clinical Psychiatry
  Albert Einstein College of Medicine

9:30 a.m.   **ADJOURN**