The National Academies of
SCIENCES · ENGINEERING · MEDICINE

COMMITTEE ON NATIONAL STATISTICS

Improving Consent and Response in Longitudinal Studies of Aging

September 27-28, 2021

AGENDA

Monday, September 27, 2021 12:00 pm – 4:45 pm

12:00 pm **Welcome and Introduction**
Brian Harris-Kojetin, CNSTAT
John Phillips, National Institute on Aging (NIA)

Goals of the Workshop
Michael Davern, NORC at the University of Chicago, Planning Committee Chair

BACKGROUND AND CONTEXT

12:15 pm **Opportunities and Challenges with Response and Consent in Longitudinal Surveys on Aging**
Chair: Vetta L. Sanders Thompson, Washington University in St. Louis

Participants:
Carol Ryff, University of Wisconsin
Linda Waite, University of Chicago
Bob Hummer, University of North Carolina, Chapel Hill
David Weir, University of Michigan

1:20 pm **Identifying and Reducing Selection Bias**
Chair: Jennifer H. Madans, retired, National Center for Health Statistics

Participants:
Joe Sakshaug, University of Mannheim
Debra Reed Gillette, Centers for Medicare and Medicaid Services
Andy Peytchev, RTI International

2:15 pm **Break**

PARTICIPATION

2:30 pm **Maximizing Respondent Retention**
Chair: Michael Davern, NORC at the University of Chicago

Participants
Nicole Watson, University of Melbourne
Eric Grodsky, University of Wisconsin, and Rachel Canas, NORC at the University of Chicago
Pam Herd, Georgetown University

DATA LINKAGE

3:30 pm **Challenges to Connecting Data across Agencies**
Chair: Jennifer H. Madans, retired, National Center for Health Statistics

Participants
Beth Virnig, University of Minnesota
Lisa Mirel, National Center for Health Statistics

4:30 pm **Day One Wrap-Up**
MICHAEL DAVERN, NORC at the University of Chicago

4:45 pm Adjourn

Tuesday, September 28, 2021 12:00 pm – 5:00 pm

12:00pm **Intro and Recap of Day One**
Michael Davern, NORC at the University of Chicago, Planning Committee Chair

INFORMED CONSENT

12:10 pm **The Complexity of Informed Consent**
Chair: Vetta L. Sanders Thompson, Washington University in St. Louis

Participants:
Annette Jäckle, University of Essex
Katie O’Doherty, NORC at the University of Chicago
Christine Grady, National Institutes of Health

1:05 pm **Ethical Considerations for Obtaining Informed Consent**

Chair: Vetta L. Sanders Thompson, Washington University in St. Louis

Participants:
Stephanie Solomon Cargill, St. Louis University
Emily Largent, University of Pennsylvania
Sunita Sah, University of Cambridge and Cornell University

2:00 pm **Break**

PARTICIPATION

2:15 pm **Participant Engagement: Insights from Behavioral Science Research**
Chair: Sunita Sah, University of Cambridge and Cornell University

Participants:
Bettina Drake, Washington University School of Medicine in St. Louis
Amelia Burke-Garcia, NORC at the University of Chicago

INNOVATION

3:15 pm **Looking Ahead: Applying Innovative Strategies to Improve Consent and Response**
Chair: Michael Davern, NORC at the University of Chicago

Participants
Annette Jäckle, University of Essex
Timothy Smeeding, University of Wisconsin
Andy Peytchev, RTI International

4:15 pm **Wrap-Up Discussion**
Chair: Brian Harris-Kojetin, CNSTAT

Participants
John Phillips, National Institute on Aging
Michael Davern, NORC at the University of Chicago
Jennifer H. Madans, retired, National Center for Health Statistics
Sunita Sah, University of Cambridge and Cornell University
Vetta L. Sanders Thompson, Washington University in St. Louis

5:00 pm **Adjourn**

Committee on Improving Consent and Response in Longitudinal Studies of Aging: A Workshop

MICHAEL DAVERN (Chair), NORC at the University of Chicago.
MICK P. COUPER, University of Michigan.
JENNIFER H. MADANS, retired, National Center for Health Statistics
SUNITA SAH, University of Cambridge and Cornell University
VETTA L. SANDERS THOMPSON, Washington University in St. Louis.

Statement of Task

An ad hoc planning committee of the National Academies of Sciences, Engineering, and Medicine will plan and execute a two-day public workshop to discuss methods to improve response/retention and enhance consent protocols for biomarker and program (administrative) data linkage in nationally representative longitudinal studies of older Americans. The methods discussed will include (1) innovations in survey methods with a multidisciplinary approach such as framing of questions and consent protocols employing insights from psychology and behavioral economics; (2) messaging and participant engagement approaches about the value of study participation; and (3) efforts to understand what would motivate consent to specific protocol and efforts to understand if a study has adequately secured a social license/trust with respondents.

The planning committee will define the specific topics to be addressed, develop the agenda, and invite speakers and other participants. After the workshop, proceedings of the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

Project Background

The National Institute on Aging (NIA) supports several nationally representative longitudinal data resources each with unique structural features to facilitate research on various dimensions of aging and health. The US aging panel studies collect data covering a vast array of domains, including socioeconomic factors, self-reported and objective measures of health, cognition, personality, family structure, health care utilization and care needs, and even genetics. Studies that include biomarker collection (e.g. blood samples, saliva collection, etc.) typically require an additional consent process. Similarly, linkage to program data from federal programs (e.g. Medicare and Social Security) or other administrative sources require separate consent. These sources of data can provide several benefits, including objective measurement of important domains and in some instances reduce respondent burden. Overall, these data resources are highly productive, supporting significant numbers of research projects by a wide array of researchers from many disciplines that can be more easily replicated and are more generalizable due to the representativeness of the data.

Maintaining these high-quality data collections requires techniques to obtain high response rates and limit panel attrition in order to preserve representativeness. Further, expanding content to keep pace with innovations in science can increase respondent burden and adversely impact participation. Specifically, requests for participation in biomarker collection, actigraphy monitoring, or linkage to program/administrative data can lead respondents to either reject the protocol (item nonresponse) or leave the study entirely (unit nonresponse).

Response and retention rates are declining across longitudinal and cross-sectional studies around the world. Much published research on protocols intended to address these types of issues are on cross-sectional studies or do not account for special issues associated with targeted midlife or older populations of interest to the NIA or rare populations of interest for studies of health disparities. Understanding the factors that limit response/consent, better ways to inform participants about the benefits of study participation and risks of consent, and novel methods to inform and establish consent, especially for vulnerable populations, can improve consent rates, data quality, and provide significant value to a study and to the research literature. While these methods are particularly important for longitudinal studies, the results of this research can spill over to other types of studies that recruit subjects (epidemiological studies, cross-sectional studies, or randomized control trials).

The 2019 National Advisory Council on Aging (NACA) Review recommended that NIA prioritize research to develop new, more effective, approaches for recruiting participants to ensure samples are population representative. The 2019 NACA Review of BSR provided several recommendations relating to response and consent rates in NIA-supported, nationally representative longitudinal studies of aging. First, several research objectives, such as the focus on investigations of various disparities in health at older ages, benefit from diverse representative national samples with high consent rates on biomarker, and program/administrative data linkage protocols to limit the risk of item nonresponse bias. Second, NACA explicitly encouraged the continued collection/linkage of biology and program data to NIA-supported studies. Most relevant to this request, NACA recommended prioritizing research to develop new and more effective methods for recruiting and retaining study participants to ensure samples are population representative.

Biosketches of Presenters at the Workshop

AMELIA BURKE-GARCIA is a seasoned health communications professional with nearly 20 years of experience in health communication program planning, implementation and evaluation, with specific expertise in developing and evaluating digital health communications campaigns and intervention studies. Over the course of her career, Dr. Burke-Garcia has spearheaded some of the most innovative communication programs and studies on a variety of health topics. Examples include investigating perspectives and motivations of non-vaccinating online influencers, designing a targeted social media intervention with mommy bloggers to help social media users lower their risk for breast cancer, and leveraging MeetUp groups and the Waze mobile application to move people to action around flu vaccination and HIV testing, respectively. Most recently, she acted as director for the award-winning *How Right Now/Que Hacer Ahora* campaign, which is aimed at increasing people's ability to cope and be resilient amidst the COVID-19 pandemic. She is also conducting three studies that examine perceptions and beliefs related to the COVID vaccine amongst hard-to-reach populations. She is the author of the book entitled, Influencing Health: A Comprehensive Guide to Working with Online

Influencers and has been named to VeryWellHealth.com's list of 10 Modern Female Innovators Shaking Up Health Care.

RACHEL CANAS is a senior research director in the Health Sciences Department at NORC at the University of Chicago. She currently serves as the assistant project director for the High School & Beyond (HS&B) Follow Up study, a longitudinal, multimode (web, CATI, paper) study looking at the intersection of health, cognition, and education. She also serves as a lead project manager for the Survey of Women multimode data collection, an address-based longitudinal study collecting sensitive health measures via web and mail surveys. Her primary expertise is with managing data collection efforts for large-scale, multimode studies. Her work spans questionnaire development, design of data collection technical systems, management of multimode data collection operations, and training of interviewers and locators. Prior to NORC, she managed multiple efforts related to questionnaire and instrument development across single-mode and multimode data collections at the University of Michigan Survey Research Operations. She has an M.S. in survey and data science from the University of Michigan.

STEPHANIE SOLOMON CARGILL is Associate Professor of Health Care Ethics at Saint Louis University, with a focus on research ethics. Dr. Solomon Cargill's empirical and theoretical research explores the ethical and policy issues that face research review boards like IRBs and Community Advisory Boards, as well as more specific issues around informed consent and research with vulnerable individuals and communities. She is the Chair of Castle IRB, a private IRB that specializes in reviewing gene and cell therapy research, as well as sits on Saint Louis University's IRB. She develops and implements curriculae in research ethics, public health ethics, and responsible conduct of research to graduate students, medical students, and researchers.

MICK P. COUPER *(Steering Committee Member)* is a research professor in the Survey Research Center Institute for Social Research at the University of Michigan. He has been doing surveys and research on surveys for over 30 years. He is author of *Designing Effective Web Surveys* (Cambridge, 2008), co-author (with Roger Tourangeau and Frederick Conrad) of T*he Science of Web Surveys* (Oxford, 2013), co-author (with Robert Groves) of *Nonresponse in Household Interview Surveys* (Wiley, 1998), and co-author (with Robert Groves, F. Jackson Fowler, James Lepkowski, Roger Tourangeau, and Eleanor Singer) of *Survey Methodology* (2nd ed. Wiley, 2009), and has published widely on survey methodology in a variety of journals. His research focuses on the application of technology to the survey process, the design of computer-assisted surveys, and the data collection process, including issues of coverage, nonresponse, and measurement. He has also conducted research on consent to biomeasures and administrative record linkage. He is a member of the Committee on National Statistics and previously served on two NASEM consensus panels (Research on Future Census Methods and ; Redesigning the BLS Consumer Expenditure Surveys). He holds a Ph.D. in Sociology from Rhodes University, an M.A. in Applied Social Research from the University of Michigan and an M.Soc.Sc. from the University of Cape Town.

MICHAEL DAVERN *(Steering Committee Chair)* is senior vice president and director of the Public Health Research Department at NORC at the University of Chicago. At NORC at the University of Chicago, his work focuses on survey research, public health data, linking surveys with administrative data, and Census Bureau data, as well as the use of these data for policy research simulation and evaluation. Previously, at the University of Minnesota, he was an assistant professor of health policy and management and research director of the State Health Access Data Assistance Center and co-director of the State Research Data Center. He also previously served as a statistician for the Labor Force and Transfer Programs Statistics Branch of the U.S. Census Bureau. A major focus of his work has involved applying state-level data to health policy issues and helping states monitor trends in health insurance coverage rates. He has an M.A. in sociology from Colorado State University, and a Ph.D. in sociology from the University of Notre Dame.

BETTINA DRAKE is Professor of Surgery at Washington University School of Medicine in the Division of Public Health Sciences and Associate Director of Community Outreach and Engagement at Siteman Cancer Center. Dr. Drake is a cancer epidemiologist and health disparities researcher with expertise in community-based reserach. Her research focuses on identifying preventive strategies to reduce disparities. The objectives of her research program are: (1) to utilize community-based approaches to design, implement and disseminate research information; (2) to promote education and awareness of research and research participation in minority communities; and (3) to identify the modifiable and non-modifiable risk factors for cancer and other chronic diseases as well as the at-risk groups for these factors. The combination of her community-based and epidemiology expertise strengthen the effectiveness of her leadership for this component. Dr. Drake builds on the synergy between her community-engaged work and cancer epidemiology research to reduce health disparities and promote health equity.

CHRISTINE GRADY is a nurse-bioethicist, senior investigator, and Chief of the Department of Bioethics at the National Institutes of Health Clinical Center. Her research focuses on clinical research ethics, including informed consent, vulnerability, study design, and recruitment, international research ethics and on ethical issues faced by nurses and other healthcare providers. Dr. Grady has authored more than 200 papers in the biomedical and bioethics literature and authored or edited several books, including *The Oxford Textbook of Clinical Research Ethics*. She is an elected fellow of the Hastings Center and the American Academy of Nursing, a research fellow at Kennedy Institute of Ethics and an elected member of the National Academy of Medicine. Dr. Grady holds a B.S. in nursing and biology from Georgetown University, a M.S.N. in community health nursing from Boston College, and a Ph.D. in philosophy from Georgetown University.

ERIC GRODSKY is Professor of Sociology and Educational Policy Studies at the University of Wisconsin- Madison and co-PI of High School & Beyond (HS&B), a longitudinal study of a nationally representative sample of approximately 25,500 people who were born between 1962 and 1965 and first observed as high school sophomores or seniors in 1980. In addition to his work with HS&B, Grodsky co-directs the Madison Education Partnership, a research-practice partnership between the Wisconsin Center for Education Research and the Madison Metropolitan School District, and leads several projects with Wisconsin's state department of education. Grodsky has written on inequality in early childhood and higher education, educational gradients in morbidity and mortality and social stratification over the lifecourse more broadly. His work has appeared in the American Journal of Sociology, American Sociological Review, Social Forces and Sociology of Education among other venues.

PAMELA HERD is a professor in the McCourt School of Public Policy at Georgetown University and a Principal Investigator of the Wisconsin Longitudinal Study (2010-present). Her research focuses on health (especially biodemography), aging, stratification, and policy, with additional expertise in survey methods. She is an MPI (with Sanjay Asthana) on a data collection project tracking dementia in the Wisconsin Longitudinal Study. She is also a member of the Principal Investigator team for the General Social Survey. She has been a member of a National Academy of Science Panel devoted to the future of NSF funded Surveys, a Chair of the Board of Overseers for the General Social Survey and a member of the Board of Overseers for the Panel Study of Income Dynamics. She is currently the NIH appointed Chair of the Data Monitoring Committee for the National Longitudinal Study of Adolescent to Adult Health (Add Health).Her research and data collection interests especially focus on relationships between social conditions, and biological processes and outcomes, with particular interests in the relationships between social environments and biological outcomes. Her work has appeared in publications such as the American Sociological Review, the Proceedings of the National Academy of Sciences, and Nature Genetics.

ROBERT A. HUMMER is the Howard W. Odum Distinguished Professor of Sociology and Fellow of the Carolina Population Center at the University of North Carolina at Chapel Hill (UNC-CH). Hummer is also currently serving as the President of the Population Association of America (PAA), the 84th president in the history of the organization. Hummer's research program is focused on the accurate description and more complete understanding of population health patterns and trends in the United States. He is currently serving as Director of the long-running National Longitudinal Study of Adolescent to Adult Health (Add Health), which is funded by the National Institute on Aging and five co-funding institutes/offices (NICHD, NIMHD, NIDA, OBSSR, ODP). Now in its sixth wave, Add Health is one of the most innovative and well-utilized nationally representative cohort studies of Americans ever undertaken. Over his career to date, Professor Hummer has published more than 150 journal articles and book chapters in his areas of interest, with attention to health disparities both during infancy/childhood as well as across the adult life course. He is also the recent co-author of *Population Health in America* (University of California Press, 2019, with Erin R. Hamilton).

ANNETTE JÄCKLE is Professor for Survey Methodology at the Institute for Social Research (University of Essex, UK) and Associate Director for Innovations in Understanding Society. Current research projects focus on methods for event-triggered data collection, collecting informed consents for data linkage, and using mobile apps for data collection.

EMILY LARGENT 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. Her work is supported by a K01 career development award from the National Institute on Aging. In 2020, Dr. Largent was named a Greenwall Faculty Scholar; her faculty scholar project, "Autonomy on the Precipice of Cognitive Decline," seeks to understand how our evolving understanding of Alzheimer's disease affects patients and their families. Dr. Largent received her PhD in Health Policy, with a concentration in ethics, from Harvard University and her JD from Harvard Law School. Dr. Largent was previously a fellow in the Department of Bioethics at the National Institutes of Health (2008-2010) and clerked for Chief Judge Jeffrey Howard of the United States Court of Appeals for the First Circuit (2016-2017).

JENNIFER H. MADANS *(Steering Committee Member)* **r**ecently retired from the National Center for Health Statistics (NCHS) serving most recently as the center's associate director for science, acting director and acting deputy director. At NCHS she was responsible for the overall plan and development of NCHS's data collection and analysis programs. Her research has focused on efforts on data collection methodology and the measurement of health and functioning. She is a founding member and served as chair of the steering committees for three U.N. sponsored initiatives to develop internationally comparable measures of disability and health, including the Washington Group on Disability Statistics, a city group under the auspices of the UN Statistical Commission making extensive contributions in all aspects of disability data collection internationally and in the U.S. She is an elected fellow of the American Statistical Association, an elected member of the International Statistical Institute, and served as a vice president of the International Association of Official Statistics. Dr. Madans received the 2015 Roger Herriot Award for Innovation in Federal Statistics from the American Statistical Association and the 2016 Excellence in Public Service Award from the Population Association of American. She served on NASEM panels on Addressing Priority Technical Issues for the Next Decade of the American Community Survey, the Future of Federal Household Surveys, and to Develop Criteria for Evaluating the Outcomes of Approaches to Prevent and Treat Obesity. She has a B.A. degree from Bard College and M.A. and Ph.D. degrees in sociology from the University of Michigan.

LISA MIREL is the Chief of the Data Linkage Methodology and Analysis Branch in the Division of Analysis and Epidemiology at the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. Ms. Mirel directs the NCHS Data Linkage program, leading Agency efforts to integrate NCHS data collection systems with external sources of health related administrative data, to both expand the analytic potential of NCHS data and to develop innovative data resources that better inform public health policy and fill critical information gaps. She also oversees the development and implementation of state-of-the-art data linkage methodologies and data quality assessment tools. Her work has focused primarily on integrating multiple sources of data through data linkage and advising on survey design and estimation techniques for large scale national health surveys. She received her Master of Science degree in Biostatistics from the University of Michigan's School of Public Health.

KATIE O'DOHERTY is a Senior Research Director in the Health Sciences department at NORC at the University of Chicago. Her expertise is in managing complex data collection projects that integrate biomeasure collection and cognitive assessments into survey research, including NIH projects such as the National Social Life, Health and Aging Project (NSHAP), the Abecedarian Project at Midlife, and High School and Beyond (HS&B).

ANDY PEYTCHEV is a senior survey methodologist and Fellow at RTI. He leads the design of large-scale surveys and PI-initiated research, and is the RTI PI for the National Survey of Family Growth. His research interests include study designs that minimize survey error with particular emphasis on nonresponse and measurement error. Dr. Peytchev's recent work includes the evaluation of split questionnaire design, development of adaptive and responsive survey designs, implementation of multimode and multiphase data collection, augmentation of survey samples with other data, and synthetic data. He has served on panels and advisory boards, including the National Academies' Panel on Redesign of the BLS Consumer Expenditure Surveys.

JOHN W. R. PHILLIPS serves as Chief of the Population and Social Processes Branch (PSP) of the NIA Division of Behavioral and Social Research (BSR). During a career spanning over 20 years, John has worked to produce research and data resources on aging related topics. Prior to joining BSR in 2018, John was Associate Commissioner for Research, Evaluation, and Statistics at the US Social Security Administration, one of the 13 principal federal statistical agencies charged with producing research and data to inform policy-makers and the public about the nation's retirement and disability programs. He previously served in other research roles in the federal government including Health Scientist Administrator for NIA, as well as Research Economist and Director of the Office of Policy Research at SSA. John received a PhD in Economics from Syracuse University. His research examined aging issues ranging from retirement security, intergenerational transfers, and distributional effects of retirement and disability programs. Both his pre-doctoral research and his post-doctoral fellowship at the University of Pennsylvania were funded by NIA. John's current portfolio at NIA focuses on the economics of aging and the development of international comparators to the US Health and Retirement Study to support aging research.

DEBRA REED-GILLETTE is currently Director of the Survey Management and Analytics Group (SMAG) within the Office of Enterprise Data and Analytics (OEDA) of the Centers for Medicare & Medicaid Services (CMS). The primary function of SMAG is conducting the Medicare Current Beneficiary Survey (MCBS), the primary survey providing linked health information and health care expenditure data on Medicare beneficiaries. The MCBS has collected data not available in CMS administrative records to aid in the development and evaluation of health care policy since 1991. The MCBS includes such topics as chronic disease, experiences with care and care transitions, access to health care, items on frailty, mobility, pain, preventative care, and experiences with COVID-19. In addition to her time at CMS, Ms Reed-Gillette has over 30 years of experience in federal health surveys with the Centers for Disease Control and Prevention (CDC), including the National Health Interview Survey and the National Health and Nutrition Examination Survey. Additionally, Ms Reed-Gillette served as a subject matter expert for the Oregon Health Study, the first New York City Health and Nutrition Examination Survey, the Canadian Health Measures Study, Survey of the Health of Wisconsin, and the National Children's Study. Her expertise is in public health informatics focusing on public health related data collection systems and data dissemination.

CAROL D. RYFF is Director of the Institute on Aging and Hilldale Professor of Psychology at the University of Wisconsin-Madison. She studies psychological well-being – how it varies by age, gender, educational status, cultural context, and how it matters for diverse aspects of health including disease outcomes, length of life, physiological regulation and neural circuitry. Her model of well-being is widely used around the world, with the assessment scales translated to more than 40 languages. Dr. Ryff is Principal Investigator of the MIDUS (Midlife in the U.S.) longitudinal study and its sister study in Japan, MIDJA (Midlife in Japan), for which she received an NIH Merit Award. MIDUS and MIDJA, both public-use datasets, have become major forums for multidisciplinary health research with over 1,500 publications generated to date. Dr. Ryff's scientific contributions (270+ publications) have been recognized with the Baltes Distinguished Research Award and the Mentoring Award from Division 20 of American Psychological Association, the Positive Health Award from the International Network of Positive Psychology, the Murray Award from the Society of Personality and Social Psychology, the Lifetime Achievement Award from the International Network for Personal Meaning, and the Matilda White Riley Award from the National Institute on Aging.

SUNITA SAH *(Steering Committee Member)* is a physician turned professor and organizational psychologist at Cornell University and an Honorary Fellow at the University of Cambridge. Dr. Sah teaches leadership, negotiations, and critical thinking. Her research expertise is in conflicts of interest, disclosure, influence, consent, compliance, and trust. Dr. Sah is the Director of Academic Leadership at Cornell University. She served as a commissioner on the National Commission of Forensic Science and on the Human Factors Committee for the National Institute of Science and Technology Forensic Science Standards Board. Dr. Sah is currently on the scientific advisory board of the Behavioral Economics in Health Network, an officer at the International Behavioural Public Policy Association, a fellow of the Society of Personality and Social Psychology, and on the editorial board of *Behavioural Public Policy*. Dr. Sah has won best paper awards from the Academy of Management, Society of Business Ethics, Society of Judgment and Decision-Making, and Society of Personality and Social Psychology, as well as scholar awards from the Russell Sage Foundation, Harvard University, Kellogg School of Management, and the U.K. Medical Research Council. Prior to Cornell University, Dr. Sah was the KPMG Professor of Management Studies at the University of Cambridge, and prior to that held academic positions at Georgetown, Duke, Russell Sage, and Harvard Universities. Before entering academia, Dr. Sah worked as a medical doctor for the U.K.'s National Health Service. Dr. Sah holds a Ph.D. and M.S. in organizational behavior from Carnegie Mellon University (2010), an M.B.A. with distinction from London Business School (2005), an M.B. Ch.B. (U.K. equivalent to the U.S. M.D.) in medicine and surgery (1997), and a B.Sc. (Hons) in psychology from the University of Edinburgh (1995).

JOE SAKSHAUG is distinguished researcher at the German Institute for Employment Research, professor of statistics at the Ludwig Maximilian University of Munich, and honorary professor in the school of social sciences at the University of Mannheim. He also teaches in the International Program in Survey and Data Science. He is well-known for his contributions to survey methodology, including the design, analysis, and quality of complex sample surveys, causes and corrections for nonresponse and measurement errors, and methods of combining multiple data sources.

TIMOTHY M. (TIM) SMEEDING is the Lee Rainwater Distinguished Professor of Public Affairs and Economics at the La Follette School of Public Affairs at the University of Wisconsin-Madison. He was the founding director of the Luxembourg Income Study from 1983-2006 and was director of the Institute for Research on Poverty at UW Madison from 2008–2014. He is the 2017 John Kenneth Galbraith Fellow of the American Academy of Political and Social Science. In recent years Smeeding has worked with DBASSE and CNSTAT committee members to develop the American Opportunity Study, as a member of the National Academy of Sciences, American Opportunity Study, Standing Committee, (2015 to 2018) and a recent paper on which his talk is based, “A New Infrastructure for Monitoring Outcomes, Evaluating Policy, and Advancing Basic Science.” Smeeding served on the Board of Directors of the National Academy on Aging and is an elected member of the National Academy of Social Insurance. He has served as head of the Economics of Aging Interest Group and is chair elect of the Public Policy Committee for the Gerontology Society of America, where he was elected a fellow in 1990. He was a member of the Federal SSI Modernization Project from 1990-92 and of the Social Security Advisory Board in 1999. Dr. Smeeding has written extensively on the topic of the economics of aging for Congress, Social Security Board of Trustees, National Academy of Sciences, National Academy of Social Insurance, Encyclopedia of Aging and the Handbook of Aging and the Social Sciences.

VETTA L. SANDERS THOMPSON *(Steering Committee Member)* is the E. Desmond Lee professor of racial and ethnic studies at the Brown School and associate dean for diversity, equity and inclusion. Dr. Sanders Thompson serves as co-director of the Center for Community Health Partnership and Research at the Institute for Public Health, is an associate member of the Siteman Cancer Center, a faculty affiliate of the Department of African and African-American Studies, and the Interdisciplinary Program in Urban Studies. She is a licensed psychologist and health service provider in the state of Missouri. Her research is focused on the health and well-being of ethnic and racial minorities, particularly the African-American community. She is known for her work on racial identity, psychosocial implications of race and ethnicity in health behavior and determinants of health and mental health disparities. Dr. Sanders Thompson has conducted research on the promotion of cancer screening among African Americans and community engagement, including a PCORI funded project to develop a measure of the quality of community and patient engaged research. Over the years she has been honored by the St. Louis community, as well as her professional colleagues for efforts to improve service delivery in Black communities, including the 2018 Terry Leet Researcher of the Year Award (Generate Health, maternal and infant mortality), the 2017 Missouri Psychological Association Dr. Richard R. Wilkerson Lifetime Achievement Award, and the Mental Health America of Eastern Region Missouri Silver Key Award. Dr. Sanders Thompson received her B.A. in psychology and social relations from Harvard University in 1981, her M.A. and Ph.D. in psychology from Duke University where she also completed clinical training.

BETH VIRNIG is the director of the Research Data Assistance Center (ResDAC) at the University of Minnesota, which is funded by a contract from CMS to provide free assistance to academic, government, and nonprofit researchers interested in using Medicare or Medicaid data for their research. She is a trained epidemiologist and with expertise in population-based measures of health and health care use with particular expertise in the use of Administrative data such as that from Medicare, Medicaid and All Payer Claims Databases (APCDs). Her research has used Medicare data alone and in combination with other data sources including cancer registry data, data from local and federal surveys and compiled geographical summaries, and she has examined access to health care and use and outcomes of that care, and how health care is influenced by patients, providers, and markets. Her research on the elderly in the Medicare program focuses on cancer surveillance and care, Medicare managed care, and end-of-life care.

LINDA WAITE is the George Herbert Mead Distinguished Service Professor of Sociology at the University of Chicago and Senior Fellow at NORC at the University of Chicago. She is

Principal Investigator of the National Social Life, Health and Aging Project (NSHAP), widely recognized as the gold standard for the collection of survey data on older adults' intimate and social relationships and innovation in the development of methods for the collection of biomarkers such as blood spots and saliva during in-home interviews. As part of NSHAP's multidisciplinary investigatory team Waite has participated in three rounds of data collection, with a fourth underway, a COVID substudy and numerous ancillary studies. Using unique data from NSHAP's partner dyads, Waite has expanded research and public discourse on later life sexuality. Her research on this topic, published in Archives of Sexual Behavior, Demography, Journals of Gerontology, Journal of Marriage and Family, Journal of Sexual Medicine, and the New England Journal of Medicine demonstrates that sexuality is not just the province of the young. Instead, sexuality is a key component of physical and emotional well-being for both older and younger adults, and it is closely connected with dynamics of social relationships and health in later life. Waite has received numerous honors and awards for her scholarly contributions. In 2012, Waite received the Matilda White Riley Award from the NIH Office of Behavioral and Social Research. This Award honors scholars who have shown remarkable achievement in research and theory of aging and the life course. She also, separately, received the Matilda White Riley Award for career achievement from the Section on Aging and the Life Course of the American Sociological Association. Waite is also past president of the Population Association of America and served as Chair of the Committee on Population, National Research Council, National Academy of Sciences. She was a member of the Advisory Board to the Director on the National Institutes of Health. She has received a MERIT Award from the National Institutes of Health, and is an elected member of the American Academy of Arts and Sciences.

NICOLE WATSON is a survey methodologist and an Associate Professor at the Melbourne Institute within the University of Melbourne. She has worked on the Household, Income and Labour Dynamics in Australia (HILDA) Survey since 2000. Her role has covered many aspects of the HILDA Survey Project, including fieldwork contract management, weighting and imputation.

DAVID WEIR is a research professor in the Survey Research Center at the Institute for Social Research at the University of Michigan and Director of the Health and Retirement Study (HRS). He has led the transformation of the HRS into a world-leading biosocial survey combining its traditional excellence as a longitudinal economic survey with direct biological measures of health, genetics, linked medical and long-term care records from the Medicare system, and enriched psychological measurement. His research increasingly includes comparative analyses from the international family of HRS studies that now cover more than half the world's population, including the dementia assessments done with the Harmonized Cognitive Assessment Protocol (HCAP) developed by HRS for international comparisons. He received his Ph.D. in economics from Stanford University and previously held faculty positions at Yale and the University of Chicago.