



NIA IMPACT

COLLABORATORY

TRANSFORMING DEMENTIA CARE

National Institute on Aging (NIA) **IM**bedded **P**ragmatic **A**lzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) **C**linical **T**rials (IMPACT) Collaboratory

September 2019

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CONTACT US: IMPACTCollaboratory@hsl.harvard.edu

ABOUT

The NIA IMPACT Collaboratory provides national leadership and serves as a national resource in all aspects of research supporting the design and execution of embedded pragmatic clinical trials (ePCTs) evaluating non-pharmacological approaches to care for people living with dementia (PLWD) and their caregivers within health care systems

MISSION:

The NIA IMPACT Collaboratory's mission is to build the nation's capacity to conduct pragmatic clinical trials of interventions embedded within health care systems for people living with dementia and their caregivers by:

- Developing and disseminating best practice research methods
- Supporting the design and conduct of pragmatic trials, including pilot studies
- Building investigator capacity through training and knowledge generation
- Catalyzing collaboration among stakeholders, healthcare providers, and investigators
- Ensuring the research includes culturally-tailored interventions and people from diverse and under-represented backgrounds

VISION:

To transform the delivery, quality, and outcomes of care provided to Americans living with dementia and their caregivers by accelerating the testing and adoption of evidence-based interventions within healthcare systems

CORE VALUES:

- Be Collaborative – create and integrate a community of researchers, health system providers and stakeholders
- Be Excellent – promote the highest quality research and integrity among investigators
- Be Generative – serve as a catalyst for novel ideas and cultivate a diverse cadre of trained investigators
- Be Transformative – develop and test interventions embedded in real-world health care systems that will make a difference in lives of PLWD and their families
- Be Inclusive – ensure research includes and is applicable to people of all backgrounds
- Be Sustainable – establish a durable research infrastructure and knowledge base

Background

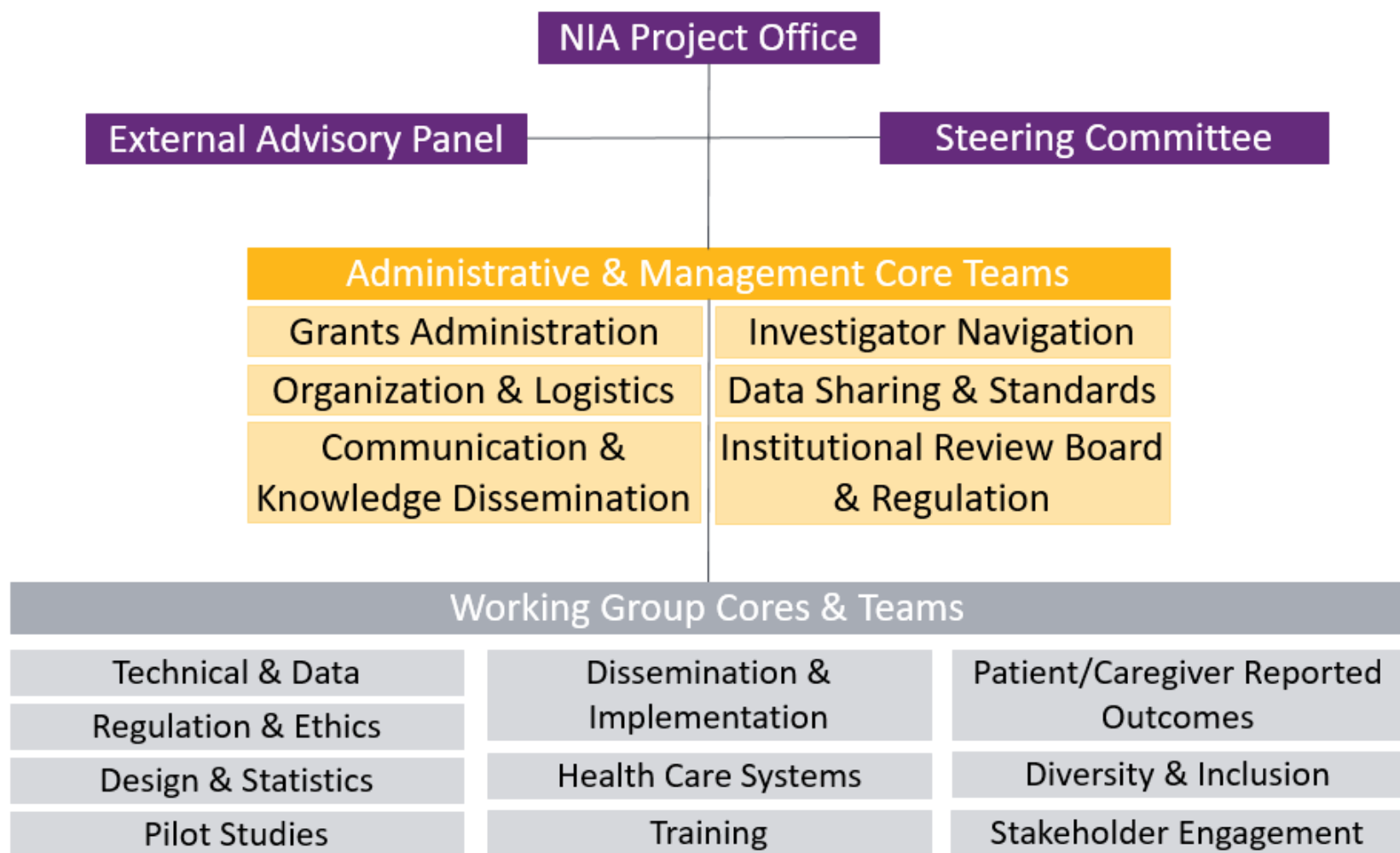
The National Institute on Aging (NIA) **IM**bedded **P**ragmatic **A**lzheimer's Disease (AD) and AD-Related Dementias (AD/ADRD) **C**linical **T**rials (IMPACT) Collaboratory was established in 2019 to meet the urgent public health need to deliver high quality, evidence-based care to people living with dementia (PLWD) and their caregivers within the health care systems (HCS) that serve them.

Over five million Americans are living with AD/ADRD. PLWD are particularly vulnerable to receiving uncoordinated and poor quality care, ultimately leading to adverse health outcomes, poor quality of life, and misuse of resources. Strategies to improve their care must be informed by high-quality evidence. While prior research has elucidated opportunities for improvement, the adoption of promising interventions has been stymied by the lack of research evaluating their effectiveness when implemented under "real-world" conditions.

[Embedded pragmatic clinical trials](#) have the potential to accelerate the translation of evidence-based interventions into clinical practice. Since its inception in 2012, the NIH Common Fund HCS Research Collaboratory ([NIH Collaboratory](#)) has accomplished foundational work towards strengthening the national capacity to conduct ePCTs in a broad array of medical disciplines and health care systems.

With this foundation, the NIA IMPACT Collaboratory is motivated by the recognition that conducting ePCTs among PLWD and their caregivers merits special focus. PLWD are served by a variety of unique HCS that employ distinct electronic health records (EHRs), registries, and administrative datasets. Novel approaches and standards are needed to identify PLWD and capture relevant outcomes using these data sources. There are also distinct ethical and regulatory considerations for involving vulnerable PLWD in ePCTs, an array of particular stakeholders that must be engaged, and the need to address diversity and inclusion in all aspects of ePCTs conducted.

The NIA IMPACT Collaboratory brings together a multidisciplinary group of over 60 investigators representing approximately 31 academic institutions with expertise in AD/ADRD, HCS, EHR and administrative data, design and analysis of ePCTs, ethics and regulatory issues specific to dementia, implementation science, research mentorship, diversity and inclusion, and stakeholder engagement. The NIA IMPACT Collaboratory provides the infrastructure for these experts to partner with industry leaders and other stakeholders from across the nation. Together, the NIA IMPACT Collaboratory is building the nation's capacity to conduct ePCTs among PLWD and their caregivers by developing and disseminating best practice research methods, supporting the design and conduct of ePCTs, building investigator capacity, and ensuring the research includes culturally-tailored interventions and people from diverse and under-represented backgrounds.



What We Do

The work of the NIA IMPACT Collaboratory is accomplished by a coordinated effort of multidisciplinary experts from across the nation organized into [10 Working Cores Groups and Teams](#) whose expert members partner with health care system leaders and key stakeholders to do the following:

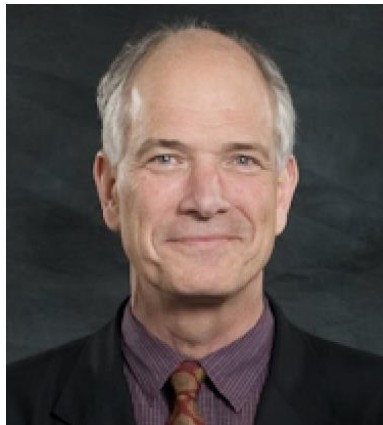
- ❖ **Develop and disseminate technical, policy, and best practices guidelines** for all aspects of conducting impactful, rigorous, ethically sound, and regulatory compliant ePCTs in partnership with the various HCSs that deliver care to PLWD and their caregivers.
- ❖ **Enhance research development and investigator capacity** by:
 - Funding and guiding pilot ePCTs and providing the methodological and technical support needed to transform pilot studies into [full-scale ePCTs](#).
 - Serving as a resource for NIA-funded investigators conducting ePCTs in PWD.
 - Supporting the [training](#) of junior investigators to become experts in this field through the funding of career development awards, training workshops, and on-line training modules.
- ❖ **Engage stakeholders**, including [health care systems](#), to partner with researchers in the conduct of ePCTs in PLWD and their caregivers.

If you are an investigator, health care industry representative or other stakeholder interested in learning more about what the NIA Collaboratory can offer please **contact us** at IMPACTCollaboratory@hsl.harvard.edu.

MULTIPLE PRINCIPAL INVESTIGATORS:



Susan L. Mitchell, MD, MPH is a professor of medicine at Harvard Medical School and senior scientist at Hebrew SeniorLife's Hinda and Arthur Marcus Institute for Aging Research in Boston, where she directs the Palliative Care in Aging Research Center and co-directs the Interventional Studies in Aging Center. She is a geriatrician and health services researcher. Her research focuses on improving outcomes for older patients with advanced illness, particularly those living with dementia. She has been the principal investigator on many large research projects, including several cluster randomized clinical trials, funded by the NIH and has authored many key scientific publications related to this topic. Dr. Mitchell is an active mentor of young investigators and was supported by an NIH-NIA K24 Mid-Career Investigator Award for ten years. She is also a current recipient of a NIH-NIA Method to Extend Research in Time (MERIT) Award.



Vincent Mor, PhD professor of health services, policy & practice and Florence Pirce Grant professor in the Brown University School of Public Health, has been principal investigator of 40+ NIH-funded grants focusing on use of health services and outcomes of frail and chronically ill people. He has evaluated the impact of programs and policies including Medicare funding of hospice, changes in Medicare nursing home payment, and the introduction of nursing home quality measures. He co-authored the Congressionally-mandated Minimum Data Set (MDS) and was architect of an integrated Medicare claims and clinical assessment data structure used for policy analysis, pharmaco-epidemiology and population outcome measurement. Dr. Mor developed summary measures using MDS data to characterize residents' physical, cognitive and psycho-social functioning. These data resources are the heart of the NIA-funded

Program Project Grant he leads, "Changing Long Term Care in America," examining the impact of Medicaid and Medicare policies on long-term care. These data are also at the core of a series of large, pragmatic cluster randomized trials of novel nursing home-based interventions led by Dr. Mor.

National Institute on Aging (NIA) Representatives

PROJECT OFFICER:

[Partha Bhattacharyya, PhD](#)

Title: Program Director

Office(s): Division of Behavioral and Social Research (DBSR)

SCIENTIFIC OFFICERS:

[Lisa Onken, PhD](#)

Title: Director Behavior Change and Intervention Program

Office(s): Division of Behavioral and Social Research (DBSR)

[Marcel Salive, MD, MPH](#)

Title: Health Scientist Administrator

Office(s): Division of Geriatrics and Clinical Gerontology (DGCG)

CORES AND TEAMS

Administration Core

The Administration Core focuses on providing the organization and services needed to manage and integrate all the activities of the NIA IMPACT Collaboratory

EXECUTIVE DIRECTORS:



Jill Harrison, PhD is assistant professor of practice in the Department of Health Services, Policy and Practice at Brown University School of Public Health. Prior to joining the NIA IMPACT Collaboratory, Dr. Harrison was the Director of Research for an international non-profit advocacy organization, founded by a patient, focused on implementing person-centered care initiatives in healthcare organizations in 27 countries. In addition to her role at IMPACT Collaboratory, Dr. Harrison is a member of the Advisory Panel for Patient Engagement at the Patient-Centered Outcomes Research Institute (PCORI). She was recently the principal investigator of a PCORI Engagement Award about how patient-family advisory councils engage in research. Her research interests include: pragmatic trials in real-world settings, engaging residents of long-term care communities as evaluators of care quality, developing culturally congruent person-centered care approaches in healthcare systems, and organizational cultural change.

She completed her post-doctorate at Brown University in health services research.



Ellen P. McCarthy, PhD, MPH is associate professor of medicine and epidemiology at Harvard and associate scientist in the Palliative Care in Aging Research Center at Hebrew SeniorLife's Hinda and Arthur Marcus Institute for Aging Research in Boston. She is an epidemiologist and health services researcher with extensive experience in research, administration, and training. Dr. McCarthy has led research aimed at improving care of older patients with advanced illness with a focus on reducing healthcare disparities among underserved, older populations. She has worked across diverse groups of patients, caregivers, providers, healthcare systems, and investigators to inform strategies to navigate research activities across these complex environments. Her expertise includes using clinical data and Medicare-linked databases to address research questions in older people. Dr. McCarthy previously served as Assistant Dean for Development and Diversity at Harvard Medical School. She participates in

several Harvard fellowship programs and has mentored many successful investigators in aging research.

Administration Core

TEAMS:

| | |
|---|--|
| Grants Administration | <i>Leader:</i> Audrey Kydd <i>Members:</i> Ann Medeiros, Andrea Medeiros |
| Organization & Logistics | <i>Leaders:</i> Faye Dvorchack / Cindy Williams |
| IRB & Regulation | <i>Leader:</i> Julie Lima, PhD, MPH |
| Data Sharing & Standards | <i>Leaders:</i> Rosa Baier, MPH / Julie Lima, PhD, MPH |
| Investigator Navigation | <i>Leader:</i> Ellen McCarthy, PhD, MPH <i>Project Director:</i> Laurie Herndon, MSN, GNP, BC |
| Communication & Knowledge Dissemination | <i>Leader:</i> Elaine Bergman, MS <i>Study Coordinator:</i> Erin Luers, MS |

What the Administration Core does:

1. Administers, manages, and integrates all the components of the NIA IMPACT Collaboratory.
2. Coordinates support and guidance for pilot project and other Collaboratory investigators.
3. Coordinates the development and dissemination of all products, guidance materials, and training opportunities generated by the NIA IMPACT Collaboratory.

Technical Data Core (TDC)

The TDC focuses on leveraging electronic health records (EHRs), administrative data and other health care system data sources to conduct ePCTs among people living with dementia (PLWD) and their caregivers

CORE LEADER:



Julie Bynum, MD, MPH is a Margaret Terpenning collegiate professor of internal medicine and Associate Director of the Division of Geriatric & Palliative Medicine at University of Michigan, earned her BS from Union College, an MPH from the Johns Hopkins School of Hygiene & Public Health, and an MD from Johns Hopkins University School of Medicine. One of Dr. Bynum's contributions to the field has been to develop a method of creating "virtual" physician-hospital networks that allows the measurement of care delivered and its outcomes for a population served by a specific group of providers. These networks were used in the conceptual development of the Accountable Care Organization legislation.

EXECUTIVE COMMITTEE:

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|----------------------------|--|
| Chiang-Hua Chang, PhD, MS | Research Assistant Professor, University of Michigan |
| David Dorr, MD, MS | Professor and Vice Chair of Medical Informatics and Clinical Epidemiology, Professor of Medicine, Division of General Internal Medicine and Geriatrics, Chief Research Information Officer, Biomedical Informatics Graduate Program, Oregon Health & Science University School of Medicine |
| Julie Lima, PhD, MPH | Assistant Professor, Health Services, Policy & Practice, Brown University School of Public Health |
| Ellen McCreedy, PhD | Assistant Professor, Brown University School of Public Health |
| Richard Platt, MD, MSc | Professor and Chair of the Department of Population Medicine, Harvard Medical School Executive Director, Harvard Pilgrim Health Care Institute |
| V.G. Vinod Vydiswaran, PhD | Assistant Professor of Learning Health Sciences, University of Michigan |

Technical Data Core (TDC)

What the TDC does:

1. Develops and disseminates data algorithms to **identify and characterize PLWD** and their caregivers from EHRs and administrative datasets.
2. Develops and disseminates algorithms that **capture relevant health outcomes** of PLWD and their caregivers from secondary and primary data sources.
3. Gives **technical assistance** to investigators conducting ePCTs in PLWD by providing data and guidance for: 1. Power calculations based on eligibility criteria, cohort size and outcome selection; 2. Real-time recruitment; 3. Automating data extraction for reporting and analysis; 4. Quantifying outcomes and; 5. Embedding trial-specific clinical notifications or adherence monitoring reports into EHRs.
4. Enables investigator **access to remote enclaves** of sensitive data (e.g., EHRs, private claims records).

Regulation and Ethics Core

The Regulation and Ethics Core focuses on clarifying the balance among the competing priorities of conducting ePCTs in people living with dementia (PLWD) and their caregivers, protecting the interests of participants, and assuring health care systems that regulatory issues are addressed

CORE LEADER:



Jason Karlawish, MD is a professor of medicine, medical ethics and health policy, and neurology at the University of Pennsylvania Perelman School of Medicine. He is board-certified in geriatric medicine. Dr. Karlawish is a senior fellow of the Leonard Davis Institute of Health Economics, senior fellow of the Penn Center for Public Health Initiatives, fellow of the University of Pennsylvania's Institute on Aging, Director of the Penn Neurodegenerative Disease Ethics and Policy Program, Associate Director of the Clinical Core and Co-Associate Director of the Alzheimer's Disease Core Center, and Co-Director of the Penn Memory Center. He is also Director of the Alzheimer's Disease Center's Outreach, Recruitment and Education Core. In addition, he directs the Penn Prevention Research Center's Healthy Brain Research Center, and is a member of the CDC-supported Healthy Brain Research Network dedicated to surveillance, education, awareness, and empowerment that promotes brain health.

ASSOCIATE CORE LEADER:



Emily Largent, PhD, JD, RN is an assistant professor of medical ethics and health policy at the University of Pennsylvania Perelman School of Medicine. Her research examines ethical and regulatory issues arising in human subjects research and when clinical research is integrated with clinical care. She has a particular focus on Alzheimer's disease research and studies issues such as gene and biomarker disclosure and the study partner requirement in Alzheimer's disease trials. Dr. Largent received her PhD in health policy, with a focus in ethics, from Harvard University and her JD from Harvard Law School. Prior to that, she received her BS in nursing from the University of Pennsylvania School of Nursing and completed a fellowship in the Department of Bioethics at the National Institutes of Health.

Regulation and Ethics Core

EXECUTIVE COMMITTEE:

| | |
|----------------------|--|
| Spencer Hey, PhD | Faculty and Co-Director of Research Ethics, Harvard Center for Bioethics Research Scientist, Brigham and Women's Hospital |
| Allison Hoffman, JD | Professor of Law, University of Pennsylvania Law School Senior Fellow, Leonard Davis Institute of Health Economics |
| Steve Joffe, MD, MPH | Founders Professor of Medical Ethics & Health Policy, University of Pennsylvania Perelman School of Medicine Professor of Pediatrics, Children's Hospital of Philadelphia Senior Fellow, Leonard Davis Institute of Health Economics |
| Julie Lima, PhD, MPH | Assistant Professor, Health Services, Policy & Practice, Brown University School of Public Health |
| Alex London, PhD | Clara L. West Professor of Ethics and Philosophy, Director of the Center for Ethics and Policy, Carnegie Mellon University |

What the Regulation and Ethics Core does:

1. Develops and disseminates guidelines and **best practices for the research community** that address the particular ethical issues and regulatory structures in conducting ePCTs with PLWD and their caregivers.
2. Identifies and addresses ethical and regulatory concerns and barriers to conducting ePCTs in PLWD and their caregivers from the **perspectives of health care system stakeholders**.
3. Provides **guidance and training to investigators**, regarding ethical and regulatory issues.

Design and Statistics Core (DSC)

The DSC focuses on the biostatistical methods needed to design, conduct, and analyze ePCTs among people living with dementia (PLWD) and their caregivers within health care systems

CORE LEADER:



Heather Allore, PhD focuses on research collaborations and methodological development work as leader of the Data Management and Statistics Core of the Yale Alzheimer's Disease Research Center and for 12 years as Director of Biostatistics at the Yale Program on Aging. She founded the field of Gerontological Biostatistics where innovative designs for multicomponent interventional trials and biostatistical methods are required to rigorously address scientific questions related to geriatric health conditions. Her research focuses on issues related to the design and analysis of studies of multiple chronic conditions using both clinical trials and observational studies. Dr. Allore has a wealth of experience conducting epidemiologic studies and is a recognized authority on longitudinal statistical methods, including extended Cox models for state transitions, generalized estimating equations, mixed effects models, latent class trajectory models, joint models, and recently modified the average attributable fraction for a time-to-event outcome with time-varying medical conditions.

EXECUTIVE COMMITTEE:

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| Darce Costello, EdD, MPH, MBA | Associate Research Scientist, Biostatistics Core, Yale University School of Medicine |
| Keith Goldfeld, DrPH, MS, MPA | Assistant Professor, Department of Population Health, NYU School of Medicine |
| Roe Gutman, PhD | Associate Professor of Biostatistics, Brown University School of Public Health |
| Joan Monin, PhD, MS | Associate Professor, Yale School of Public Health |
| Monica Taljaard, PhD | Senior Scientist, Ottawa Hospital Research Institute Associate Professor, University of Ottawa |
| Thomas Trivison, PhD | Senior Scientist, Director of Biostatistics, Co-Director of the Interventional Studies in Aging Center, Hebrew SeniorLife's Hinda and Arthur Marcus Institute for Aging Research Associate Professor of Medicine, Harvard Medical School Faculty, Division of Gerontology, Beth Israel Deaconess Medical Center |

Design and Statistics Core (DSC)

What the DSC does:

1. Provides biostatistical **assistance and guidance to investigators** planning or conducting ePCTs in PLWD concerning: 1. Study design and randomization; 2. Analytic approaches; 3. Power and sample size calculations; and, 4. Quality assurance of biostatistical elements during project conduct.
2. Develops and disseminates **novel biostatistical approaches** for the design and conduct of ePCTs among PLWD and their caregivers within health care systems.
3. Collaborates with the Technical/Data Core in providing advice and guidance on **reproducible analyses and replication studies**.

Pilot Studies Core

The Pilot Studies Core focuses on soliciting, funding and guiding pilot ePCTs among people living with dementia (PLWD) within health care systems

CORE LEADER:



Ab Brody, PhD, RN, FAAN is associate professor of nursing and medicine, Associate Director of Hartford Institute for Geriatric Nursing, and Founder of Aliviado. His work focuses on the intersection of geriatrics, palliative care, and equity, seeking to improve quality of care for older adults with serious illness. He is principal investigator for two NIH-funded large-scale pragmatic clinical trials: one focusing on improving care quality, quality of life, and healthcare utilization for people living with dementia in home health (R01AG056610) through Aliviado Dementia Care for Home Health; another, the HAS-QOL trial (R61AG061904), focusing on implementing Aliviado Dementia Care for Hospice, with a primary outcome of reducing inappropriate antipsychotic use that can lead to reduced function and quality of life. He is passionate about mentoring and developing the nursing and scientific workforce, leads the Hospice and Palliative Nurses Association Leadership Development Program, is Enrichment Program Director of NYU Meyer's P20 Exploratory Center for Precision Health in Diverse Populations (P20NR018075), and maintains an active practice on the Geriatric and Palliative Consult Services at NYU Langone Health.

EXECUTIVE COMMITTEE:

| | |
|--------------------------|---|
| Deborah Barnes, PhD, MPH | Professor of Psychiatry, Epidemiology & Biostatistics, University of California, San Francisco Research Health Science Specialist, San Francisco VA Health Care System |
| Joshua Chodosh, MD, MSHS | Professor, Departments of Medicine and Population Health, NYU Langone Health Staff Physician, VA New York Harbor Healthcare System |
| James Galvin, MD, MPH | Professor, Charles E. Schmidt College of Medicine, Florida Atlantic University |
| Kenneth Hepburn, PhD | Professor, Nell Hodgson Woodruff School of Nursing, Emory University |
| Andrea Troxel, ScD | Professor of Population Health and Director of Biostatistics, NYU School of Medicine |
| Kathleen Unroe, MD, MHA | Associate Professor, Indiana University Department of Medicine Center Scientist, Indiana University Center for Aging Research Investigator, Regenstrief Institute, Inc. |

Pilot Studies Core

What the Pilot Studies Core does:

1. **Solicits and funds pilot projects** that will lead to future full-scale ePCTs focused on PLWD and their caregivers.
2. Provides the **monitoring, mentorship, and resources** to ensure rigorous, timely conduct of pilot studies.
3. **Promotes the expertise of pilot project investigators** by integrating them into IMPACT Collaboratory's activities, training opportunities, and Scientific Conference.
4. Assists **transforming completed pilot projects into full-scale ePCTs** among PLWD and their caregivers within health care systems.

Patient and Caregiver Reported Outcomes (PCRO) Core

The PCRO Core focuses on developing and supporting use of PCROs relevant to people living with dementia (PLWD) and their caregivers in the design and conduct of ePCTs

CORE LEADER:



Laura Hanson, MD, MPH is a tenured professor in the Division of Geriatric Medicine, Department of Medicine, University of North Carolina, Chapel Hill and Director of the UNC Palliative Care Program. As a board-certified physician in internal medicine, geriatric medicine, and hospice and palliative medicine, she provides care for frail and medically complex older patients, and adults of all ages with serious and potentially life-limiting illness. Dr. Hanson leads a research program to understand, measure and improve quality of palliative care for people living with late-stage AD/ADRD, nursing home residents and other vulnerable populations. As lead clinical investigator on the PEACE Project, she helped develop and test clinical palliative care quality measures, now endorsed by the National Quality Forum and applied nationwide in hospice care. She has been the principal investigator/co-investigator for numerous real-world and pragmatic clinical trials to improve nursing home dementia care, including two NIH-NIA funded randomized clinical trials of decision aids for family caregivers of people living with advanced dementia, and serves as site-based principal investigator for the Measurement Core, Palliative Care Research Cooperative group.

EXECUTIVE COMMITTEE:

| | |
|-----------------------------|---|
| Antonia Bennet, PhD | Associate Professor, Department of Health Policy and Management, University of North Carolina |
| Amy Kelley, MD, MSHS | Vice Chair for Health Policy and Faculty Development, Brookdale Department Geriatrics & Palliative Medicine, Icahn School of Medicine at Mount Sinai Staff Physician, Geriatric Research Education and Clinical Centers, James J Peters VA Medical Center, Bronx, NY |
| Christine Ritchie, MD, MSPH | Professor of Medicine, Harvard Medical School, Massachusetts General Hospital |
| Debra Saliba, MD, MPH | Anna and Harry Borun Endowed Chair in Geriatrics and Gerontology at UCLA Director, UCLA/JH Borun Center for Gerontological Research Associate Director for Education, VA Los Angeles HSR&D Center of Innovation Senior Natural Scientist, RAND Corporation |

Patient and Caregiver Reported Outcomes (PCRO) Core

EXECUTIVE COMMITTEE:

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| Joan Teno, MD, MS | Professor of Medicine, Oregon Health & Science University Adjunct Professor of Health Services, Policy, and Research, Brown University School of Public Health |
| Sheryl Zimmerman, PhD | University Distinguished Professor and Co-Director, Program on Aging, Disability, and Long-Term Care, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill |

What the PCRO Core does:

1. Synthesizes evidence and creates a **library of Clinical Outcome Assessments (COAs)**, relevant to conducting ePCTs among PLWD and their caregivers, including: patient-reported, caregiver-reported, observer-reported, performance, and clinician-reported outcomes.
2. Defines and disseminates **best practices for collecting COAs** from electronic health records, registries, and administrative databases in collaboration with the Technical and Data Core for ePCTs among PLWD and their caregivers.
3. Provides **guidance and consultation** to investigators on measuring and applying COAs in the design and conduct of ePCTs among PLWD and their caregivers.

Dissemination and Implementation (D&I) Core

The D&I Core focuses on implementing and disseminating dementia care interventions in the context of ePCTs and optimizing the potential for integrating the intervention into health care systems

CORE LEADER:



Laura Gitlin, PhD, FGSA, FAAN is Dean and distinguished professor at College of Nursing and Health Professions, Drexel University. She also has an adjunct appointment in the Johns Hopkins School of Nursing and School of Medicine. Her research focuses on developing strategies for aging at home with a particular focus on dementia care. Dr. Gitlin and her teams have conducted over 20 clinical trials with some interventions being implemented worldwide. She currently has several multi-site studies, one of which is a pragmatic trial to test a caregiver support program that augments adult day services with Dr. Gaugler. She recently co-authored a book with Dr. Hodgson, *Better Living with Dementia: Implications for Individuals, Families, Communities and Societies* (Academic Press), based on a MOOC with over 80,000 participants worldwide; and another with Dr. Piersol, *A Caregiver's Guide to Dementia: Using Activities and Other Strategies to Prevent, Reduce and Manage Behavioral Symptoms* (Camino Books).

ASSOCIATE CORE LEADER:



Joseph E. Gaugler, PhD is the Robert L. Kane Endowed professor in long-term care & aging in the Division of Health Policy and Management and School of Public Health at the University of Minnesota. Dr. Gaugler's research examines the sources and effectiveness of long-term care for people living with Alzheimer's disease and other chronic conditions. An applied gerontologist, Dr. Gaugler's interests include Alzheimer's disease and long-term care, the longitudinal ramifications of family care for people living with dementia and other chronic conditions, and the effectiveness of community-based and psychosocial services for older people living with dementia and their caregiving families. Underpinning these substantive areas, Dr. Gaugler also has interests in longitudinal and mixed methods.

Dissemination and Implementation (D&I) Core

EXECUTIVE COMMITTEE:

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|--------------------------------------|--|
| Rosa Baier, MPH | Associate Director, Center for Long-Term Care Quality & Innovation, Associate Professor of Practice, Department of Health Services, Policy & Practice, Brown University School of Public Health |
| Marie Boltz, PhD, GNP-BC, FGSA, FAAN | Elouise Ross Eberly and Robert Eberly Endowed Chair and Professor, Pennsylvania State University College of Nursing Associate Director, Pennsylvania State University Center of Geriatric Nursing Excellence |
| Rick Fortinsky, PhD | Professor and Health Net, Inc. Endowed Chair in Geriatrics and Gerontology, University of Connecticut School of Medicine |
| Nancy Hodgson, PhD, RN, FAAN | Associate Professor, University of Pennsylvania |
| Eric Jutkowitz, PhD | Assistant Professor, Brown University School of Public Health |
| Kimberly Van Haitsma, PhD | Associate Professor, Director, Program for Person Centered Living Systems of Care, College of Nursing, Pennsylvania State University Senior Research Scientist, Polisher Research Institute, Abramson Senior Care |

What the D&I Core does:

1. Conducts and disseminates syntheses of the literature regarding implementation of non-pharmacologic interventions for people living with dementia (PLWD) and their caregivers and helps **identify interventions potentially ready for an ePCT**.
2. Identifies the readiness of pilot ePCT interventions for full scale evaluation and **maximize the likelihood of their successful implementation and dissemination** within a health care system.
3. Provides **technical assistance** tailored to investigators conducting ePCTs in PLWD to advance their implementation and dissemination plans.

Health Care Systems (HCS) Core

The HCS Core focuses on engaging the varied health care systems providing care for people living with dementia (PLWD) and their caregivers in the conduct of ePCTs

CORE LEADER:



Eric B. Larson, MD, MPH, is Executive Director of Kaiser Permanente Washington Health Research Institute (KPWHRI) and Vice President for research and health care innovation at Kaiser Foundation Health Plan of Washington. A general internist, Dr. Larson is a national leader in geriatrics, health services, and clinical research and has been an elected member of the National Academy of Medicine since 2007. Dr. Larson pursues an array of research, ranging from clinical interests such as Alzheimer's disease and genomics to health services research involving technology assessment, cost-effectiveness analysis, and quality improvement. His research on aging includes a longstanding collaboration between Kaiser Permanente Washington and the University of Washington called the Adult Changes in Thought (ACT) study. With colleagues from Duke and Harvard, Dr. Larson started and now helps lead the NIH Health Care Systems Research Collaboratory.

ASSOCIATE CORE LEADER:



Leah Hanson, PhD is a senior research investigator and Senior Director of Research at HealthPartners Neuroscience Center, HealthPartners Institute and Co-Director of Research at the HealthPartners Center for Memory & Aging. For over 15 years, her research has focused on the development of novel therapeutic delivery methods for the treatment and prevention of neurologic diseases, especially those that impact older adults such as Alzheimer's disease, Parkinson's disease, and stroke. In 2010, she initiated the Minnesota Memory Project, a longitudinal cohort study of memory changes in adults and associated risk and protective factors, and she continues to serve as the principal investigator. Her experience includes recruitment for clinical research and trials in dementia via electronic medical record and healthcare claims data, conducting trials of non-medication interventions including education and support for patients and

caregivers, mindfulness-based stress reduction, and aromatherapy.

Health Care Systems (HCS) Core

EXECUTIVE COMMITTEE:

| | |
|-----------------------------|---|
| Rosa Baier, MPH | Associate Director, Center for Long-Term Care Quality & Innovation, Associate Professor of Practice, Department of Health Services, Policy & Practice, Brown University School of Public Health |
| Elizabeth Bayliss, MD, MSPH | Senior Investigator, Kaiser Permanente Colorado Institute for Health Research Professor, Department of Family Medicine, University of Colorado School of Medicine |
| Jerry Gurwitz, MD | Executive Director, Meyers Primary Care Institute Chief, Division of Geriatric Medicine, University of Massachusetts Medical School |
| David Reuben, MD | Archstone Professor of Medicine, Director, UCLA Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine at UCLA |
| Jeff Williamson, MD, MHS | Professor, Chief of Geriatric Medicine, and Director for Center for Healthcare Innovation, Wake Forest School of Medicine |

HEALTH SYSTEM LEADERS COUNCIL:

| | |
|--------------------------------|---|
| David Gifford, MD, MPH (Chair) | Senior Vice President, Quality and Regulatory Affairs, American Health Care Association/National Center for Assisted Living (AHCA/NCAL) |
| Sarah Greene, MPH | Executive Director, Health Care Systems Research Network |
| Alan Stevens, PhD | Director, Center for Applied Health Research, Baylor Scott & White Health |
| Stephen Waring, DVM, PhD | Senior Research Scientist, Essentia Institute of Rural Health Essentia Health |
| Christopher Callahan, MD, MACP | Physician-Scientist, Chief Research and Development Officer, Eskenazi Health |

Health Care Systems (HCS) Core

HEALTHCARE SYSTEM PARTNERS:



What the HCS Core does:

1. Establishes a **collaborative research resource** involving leaders from diverse health care systems to support and facilitate the conduct of ePCTs among PLWD and their caregivers.
2. Creates and disseminates **setting-specific approaches** to conducting ePCTs in PLWD and their caregivers within health care systems.
3. **Assists investigators** partner with health care systems to conduct ePCTs of non-pharmacological interventions for PLWD and their caregivers.

Training Core

The Training Core focuses on training junior investigators to become experts in the conduct of ePCTs among people living with dementia (PLWD) and their caregivers with health care systems

CORE LEADER:



Christopher M. Callahan, MD, MACP is a physician-scientist and Chief Research and Development Officer at Eskenazi Health in Indianapolis, Indiana. Dr. Callahan graduated from St. Louis University School of Medicine in 1985 and completed his Internal Medicine residency at Baylor College of Medicine and a fellowship in Health Services Research at Indiana University. He has served on the faculty at the Indiana University School of Medicine for 30 years. His clinical practice at Eskenazi Health in Indianapolis focuses on the care of older people living with Alzheimer's disease and AD-related dementias. He is a Scientist in the Regenstrief Institute, Inc. Dr. Callahan served as Director of the Indiana University Center for Aging Research for over 20 years. He conducts clinical research to improve care of older adults in primary care settings, including clinical trials exploring new models of care which increasingly focus on the integration of family, community, and medical services. He studies new approaches to facilitate implementation of care models into routine clinical practice, with emphasis on vulnerable elders.

ASSOCIATE CORE LEADER:



Alexia Torke, MD is an associate professor of medicine and Associate Division Chief of General Internal Medicine and Geriatrics, Indiana University School of Medicine. She is a research scientist with the Indiana University Center for Aging Research, Regenstrief Institute and Director of the Evans Center for Religious and Spiritual Values in Healthcare. Dr. Torke received her undergraduate degree from Carleton College, MD from Indiana University, and completed her primary care-internal medicine residency at Emory University in Atlanta. She completed fellowship training at the University of Chicago in primary care health services research and ethics. Dr. Torke's research focuses on ethical, communication and spiritual aspects of medical decision-making for older adults and currently on surrogate decision-making for older people living with dementia and other forms of cognitive impairment. Her research has been published in *Archives of Internal Medicine*, the *Journal of General Internal Medicine* and the *Journal of Clinical Ethics*. She has received funding from the NIH, the Greenwall Foundation and other foundation sources. She practices outpatient palliative care at IU Health Methodist Hospital.

Training Core

What the Training Core does:

1. Develops, funds, and coordinates a two-year **junior career development award (CDA) program** for MD and PhD early trainees seeking to build their career conducting ePCTs in PLWD.
2. Develops and implements **structured training activities** for junior investigators that address all aspects of conducting ePCTs in PLWD, including an annual in-person Training Workshop and web-based video training modules.
3. **Integrates CDA recipients and other junior investigators into the IMPACT Collaboratory's** academic activities to promote their professional expertise and individual productivity.

Diversity and Inclusion Team

The Diversity and Inclusion Team focuses on developing and implementing strategies to address diversity and inclusion in the conduct of ePCTs among people living with dementia (PLWD) and their caregivers to ensure the IMPACT Collaboratory is a national resource for all Americans afflicted with dementia

TEAM LEADER:



Ana Quiñones, PhD, MS, is an associate professor of family medicine at Oregon Health & Science University with an affiliate appointment at the OHSU-PSU School of Public Health. Dr. Quiñones is a gerontologist trained in health services organization and policy from the University of Michigan's School of Public Health. Her research interests are focused on addressing racial and ethnic differences in trajectories of age-related changes in health, particularly in co-existing chronic disease (multimorbidity), including dementia, and evaluating health care delivery changes designed to improve the management of multimorbidity for vulnerable older adults. She has led multiple NIH, NIA, and foundation-funded studies investigating racial and ethnic differences in multimorbidity. These include studies that trace the development and progression of multimorbidity over time and that seek to identify chronic disease combinations associated with greater cognitive decline and dementia among racially and ethnically-diverse populations.

TEAM MEMBERS:

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|-------------------------------|---|
| Maria Aranda, PhD | Associate Professor, USC Suzanne Dworak-Peck School of Social Work Executive Director, USC Edward R. Roybal Institute on Aging Director, Outreach, Recruitment and Engagement Core, USC Alzheimer's Disease Research Center |
| Peggye Dilworth-Anderson, PhD | Professor of Health Policy & Management, Gillings School of Global Public Health, University of North Carolina, Chapel Hill (UNC) |
| Gina Green-Harris, MBA | Director, University of Wisconsin School of Medicine and Public Health Center for Community Engagement and Health Partnerships (CCE), Wisconsin Alzheimer's Institute (WAI), Regional Milwaukee Office, Lifecourse Initiative for Healthy Families (LIHF) |
| Ladson Hinton, MD | Professor, Department of Psychiatry and Behavioral Sciences, University of California, Davis |
| Jonathan Jackson, PhD | Instructor in Neurology, Massachusetts General Hospital Instructor, Harvard Medical School |

Diversity and Inclusion Team

What the Diversity and Inclusion Team does:

1. **Guides, supports and monitors pilot studies** to ensure issues related to diversity and inclusion are fully integrated into the scientific design and conduct of the research.
2. **Integrates with Core Working Groups** to ensure issues related to diversity and inclusion are integrated into their specific research activities.
3. **Develops and disseminates guidance and training materials** related to integrating issues related to diversity and inclusion into the conduct of ePCTs among PLWD and their caregivers with health care systems.

Stakeholder Engagement Team

The Stakeholder Engagement focuses on engaging stakeholders, including health care systems, in the conduct of ePCTs among people living with dementia (PLWD) and their CGs

TEAM LEADER:



Gary Epstein-Lubow, MD earned his MD from The Ohio State University’s College of Medicine and Public Health; he completed his general psychiatry residency, geriatric psychiatry fellowship, and postdoctoral research at Brown University and Butler Hospital. He is associate professor of psychiatry at Brown University. Dr. Lubow was a recent fellow in the Health and Aging Policy Fellows Program. He served as a non-federal member of the U.S. Department of HHS Advisory Council for Alzheimer’s Research, Care, and Services, including work he organized regarding people living with dementia as stakeholders informing national research efforts for dementia care.

TEAM MEMBERS:

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|----------------------|---|
| Katie Maslow, MSW | Visiting Scholar, Gerontological Society of America |
| Ellen Tambor, MA | Research Director, Center for Medical Technology Policy |
| Brenda Nicholson, MD | Retired Physician |
| Louise Phillips, MD | Retired Physician |

What the Stakeholder Engagement Team does:

1. **Guides and, supports investigators** conducting ePCTs among PLWD and their caregivers in stakeholder engagement activities.
2. **Develops and disseminates guidance and training materials** about engaging stakeholders in the conduct of ePCTs among PLWD and their caregivers with health care systems.
3. Convenes a **Stakeholder Advisory Committee** that advises the NIA IMPACT Collaboratory about stakeholder engagement activities, strategies to assist investigators with stakeholder engagement, and priority topics for the development of guidance materials.