NATIONAL ACADEMIES *Sciences Engineering Medicine*

A WORKSHOP

Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias

May 23-24, 2022

The National Academies of SCIENCES ENGINEERING MEDICINE

May 23, 2022 | 9:00 AM – 4:10 PM (ET)
May 24, 2022 | 9:30 AM – 12:00 PM (ET)

Meeting Location

National Academy of Sciences Building
Lecture Room
2101 Constitution Avenue, NW
Washington, DC 20418

Public Webcast

https://www.nationalacademies.org/event/05-23-2022/mechanisms-for-organizational-behavior-change-to-address-the-needs-of-people-living-with-alzheimers-disease-and-related-dementias-a-workshop

Meeting Contacts

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NATIONAL ACADEMIES Sciences Engineering Medicine

Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias: A Workshop

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Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias

A Workshop

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MONDAY, MAY 23, 2022

9:00–9:20 **Welcome and Workshop Overview**
Richard Frank, PhD
Planning Committee Chair, The Brookings Institution, Harvard Medical School

Sponsor Remarks from NIA
Melinda Kelley, PhD*
Acting Deputy Director, National Institute on Aging at the National Institutes of Health

Theresa Y. Kim, PhD, MS
Social and Behavioral Science Program Official, Division of Behavioral and Social Research, National Institute on Aging at the National Institutes of Health

Keynote
9:20–10:10 Introduction and Moderation by Richard Frank

Keynote Speakers:
David Reuben, MD, University of California, Los Angeles*
Meena Seshamani, MD, PhD, Center for Medicare*

Break
10:10–10:25

Session 1: Defining Quality
10:25–11:55 Moderator: Terry Fulmer, PhD, RN, FAAN, The John A. Hartford Foundation

Speakers:

- Betty Ferrell, PhD, FAAN, City of Hope*
- Eric Schneider, MD, MSc, National Committee for Quality Assurance
- Lisa Gwyther, MSW, LCSW, Duke School of Medicine*

Moderated Discussion

11:55–12:55 **Lunch Break**

*presenting remotely

12:55–2:25 **Session 2: Transforming the Role of Payment System Incentives to Improve Quality**

Moderator: Richard Frank, PhD, Planning Committee Chair, The Brookings Institution, Harvard Medical School

Speakers:

- TisaMarie Sherry, MD, PhD, Office of the Assistant Secretary for Planning and Evaluation
- Bruce Vladeck, PhD, Greater New York Hospital Association, LiveOnNY
- Emily Largent, JD, PhD, RN, University of Pennsylvania*
- Amol Navathe, MD, PhD, University of Pennsylvania

Moderated Discussion

2:25–2:40 **Break**

2:40–4:10 **Session 3: Evidence on Impact of Existing Models and Research and Innovation to Address Gaps in Data/Evidence**

Moderator: Sharon Inouye, MD, MPH, Hinda and Arthur Marcus Institute for Aging Research-Hebrew Senior Live, Harvard Medical School*

Speakers:

- Julie Robison, PhD, University of Connecticut School of Medicine Center on Aging*
- Jennie Chin Hansen, RN, MS, FAAN, SCAN Health Plan, former CEO American Geriatrics Society*
- Hyobum Jang, MD, MPH, World Health Organization*
- Peter Hollmann, MD, Brown University, Lifespan Health Alliance

Moderated Discussion

END OF DAY 1

*presenting remotely

TUESDAY, MAY 24, 2022

9:30–11:00 **Session 4: Creating Change**
Moderator: Faith Mitchell, PhD, Urban Institute

Speakers:
- Sarah Lenz Lock, JD, AARP, Global Council on Brain Health
- Leslie Pelton, MPA, Institute for Healthcare Improvement*
- Kate McEvoy, JD, Milbank Memorial Fund*
- Helen Lamont, PhD, Office of the Assistant Secretary for Planning and Evaluation

Moderated Discussion

11:00–11:15 **Break**

11:15–11:55 Planning Committee Discussion – What We Learned and Where to Go from Here

Speakers:
- Richard Frank, PhD, Planning Committee Chair, The Brookings Institution, Harvard Medical School
- Elisabeth Belmont, JD, MaineHealth*
- Terry Fulmer, PhD, RN, FAAN, The John A. Hartford Foundation
- Scott Halpern, MD, PhD, University of Pennsylvania*
- Sharon Inouye, MD, MPH, Hinda and Arthur Marcus Institute for Aging Research-Hebrew Senior Live, Harvard Medical School*
- Faith Mitchell, PhD, Urban Institute
- Julie Robison, PhD, University of Connecticut School of Medicine, Center on Aging*

11:55–12:00 **Closing Remarks**
Richard Frank, PhD
Planning Committee Chair, The Brookings Institution, Harvard Medical School

END OF DAY 2

*presenting remotely

Notes for Virtual Attendees

- The livestream of the webcast is available at: https://www.nationalacademies.org/event/05-23-2022/mechanisms-for-organizational-behavior-change-to-address-the-needs-of-people-living-with-alzheimers-disease-and-related-dementias-a-workshop.
- We welcome your involvement in the workshop. Please use the chatbox on our website (located below the livestream) to ask questions, and please include your name and affiliation.
- This workshop is being webcast and recorded. The webcast and presentation files will be archived on the project webpage.
- Interested in receiving updates from the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division? Sign up at: https://nationalacademies.us8.list-manage.com/subscribe?u=ab74d126b7d2db12591de5c2c&id=211686812e

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Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias: A Workshop

Planning Committee Roster

Richard Frank, Ph.D. *(Chair)*
Leonard Schaeffer Chair in Economic Studies
Director of Schaeffer Initiative on Health Policy
The Brookings Institution
Margaret T. Morris Professor of Health Economics Emeritus
Department of Health Care Policy
Harvard Medical School

Elisabeth Belmont, J.D.
Corporate Counsel
MaineHealth

Terry Fulmer, Ph.D., RN, FAAN
President
The John A. Hartford Foundation

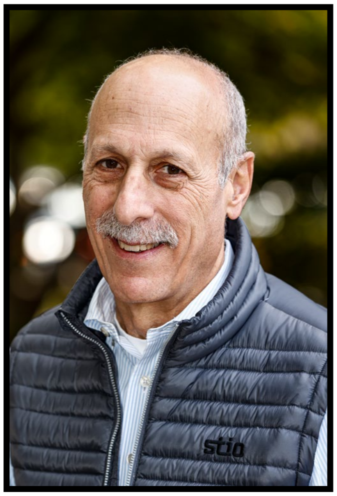
Scott Halpern, M.D., Ph.D.
John M. Eisenberg Professor of Medicine, Epidemiology, and Medical Ethics and Health Policy
University of Pennsylvania
Founding Director
Palliative and Advanced Illness Research (PAIR) Center
Director
Penn Roybal P20 Center on Palliative Care in Dementia

Sharon Inouye, M.D., M.P.H.
Director
Aging Brain Center, Hinda and Arthur Marcus Institute for Aging Research, Hebrew SeniorLife
Milton and Shirley F. Levy Family Chair and Professor of Medicine
Harvard Medical School

Faith Mitchell, Ph.D.
Institute Fellow
Urban Institute

Julie Robison, Ph.D.
Professor of Medicine
Center on Aging
University of Connecticut School of Medicine

Planning Committee Biographical Information



Richard Frank, Ph.D., (*Chair*) is a Senior fellow in Economic Studies and director of the USC-Brookings Schaeffer Initiative on Health Policy. He is the Margaret T. Morris Professor of Health Economics, Emeritus, in the Department of Health Care Policy at Harvard Medical School. From 2014 to 2016 he served as Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services. His research is focused on the economics of mental health and substance abuse care, long term care financing policy, health care competition, implementation of health reform and disability policy. Dr. Frank served as an editor for the Journal of Health Economics from 2005 to 2014. Dr. Frank was awarded the Georgescu-Roegen Prize from the Southern Economic Association, the Carl A. Taube Award from the American Public Health Association, and the Distinguished Investigator Award from AcademyHealth. He was elected to the Institute of Medicine (National Academy of Medicine) in 1997. He is co-author with Sherry Glied of the book "Better but Not Well" (Johns Hopkins Press).

Elisabeth Belmont, J.D., serves as Corporate Counsel for MaineHealth which is ranked among the nation's top 100 integrated healthcare delivery networks and has combined annual revenues of nearly $2 billion. She is responsible for a myriad of complex issues faced by an integrated delivery system on a daily basis and has a specialty concentration in health information and technology. Ms. Belmont has participated in a number of national initiatives where quality improvement, patient safety and information technologies intersect including events sponsored by the DHHS Office of the National Coordinator, DHHS Office of the Inspector General, American Health Lawyers Association, American Society of Healthcare Risk Management and American Association for the Advancement of Science. She serves as a member of the Division Committee of the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine. She is a former member of the National Academies' Board on Health Care Services of the Health and Medicine Division, and participated as a member of the National Academies' Consensus Study Committees on Improving Diagnosis in Health Care and Systems Approaches to Improve Patient Care by Supporting Clinician Well-Being. Additionally, Ms. Belmont is a Past President of the American Health Lawyers Association, former Chair of the Association's Health Information & Technology Practice Group, and former Chair of the Association's Quality in Action Task Force. She also was appointed co-Chair of the National Quality Forum's Health IT Patient Safety Measures Standing Committee. She previously served on the Advisory Boards of Bloomberg's Health Law Reporter and Health Law & Business News. Ms. Belmont co-authored agency guidance, EHR Contracts Untangled: Selecting Wisely, Negotiating Terms and Understanding the Fine

Print, for the DHHS Office of the National Coordinator. She is the recipient of numerous honors including being named by Modern Healthcare as one of the 2007 Top 25 Most Powerful Women in Healthcare, being selected to receive the American Health Lawyers Association 2014 David J. Greenburg Service Award, and being named by the National Academies of Sciences, Engineering, and Medicine as a 2016 National Associate for outstanding contributions to the work of the National Academies.

Terry Fulmer, Ph.D., RN, FAAN, is the President of The John A. Hartford Foundation in New York City, a foundation dedicated to improving the care of older adults. Established in 1929, the Foundation has a current endowment of more than $650 million. She serves as the chief strategist for the Foundation and her vision for better care of older adults is catalyzing the Age-Friendly Health Systems social movement. She is an elected member of the National Academy of Medicine and recently served on the independent Coronavirus Commission for Safety and Quality in Nursing Homes established to advise the Centers for Medicare and Medicaid Services. She previously served as Distinguished Professor and Dean of Health Sciences at Northeastern University. Prior, she served as the Erline Perkins McGriff Professor and Founding Dean of the New York University College of Nursing. She received her bachelor's degree from Skidmore College, her master's and doctoral degrees from Boston College and her Geriatric Nurse Practitioner Post-Master's Certificate from NYU. She completed a Brookdale National Fellowship and she is the first nurse to have served on the board of the American Geriatrics Society. She is also the first nurse to have served as President of the Gerontological Society of America, which awarded her the 2019 Donald P. Kent Award for exemplifying the highest standards for professional leadership in the field of aging.

Scott D. Halpern, M.D., Ph.D., is the John M. Eisenberg Professor of Medicine, Epidemiology, and Medical Ethics and Health Policy at the University of Pennsylvania, and a practicing critical care doctor. He is the founding Director of the Palliative and Advanced Illness Research (PAIR) Center, which generates evidence to advance policies and practices with the goals of improving the lives of all people affected by serious illness and removing the barriers to health equity that commonly face seriously ill patients. He is also Director of the NIA-funded Penn Roybal P30 Center on Palliative Care in Dementia. His research awards include AcademyHealth's Alice S. Hersh New Investigator Award, the Young Leader Award from the Robert Wood Johnson Foundation, the American Federation for Medical Research's Outstanding Investigator Award for the best scientist in any field under the age of 45, and the Association of Clinical and Translational Science's Distinguished Investigator Award. His mentoring awards include the John Hansen-Flaschen Award for Outstanding Mentorship and the Arthur K. Asbury Outstanding Faculty Mentor Award. He is an elected member of the American Society of Clinical Investigation and the Association of American Physicians, an elected Fellow of The Hastings Center, and serves on the Editorial Boards of the Annals of Internal Medicine and the American Journal of Bioethics.

Sharon K. Inouye, M.D., M.P.H., is the Director of the Aging Brain Center at the Hinda and Arthur Marcus Institute for Aging Research, Hebrew SeniorLife in Boston, Massachusetts. She holds the Milton and Shirley F. Levy Family Chair and is a Professor of Medicine at Harvard Medical School (Beth Israel Deaconess Medical Center). Her research focuses on delirium and functional decline in hospitalized older patients, resulting in more than 300 peer-reviewed original articles to date. Currently, she is the overall principal investigator of the Successful Aging after Elective Surgery (SAGES) study, an $11 million Program Project on delirium funded by the National Institute on Aging, as well as other active research projects. The purpose of the SAGES study is to examine the interface of delirium and dementia, whether delirium alters the course of dementia, and whether delirium leads to longstanding cognitive impairment and pathologic changes in the brain. Dr. Inouye is committed to improving health and quality of life for older persons and their families. Dr. Inouye developed and validated the Confusion Assessment Method (CAM), the most widely-used instrument for the identification of delirium. She conceptualized the multifactorial model for delirium, which focuses on identification of predisposing and precipitating factors for delirium. Her work involves translating theories of clinical investigation into practical applications that directly improve the quality of life for older adults. She developed the Hospital Elder Life Program (HELP), a multicomponent intervention strategy designed to prevent delirium by targeting six delirium risk factors. HELP was successful in reducing delirium by 40 percent and was published in a landmark study in the New England Journal of Medicine. This study was the first to show that a substantial proportion of delirium is preventable. Additionally, HELP has been shown to reduce falls, functional decline, and hospital costs, and to improve patient, family, and nursing satisfaction. The HELP program has been adopted by hundreds of hospitals worldwide.

Faith Mitchell, Ph.D., is an Institute Fellow at the Urban Institute, working with the Center on Nonprofits and Philanthropy and the Health Policy Center. She is also developing Urban's American Transformation project, that looks at the implications—and possibilities—of this country's racial and ethnic evolution. Over several decades, her career has bridged research, practice, and social and health policy. Previously, Mitchell was President and CEO of Grantmakers In Health, a Washington DC-based national organization that advises, informs, and supports the work of health foundations and corporate giving programs. Before that, she held leadership positions at the National Academies (National Research Council and Institute of Medicine), U.S. Department of State, William and

Flora Hewlett Foundation, and San Francisco Foundation. Mitchell has a doctorate in medical anthropology from the University of California, Berkeley. She has written or edited numerous policy-related publications and is the author of Hoodoo Medicine, a groundbreaking study of Black folk medicine. She co-chairs the advisory group for the John A. Hartford Foundation/Institute for Healthcare Improvement Age-Friendly Health Systems initiative; serves on the advisory committee of the National Collaborative for Health Equity, the editorial board of Health Affairs, and the boards of directors of Community Wealth Partners and The Jacob & Valeria Langeloth Foundation; and is a member of Board on Health Care Services of the National Academies of Sciences, Engineering, and Medicine.

Julie Robison, Ph.D., is a Professor of Medicine in the Center on Aging at the University of Connecticut School of Medicine. Dr. Robison conducts evidence-based health services research and intervention studies focused on aging families; long term services, supports and policy; dementia and health disparities using quantitative and qualitative research methods. She completed her Ph.D. at Cornell University and a post-doctoral fellowship in the epidemiology of aging at the Yale School of Medicine. Her work has been funded since 1997 by a range of sources including the Centers for Medicare and Medicaid Services (CMS), the Administration on Community Living, Connecticut State Agencies and the State Legislature, medical research foundations, and the National Institutes of Health. The results of her work directly impact the implementation of policies and programs that serve extremely vulnerable populations in Connecticut and nationally. She has served as Principal Investigator or Co-Principal Investigator on over 50 funded research studies and regularly present research findings in national and community forums. She has published over 55 scientific articles and book chapters as well as over 70 legislative and policy reports.

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Speakers Roster

Betty Ferrell, Ph.D., FAAN
Director and Professor
Division of Nursing Research and Education
Department of Population Sciences
City of Hope

Lisa P. Gwyther, M.S.W., LCSW
Associate Professor Emerita
Duke Department of Psychiatry and Behavioral Sciences
Duke School of Medicine
Founder
Duke Dementia Family Support Program

Jennie Chin Hansen, M.S., RN, FAAN
SCAN Health Plan
Former CEO
American Geriatrics Society

Peter Hollmann, M.D.
Chief Medical Officer and Clinical Assistant Professor of Family Medicine
Brown University
Medical Director
Lifespan Health Alliance

Hyobum Jang, M.D., M.P.H.
Technical Officer
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Helen Lamont, Ph.D.
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U.S. Department of Health and Human Services

Emily Largent, J.D., Ph.D., RN
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Penn IMPACT Ethics Core
University of Pennsylvania

Sarah Lenz Lock, J.D.
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Executive Director
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National Committee for Quality Assurance

Meena Seshamani, M.D., Ph.D.
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Center for Medicare

Tisamarie B. Sherry, M.D., Ph.D.
Deputy Assistant Secretary for Behavioral Health, Disability, and Aging Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services

Bruce Vladeck, Ph.D.
Senior Advisor
Greater New York Hospital Association
LiveOnNY

Speakers Biographical Information

Keynote Speakers

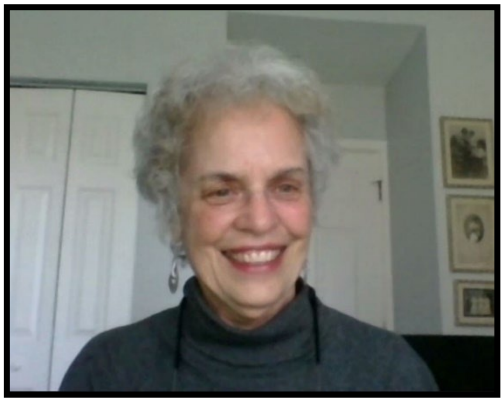
David Reuben, M.D., is Director, Multicampus Program in Geriatrics Medicine and Gerontology and Chief, Division of Geriatrics at the University of California, Los Angeles (UCLA) Center for Health Sciences. He is the Archstone Foundation Chair and Professor at the David Geffen School of Medicine at UCLA and Director of the UCLA Alzheimer's and Dementia Care program. Dr. Reuben is a past President of the American Geriatrics Society and the Association of Directors of Geriatric Academic Programs. He served for 8 years on the American Board of Internal Medicine's Board of Directors, including as Chair from 2010-2011. Since 2016, Dr. has served as a trustee of the American Board of Internal Medicine Foundation. In 2000, Dr. Reuben received the Dennis H. Jahnigen Memorial Award for outstanding contributions to education in the field of geriatrics and, in 2008, he received the Joseph T. Freeman Award from the Gerontological Society of America. He was part of the team that received the 2008 John M. Eisenberg Patient Safety and Quality Award for Research – Joint Commission and National Quality Forum, for Assessing Care of the Vulnerable Elderly. In 2012, he received the Henderson award from the American Geriatrics Society. In 2012, Dr. Reuben received one of the first CMMI Innovations Challenge awards to develop a model program to provide comprehensive, coordinated care for patients with Alzheimer's Disease and other dementias. In 2014, he was one of three principal investigators to be awarded a multicenter clinical trial (STRIDE) by the Patient-Centered Outcomes Research Institute (PCORI) and the National Institute on Aging (NIA) to reduce serious falls related injuries; it is the largest grant that PCORI has awarded. In 2018, he was awarded a multi-site PCORI- and NIA-funded pragmatic trial to compare the effectiveness of health system-based dementia care versus community-based dementia care versus usual care. Dr. Reuben was co-chair of the 2020 National Research Summit in Care, Services, and Supports for Persons with Dementia and their Caregivers. He is a member of the National Advisory Council on Aging for the National Institute on Aging. Dr. Reuben continues to provide primary care for frail older persons, including attending on inpatient and geriatric psychiatry units at UCLA, and making house calls. In his spare time, Dr. Reuben has written seven plays and lyrics for more than 20 songs with composer Sidney Sharp. A compilation of the first 10 has been recorded.

Meena Seshamani, M.D., Ph.D. is an accomplished, strategic leader with a deep understanding of health economics and a heart-felt commitment to outstanding patient care. Her diverse background as a health care executive, health economist, physician and health policy expert has given her a unique perspective on how health policy impacts the real lives of patients. She most recently served as Vice President of Clinical Care Transformation at MedStar Health, where she conceptualized, designed, and implemented population health and value-based care initiatives and served on the senior leadership of the 10 hospital, 300+ outpatient care site health system. The care models and service lines under her leadership, including community health, geriatrics, and palliative care, have been nationally recognized by the Institute for Healthcare Improvement and others. She also cared for patients as an Assistant Professor of Otolaryngology-Head and Neck Surgery at the Georgetown University School of Medicine. Dr. Seshamani also brings decades of policy experience to her role, including recently serving on the leadership of the Biden-Harris Transition HHS Agency Review Team. Prior to MedStar Health, she was Director of the Office of Health Reform at the US Department of Health and Human Services, where she drove strategy and led implementation of the Affordable Care Act across the Department, including coverage policy, delivery system reform, and public health policy. She received her B.A. with Honors in Business Economics from Brown University, her M.D. from the University of Pennsylvania School of Medicine, and her Ph.D. in Health Economics from the University of Oxford, where she was a Marshall Scholar. She completed her residency training in Otolaryngology-Head and Neck Surgery at the Johns Hopkins University School of Medicine, and practiced as a head and neck surgeon at Kaiser Permanente in San Francisco.

Session 1: Betty Ferrell, Lisa Gwyther, Eric Schneider

Betty Ferrell, RN, Ph.D., FAAN, has been in nursing for 44 years and has focused her clinical expertise and research in pain management, quality of life, and palliative care. Dr. Ferrell is the Director of Nursing Research & Education and a Professor at the City of Hope Medical Center in Duarte, California. She is a Fellow of the American Academy of Nursing and she has over 480 publications in peer-reviewed journals and texts. She is Principal Investigator of the “End-of-Life Nursing Education Consortium (ELNEC)” project. She directs several other funded projects related to palliative care in cancer centers and QOL issues. Dr. Ferrell was Co-Chairperson of the National Consensus Project for Quality Palliative Care. Dr. Ferrell completed a Masters degree in Theology, Ethics and Culture from Claremont Graduate University in 2007. She has authored eleven books including the Oxford Textbook of Palliative Nursing (5th Edition, 2019) published by Oxford University Press. She is co-author of the text, The Nature of Suffering and the Goals of Nursing published in 2008 by Oxford University Press and Making Health Care Whole: Integrating Spirituality into

Patient Care (Templeton Press, 2010). In 2013 Dr. Ferrell was named one of the 30 Visionaries in the field by the American Academy of Hospice and Palliative Medicine. In 2019 she was elected a member of the National Academy of Medicine. In 2021 Dr. Ferrell received the Oncology Nursing Society Lifetime Achievement Award and she was inducted as a “Living Legend” by the American Academy of Nursing.



Lisa P. Gwyther, M.S.W., LCSW is a clinical social worker with forty-two years of experience working with older adults and dementia-specific services. She is an Associate Professor Emerita at the Duke School of Medicine's Department of Psychiatry and Behavioral Sciences, and a Senior Fellow at Duke University's Center for Aging. Ms Gwyther is the founding director (1980) of the Duke Dementia Family Support Program, a community-based program offering education, consultation, support and engagement opportunities for individuals living with dementia, their families and the professionals serving them. Program services are provided at no cost and are not limited to Duke patients. Ms Gwyther was principal investigator for education, minority engagement and outreach for an NIA Alzheimer’s Disease Research Center at Duke from 1985-2011. Her 160 peer-reviewed research articles, books, award-winning documentary films and book chapters focus on developing and testing effective educational and support strategies targeting individuals living with dementia and their families to improve the quality of care and decision-making for individuals while reducing the negative health, emotional and financial consequences for families providing that care. Ms. Gwyther served on two recent American Bar Association (ABA) panels representing interests of families of persons living with dementia, and she currently serves on the ABA Commission on Law and Aging. She was a consensus panelist on the National Academies of Sciences, Engineering, and Medicine (NASEM) 2016 report, Families Caring for an Aging America, and she co-chaired the North Carolina 2016 Dementia-Capable NC State Plan. Ms. Gwyther was the first John Heinz Congressional Fellow in Health and Aging, and she served for nine years on the first U.S. federal Alzheimer’s Advisory Panel. Ms. Gwyther was named the 2019 NC Pioneer in Aging by the NC Coalition on Aging representing all state aging services, policy and advocacy organizations. She is a former president of the Gerontological Society of America.

Eric Schneider, M.D., M.Sc. leads NCQA's measurement, research and contracting agenda as Executive Vice President of the Quality Measurement and Research Group. In this role, he helps drive NCQA's efforts to create a more equitable health care system and to advance the move to digital quality measurement. Dr. Schneider came to NCQA from The Commonwealth Fund, where he was Senior Vice President for Policy and Research and a member of its executive management team. He has a long history with NCQA, most recently as Co-Chair of its Committee on Performance Measurement. He served on that committee for more than 10 years, including nine as Co-Chair. Prior to his tenure at The Commonwealth Fund, Dr. Schneider was principal researcher at the RAND Corporation and held the RAND Distinguished Chair in Health Care Quality. As the first director of Rand's Boston office, Schneider built its highly regarded multidisciplinary team of health services researchers. As a professor at the T.H. Chan Harvard School of Public Health and Harvard Medical School Eric taught health policy and practiced primary care internal medicine for 25 years. Widely regarded as one of the nation's preeminent health services researchers, Dr. Schneider has authored more than 125 published peer-reviewed research investigations and dozens of other scientific or medical research publications, reviews, chapters, editorials, and more. His work has focused on four aspects of health care quality — performance measurement methods; evaluation of quality and safety measurement in public reporting and financial incentive programs; use of health care quality measures to assess racial, ethnic, and socioeconomic disparities in health care quality; and evaluation of innovative approaches in health insurance, organization and financing of health care, and the organization of health care delivery. Dr. Schneider trained in health services research, public health and primary care general internal medicine. He holds a Bachelor of Science, cum laude, in biology from Columbia University and a Master of Science from the University of California, Berkeley. He earned his medical degree from the University of California, San Francisco. He is a member of the AcademyHealth Board of Directors and a fellow of both the American College of Physicians and the National Academy of Social Insurance.

Session 2: Emily Largent, Amol Navathe, Tisamarie Sherry, Bruce Vladeck

Emily Largent, J.D. Ph.D., RN, is the Emanuel and Robert Hart Assistant Professor of Medical Ethics and Health Policy; she holds a secondary appointment at Penn Law. Dr. Largent's work explores ethical and regulatory aspects of human subjects research and the translation of research findings into care with a particular focus on Alzheimer's disease and patient-caregiver dyad. Her research is supported by the National Institute on Aging and the Greenwall Foundation.

Amol Navathe, M.D., Ph.D., is co-Director of the Healthcare Transformation Institute and Director of the Payment Insights Team at the University of Pennsylvania, where he is also an Associate Director of the Center for Health Incentives and Behavioral Economics. He is also physician and core investigator at the Philadelphia Veterans Affairs Medical Center. He is a Commissioner of the Medicare Payment Advisory Commission (MedPAC), a non-partisan agency that advises the US Congress on Medicare policy, and serves as an advisor to the governments of Singapore and Canada on health care financing and delivery models. Dr. Navathe also is a co-founder of Embedded Healthcare, a healthcare technology company that brings behavioral economics solutions to improving health care affordability and quality. Dr. Navathe is a leading scholar on payment model design and evaluation, particularly bundled payments. His scholarship is unique because of its bi-directional translation between scientific discovery and real-world practice, including focus on: (1) the impact of value based care and payment models on health care value; (2) financial and non-financial incentive design, including applications of behavioral economics, to drive clinician practice change; and (3) a mix of pragmatic clinical trials and observational data analyses. He has published over 100 peer-reviewed articles in Science, The New England Journal of Medicine, The Journal of the American Medical Association (JAMA), Health Affairs, and other leading journals, as well as The New York Times and other news outlets. Dr. Navathe completed medical school at the University of Pennsylvania School of Medicine and internal medicine residency at the Brigham and Women's Hospital at Harvard Medical School. He obtained his PhD in Health Care Management and Economics from The Wharton School at the University of Pennsylvania.

Tisamarie Sherry, M.D., Ph.D. is a Deputy Assistant Secretary in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the US Department of Health and Human Services (HHS). ASPE conducts policy research, coordinates policy across HHS, and advises the Secretary of HHS on policy development. Dr. Sherry leads ASPE's Office of Behavioral Health, Disability and Aging Policy, which also coordinates dementia care research and policy across HHS through its role overseeing implementation of the National Alzheimer's Project Act, including convening the Advisory Council on Alzheimer's Research, Care and Services, and updating the National Plan to Address Alzheimer's Disease. Her previous experience includes working as a policy researcher at the RAND Corporation, and as a primary care physician. Dr. Sherry is a health economist and general internist whose research has investigated health care delivery, financing, and policy strategies to improve the health and economic status of adults with chronic medical conditions. Dr. Sherry has also served as a fellow with the Centers for Disease Control and Prevention's Global AIDS Program, and has served on the National Academies of Sciences, Engineering and Medicine's Committee on Identifying Disabling Medical Conditions Likely to Improve with Treatment. She received her A.B. in molecular biology and public policy from Princeton University, her M.D. and Ph.D. in health policy (concentrating in economics) from Harvard University, and completed residency training in internal medicine at Brigham and Women's Hospital.

Bruce C. Vladeck currently serves as a Senior Advisor to the Greater New York Hospital Association and LiveOnNewYork, and as a consultant to a number of other health care organizations. He is Chairman Emeritus of the Board of Medicare Rights Center, and serves on the boards of Penn Medicine and the Mary Imogene Bassett Hospital. During his professional career, Vladeck held a number of senior positions, including: Assistant Commissioner, New Jersey State Department of Health; President, United Hospital Fund ; Administrator, Health Care Financing Administration (now called CMS); Senior Vice President, Mount Sinai Medical Center; and Interim President, University of Medicine and Dentistry of New Jersey. At the Health Care Financing Administration, Vladeck was the principal federal official responsible for Medicare and Medicaid; of his many accomplishments in that position, he is proudest of refocusing the organization on services to beneficiaries. Previously, Vladeck also served as full-time faculty at Columbia University and the Mount Sinai School of Medicine, and as a trustee or director of many organizations, including New York City Health and Hospitals Corporation, Ascension Health, the Hadassah Hospital, the Kaiser Family Foundation, Health Care for the Homeless, the Primary Care Development Corporation; and the March of Dimes. He is also an elected member of the National Academy of Medicine, the New York Academy of Medicine, and the National Academy of Social Insurance. Vladeck received his BA, magna cum laude, from Harvard College, and an MA and PhD in Political Science from the University of Michigan. He is the author of Unloving Care: The Nursing Home Tragedy (Basic Books, 1980), still considered the standard reference on nursing home policy in the United States, and of more than one hundred articles in the professional literature.

Session 3: Jennie Chin Hansen, Peter Hollmann, Hyobum Jang, Julie Robison

Jennie Chin Hansen is the immediate past CEO of the American Geriatrics Society, the largest professional membership organization of gero-clinicians committed to the care of older adults living with care complexity. Prior to this position she completed her role as president of the 38 million member AARP during the negotiations and development of the Affordable Care Act. She currently contributes in content areas of dementia, workforce, chronic complex care and health equity. Her primary career includes nearly 25 years in San Francisco providing integrated, globally financed and comprehensive medical and community- based service, including home care sites, for nursing home eligible older persons. Its groundbreaking fully capitated, integrated and coordinated service delivery system became the prototype for the 1997 federal law that established the Program of All Inclusive Care to the Elderly (PACE) into the Medicare and Medicaid programs. PACE now operates extensively in California and in 30 other states. She has served as a federal commissioner on MedPAC (Medicare policy and payment) and serves/served recently on several boards related health care and philanthropy (including twelve years on the SCAN Foundation). In 2021 she completed her formal role as one of the Stakeholders who crafted the first ever California MasterPlan for Aging.

Peter Hollmann, M.D., is Chief Medical Officer for Brown Medicine, the practice group of the Brown University, Warren Alpert School of Medicine Department of Medicine. Until 2015, he was Associate Chief Medical Officer for Blue Cross & Blue Shield of Rhode Island. He has a part time geriatric primary care practice in RI. He has over 30 years of experience in medical management, including as a medical director of an HMO with a Medicare product, a Medicaid plan, and a commercial PPO. He has been a long-term care hospital, nursing home, home care and Medicare shared savings program ACO medical director. He chairs the American Geriatrics Society (AGS) committee that works on the Medicare Physician Fee Schedule, is a member of the AGS Beers criteria panel and is the AGS Board Chair. He has been active in creating geriatric measures for Medicare and NCQA. He is past Chair of the CPT Editorial Panel and currently Vice Chair of the RBRVS Update Committee (RUC). He is Chair of the HRSA Council on Graduate Medical Education (COGME). His major duties presently involve practice transformation, development of systems of care and population management. Much of his career has been devoted to quality improvement at the local and national level.

Hyobum Jang M.D., M.P.H., is a Technical Officer responsible for long-term care, in the Ageing and Health Unit, WHO. Dr Jang joined WHO in 2015 and has worked at global, regional and country levels, in the Philippines, Samoa, and Fiji, and now WHO headquarters in Geneva, Switzerland. His professional experience covers a wide range of health programme areas including community-based primary health care, non-communicable diseases, climate change and health, sexual and reproductive health and rights, and most recently healthy ageing and long-term care. Dr Jang received his medical degree from Seoul University College of Medicine and masters' degree in public health from Harvard School of Public Health.

Julie Robison, PhD., is a Professor of Medicine in the Center on Aging at the University of Connecticut School of Medicine. Dr. Robison conducts evidence-based health services research and intervention studies focused on aging families; long term services, supports and policy; dementia and health disparities using quantitative and qualitative research methods. She completed her Ph.D. at Cornell University and a post-doctoral fellowship in the epidemiology of aging at the Yale School of Medicine. Her work has been funded since 1997 by a range of sources including the Centers for Medicare and Medicaid Services (CMS), the Administration on Community Living, Connecticut State Agencies and the State Legislature, medical research foundations, and the National Institutes of Health. The results of her work directly impact the implementation of policies and programs that serve extremely vulnerable populations in Connecticut and nationally. She has served as Principal Investigator or Co-Principal Investigator on over 50 funded research studies and regularly present research findings in national and community forums. She has published over 55 scientific articles and book chapters as well as over 70 legislative and policy reports.

Session 4: Helen Lamont, Sarah Lenz Lock, Kate McEvoy, Leslie Pelton

Helen Lamont is the Director of the Division of Disability and Aging Policy where she manages a team of professional staff that conduct policy analysis, research and evaluation related to disability, aging, and long-term care issues and programs. Helen also leads the implementation of the National Alzheimer's Project Act, coordinating both the Advisory Council on Alzheimer's Research, Care, and Services as well as an interagency group that writes the annual National Plan to Address Alzheimer’s Disease. Helen also leads a portfolio of research in dementia, including a project to examine use of inpatient psychiatric facilities by people with dementia. She works on family and informal caregiving, as well as elder justice and adult maltreatment. Helen has worked across the Department on disability data issues and has a current project to explore the feasibility of using an internet panel study to collect data on disability. She joined ASPE in 2007 and has a PhD in Aging Studies from the University of South Florida and a BS in Human Development from Duke University.

Sarah Lenz Lock is Senior Vice President for Policy and Brain Health in AARP's Policy, Research and International Affairs Department. Ms. Lock leads AARP's policy initiatives on brain health and care for people living with dementia, including serving as the Executive Director of the Global Council on Brain Health, an independent collaborative of scientists, doctors, and policy experts. Ms. Lock also coordinates AARP's role in the Leadership Council of Aging Organizations. Previously at AARP, Sarah directed the Office of Policy Development and Integration, where she led the office responsible for the development of AARP's public policies. Her first role at AARP was as a Senior Attorney/Manager at AARP Foundation Litigation conducting health care impact litigation on behalf of older persons. She has authored numerous amicus briefs in appellate courts all over the country on health care issues impacting older Americans. Ms. Lock is a frequent writer and public speaker on issues related to healthy aging. She has been quoted or appeared in numerous media outlets including The New York Times, NPR, The Washington Post, the Wall Street Journal, CBS News, the Baltimore Sun, and the Chicago Tribune.

Kate McEvoy, J.D., is a program officer for the Milbank Memorial Fund. In this capacity, she leads the Fund's state leadership programs and network and guides the Fund's healthy aging work. Ms. McEvoy was previously director of health services in the Connecticut Department of Social Services, where she oversaw care delivery and payment reform work in Medicaid, CHIP, and long-term services and supports. She is a former president and vice president of the National Association of Medicaid Directors Board of Directors and served on the steering committee of the Reforming States Group, the predecessor to the Milbank State Leadership Network. She also contributed to state health reform initiatives as assistant comptroller for the State of Connecticut. An elder law attorney by training, Ms. McEvoy spent her early career working for a regional Agency on Aging and as a legislative liaison for the Connecticut Association of Area Agencies on Aging. She is a past chair of the Elder Law Section of the Connecticut Bar Association, is the author of a treatise on elder law, and led several major coalition-based projects around advance directives. She has a JD from the University of Connecticut School of Law and a BA in English and Economics from Oberlin College.

Leslie Pelton, M.P.A., is an outcome-oriented leader who catalyzes innovation in health systems and transforms passion into impactful action. Throughout her twenty-four year career, Leslie has brought these talents to the improvement of health and health care of adults of all ages in community, health care practice, hospital and nursing home-based care. Leslie listens deeply to the challenges that executives and front line teams face. She collaboratively designs responses and leads the application of improvement science to build on will and drive improved outcomes. Leslie is a nationally recognized leader in the Age-Friendly Health Systems movement improving the health and health care of older adults across the US. With funders, national partners, leading health systems and the Institute for Healthcare Improvement team, she designed the campaign that has resulted in improved care of older adults in 1000 places of care across the US. Throughout her career, Leslie has consulted with major academic medical centers including building new models of integrating research, clinical care and policy resulting in improved outcomes. She built and led her own consulting firm and served as faculty for the Institute for Healthcare Improvement. Leslie also built a practice at Deloitte Consulting addressing the human factors associated with strategy and operational innovations.

Mechanisms for Organizational Behavior Change to Address the Needs of People Living with Alzheimer's Disease and Related Dementias: A Workshop

Statement of Task:

A planning committee of the National Academies of Sciences, Engineering, and Medicine will plan and execute a public, 2-day workshop to explore mechanisms that might improve care to meet the needs of people living with Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD), connected to sustainable payment models that can be adopted by organizations. While many health systems, public health, and social service systems are re-designing their programs and processes to address the current siloed nature of care and service delivery, there remains a gap in understanding how to reliably implement organizational behavior change initiatives to better serve people living with AD/ADRD. Possible health outcomes and care processes that may be explored as highly responsive to hospital organizational behavioral changes include:

1. healthcare associated infections (HAIs);
2. in-facility safety (mobility promotion, fall prevention, physical restraints);
3. mentation management services (evaluating and addressing psychological and psychiatric symptoms);
4. care transitions (including medication reconciliation); and
5. person-centered care (assessments of what matters to people living with AD/ADRD, including person- centered care goals and advance care planning).

The planning committee of approximately 6-8 members will develop the agenda for workshop sessions, select and invite speakers and discussants, and moderate the discussions. Initial activities will focus on meeting planning via a series of virtual working meetings to:

1. scope and refine the topic areas and
2. generate a list of potential participants for the workshop.

The workshop planning committee will define the specific topics to be addressed, develop the agenda, and select and invite speakers and other participants. After the workshop, proceedings of a workshop of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines. An in-person workshop is proposed, dependent on safety conditions and travel restrictions at the time of the workshop.

Workshop Sponsor:

NIA Division of Behavioral and Social Research, Department of Health and Human Services

Planning Committee:

Richard Frank, *Chair,* Senior Fellow in Economic Studies and Director, USC Brookings Schaeffer Initiative on Health Policy; Margaret T. Morris Professor of Health Economics Emeritus, Harvard Medical School
Elizabeth Belmont, Corporate Counsel, MaineHealth
Terry Fulmer, President, The John A. Hartford Foundation
Scott Halpern, John M. Eisenberg Professor of Medicine, Epidemiology, Medical Ethics, and Health policy, University of Pennsylvania
Sharon Inouye, Milton and Shirley L. Levy Family Chair and Professor of Medicine, Harvard Medical School; Director, Aging Brain Center, Hind and Arthur Marcus Institute for Aging Research, Hebrew SeniorLife
Faith Mitchell, Institute Fellow, Urban Institute
Julie Robison, Professor of Medicine, Center on Aging, University of Connecticut School of Medicine

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Sharyl Nass, Director, Board on Health Care Services
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Rukshana Gupta, Research Assistant

Website:

https://www.nationalacademies.org/our-work/mechanisms-for-organizational-behavior-change-to-address-the-needs-of-people-living-with-alzheimers-disease-and-related-dementias-a-workshop

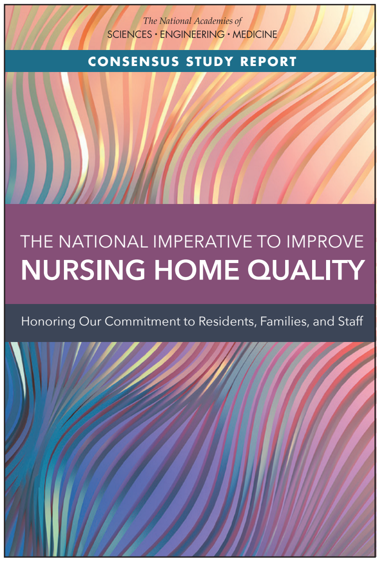
Consensus Study Report
HIGHLIGHTS
APRIL 2022

The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff

Nursing homes play a unique dual role in the long-term care continuum, serving as a place where people receive needed health care and a place they call home.

The 1986 Institute of Medicine report *Improving the Quality of Care in Nursing Homes* identified a range of challenges to the quality of care in nursing homes. While many important improvements have been made since the enactment of the Omnibus Budget Reconciliation Act of 1987, the provision of high-quality comprehensive care to all nursing home residents remains an elusive goal.

Ineffective responses to the complex challenges of nursing home care have resulted in a system that often fails to ensure the well-being and safety of nursing home residents—an unacceptable situation, documented by research, that has long been apparent to those who research, work in, or have loved ones in nursing homes.



The National Academies of
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CONSENSUS STUDY REPORT
THE NATIONAL IMPERATIVE TO IMPROVE
NURSING HOME QUALITY
Honoring Our Commitment to Residents, Families, and Staff

The devastating impact of the COVID-19 pandemic on nursing home residents and staff has renewed attention to the long-standing weaknesses that impede the provision of high-quality nursing home care. In this context, with support from a coalition of sponsors, the National Academies of Sciences, Engineering, and Medicine formed the Committee on the Quality of Care in Nursing Homes to examine how the United States delivers, finances, regulates, and measures the quality of nursing home care.

The committee's investigation led to several key conclusions about the current state of nursing home care, which does not align with the committee's vision of high-quality nursing home care (see Box 1).

1. The way in which the United States finances, delivers, and regulates care in nursing home settings is ineffective, inefficient, fragmented, and unsustainable.
2. Immediate action to initiate fundamental change is necessary.
3. Federal and state governments, nursing homes, providers, payers, researchers, and others need to make clear a shared commitment to the care of nursing home residents.

> ***The way in which the United States finances, delivers, and regulates care in nursing home settings is ineffective, inefficient, fragmented, and unsustainable.***

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4. Extreme care needs to be taken to ensure that quality improvement initiatives are implemented using strategies that do not exacerbate disparities in resources, quality of care, or resident outcomes.
5. High-quality research is needed to advance the quality of care in nursing homes.
6. The nursing home sector has suffered for many decades from underinvestment in ensuring the quality of care in nursing homes and a lack of accountability in how resources are allocated.
7. All relevant federal agencies need to have authority and resources from the U.S. Congress to implement the recommendations of this report.

The committee identified seven broad goals, which provide the overarching framework for a comprehensive approach to improving the quality of care in nursing homes. The committee developed an interrelated set of recommendations to achieve each of these goals.

BOX 1
Vision of High-Quality Nursing Home Care

Nursing home residents receive care in a safe environment that honors their values and preferences, addresses goals of care, promotes equity, and assesses benefits and risks of care and treatments.

To achieve this vision, nursing homes should deliver comprehensive, person-centered, interdisciplinary, team-based care that meets or exceeds established quality standards and supports strong connections to health care and social services systems and resources, family, friends, and the community more broadly.

GOAL ONE: DELIVER COMPREHENSIVE, PERSON-CENTERED, EQUITABLE CARE THAT ENSURES THE HEALTH, QUALITY OF LIFE, AND SAFETY OF NURSING HOME RESIDENTS; PROMOTES RESIDENT AUTONOMY; AND MANAGES RISKS

Attention to quality improvement in nursing home care delivery across a wide range of areas is required, from ensuring that federally mandated, person-centered care is a reality for all nursing home residents to ensuring resident safety in the event of a public health emergency or natural disaster. Moreover, nursing homes should be redesigned as smaller, more home-like environments with single occupancy rooms and private bathrooms to improve resident safety and enhance quality of life.

GOAL TWO: ENSURE A WELL-PREPARED, EMPOWERED, AND APPROPRIATELY COMPENSATED WORKFORCE

The committee recommends transforming the professionalism of the nursing home workforce through a range of actions. Specifically:

- Nursing home owners and administrators should ensure competitive wage and benefits.
- The U.S. Department of Health and Human Services (HHS) should immediately implement minimum staffing standards and determine minimum and optimum staffing standards for all direct care staff.
- The Centers for Medicare & Medicaid Services (CMS) should establish minimum education and national competency requirements.
- Nursing homes and state and federal governments should advance the role of and empower certified nursing assistants (CNAs) by providing free training and career advancement opportunities and by funding training grants and models of care to expand the role of the CNA.
- Nursing homes should support family caregivers to the extent that residents desire their chosen family members to be involved.

GOAL THREE: INCREASE TRANSPARENCY AND ACCOUNTABILITY OF FINANCES, OPERATIONS, AND OWNERSHIP

The committee calls for HHS to:

- Collect, audit, and make publicly available detailed facility-level data on the finances, operations, and ownership of all nursing homes; and

- Ensure that data allow for the evaluation and tracking of care quality by common owner or management company and the assessment of the impact of ownership models and related-party transactions.

GOAL FOUR: CREATE A MORE RATIONAL AND ROBUST FINANCING SYSTEM

- HHS should study the establishment of a federal long-term care benefit.[1]
- CMS should ensure financing levels are adequate to cover the delivery of comprehensive nursing home care to all.
- HHS should require a specific percentage of nursing home payments be designated for direct care services.
- To enhance the value of care provided in nursing homes, CMS should extend current bundled payment initiatives to all conditions for short-stay post-acute care, while conducting demonstration projects to explore the use of alternative payment models for long-term nursing home care.

GOAL FIVE: DESIGN A MORE EFFECTIVE AND RESPONSIVE SYSTEM OF QUALITY ASSURANCE

- CMS should provide state survey agencies with necessary resources.
- CMS should refine and expand oversight performance metrics of survey agencies and use existing strategies of enforcement where states have consistently fallen short of standards.
- CMS should develop and evaluate strategies to enhance nursing home quality assurance efforts.
- The Administration for Community Living should advocate for increased funding for the Long-Term Care Ombudsman Program.
- Federal and state oversight agencies should impose oversight and enforcement actions on owners with poor quality care across facilities.
- States should eliminate certificate-of-need requirements and construction moratoria to encourage the entry of innovative care models.

GOAL SIX: EXPAND AND ENHANCE QUALITY MEASUREMENT AND CONTINUOUS QUALITY IMPROVEMENT

- CMS should add the Consumer Assessment of Healthcare Providers and Systems measures of resident and family experience to Care Compare.
- HHS should expand and enhance existing quality measures on Care Compare.
- HHS should fund the development and adoption of new measures to Care Compare, including in the areas of palliative care and end-of-life care, implementation of the care plan, receipt of care that aligns with the resident’s goals, staff well-being, psychosocial and behavioral health, emergency preparedness, and health information technology adoption and interoperability.
- HHS should develop an overall health equity strategy for nursing homes.
- CMS should allocate funds for grants for state governments to develop and operate technical assistance programs with an ongoing and consistent focus on nursing homes.

GOAL SEVEN: ADOPT HEALTH INFORMATION TECHNOLOGY IN ALL NURSING HOMES

- The Office of the National Coordinator for Health Information Technology and CMS should provide financial incentives to nursing homes to support the adoption of certified electronic health records.

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[1] One committee member declined to endorse this recommendation.

CONCLUSION

The COVID-19 pandemic provided powerful evidence of the deleterious impact of inaction and inattention to long-standing nursing home quality concerns. At the same time, the pandemic can serve as a potent catalyst to drive urgently needed innovations to improve the quality of nursing home care. Implementing the committee's integrated set of recommendations will move the nation closer to making high-quality, person-centered, and equitable care a reality for all nursing home residents, their chosen families, and the nursing home workforce.

Committee on the Quality of Care in Nursing Homes

Betty R. Ferrell (*Chair*)
City of Hope National Medical Center, Division of Nursing Research Education

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Columbia University School of Nursing

Mary Ersek
University of Pennsylvania Schools of Nursing and Medicine;
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University of Wisconsin–Milwaukee; Medical College of Wisconsin

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The Commonwealth Fund

The Fan Fox & Leslie R. Samuels Foundation

Jewish Healthcare Foundation

The John A. Hartford Foundation

The Sephardic Foundation on Aging

To read the full report, please visit
https://www.nationalacademies.org/nursing-homes

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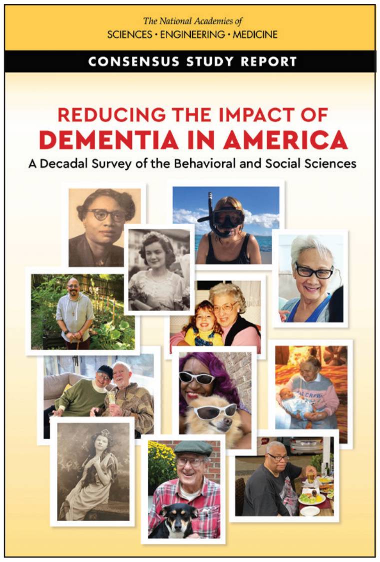
Consensus Study Report

JULY 2021

HIGHLIGHTS

Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences

Highlights



The National Academies of
SCIENCES • ENGINEERING • MEDICINE
CONSENSUS STUDY REPORT
REDUCING THE IMPACT OF
DEMENTIA IN AMERICA
A Decadal Survey of the Behavioral and Social Sciences

Few diseases have had as far reaching and devastating an impact on society as Alzheimer's disease and related dementias (AD/ADRD). Nearly everyone has a direct connection to a person living with or caring for someone living with dementia. More than 6 million people in the United States are currently living with AD. For those living with and caring for people experiencing AD/ADRD, the challenges are numerous and complex, and include physical and emotional stress, loss of income, loss of function, loss of the ability to participate in valued activities, and interrupted connections to family and friends. These diseases also place a substantial demand on communities and on the institutions and government entities that support people living with dementia and their families. The COVID-19 pandemic also exposed and seriously exacerbated the long-standing challenges for persons living with dementia. In addition to the risk of serious illness and death, the virus posed challenges for persons living with dementia, regardless of whether they resided in care facilities, including social isolation and loss of access to vital resources, overcrowded and intergenerational households, shortages of care options, and risks to their care partners. Family caregivers also experienced hardship, unable to visit loved ones with dementia in facilities, and often times withdrew them from nursing homes due to fear of contacting COVID-19. The pandemic presented an opportunity to systematically examine an infrastructure that is not only vulnerable to disaster, but also inadequate in ordinary times.

The economic cost of dementia is significant, with estimates ranging from $305 billion for 2020 in the United States, rising to about $1.5 trillion by 2050. Recently, the drug aducanumab was approved by the U.S. Food and Drug Administration, sparking an ongoing controversy. While this drug may slightly decrease the progression of dementia, it will not eradicate the disease. The rapidly growing and diverse population living with dementia will continue to require support across a broad range of domains, and social and behavioral sciences research can help improve safeguards to provide Americans with access to effective and safe medications.

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Despite these significant challenges, there is hope that research in the social and behavioral sciences will contribute to knowledge and interventions to prevent or slow the development of dementia and ameliorate the experience of living with dementia, thus substantially reducing its negative impact on society. To more fully elucidate what research is needed, the National Institute on Aging of the U.S. Department of Health and Human Services requested that the National Academies of Sciences, Engineering, and Medicine conduct a consensus study to produce a decadal survey[1] of research in the social and behavioral sciences with the potential to mitigate the negative impacts of AD/ADRD. To carry out the study, the National Academies convened a committee with a broad range of expertise in sociology, epidemiology, biostatistics, public health, geriatric medicine, psychology, psychiatry, neurology, bioethics, and public policy.

The committee's report, *Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences,* offers a broad research roadmap for the behavioral and social sciences over the next decade, noting promising interventions and programs that require additional confirmatory evidence. The report also describes social and behavioral research that can provide the foundation for the development of programs and policies, as well as ethical safeguards that would serve the needs of all Americans affected by dementia. With the number of Americans living with dementia expected to grow exponentially in the coming years, the committee recommends immediate action to improve the health and well-being of those living with or affected by these diseases and to reduce the significant related economic and social costs.

KEY RESEARCH AREAS FOR REDUCING THE IMPACT OF DEMENTIA IN AMERICA

In its review of the literature, the committee looked across the potential impacts of dementia and identified the key areas below for further examination and research.

Understanding risk and preventive factors for dementia. Rigorous research is needed to determine how to prevent dementia, including how behavior changes, such as diet and exercise; socioeconomic conditions; and structural and interpersonal racism and discrimination may impact development of the disease. For example, evidence suggests that people who eat a healthy diet, exercise regularly, maintain a healthy weight, and reduce their cardiovascular risk have a lower risk of dementia. Similarly, clear evidence indicates that disparities in socioeconomic resources, negative social interactions (e.g., overt racism and discrimination), systemic racism, and other socioeconomic factors contribute to stark disparities in dementia risk across population groups. The report outlines specific research needed to assess these factors, for example, examining the effects of social factors, health-related behaviors, and modifiable drivers of racial/ethnic inequality on dementia risk. The committee also identified the need for developing effective means of communicating the magnitude and degree of potential risk and protective factors to support informed decision making.

Examining the experience of living with dementia, including diagnosis, care, and treatment. Much of the research on interventions for people living with dementia is primarily observational or conducted using conventional rather than pragmatic trials. The committee identified the need for both qualitative and quantitative research related to the needs of people at all stages of dementia that is interdisciplinary, involving ethicists, legal experts, and others, as well as clinicians and researchers. The report also describes the need for improved screening and diagnosis to identify people living with dementia, including in diverse communities. The report notes the importance of measures that assess outcomes relevant to people living with dementia and their caregivers throughout the course of the disease.

Identifying the needs of family caregivers. Although much is known about interventions that can effectively support caregivers, there are also significant gaps in the existing research. Important aspects of the caregiving experience and its effects on both caregivers and people living with dementia have not yet been studied; an example is the need for better research on differences in caregiver needs across diverse populations. Among other areas, research is needed to identify the highest priority needs for resources and support for family caregivers, including supplemental skills and training, and other resources to enhance their capacity to provide care while maintaining the safety and well-being of both care recipients and caregivers.

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[1] A decadal survey is a method for engaging members of a scholarly community to identify lines of research with the greatest potential to be of use over a 10-year period in pursuit of a particular goal. The National Academies developed this type of survey to support the planning of future research for government agencies and other entities.

Understanding the role of community characteristics in dementia risk and quality of life for people living with dementia and their families. There is strong evidence that community factors shape the exposures and behaviors that influence dementia risk. Community supports are also key resources for those living with and affected by dementia. Innovative approaches to the design of communities in which people living with dementia can thrive do show promise, although their application to diverse contexts and populations has yet to be systematically demonstrated. Research is needed on the characteristics of communities that influence the risk of developing dementia and the experience of living with the disease, along with community characteristics necessary to foster dementia-friendly environments and innovative approaches to adapting housing, services, and supports so that persons with dementia can remain in the community.

Strengthening the role of the health care system and institutions that provide care to people living with dementia. People living with dementia interact with many different institutions that provide health care and social support. For example, many spend time living in long-term care facilities and ultimately receive care, such as hospice resources at the end of life, interacting with a myriad of professionals, including neurologists, social workers, geriatricians, among many others. To strengthen how people living with dementia and their caregivers interact with and are served by the health care and social service systems, the committee makes a number of related research recommendations regarding the quality and structure of health care along with long-term and end-of-life care.

While health care and long-term care systems employ millions of individuals who care for people living with dementia, examining issues that affect these workforces was beyond the scope of this study. However, the committee acknowledges that improving knowledge and correcting challenges related to workforce issues are vitally important to the research directions outlined in the report.

Understanding the economic costs of dementia. Examining the economic impacts of dementia will be key to mitigating the overall impact of the disease on individuals and society. Both reducing unnecessary costs and achieving significant improvements in health, quality of life, and other outcomes that justify the associated costs will result in economic benefit. Research needs include an assessment and quantification of the total economic impact of dementia for individuals and families, including current and future national costs; improved understanding of drivers of dementia-related costs; and estimation of the value to individuals, families, and society of innovations in prevention, diagnostics, and treatment, including pharmacologic treatments.

Strengthening data collection and research methodology. Advances in data collection and research methodology are needed to support progress in virtually every domain of dementia research. This includes the expansion of data infrastructure, improved measurement of exposure and outcomes, support for the adoption of more rigorous study designs, and development of systematic approaches for integrating evidence from disparate studies.

10-YEAR RESEARCH PRIORITIES

Recognizing that resources are finite, the committee identified the following five highest research priorities for the next decade, selected to have maximal effect in reducing the negative impacts of dementia and improving quality of life:

1. Improve the lives of people affected by dementia, including those who develop it, their families and caregivers, and their social and clinical networks, through research on factors that affect the development of the disease and its outcomes, promising innovative practices, and new models of care and policies that facilitate the dissemination of effective interventions.
2. Rectify disparities across groups and geographic regions that affect who develops dementia, how dementia is identified in different communities, how the disease progresses, outcomes and quality of life, and access to health care and supportive services.
3. Develop innovations to improve the quality of care and social supports for individuals and communities and to support improved quality of life (e.g., reducing financial abuse and stressors, finding relevant affordable housing and care facilities, gaining access to important services).
4. Ease the financial and economic costs of dementia for individuals, families, and society and balance long-term costs with long-term outcomes across the life span.
5. Pursue advances in research capability, including study design, measurement, analysis, and evidence integration, as well as the development of data infrastructure needed to study key dementia-related topics.

In addition to these broad priorities, the committee offers guidelines for the design of an effective portfolio of research. A 10-year research agenda will be optimally effective if it:

- is **coordinated** to ensure that the breadth of topics identified in this report is addressed sufficiently without redundancy and competing initiatives;
- consistently takes into account **fundamental socioeconomic factors** that influence who develops dementia, access to high-quality care, and outcomes;
- includes pragmatic, implementation, and dissemination research needed to ensure that findings can be **implemented effectively** in clinical and community settings; and
- addresses potential **policy implications** that are articulated beginning in the planning stages and assessed during the course of the investigations.

CALL TO ACTION

To support the above 10-year research agenda, sustained leadership and funding are needed. The committee therefore makes the following recommendation:

Funders of dementia-related research, including federal agencies, such as the National Institutes of Health and the Agency for Healthcare Research and Quality, along with relevant philanthropic and other organizations, such as the Patient-Centered Outcomes Research Institute, should use guidelines for awarding research grants to establish incentives for

- coordination of research objectives with the research agenda priorities identified in this report to ensure that key areas are funded without undue overlap and to foster links across research efforts;
- interdisciplinary research and inclusion of stakeholders in research partnerships;
- attention to topics that have not typically been part of standard medical research but are important to those living with dementia, including isolation, financial security, and housing options;
- rigorous evaluation and implementation research needed to translate findings into programs with impact on a broad scale; and
- dissemination of research findings to policy makers.

The report's broad research roadmap will promote progress in addressing high-priority research within the behavioral and social sciences over the next decade. This research will provide the foundation for the development of innovative programs and policies, as well as ethical safeguards, to serve the needs of those affected by dementia. By 2030, an estimated 8.5 million Americans will have AD and many more will have other forms of dementia. Those living with dementia and their caregivers deserve the support and resources needed to lead lives of dignity and well-being. To attain this goal, the time to act is now.

Committee on the Decadal Survey of Behavioral and Social Science Research on Alzheimer's Disease and Alzheimer's Disease-Related Dementias

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AARP

Alzheimer's Association

American Psychological Association

Division of Behavioral and Social Research, National Institute on Aging

Office of Behavioral and Social Sciences Research, National Institutes of Health

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To read the full report, please visit
https://www.nationalacademies.org/our-work/decadal-survey-of-behavioral-and-social-science-research-on-alzheimers-disease-and-alzheimers-disease-related-dementias

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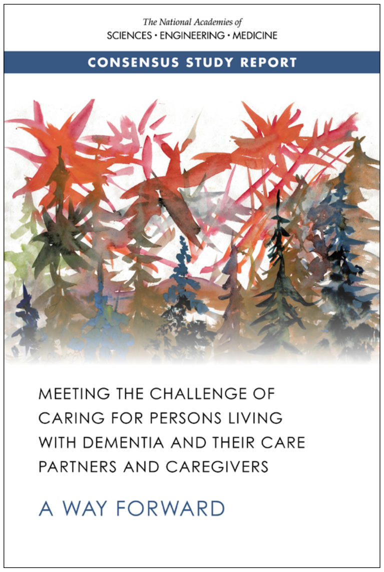
Consensus Study Report

FEBRUARY 2021

HIGHLIGHTS

Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers

A Way Forward



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CONSENSUS STUDY REPORT

MEETING THE CHALLENGE OF
CARING FOR PERSONS LIVING
WITH DEMENTIA AND THEIR CARE
PARTNERS AND CAREGIVERS

A WAY FORWARD

Millions of people in the United States and globally live with dementia, and many desire support in leading meaningful and rewarding lives, maintaining independence and agency, enjoying activities of interest, sustaining social relationships, and connecting to familiar environments and communities. To live well with dementia, people need care, services, and supports that reflect their values and preferences, build on their strengths and abilities, promote well-being, and address needs that evolve as cognitive impairment deepens.

Persons living with dementia co-manage their care with or rely on the support of a wide range of care partners and caregivers, including spouses, other family members and friends, and direct care workers in homes or residential care settings. While dementia care has improved since the 1970s, many still lack access to high-quality care and are not living as well as they might. Disadvantaged groups, especially racial and ethnic minorities, still face challenges in access to care, services, and supports, due to deep and persistent inequities.

At the request of the National Institute on Aging (NIA), the National Academies of Sciences, Engineering, and Medicine convened an ad hoc expert committee to assist NIA and the broader dementia community in (1) assessing the evidence on care interventions for persons living with dementia and caregivers, (2) informing decision making about which interventions should be broadly disseminated and implemented, and (3) guiding future actions and research.

The committee's primary source of evidence was an Agency for Healthcare Research and Quality (AHRQ) systematic review of the available evidence on care interventions for persons living with dementia and their care partners and caregivers. The committee also considered additional evidence and input, including perspectives from persons living with dementia, care partners, and caregivers.

ASSESSING THE STATE OF THE EVIDENCE

While hundreds of dementia care interventions have been tested in randomized controlled trials (RCTs), assessing the evidence to learn what is effective, for whom, and in what circumstances is challenging. The committee concluded that the evidence needed to inform decisions about policy and the implementation of specific interventions broadly—including prioritizing the many interventions that could be helpful but require resources—is limited. This is partly due to inherent complexity. Dementia care interventions often involve multiple components and can be implemented at multiple levels and in diverse contexts, which can impact their effectiveness. In addition, persons living with dementia and their care partners and caregivers are as diverse as the general population—representing different ages, genders, races, ethnicities, sexual orientations, and disabilities—and their needs change as cognitive impairment progresses.

Importantly, the AHRQ systematic review and the committee's analysis also highlight limitations in the existing research base that can be addressed. While some interventions have been tested in large RCTs and are beginning to be implemented more broadly in various communities, many more have only been tested in academic settings with fewer participants not representative of the diverse population of persons living with dementia. Over time, standards for research have become more rigorous; older studies often did not meet current standards. This progress is not yet fully reflected in the overall body of literature assessed in the AHRQ systematic review.

INTERVENTIONS READY FOR IMPLEMENTATION IN REAL-WORLD SETTINGS WITH EVALUATION

The AHRQ systematic review identified no interventions that met its criteria for high-strength or moderate evidence of benefit and two types of interventions with low-strength evidence of benefit, which incorporate many of the core components of care, services, and supports listed in Box 2. Collaborative care models use multidisciplinary teams that integrate medical and psychosocial approaches to care. The AHRQ systematic review found low-strength evidence that such models benefit quality of life, quality indicators, and emergency room visits. REACH (Resources for Enhancing Alzheimer's Caregiver Health) II is a multicomponent intervention that supports family care partners and caregivers through a combination of strategies (e.g., problem solving, skills training, stress management, support groups, information and education, role playing). The AHRQ review found low strength evidence that REACH II and its adaptations reduce caregiver depression. For both collaborative care and REACH II interventions, additional studies show benefits on a wide range of other outcomes, although the evidence was not sufficient to reach conclusions on effectiveness for these outcomes, generally due to inconsistent findings across studies.

Both collaborative care models and REACH II and its adaptations are already being implemented in a variety of settings with promising results. Notably, REACH II has been studied in and adapted for diverse populations to a greater extent than is usual in the field. **The committee concluded that the evidence is sufficient to justify implementation of these two types of interventions in a broad spectrum of settings, with evaluation conducted to continue expanding the evidence base to inform future implementation.** Additional research on other promising interventions is needed to develop better ways of meeting the urgent needs of persons living with dementia and their care partners and caregivers. For a full list of the committee's recommendations, see the Recommendations insert.

Beyond collaborative care models and REACH II, the AHRQ systematic review found insufficient evidence to support conclusions about benefits for all other interventions. This does not imply these interventions are ineffective. Instead, it reflects the high uncertainty given the limitations of the evidence base and the approach used in the AHRQ systematic review to support conclusions on readiness for broad dissemination and implementation.

These conclusions do not call into question fundamental aspects of high-quality dementia care, services, and supports. Rather, they suggest a need for additional research on specific interventions. In the meantime, organizations, agencies, communities, and individuals can use the guiding principles (see Box 1) and the core components of care, services, and supports (see Box 2) to immediately improve dementia care. Individuals and families may also want to experiment with activities such as listening to music and dancing that, when tailored to personal interests and preferences, can provide pleasure with little potential harm.

BOX 1 GUIDING PRINCIPLES FOR DEMENTIA CARE, SERVICES, AND SUPPORTS

These principles can guide ideal care, services, and supports for persons living with dementia and their care partners and caregivers. Unfortunately, their application is currently limited.

- Person-centeredness
- Promotion of well-being
- Respect and dignity
- Justice
- Racial, ethnic, sexual, cultural, and linguistic inclusivity
- Accessibility and affordability

BOX 2 CORE COMPONENTS OF CARE, SERVICES, AND SUPPORTS FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS

Several existing frameworks describe core components of ideal dementia care. The components below are designed with the participation of the individuals involved; managed throughout the course of the condition; and adjusted to the changes experienced by persons living with dementia and their care partners and caregivers:

- Detection and diagnosis
- Assessment of symptoms to inform planning and deliver care, including financial and legal planning
- Information and education
- Medical management
- Support in activities of daily living
- Support for care partners and caregivers
- Communication and collaboration
- Coordination of medical care, long-term services and supports, and community-based services and supports
- A supportive and safe environment
- Advance care planning and end-of-life care

A BLUEPRINT FOR FUTURE RESEARCH

The committee offered a blueprint for future research including methodological improvements aimed at limitations frequently found in the current evidence base, as well as approaches that can complement RCTs to better understand complex dementia care interventions and the systems in which they operate. The blueprint prioritizes research that promotes equity, diversity, and inclusion, as well as focusing on the priorities of persons living with dementia and their care partners and caregivers. It also emphasizes providing the evidence necessary to make inclusive decisions and implement interventions in the real world, including expanding the focus on community- and policy-level interventions.

CONCLUDING REMARKS

Studying dementia care interventions is challenging and complex, and the body of evidence is complicated to interpret. Two types of interventions are supported by sufficient evidence for implementation in real-world settings with evaluation to continue to expand the evidence base. Given current major deficits in care, services, and supports, providing these interventions to those who could benefit would be a step forward. Still, research should continue to develop and evaluate other potentially promising interventions. The committee's recommendations provide a path forward for building a more robust evidence base by using rigorous, cutting-edge methods that are inclusive, equitable, and yield critical information for real-world implementation. This information can be employed throughout the field by early-career researchers and others who want to harness new approaches to better support persons living with dementia and their care partners and caregivers in living as well as possible.

Committee on Care Interventions for Individuals with Dementia and Their Caregivers

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To read the full report, please visit
nationalacademies.org/dementiacare

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PROJECT SUMMARY

Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop

Statement of Task:
A National Academies of Sciences, Engineering, and Medicine planning committee will organize and host a 1.5-day public workshop that will examine opportunities to better support family caregiving for people with cancer or other serious illnesses. The workshop will feature invited presentations and panel discussions on topics that may include:

- Strategies to better capture, understand, and act on family caregiver input and experience to improve patient care and to support family caregivers.
- Research gaps and opportunities to improve the evidence base to guide caregiving for patients with serious illnesses.
- Potential policy and practice opportunities to support family caregivers and advance family-centered care for serious illness, including new models of care delivery and payment.
- Opportunities to better embed a health equity focus across family caregiving research, policy, and practice.
- Lessons learned from the COVID-19 pandemic (e.g., use of telehealth and other remote technologies) that could be applied in the context of caregiving for people with cancer and other serious illnesses.

The planning committee will develop the agenda for the workshop sessions, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

Sponsor/s:
Department of Health and Human Services; Private: For Profit; Private: Non Profit*

**This is a collaborative workshop hosted by the Roundtable on Quality Care for People with Serious Illness, the National Cancer Policy Forum, and the Forum on Aging, Disability and Independence.*

Timeline:
May 16 and 17, 2022

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Sharyl Nass, Director, Board on Health Care Services

Website:
https://www.nationalacademies.org/our-work/family-caregiving-for-people-with-cancer-and-other-serious-illnesses-a-workshop

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- Filing a complaint with the Office of Human Resources at 202-334-3400, or
- Reporting the incident to an employee involved in the activity in which the member or volunteer is participating, who will then file a complaint with the Office of Human Resources.

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Updated June 7, 2018