

**A National Cancer Policy Forum Workshop
convened in collaboration with the
Forum on Aging, Disability, and Independence**

Addressing the Adverse Consequences of Cancer Treatment

A WORKSHOP

November 9-10, 2020


#NatlCancerForum



Webcast:

<https://www.nationalacademies.org/event/11-09-2020/addressing-the-adverse-consequences-of-cancer-treatment-a-workshop>

Help Spread the Word! Please use hashtag #natlcancerforum

 [Share on Twitter:](#) On 11/9-11/10, speakers at @NASEM_Health virtual workshop will examine the array of adverse effects that patients may experience as a result of cancer treatment and opportunities to improve quality of life across the lifecourse. Register: <https://bit.ly/3le34GE> #natlcancerforum

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November 9, 2020

Dear Colleagues,

We welcome you to the virtual workshop, Addressing the Adverse Consequences of Cancer Treatment, convened by the National Cancer Policy Forum, in collaboration with the Forum on Aging, Disability, and Independence.

The intent of the workshop is to examine the significant physical, mental, and socioeconomic consequences that patients may experience as a result of cancer treatment and consider opportunities to improve quality of life for cancer survivors and their families. The workshop begins with a conversation about individuals' lived experiences after diagnosis and treatment and the adverse consequences from cancer treatment. This will be followed by sessions on how these effects can vary across the lifecourse, as well as the psychosocial and socioeconomic consequences of cancer diagnosis and treatment. Speakers and panelists will also highlight strategies to improve informed and goal-concordant care, especially in light of evidence gaps on the long-term consequences of cancer treatment, as well as review strategies to redesign cancer treatment and survivorship care to screen for and reduce toxicities. On the second day, workshop participants will discuss how the evidence base for addressing the adverse consequences of cancer treatment can be strengthened, and potential policy opportunities to improve cancer survivorship care. The workshop concludes with a forward-looking panel discussion in which panelists will discuss their recommendations for capturing and addressing the adverse consequences of cancer treatment to improve long term cancer outcomes and quality of life.

We welcome your involvement in the workshop. Please use the chatbox on our website (<https://www.nationalacademies.org/event/11-09-2020/addressing-the-adverse-consequences-of-cancer-treatment-a-workshop>) to ask questions, and please include your name and affiliation. The proceedings of the workshop will be published by the National Academies Press and may incorporate your comments and ideas. Archived presentations and videos from the workshop will also be available on the website.

Sincerely,

Cathy Bradley, PhD
Planning Committee Co-Chair
David F. and Margaret Turley Grohne Endowed Chair for
Cancer Prevention and Control Research Professor
Associate Dean for Research
Colorado School of Public Health
Deputy Director
University of Colorado Comprehensive Cancer Center

Lisa Kennedy Sheldon, PhD, ANP-BC, AOCNP®, FAAN
Planning Committee Co-Chair
Clinical and Scientific Affairs Liaison
Oncology Nursing Society



Webcast Notes for Attendees

Addressing the Adverse Consequences of Cancer Treatment: A Virtual Workshop

Dates

Monday, November 9 – Tuesday, November 10, 2020

Joining the Workshop

The livestream of the webcast will be available on November 9th here:

<https://www.nationalacademies.org/event/11-09-2020/addressing-the-adverse-consequences-of-cancer-treatment-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.
- Please use hashtag **#NatlCancerForum** to tweet about the workshop.
- Interested in receiving updates from the National Cancer Policy Forum or 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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Addressing the Adverse Consequences of Cancer Treatment

A National Cancer Policy Forum Virtual Workshop

In Collaboration with the Forum on Aging, Disability, and Independence

Workshop Agenda

Monday, November 9, 2020 (Eastern Time Zone)	
10:00 am	<p>Welcome from the National Cancer Policy Forum and Forum on Aging, Disability, and Independence</p> <p>Cathy J. Bradley, University of Colorado Comprehensive Cancer Center Lisa Kennedy Sheldon, Oncology Nursing Society Workshop Planning Committee Co-Chairs</p> <p>Julie Bynum, University of Michigan Forum on Aging, Disability, and Independence</p>
10:15 am	<p>Session 1: Lived Experiences with the Adverse Consequences of Cancer Treatment <i>Moderators (with introductory comments – 5 minutes):</i></p> <ul style="list-style-type: none"> Gwen Darien, National Patient Advocate Foundation Robert Winn, Virginia Commonwealth University Massey Cancer Center <p>Keynote Presentation: A Physician-Survivor's Perspective (15 minutes) Wendy S. Harpham, Columnist, Author, Patient Advocate</p> <p>Panel Discussion (35 minutes) Include keynote speaker and:</p> <ul style="list-style-type: none"> Meg Gaines, University of Wisconsin-Madison Candace Henley, The Blue Hat Foundation, Inc. Mary (Dicey) Jackson Scroggins, International Gynecologic Cancer Society <p>Closing Remarks (5 minutes)</p>
11:15 am	Break
11:30 am	<p>Session 2: Overview and Evidence Gaps Across the Lifecourse <i>Moderator: Smita Bhatia, University of Alabama at Birmingham</i></p> <ul style="list-style-type: none"> Pediatric Cancer Survivorship (20 minutes) <ul style="list-style-type: none"> Leslie Robison, St. Jude Children's Research Hospital Adolescent and Young Adult Survivorship: Knowledge Gaps and Challenges for the Future (20 minutes) <ul style="list-style-type: none"> K. Scott Baker, Fred Hutchinson Cancer Research Center Older Survivors (20 minutes) <ul style="list-style-type: none"> Supriya Gupta Mohile, University of Rochester Medical Center
12:30 pm	Lunch Break

1:00 pm	<p>Session 3: Psychosocial and Socioeconomic Consequences and Data Needs Moderator: Cathy J. Bradley, University of Colorado Comprehensive Cancer Center</p> <ul style="list-style-type: none"> • Psychosocial Considerations (10 minutes) <ul style="list-style-type: none"> ○ David Cella, Northwestern University • Health Equity Considerations (10 minutes) <ul style="list-style-type: none"> ○ Cleo A. Samuel-Ryals, University of North Carolina, Chapel Hill • Financial Hardship Among Cancer Survivors in the United States (10 minutes) <ul style="list-style-type: none"> ○ Robin Yabroff, American Cancer Society <p>Panel Discussion (30 minutes) Include speakers and:</p> <ul style="list-style-type: none"> • Michael Halpern, National Cancer Institute
2:00 pm	Break
2:15 pm	<p>Session 4: Opportunities to Improve Informed Decision Making and Goal-Concordant Cancer Care: Long-Term Adverse Consequences Moderator: Julie Bynum, University of Michigan</p> <p>Providing Decision Support: Balancing Benefits and Risks (10 minutes)</p> <ul style="list-style-type: none"> • Karen Sepucha, Massachusetts General Hospital and Harvard Medical School <p>Communicating About the Financial Consequences of Cancer Care (10 minutes)</p> <ul style="list-style-type: none"> • Yousuf Zafar, Duke University <p>Lessons Learned from Brushes with Death Serious Illness: Mine and Others (10 minutes)</p> <ul style="list-style-type: none"> • Thomas J. Smith, Johns Hopkins Medical Institutions <p>Opportunities to Better Align Care with Patient Goals (10 minutes)</p> <ul style="list-style-type: none"> • Kathlyn Conway, Women's Therapy Center Institute, Psychotherapist (Private Practice) and Author <p>Panel Discussion (35 minutes) Include speakers and:</p> <ul style="list-style-type: none"> • Melisa Wong, University of California, San Francisco
3:30 pm	Break
3:45 pm	<p>Session 5: Opportunities to Redesign Cancer Treatment to Screen for and Reduce Toxicities Moderators:</p> <ul style="list-style-type: none"> • Wui-Jin Koh, National Comprehensive Cancer Network • Randall Oyer, Penn Medicine Lancaster General Health <p>Strategies to Reduce Adverse Outcomes: Perspectives from the Office of Cancer Survivorship (15 minutes)</p> <ul style="list-style-type: none"> • Emily S. Tonorezos, National Cancer Institute <p>Lightning Round Presentations (30 minutes)</p>

	<ul style="list-style-type: none"> • The role of the PCP in cancer care <ul style="list-style-type: none"> ○ Kevin Oeffinger, Duke University (7 minutes) • Integrating cardio-oncology expertise in cancer treatment and survivorship care (7 minutes) <ul style="list-style-type: none"> ○ Javid J. Moslehi, Vanderbilt University Medical Center • Approaches to redesigning radiation therapy and opportunities for further progress <ul style="list-style-type: none"> ○ Justin Bekelman, University of Pennsylvania (7 minutes) • De-implementation of ineffective cancer treatment strategies (7 minutes) <ul style="list-style-type: none"> ○ David Howard, Emory University <p>Panel Discussion (45 minutes)</p> <ul style="list-style-type: none"> • Shannon MacDonald, Harvard Medical School • Supriya Gupta Mohile, University of Rochester Medical Center • Thomas J. Smith, Johns Hopkins Medical Institutions
5:15 pm	Adjourn Day 1
Tuesday, November 10, 2020 (Eastern Time Zone)	
10:00 am	Welcome and Overview of Day 2
10:05 am	<p>Session 6: Improving the Evidence Base for Addressing the Adverse Consequences of Cancer Treatment</p> <p><i>Moderators:</i></p> <ul style="list-style-type: none"> • Lawrence Shulman, University of Pennsylvania • Scott Ramsey, Fred Hutchinson Cancer Research Center <p>Late Effects of Cancer and Cancer Treatment: How Little We Know... (10 minutes)</p> <ul style="list-style-type: none"> • Lawrence Shulman, University of Pennsylvania <p>Ongoing Data Collection Efforts to Fill Evidence Gaps (40 minutes)</p> <ul style="list-style-type: none"> • SEER program: Overview of Enhancements <ul style="list-style-type: none"> ○ Lynne Penberthy, National Cancer Institute • Integrated Healthcare System Perspective <ul style="list-style-type: none"> ○ Lawrence Kushi, Kaiser Permanente Northern California Division of Research • A Novel Data Linkage to Examine the Long Term Adverse Consequences of Cancer Treatment: The SWOG-Medicare Database <ul style="list-style-type: none"> ○ Joseph Unger, Fred Hutchinson Cancer Research Center • Harnessing Electronic Health Records to Address the Adverse Consequences of Cancer Treatment <ul style="list-style-type: none"> ○ Kelly Magee, Flatiron Health <p>Panel Discussion (35 minutes)</p> <p>Include speakers and:</p> <ul style="list-style-type: none"> • Christopher Flowers, MD Anderson Cancer Center
11:30 am	Break

12:00 pm	<p>Session 7: Opportunities for System-level Redesign and Policy Change</p> <p>Moderators:</p> <ul style="list-style-type: none"> ○ Lisa Kennedy Sheldon, Oncology Nursing Society ○ Cleo A. Samuel-Ryals, University of North Carolina, Chapel Hill <p>Guidelines for Cancer Survivorship Care (10 minutes)</p> <ul style="list-style-type: none"> • Smita Bhatia, University of Alabama at Birmingham <p>Models of Care that Integrate Services and Stratify Delivery by Risk and Needs (10 minutes)</p> <ul style="list-style-type: none"> • Catherine Alfano, Northwell Health <p>Payment and Models of Care to Address Adverse Consequences of Cancer Treatment (10 minutes)</p> <ul style="list-style-type: none"> • Nancy Keating, Harvard Medical School <p>Education and Training Needs for Healthcare Professionals (10 minutes)</p> <ul style="list-style-type: none"> • Ashley Leak Bryant, University of North Carolina <p>Panel Discussion (35 minutes)</p> <p>Include speakers and:</p> <ul style="list-style-type: none"> • Jennifer Malin, UnitedHealthcare • Timothy Mullett, Commission on Cancer
1:15 pm	Break
1:30 pm	<p>Session 8: Panel Discussion: Participant Recommendations for the Path Forward</p> <p><i>Moderator: J. Leonard Lichtenfeld, Independent Consultant</i></p> <p>Panelists:</p> <ul style="list-style-type: none"> • Emily S. Tonorezos, National Cancer Institute • Smita Bhatia, University of Alabama at Birmingham • Howard A. Burris, Sarah Cannon • Shelley Fuld Nasso, National Coalition for Cancer Survivorship • Gary Lyman, Fred Hutchinson Cancer Research Center • Mary (Dicey) Jackson Scroggins, International Gynecologic Cancer Society • Lawrence Shulman, University of Pennsylvania • Lara Strawbridge, Centers for Medicare & Medicaid Services
2:45 pm	<p>Concluding Remarks</p> <p><i>Cathy J. Bradley, University of Colorado Comprehensive Cancer Center</i></p> <p><i>Lisa Kennedy Sheldon, Oncology Nursing Society</i></p>
3:00 pm	Adjourn



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Catherine M. Alfano, Ph.D.

Northwell Health

Catherine Alfano, PhD, is an international leader in cancer survivorship and cancer rehabilitation. At Northwell Health, she leads both clinical care design and research across the health system. Clinically, she develops and oversees the implementation and integration of a high-quality cancer survivorship program for the health system with a goal of reducing unnecessary costs as a result of more timely and effective care while simultaneously improving long-term patient outcomes. She also oversees the growth of new research development and training programs and research projects. Before joining Northwell, she served as the Vice President of Survivorship at the American Cancer Society where she provided vision and leadership to ACS research, programming, and policy efforts nationwide to improve the lives of cancer survivors. She previously served as the Deputy Director of the National Cancer Institute's Office of Cancer Survivorship where she created funding opportunity announcements to fill gaps in cancer survivorship and transdisciplinary research and administered a grant portfolio of cancer rehabilitation, symptom management, and behavior change trials. Dr. Alfano's research aims to speed the effective translation of research into practice and inform supporting policy to optimize patient outcomes and clinic efficiency, address provider shortages, and decrease healthcare costs. This research focuses on: 1) Domestic and global efforts to improve interventions and models of care delivery for oncology, cancer rehabilitation, and survivorship; 2) Integrating multi-source Big Data including Real World Evidence to generate insights for predictive and prescriptive analytics and creating mobile health and other digital health tools leading to better-personalized care approaches; 3) Incorporating rehabilitation, healthy behavior change, and self-management into oncology and cancer follow-up care; and 4) The integration of biological and behavioral pathways governing health, accelerated aging, function, and cancer prognosis.

K. Scott Baker, MD, MS

Fred Hutchinson Cancer Research Center

K. Scott Baker, MD, MS, is a Professor in the Clinical Research and Public Health Sciences Divisions at the Fred Hutchinson Cancer Research Center and Professor in the Department of Pediatrics at the University of Washington, Seattle WA. He holds the Gloria and Gerald Swanson Endowed Chair for Pediatric Blood and Marrow Transplant Research and is the Director of the Pediatric Blood and Marrow Transplantation and Cancer Survivorship Programs. He is a nationally recognized expert in the field of hematopoietic stem cell transplantation (HCT) and in cancer survivorship and late effects.

Dr. Baker's research interests are in the acute and long term-effects of HCT and his current grant support is examining the incidence, risk factors, and characteristics of cardiac, renal, bone, and QOL outcomes in HCT survivors. Recently funded work will examine survivorship issues in adolescent and young adult survivors and include an intervention to improve screening for cardiometabolic disease and subsequent malignant neoplasms. He has authored over 200 peer reviewed manuscripts, and numerous other publications and book chapters.

Smita Bhatia, MD, MPH

University of Alabama at Birmingham

Smita Bhatia, MD, MPH completed her training in Blood Banking, Hematology/Oncology and BMT from the University of Minnesota, where she also received her MPH in Epidemiology. She joined the Dept. of Pediatric Oncology at the City of Hope in 1996. In 2006, she established a new Dept. of Population Sciences at City of Hope, and served as founding chair of the department until 2014. Dr. Bhatia joined UAB in 2015 to establish the Institute for Cancer Outcomes and Survivorship. She is the Gay and Bew White Endowed Professor in Pediatric Oncology and serves as Vice Chair for Outcomes in the Dept. of Pediatrics. With over 315 peer-reviewed publications and 22,920 citations, an H-INDEX of 81 and an i10-index of 231, she is an internationally renowned leader in cancer survivorship and outcomes research, with a particular focus on blood or marrow transplant outcomes, in childhood cancer outcomes, and in determining the molecular basis of treatment-related complications. She has been continually funded by the NIH and by the Leukemia Lymphoma Society since 2000. She has also received funding from the Dept. of Defense, St. Baldrick's Foundation, V Foundation and ASCO. Dr. Bhatia continues to serve on several Study Sections for the NCI. She serves on the scientific advisory board for several cancer centers as well as several T32 Training grants. She has served (or is currently serving) on the editorial boards of multiple journals including the *JCO*, and *BBMT*; she serves as Section Editor for *Cancer* and senior editor for *CEBP*. She is a past scholar of the Leukemia Lymphoma Society. She was elected to membership to the American Society for Clinical Investigation and to the Association of American Physicians. She is the recipient of the Frank H Oski Lectureship Award from the American Society of Pediatric Hematology Oncology. She recently received the Outstanding Investigator Award from the NCI. She served on the Pediatric Cancer Working Group for the NCI Cancer "Moonshot" initiative and on the National Academy of Science, Engineering and Medicine Committee on a National Strategy for Cancer Control in the United States. She is serving on the National Cancer Policy Forum. She is passionate about mentoring junior investigators.

Justin E. Bekelman, MD

University of Pennsylvania

Justin E. Bekelman, M.D., is Director of the Penn Center for Cancer Care Innovation at the Abramson Cancer Center, Professor in the Departments of Radiation Oncology and Medical Ethics and Health Policy at the Perelman School of Medicine, Faculty in the Center for Health Incentives and Behavioral Economics, and Senior Fellow at the Penn Center for Precision Medicine and the Leonard Davis Institute for Health Economics, all at the University of Pennsylvania. Dr. Bekelman leads research programs to improve the length and quality of life for patients with cancer. His research focuses on health care delivery, payment reform and cancer care transformation, integrating methods from the fields of innovation, epidemiology, clinical trials, behavioral and health economics and public policy. Dr. Bekelman's research has appeared in high-impact scientific journals and has been featured by media outlets in the United States, Canada, Europe, Asia and Latin America. He has received research funding from the National Cancer Institute, the American Cancer Society, the Patient-Centered Outcomes Research Institute, the Commonwealth of Pennsylvania, and industry. He has served as an advisor to the Centers for Medicare and Medicaid Services (CMS) on cancer care payment reform and innovation. Dr. Bekelman is an elected member of the American Society for Clinical Investigation. Dr. Bekelman completed his undergraduate studies at Princeton University in the Princeton School of Public and International Affairs and his medical training at Yale University, Johns Hopkins, and Memorial Sloan Kettering Cancer Center. Previously, he was a management consultant at the Kalchas Group in

London and New York, advising senior executives of health care and insurance clients on corporate strategy. Dr. Bekelman also served as Special Assistant to the Under Secretary of Defense in the US Department of Defense. He is a board-certified radiation oncologist and practicing physician at the University of Pennsylvania Perelman School of Medicine.

Cathy J. Bradley, PhD

University of Colorado Comprehensive Cancer Center

Cathy J. Bradley, Ph.D., is the Associate Dean for Research in the Colorado School of Public Health and the Deputy Director of the University of Colorado Comprehensive Cancer Center. She holds the Grohne Chair for Cancer Prevention and Control Research. Prior to joining the University of Colorado, she was the founding Chair of the Department of Healthcare Policy and Research, and Associate Director of Cancer Prevention and Control at Virginia Commonwealth University School of Medicine. Dr. Bradley is an internationally recognized expert in health services research and health economics. Her expertise is in labor market outcomes of cancer survivors, health policy, and health disparities. Dr. Bradley is on the editorial board of the *Journal of Cancer Survivorship*, and is a member of the National Academies of Sciences, Engineering, and Medicine National Cancer Policy Forum.

Ashley Leak Bryant, PhD, RN-BC, OCN, FAAN

University of North Carolina at Chapel Hill

Dr. Ashley Leak Bryant, Associate Professor at the University of North Carolina at Chapel Hill School of Nursing and Anne Belcher Interprofessional Faculty Scholar in Nursing, is a clinical and research expert in symptoms and function of adults with blood cancers during and beyond treatment. These blood cancers include lymphomas, leukemias, and multiple myeloma, which, although occurring across the life span, are diagnosed most often in older adults. Her research concentrates developing, testing, and implementing palliative and supportive care interventions for older adults with acute leukemia. She is certified in both gerontological (RN-BC) and oncology (OCN) nursing.

Dr. Bryant is actively engaged with UNC Project-Malawi, Kamuzu Central Hospital, and Kamuzu College of Nursing to build the oncology nursing, education, and research workforce. She also leads the UNC Lineberger-Sylvia Lauterborn-Warren Piver Oncology Nursing Fellowship for undergraduate students. Dr. Bryant earned her BSN and MSN-Nursing Administration from UNC-Greensboro, PhD in Nursing from UNC-Chapel Hill, and completed post-doctoral training in cancer care quality at the Gillings School of Global Health at UNC-Chapel Hill.

Howard A. Burris, III, MD, FACP, FASCO

Sarah Cannon

Howard A. "Skip" Burris III, MD, FASCO, FACP serves as president and chief medical officer of Sarah Cannon, as well as the executive director, drug development for Sarah Cannon Research Institute. He is an associate of Tennessee Oncology, PLLC, where he practices medical oncology. Dr. Burris' clinical research career has focused on the development of new cancer agents with an emphasis on first-in-human therapies, having led the trials of many novel antibodies, small molecules, and chemotherapies now FDA approved. In 1997, he established in Nashville the first community-based early phase drug

development program, which grew into the Sarah Cannon Research Institute. He has authored over 400 publications and 700 abstracts.

Dr. Burris served as president of ASCO in 2019-2020 and is serving as Chair of the Board for the 2020-2021 term. He also currently serves on the Board of ASCO's Conquer Cancer Foundation. Additionally in 2014, Dr. Burris was selected by his peers as a Giant of Cancer Care for his achievements in drug development.

Dr. Burris completed his undergraduate education at the United States Military Academy at West Point, his medical degree at the University of South Alabama, and his internal medicine residency and oncology fellowship at Brooke Army Medical Center in San Antonio. While in Texas, he also served as the Director of Clinical Research at The Institute for Drug Development of the Cancer Therapy and Research Center and The University of Texas Health Science Center. He attained the rank of lieutenant colonel in the US Army, and among his decorations, he was awarded a Meritorious Service Medal with oak leaf cluster for his service in Operation Joint Endeavor.

Julie Bynum, MD, MPH
University of Michigan

Julie Bynum, MD, MPH, is the Margaret Terpenning Professor of Medicine in the Division of Geriatric Medicine, Vice Chair for Faculty Affairs, Research Professor in the Institute of Gerontology, Geriatric Center Associate Director for Health Policy and Research, and a member of the Institute for Healthcare Policy and Innovation. Dr. Bynum received her medical and public health degrees from Johns Hopkins, did her residency and chief residency at Dartmouth, and completed specialty training in Geriatric Medicine back at Johns Hopkins. She then joined the faculty at Dartmouth Medical School where she received prestigious career development awards from the Robert Wood Johnson Physician Faculty Scholar Program and the National Institute of Aging Beeson Scholar Program. She is known for leading interdisciplinary research teams to study questions about the complex drivers of quality and costs for older adults and how to improve health care policy and performance using national administrative data. In addition, she has been an Atlantic Philanthropies Health & Aging Policy Fellow, was a member of the National Academy of Medicine Committee that published "Vital Signs: Core Metrics for Health and Health Care Progress" and was recently a Deputy Editor of the Journal of the American Geriatrics Society. She is currently a member of the National Academy of Medicine Forum on Aging, Disability and Independence and on a NAM workshop planning committee on adverse consequences of cancer treatment. She currently leads a robust portfolio of research largely focusing health and health care for people living with dementia including a newly-funded NIA Center to Accelerate Population Research in Alzheimers.

David Cella, PhD
Northwestern University

David Cella, PhD, is The Ralph Seal Paffenbarger Professor and Chair of the Department of Medical Social Sciences, and an elected member of the National Academy of Medicine. He was the recipient of the NAM 2016 Gustav O. Lienhard Award. Dr. Cella's research portfolio extends from health outcomes measurement and applications to clinical trials, comparative effectiveness, and learning health system implementation. As an expert in applied health status measurement, he has led the development and

validation of the FACIT Measurement System, PROMIS, Neuro-QoL, and the emotional health domain of the NIH Toolbox. These measurement systems are used around the world by thousands, in clinical practice and research.

Kathlyn Conway, PhD, MSW

Women's Therapy Center Institute, Psychotherapist (Private Practice) and Author

Kathlyn Conway has a PhD in English Literature from Harvard University and an MSW from Columbia University. She is a psychotherapist in Manhattan in private practice and is on the faculty of the Women's Therapy Center Institute. She is also the author of *Ordinary Life: A Memoir of Illness and Illness and the Limits of Expression*.

Gwen Darien, BA

National Patient Advocate Foundation and Patient Advocate Foundation

Gwen Darien is a longtime patient advocate who has played leadership roles in some of the country's preeminent nonprofit organizations. As executive vice president for patient advocacy and engagement, Gwen leads programs that link Patient Advocate Foundation's patient service programs to NPAF initiatives, with the goal of improving access to affordable, equitable quality health care. Called "[a bit of a renegade](#)" by *People* magazine, Gwen has long insisted on pushing boundaries while maintaining a safe space for patients. As editor and publisher of *Mamm*, a magazine for women with breast or reproductive cancer, Gwen published features on previously taboo subjects, such as dating after a mastectomy, along with the more expected academic features on news and policy analysis. Her media leadership was recognized by the Avon Foundation, which honored her as one of "the most powerful women in breast cancer."

As a three-time cancer survivor herself, Gwen came into patient advocacy expressly to change the experiences and outcomes for the patients who came after her and to change the public dialogue about cancer and other life-threatening illnesses. With these goals in mind, in 2005 she started the first stand-alone advocacy entity in a professional cancer research organization at the American Association for Cancer Research, causing outside observers to note the organization's "[progressive commitment to patient advocacy](#)." At AACR, she launched *CR* magazine – a magazine for people with cancer and those who care for them. Later, she served as the executive director of the Samuel Waxman Cancer Research Foundation; director of The Pathways Project; and executive vice president of programs and services at the Cancer Support Community. In each role, Gwen championed placing patients at the center of health system change, whether it is for research, public policy or direct services.

While serving as the chair or on the board of a wide range of program committees and workshop faculties, including the [Community Engagement in Genomics Working Group](#) of the National Human Genome Research Institute; a member of the US Pharmacopeia Board of Trustees; as the chair of PCORI's Patient Engagement Advisory Panel; and a member of the National Cancer Policy Forum, Gwen also writes about her experiences. A recent piece, [Transformation: My Experience as a Patient and an Advocate in Three Chapters](#) appeared in the National Academy of Medicine Perspectives. Gwen is a graduate of Sarah Lawrence College, where she also served as an advisor for their Health Advocacy program.

Christopher R. Flowers, MD, MS, FASCO
MD Anderson Cancer Center

Christopher Flowers, MD, joined The University of Texas MD Anderson Cancer Center in August 2019 as Department Chair of Lymphoma/Myeloma and was appointed Division Head *ad interim* of Cancer Medicine in August 2020. Prior to MD Anderson, he was professor of Hematology and Oncology with a joint appointment in Biomedical Informatics at Emory University School of Medicine in Atlanta. During his tenure there, he served the Winship Cancer Institute as director of the Emory Healthcare-Lymphoma Program for 13 years and as scientific director of Research Informatics for four years. An internationally recognized expert in lymphoma clinical care, epidemiology and outcomes research, Dr. Flowers is an innovator who has a passion for facilitating new drug development. He is an active clinician who conducts clinical research involving cancer outcomes, cancer informatics, and phase I/II trials, focusing on the clinical development of novel therapeutics for B-cell lymphomas. His broader research interests include patient-oriented research in lymphoma and computer microsimulation models and cost-effectiveness analyses aimed at developing strategies to individualize care for cancer patients and improve systems of care. His work has resulted in >200 peer-reviewed publications. He has received peer-reviewed funding from foundations and the NIH including leading two U01 awards and two multi-institutional team science grants.

Dr. Flowers earned his medical degree from Stanford University School of Medicine where he also completed an MSc in Medical Informatics to gain expertise developing information systems to improve clinical research. He completed his internship and residency in Internal Medicine from the University of Washington in Seattle, where he continued his research training as a fellow in the Robert Wood Johnson Clinical Scholars Program and earned a second master's degree in Pharmaceutical Outcomes Research and Policy. During this time, he also completed his fellowship in Medical Oncology from the Fred Hutchinson Cancer Research Center. Dr. Flowers has served in many capacities for national professional societies and was elected to membership in the American Society of Clinical Investigation. In 2018, he was named a Fellow of the American Society of Clinical Oncology (ASCO), and served as chair of both the ASCO guidelines on management of febrile neutropenia and ASCO health disparities committees.

Shelley Fuld Nasso, MPP
National Coalition for Cancer Survivorship

Shelley Fuld Nasso, MPP, is CEO of the National Coalition for Cancer Survivorship, where she advocates to transform the cancer care system for everyone touched by cancer. NCCS engages in public policy efforts to improve cancer care and empowers cancer survivors and caregivers to be a voice in public policy debates. Prior to joining NCCS in 2013, she led public policy efforts at Susan G. Komen. She is a graduate of Rice University and the Harvard Kennedy School. She advocates in honor of her dear friend, Dr. Brent Whitworth, a beloved physician who died of cancer at the age of 43.

Martha E. "Meg" Gaines, JD, LL.M.
University of Wisconsin School of Law

Meg Gaines founded the interdisciplinary Center for Patient Partnerships at the University of Wisconsin and served as director for 20 years. The Center's mission is to disrupt dysfunctional health care by restoring people to the core of care. Professor Gaines' work focuses on consumer engagement and

empowerment in health care reform, health professionals' education, and access to high quality, effective health care.

She has collaborated with the Robert Wood Johnson Foundation, the Kaiser Family Foundation, the American Board of Internal Medicine Foundation, the Josiah Macy Jr Foundation, and the National Cancer Institute among others. She currently serves on the Board of the National Quality Forum and previously served on the National Cancer Research Advocates of the NCI and the Board of the Academy on Communication in Healthcare. She co-chaired the Josiah Macy Jr Foundation annual conference "*Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education.*" Recent publications include the NASEM's *Vital Directions for Health and Healthcare* and the *Making Medicines Affordable: A National Imperative* Committee reports, the *Charter on Organizational Professionalism for Healthcare Organizations* as a companion to the *Charter on Medical Professionalism* of the Choosing Wisely Campaign, and JAMA Viewpoints: *How HIPAA Harms Care, and How to Stop It*, and *Changing the Game of Prior Authorization: The Patient Perspective* with Dr. Don Berwick, MD.

She is a graduate of Vassar College (A.B.) and the University of Wisconsin Law School (JD, LLM) and a "durable survivor" of metastatic ovarian cancer.

Michael T. Halpern, MD, PhD, MPH

National Cancer Institute

Dr. Michael Halpern is a Medical Officer in the Healthcare Assessment Research Branch (HARB), Healthcare Delivery Research Program of the National Cancer Institute (NCI). His expertise is in health service research, focused on access to care, quality of care, disparities, treatment patterns, health economics, and patient outcomes. Dr. Halpern's responsibilities include coordinating the Congressionally-mandated NCI Patterns of Care program to evaluate dissemination of state-of-the art cancer care into the oncology community and to identify patient-, provider-, and system-level factors associated with cancer care. He is also a Project Scientist on NCI's Accelerating Colorectal Cancer Screening and follow-up through Implementation Science (ACCSIS) research network and serves as the Program Chair for the American Public Health Association's Cancer Forum.

Wendy S. Harpham, MD, FACP

Columnist, Author, and Patient Advocate

Wendy S. Harpham is a doctor of internal medicine, 30-year lymphoma survivor, author and public speaker on survivorship, and adjunct professor at the University of Texas at Dallas. She received her medical degree from the University of Rochester School of Medicine and Dentistry. She completed her internship at UT Houston and residency at Presbyterian Hospital of Dallas where she opened her solo practice of internal medicine.

In 1990, she developed indolent lymphoma. When ongoing illness forced her to retire, she turned to writing, speaking and patient advocacy. She's written eight books, including *Only 10 Seconds to Care* for clinicians and two children's books. For her first eBook, NCBF sponsored the free resource, [Finding Hope That Heals](#). She's written oncology textbook chapters and many articles in major media and professional publications, including an award-winning regular column in *Oncology Times*, "View from the Other Side of the Stethoscope."

Until the pandemic, Dr. Harpham traveled nationally and internationally, lecturing to survivors and families, and advocating for science-based interventions, healing clinician-patient bonds, and finding hope. She serves as a consultant and patient advocate for projects and organizations on the local and national levels.

Her work has received numerous prestigious awards, including the American College of Physicians 2018 Nicholas E. Davies award for contributions to the medical humanities, and the 2000 Governor's Award for Health, which led to her induction into the Texas Women's Hall of Fame.

Candace Henley, CPN

The Blue Hat Foundation, Inc.

Candace is an accomplished Executive Director with significant experience in community outreach and patient advocacy. She has a superior record of successful community partnerships to advance the importance of putting the needs of patients first. Candace is a 17 year colon cancer survivor who shares her story of a challenging battle with a positive attitude and faith that inspires others to never give up. Her greatest fight was against the financial toxicity of cancer and the tragic turn of events that her life took after her cancer diagnosis, which overwhelmed her, robbed her of hope, tested her faith, and threatened her with defeat. Her story will make you sad, angry, cry and cheer because it's an incredible example of perseverance and strength.

After years of advocating, Candace identified a need for grassroots awareness and education of colorectal cancer in minority and medically underserved communities and started the Blue Hat Foundation in 2015. The organization utilizes community partnerships with healthcare providers, physicians, and hospital systems to deliver the message of the importance of early detection, knowing your family medical history, and free screening. Out of those efforts, she created a faith-based colon cancer awareness campaign, Blue Hat Bow Tie Sunday, now in its 10th year. Candace has shared her story with national audiences on The Steve Harvey Show and with Katie Couric. She has contributed to several articles regarding colorectal cancer and has several articles written about her cancer journey and her tireless advocacy.

Lori Hoffman Högg, MS, RN, CNS, AOCN®

Veterans Health Administration

Lori Hoffman Högg MS, RN CNS, AOCN® is the VHA National Program Manager for Prevention Policy in the National Center for Health Promotion and Disease Prevention, which is field-based, in Durham, North Carolina. She is also the National Oncology Clinical Advisor for the Office of Nursing Services, Department of Veterans Affairs in Washington, D.C. She served a six year appointment as a member of the National Cancer Policy Forum. A graduate of the Robert Packer Hospital School of Nursing in Sayre, Pennsylvania, she completed her graduate studies at the State University of New York's Health Science Center in Syracuse, New York. She previously served as Cancer Program Director at the Albany, New York Stratton VA Medical Center; Administrator of the Breast Center, through a joint appointment in the Divisions of General Surgery and Radiology, at the Cleveland Clinic Foundation in Ohio; and began her career at the the Guthrie Robert Packer Hospital. She held other advanced practice and staff roles in both academic medical centers and private practice. She's published a number of book chapters, peer reviewed articles, has been honored as a Kizer Grant Money recipient for her commitment to lead

innovation and performance excellence and received the Distinguished Federal Government Service Award for demonstrating high standards in government and community service.

Her research interests include development of nursing-sensitive quality measures for breast cancer using the National Oncology Nursing Society's "Putting Evidence into Practice" resources. This work received international recognition for best research awarded at the ISNCC- International Society of Nurses in Cancer Care. Additional interests include initiatives for lung cancer screening, cancer survivorship and life sustaining treatment/goals of care conversation projects. Nationally recognized for her clinical and leadership expertise, she's presented at national conferences on timely access to care and quality initiatives within the continuum of cancer care. She's served national conferences on timely access to care and quality initiatives within the continuum of cancer care. She's served as Editorial Review Board Member for the Clinical Journal of Oncology Nursing and held Clinical Associate Faculty positions in the Graduate Program in Nursing of the Sage Colleges; Clinical Instructor of Nursing, Frances Payne Bolton School of Nursing, Case Western Reserve University; and Clinical Faculty, Breen School of Nursing, Ursuline College. She is past president of the Capital District Chapter of the Oncology Nursing Society. She currently serves on the NCI's Healthy People 2030 Cancer Workgroup and received the NIH National Cancer Institute Director's Award of Merit in recognition of outstanding leadership and contributions to the development of National Cancer Health Objectives for Healthy People 2030.

David H. Howard, PhD

Emory University

David H. Howard, PhD, is a faculty member in the Department of Health Policy and Management at Emory University. A health economist by training, Dr. Howard studies technological abandonment in medicine. He has conducted a number of studies that examine how results from randomized trials affect treatment patterns, with a focus on trials that find that widely-used treatments are ineffective. He is also studying the impact of payment policies, the False Claims Act, and mandatory shared decision making on treatment patterns and overuse. Dr. Howard received his doctorate in health policy from Harvard University in 2000.

Nancy Keating, MD, MPH

Harvard Medical School

Nancy Keating, MD, MPH, is Professor of Health Care Policy and Medicine at Harvard Medical School and a primary care physician at Brigham and Women's Hospital. Dr. Keating's research examines provider, patient, and health system factors that influence the delivery of high-quality care for individuals with cancer.

Dr. Keating is currently Clinical Lead of the Evaluation Team for the Center for Medicare and Medicaid Service's Oncology Care Model, an alternate payment and delivery model for oncology practices administering chemotherapy. The evaluation is assessing patients' experiences with care, quality of care, health care utilization, and outcomes for patients in more than 175 participating practices and in comparison practices. In other work, she is assessing quality of care for Medicare beneficiaries with cancer, assessing the reliability and consistency of quality measurement across surgical and medical oncology practices caring for individuals with cancer. Other work has examined patient, physician, and health system factors contributing to the variations in the intensity of end-of-life (EOL) care for individuals with advanced cancer. In addition, she is examining the influence of physician networks on care to understand the diffusion of cancer care practices over time, focusing on the use of new biologic

therapies for cancer and care at the end of life. She is currently pilot testing two interventions to improve patients' understanding of the goals of chemotherapy and to improve patients' discussions with their clinicians about their preferences and goals of care.

Dr. Keating received her MD degree from the University of Chicago Pritzker School of Medicine, and her MPH degree from the Harvard School of Public Health. She was awarded the Outstanding Junior Investigator Award from the Society of General Internal Medicine in 2005. She is an elected member of the American Society for Clinical Investigation and the Association of American Physicians. She currently serves as an Associate Editor at the Journal of the National Cancer Institute, a member of the editorial board of the Journal of Geriatric Oncology, and a member of the National Comprehensive Cancer Center Senior Oncology Guideline Panel. She previously completed 3-year terms on the Council of the Society of General Internal Medicine and the American Society of Clinical Oncology Clinical Practice Guidelines Committee.

Lisa Kennedy Sheldon, PhD, ANP-BC, AOCNP®, FAAN
Oncology Nursing Society

Lisa Kennedy Sheldon is the Clinical and Scientific Affairs Liaison at the Oncology Nursing Society (ONS). She connects the ONS members and the oncology nursing profession with professional organizations, advocates and policy makers to support oncology nurses, advanced practice nurses and researchers, and develop leaders to transform cancer care.

As experienced faculty and former Associate Professor at the University of Massachusetts-Boston, Dr. Sheldon has taught nurses for over 25 years at the undergraduate and masters levels and PhD students in health policy with a focus on disparities in cancer care and outcomes. Dr. Sheldon's program of research has focused on patient-provider communication and psychosocial issues in cancer care. Dr. Sheldon has received numerous honors and awards including induction as a fellow in the American Academy of Nursing (FAAN).

Dr. Sheldon is passionate about improving nursing education nationally and globally. Her work has included programs on cancer and palliative care, safe handling of hazardous drugs, and health promotion and cancer prevention. She serves on the National Cancer Policy Forum, and was the President of the Theta Alpha chapter of Sigma Theta Tau International. She has volunteered in numerous countries with ONS and other organizations such as the American Society of Clinical Oncology, Oman Cancer Association, Middle East Cancer Consortium and Health Volunteers Overseas. She is particularly interested in connecting nurses to improve nursing care and cancer outcomes. Dr. Sheldon has served as the Editor of the *Clinical Journal of Oncology Nursing* and authored numerous publications and three books including *Communication for Nurses: Talking with Patients*. Dr. Sheldon continues to practice as a certified oncology nurse practitioner (AOCNP®) at St. Joseph Hospital in Nashua, NH.

Samir N. Khleif, MD
Georgetown University Medical School

Dr. Samir N. Khleif is currently the Director of the Loop Immuno-Oncology Laboratory and is a Biomedical Scholar and a professor in Medicine and Oncology at Georgetown University Medical School at the Lombardi Comprehensive Cancer Center. He earned his medical degree from the University of Jordan, completed a residency in internal medicine from the Medical College of Ohio, and a fellowship in medical oncology from the National Cancer Institute.

Dr. Khleif is a pioneer and a leading researcher, as well as a Key Opinion Leader, in the field of immunotherapy and has over 25 years of vast experience in both clinical and basic research in immunoncology. He has served as Chief of the Cancer Vaccine Section at the National Cancer Institute, where he established one of the first immune therapy and cancer vaccine programs, under which he pioneered the clinical trials of neoantigen-directed cancer vaccines, particularly targeting antigenic oncoproteins. These included some of the seminal early-phase cancer vaccine clinical trials helping the FDA to set some approval standards.

Dr. Khleif served as the Director the Georgia Cancer Center of Augusta University, the State's cancer center of the University System of Georgia. During his tenure, he established a comprehensive Immuno-Oncology Program connecting basic research discovery to clinical trials with highly integrated translational elements; all of which have led to the development of many innovative first-in-human clinical trials.

He was honored to hold the position of Special Assistant to the Commissioner of the Food and Drug Administration (FDA). For 3 years, he led the Critical Path Initiative for Oncology, a project that reformed the process of cancer drug development in the US. Also, at the request of the HHS Secretary, he served as the founder and CEO/Director General of the King Hussein Cancer Center (KHCC) in Jordan, the main cancer center in the Middle East.

Dr. Khleif sits on many national and international committees that are driving the immune-oncology field forward and has been requested to speak as a subject matter expert on numerous occasions. He has led many national committees, including the AACR-NCI-FDA Cancer Biomarker Collaborative and the NCI-FDA-ASCO Alternative Clinical Trial Design, and currently chairs the NRG Cooperative Group Immune Therapy Committee and the NCI Working Group of Radiation and Immunotherapy. He holds more than 20 US and international patents in therapeutic approaches to cancer and is the founder of Georgiamune, an immune-oncology company. He has also edited two textbooks on cancer therapeutics, tumor immunology and cancer vaccines.

He has been the recipient of many national and international awards: the National Cancer Institute's Director Golden Star Award, the National Institutes of Health Award for Merit, the Commendation Medal of the US Public Health Service, the GRA Distinguished Cancer Scientist and Clinician and, most recently, the Distinguished Alumnus of the Year for the University of Toledo. He was inducted into the American Society for Clinical Investigation, appointed to the National Academies of Sciences, Engineering, Medicine National Cancer Policy Forum and elected to be a national board member of the Society for Immunotherapy of Cancer. For the role he played in the development of health care in Jordan, he received the Lifetime Achievement Award of the Jordan Medical Association/General Union of Physician honoring 10 physicians who contributed the most for advancing the health care system in Jordan in 50 years.

Wui-Jin Koh, MD

National Comprehensive Cancer Network

Wui-Jin Koh, MD, is the Senior Vice President and Chief Medical Officer at the National Comprehensive Cancer Network (NCCN). In this role, Dr. Koh oversees the NCCN Oncology Research Program (ORP), which strives to improve and prolong the lives of people with cancer by advancing collaborative

research. Dr. Koh also helps oversee the flagship NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) program. In addition, he is responsible for medical leadership and oversight for NCCN's continuing medical education program, and represents the organization at clinical and scientific meetings.

Prior to his role at NCCN, he served as Professor of Radiation Oncology at University of Washington and Medical Director for Radiation Oncology at Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance.

Dr. Koh earned his medical degree at Loma Linda University School of Medicine. He conducted his post-graduate training at the University of Washington Medical Center, completing a residency and internship in radiation oncology and a clinical fellowship in tumor imaging. He is board-certified in radiation oncology.

Dr. Koh's research interests include combined chemo-radiation strategies, cancer management guidelines development, and the role of imaging in radiotherapy and cancer care. He specializes in gynecologic tumors, lung cancer, ocular tumors, and sarcomas, as well as intraoperative radiotherapy, brachytherapy including radioactive implants, high-dose radiation and low-dose radiation implants. He also treats rectal, esophageal, stomach, pancreas, colon, and biliary tract cancers.

Dr. Koh is well-published and involved in numerous professional societies, including the Society of Gynecologic Oncology, the American Society for Therapeutic Radiology and Oncology, the American Society of Clinical Oncology, the Gynecologic Oncology Group, the Western Association of Gynecologic Oncology, and the International Gynecologic Cancer Society.

Lawrence H. Kushi, ScD

Kaiser Permanente Northern California

Larry Kushi is an epidemiologist conducting research in cancer prevention and outcomes. He was PI of the NCI-funded Cancer Research Network (CRN), providing infrastructure support for cancer research in a nationwide consortium of health care systems. The CRN developed one of the first common data models for research use, known as the Virtual Data Warehouse (VDW), first implemented in the early 2000s. These provide relatively efficient collaborative use of data from electronic health records and other clinical and administrative databases, and have supported numerous research projects in cancer and other conditions. His current NCI-supported research projects include the Pathways Study, a prospective cohort study investigating diet, physical activity, and other factors in breast cancer outcomes and supported through the NCI's cancer epidemiology cohort infrastructure program; the Be-Well Study, a project examining dietary factors including cruciferous vegetable intake and bladder cancer recurrence; a project examining racial and ethnic disparities in ovarian cancer outcomes; and a program project grant focused on cancer care and outcomes among adolescents and young adults diagnosed with cancer. Among other activities, he chaired the 2012 American Cancer Society Committee on Nutrition and Physical Activity Guidelines for Cancer Prevention, led the methodology committee for the World Cancer Research Fund on its review of the literature relating food, nutrition and physical activity to breast cancer outcomes, and served on the Council for Extramural Grants for the American Cancer Society and the Integration Panel for the Department of Defense Breast Cancer Research Program. A graduate of Amherst College and the Harvard School of Public Health, Larry has held research and

faculty positions at the Fred Hutchinson Cancer Research Center, the University of Minnesota, and Columbia University where he held the Ella McCollum Vahlteich Chair in Nutrition. In 2002, he joined the Division of Research, Kaiser Permanente Northern California, where he is currently Director of Scientific Policy.

J. Leonard Lichtenfeld, MD, MACP
Independent Consultant

J. Leonard Lichtenfeld, MD, MACP, is a medical oncologist who most recently served as Deputy Chief Medical Officer for the American Cancer and co-leader for the Society's nationwide response team for the corona virus pandemic.

Dr. Lichtenfeld joined the Society in 2001 as a medical editor, and from 2002 through 2014 managed the Society's Cancer Control Science Department, which was best known for the Society's widely respected guidelines on the prevention and detection of cancer. He joined the Office of the Chief Medical and Scientific Officer in 2014. Dr. Lichtenfeld also served as interim Chief Medical and Scientific Officer for the Society from November 2018 through October 2019. He left the Society in September 2020. Dr. Lichtenfeld has been widely quoted in the print and electronic media and is recognized for his expertise in medical policy and cancer care. He is well known for his blog which began in 2005 (www.cancer.org/drlen) and now continues at www.drlen.blog, focusing on various topics related to cancer research and treatment as well as COVID 19 and general medical care and policy.

A board-certified medical oncologist and internist who was a practicing physician for over 19 years, Dr. Lichtenfeld remains active in several state and national medical organizations and has a long-standing interest in legislative and regulatory issues related to health care including physician payment, medical care delivery systems, and health information technology among others. He is active as an advisor and board member for professional and cancer-related organizations and early stage companies.

Dr. Lichtenfeld is a graduate of the University of Pennsylvania and Hahnemann Medical College (now Drexel University College of Medicine) in Philadelphia. His postgraduate training was at Temple University Hospital in Philadelphia, Johns Hopkins University School of Medicine and the National Cancer Institute in Baltimore. He is a member of Alpha Omega Alpha, the national honor medical society. Dr. Lichtenfeld has received several awards in recognition of his leadership and efforts on behalf of his colleagues and his professional activities. He has been designated a Master of the American College of Physicians in acknowledgement of his contributions to internal medicine. He is married and currently resides with his wife in Atlanta, Georgia.

Gary H. Lyman, MD, MPH, FASCO, FACP
Fred Hutchinson Cancer Research Center

Dr Lyman is Professor of Public Health Science and Clinical Research at the *Fred Hutchinson Cancer Research Center* where he is also Senior Lead of Healthcare Quality and Policy at the Hutchinson Institute for Cancer Outcomes Research. He also is Professor of Medicine, Public Health and Pharmacy at the *University of Washington* and Adjunct Professor at the *Duke University School of Medicine*. Dr Lyman is board certified in Medical Oncology and Hematology with a strong background in biostatistics and clinical research methodology. He is nationally and internationally recognized as an expert in comparative

effectiveness and outcomes research, the evaluation and management of cancer treatment-related complications, the conduct of formal systematic reviews and meta-analyses, and the application of mathematical and statistical models to enhance the clinical effectiveness and cost-effectiveness of new diagnostic, therapeutic and supportive care modalities.

He is active with the *American Society of Clinical Oncology* (ASCO) having served on the Board of Directors and chairing the Database Research Oversight and Biosimilars Working Groups and several ASCO clinical practice guidelines. He chairs the Discovery Research and Publications Committee for the ASCO Big Data program (CancerLinQ). He also serves on clinical practice guidelines for the *National Comprehensive Cancer Network* (NCCN), the *American Society of Hematology* (ASH) and the *European Organization for Research and Treatment of Cancer* (EORTC). Dr Lyman is an Executive Officer for the SWOG Cancer Research Network with responsibility for Immunotherapy, Cancer Care Delivery and Symptom Management and QOL studies through SWOG and the NCORP. He is supporting SWOG's involvement in the NCI *ComboMATCH* and SWOG's leading effort in the forthcoming NCI *ImmunoMatch* trial along with related efforts on immune-related adverse events both within SWOG and the larger NCTN. He is a member of the Board of Directors of *The Hope Foundation for Cancer Research*. Dr Lyman has served as Editor-In-Chief of *Cancer Investigation* and has personally published more than 600 articles in the medical literature with nearly 66,000 citations. He is listed by *Web of Science* among the top 1% of cited investigators and has also authored/edited more than 20 medical texts and over 70 book chapters. Currently Dr Lyman is a founding member of *COVID-19 and Cancer Consortium* represents the largest global registry of patients with cancer and confirmed COVID-19.

Shannon MacDonald, MD

Harvard Medical School

Shannon MacDonald, MD is currently an Associate Professor of Radiation Oncology at Harvard Medical School (HMS) and serve as Director of the Base of Skull Service and a member of the Pediatric Service in the Department of Radiation Oncology at the Massachusetts General Hospital (MGH). Previously, she also served as a member of the Breast Service from 2006 to 2018 and Director of the Breast Service. Since joining the department in 2006, her clinical practice has expanded from solely treating breast cancer patients and is now focused on treating pediatric and base-of-skull malignancies. Dr. MacDonald's expertise lies in the treatment of breast, pediatric and base-of-skull tumors with a technology called proton therapy. She has worked with Dana-Farber Cancer Institute, Brigham and Women's Hospital and Boston Children's Hospital to provide proton therapy for their pediatric patients and promote collaboration and appropriate utilization of this costly therapy. Providing comprehensive care to patients and their families remains the most fulfilling aspect of her career.

Dr. MacDonald has authored >130 publications (> 50 as first or senior author) including in *JCO*, *NEJM*, *Lancet Oncology*, *Journal Of Pediatrics*, *Cancer*, *Neuro Oncology*, and *IJROBP*. She is currently in a primary investigator or co-chair role of 2 large multi-institutional clinical trials. She is the Primary Investigator of a Children's Oncology Group (COG) Trial for Central Nervous System (CNS) Germ Cell Tumors that will open late 2020 or early 2021 in COG sites in the United States, Canada, Australia and New Zealand. I am the Clinical Co-Chair of The Radiotherapy Comparative Effectiveness (RADCOMP) Consortium Trial, A Pragmatic Randomized Trial of Proton vs. Photon Therapy for Patients with non-Metastatic Breast Cancer funded by Patient-Centered Outcomes Research Institute (PCORI), which is open at 69 sites and 24 proton centers in the United States. For this trial, Dr. MacDonald is the lead clinical investigator and substantially contributed to the grant submission, design and execution of this

trial. She is also the primary investigator for a pilot study open at the Massachusetts General Hospital and MD Anderson Cancer Center investigating a novel way to administer cranio-spinal irradiation for children that will allow for sparing of the bony vertebral column. She was the primary investigator of a phase II study using proton therapy for locally advanced breast cancer which provided the preliminary data for RADCOMP and was the first study to use protons for advanced breast cancer. This indication has now been widely adopted for use on and off clinical trials at proton centers around the world. She also served as a Senior Associate Editor for the International Journal of Radiation Oncology, Biology & Physics and have contributed as an Ad Hoc Editor for multiple journals.

Kelly Magee, FNP-BC

Flatiron Health

Kelly Magee is a nurse practitioner and health outcomes researcher who serves as senior clinical director at Flatiron Health. In this role, Kelly focuses on the development of novel approaches for using electronic health record data to understand the experiences of people with cancer.

Prior to joining Flatiron Health, Kelly was Nurse Practitioner Clinical Program Director at Memorial Sloan Kettering Cancer Center, leading nurse practitioners across the institution and maintaining a clinical practice caring for critically ill medical and surgical inpatients in the Advanced Care Unit.

Ms. Magee received her undergraduate degree in health studies from Georgetown University, registered nursing education from Massachusetts General Hospital Institute for Health Professions, and Master's degree in Nursing from Pace University. She also spent 3.5 months serving on the USNS Comfort Continuing Promise 2009 mission, providing primary and post-operative care in several Central and South American countries.

Jennifer Malin, MD, PhD

UnitedHealthcare

Jennifer Malin, MD, PhD, is a Senior Medical Director, Oncology and Genetics, at UnitedHealthcare. In this role, she provides clinical and strategic leadership for improving the health and outcomes of cancer and genomic medicine for United Healthcare members.

After graduating from Harvard University, Dr. Malin received her medical degree and doctorate in public health from UCLA. She is board certified in internal medicine and medical oncology. A Clinical Professor of Medicine at the UCLA David Geffen School of Medicine, she is the author of more than 100 peer-reviewed articles and is widely recognized for her research on the quality of cancer care. She has served on a number of advisory boards and national committees, including the American Society of Clinical Oncology's Quality of Care Committee and the National Quality Forum's Cancer Steering Committee. Prior to joining UnitedHealthcare, she was the architect of the cancer care quality program at Anthem.

Dr. Malin continues her clinical practice by volunteering at the Veterans Affairs Greater Los Angeles Health Care System. She lives in Santa Monica, California with her two children and three dogs.

Supriya Gupta Mohile, MD, MS

University of Rochester Medical Center

Dr. Supriya Mohile is the Philip and Marilyn Wehrheim Professor of Medicine in the Division of Hematology and Oncology at the Wilmot Cancer Institute. She is board-certified geriatrician and oncologist, and has developed a clinical and research program in geriatric oncology. She leads the Cancer Care Delivery Research (CCDR) efforts in the URCC Research Base. She is an expert in geriatric oncology with over 200 publications, and serve as Editor-in-Chief of the Journal of Geriatric Oncology. She Chair for the ASCO Geriatric Oncology Clinical Guideline panel and received ASCO's BJ Kennedy Award in 2018. She is also the recipient of a NIA K24 grant, which provides effort to provide mentorship to early career faculty interested in geriatric oncology and she is the MPI of a NIA R21/R33 grant which has developed a national infrastructure for the Cancer and Aging Research Group.

Javid J. Moslehi, MD

Vanderbilt University

Javid Moslehi, MD is a cardiologist and myocyte biologist. Dr. Moselhi's clinical focus is cardio-oncology (the cardiovascular care of cancer patients and cancer survivors). His basic and translational NIH-funded laboratory addresses myocardial responses to various stresses including hypoxia, aging and toxins. Over the last several years, given his clinical interest in cardio-oncology, Dr. Moselhi's laboratory focus has been in delineating the mechanistic underpinnings of cardiovascular toxicities from novel targeted cancer therapies. He believes because of the targeted nature of the toxicities, cardio-oncology can provide insights into novel signaling pathways that are relevant in human cardiovascular biology and pathology.

At Vanderbilt, Dr. Moselhi is an Associate Professor of Medicine, Director of Cardio-Oncology and Co-director of Vanderbilt Program for Optimizing Immuno-oncology Therapy (V-POINT). He works closely with cardiologists and oncologists, basic, translational researchers and clinicians locally, nationally and internationally. He has also started several collaborations with industry and regulatory bodies (including the US FDA). Dr. Moselhi was recently named the first chair of the American Heart Association (AHA) cardio-oncology subcommittee. At Vanderbilt, he has established a Graduate Medical Education (GME) approved fellowship training the next generation of physician-scientists in the field of cardio-oncology. I am an elected member of American Society of Clinical Investigation (ASCI).

Since 2016, a major focus of his clinical and research program has been the interaction between the cardiovascular and immune systems. His group initially described a novel clinical syndrome of fulminant myocarditis that arises from (ICI) immune checkpoint inhibitors (Johnson et al, *NEJM*, 2016). They further defined the clinical characteristics of ICI-associated myocarditis (Moslehi et al, *Lancet*, 2018) and showed that cardiovascular sequelae of ICI include pericarditis, vasculitis and arrhythmias (Salem et al, *Lancet Oncology*, 2018). His laboratory has generated mouse models that recapitulate these novel immune-based clinical syndromes which have provided insights into new diagnostic and treatment strategies for these complications (Bonaca et al, *Circulation*, 2019; Salem et al, *NEJM*, 2019).

Timothy Wm. Mullett, MD, MBA, FACS

Commission on Cancer

Timothy Wm. Mullett, MD, MBA, FACS a Professor of Surgery in the Division of Cardiothoracic Surgery at the University of Kentucky. Although he has experience in cardiac surgery and transplantation, the overwhelming burden of lung cancer in Kentucky led Dr. Mullett to focus his clinical practice and research in this area. Following his medical school and surgical training at the University of Florida, he has served Kentucky for nearly 25 years. He is a retired Colonel with 27 years in the US Army Reserves Medical Corps with tours of duty in Iraq, Afghanistan and with Homeland Security in response to terrorist threat. He serves as the Chair of the Cancer Committee for UK HealthCare and is a member of the Markey Cancer Center, the NCI-designated cancer center representing Kentucky. This CoC program achieved Outstanding Achievement Award in 2017. He has served as CoC State Chair for 6 years, awarded Outstanding State Chair in 2019. Mullett serves as the Medical Director of the Markey Cancer Center Affiliate Network, providing high-quality cancer care closer to home at collaborating centers, through specialty services, education and outreach programs. Additionally, he is the Medical Director of the Markey Research Network, a collaborative network of sites conducting a portfolio of high priority trials. These include therapeutic oncology trials, interventional and non-interventional studies appropriate for community centers. His research has recently been studying quality implementation of lung cancer screening. Tim serves as PI of the Kentucky LEADS Collaborative, a portfolio of studies to reduce the burden of lung cancer in Kentucky. For several years he has been the clinical champion for the L.A.U.N.C.H. Collaborative, working with NCI, the FCC, Amgen, and other stakeholders, studying barriers to cancer care and impact of limited broadband access. The team is studying patient reported outcomes through an interactive phone app featuring user-centered design with input from the Affiliate Network. Dr. Mullett is also a cancer survivor, successfully treated with targeted therapy for a metastatic sarcoma, now 8 years, and counting.

Kevin C. Oeffinger, MD, FASCO

Duke University

Dr. Oeffinger is a family physician, the founding Director of the Duke Center for Onco-Primary Care, and the Director of the Supportive Care and Survivorship Center at Duke Cancer Institute. He is a Professor in the Department of Medicine with secondary appointments in the Departments of Community & Family Medicine and Population Health Sciences. Dr. Oeffinger has a long-standing record of NIH-supported research in cancer screening and survivorship and serves as the chair of the American Cancer Society Cancer Screening Guideline Panel.

Randall A. Oyer, MD

Penn Medicine Lancaster General Health

Randall A. Oyer, MD is a practicing medical oncologist at the Ann B. Barshinger Cancer Institute at Penn Medicine Lancaster General in Lancaster, Pennsylvania. Dr. Oyer serves as the Medical Director of the Cancer Institute, Medical Director of Oncology, Chairman of Cancer Committee, Chair of the Oncology Physicians Advisory Council, and Medical Director of the Cancer Risk Evaluation Program at Penn Medicine Lancaster General.

Dr. Oyer is a member of the Cancer Service Line Executive Committee and the Cancer Service Line Quality Committee at the Abramson Cancer Center- University of Pennsylvania, Philadelphia. Dr. Oyer is also a member of the Board of Directors, and currently serving as President of the Association of Community Cancer Centers, Rockville, Maryland. Dr. Oyer is an ex-officio Commissioner of the American College of Surgeons Commission on Cancer, representing the Association of Community Cancer Centers. He also is a member of the National Cancer Policy Forum at the National Academies of Science, Engineering, and Medicine.

Lynne Penberthy, MD, MPH

National Cancer Institute

Lynne Penberthy, MD, MPH, is the Associate Director for the Surveillance Research Program (SRP), which is within the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI). Dr. Penberthy obtained her MD from the University of Michigan and her MPH in epidemiology at Johns Hopkins. Dr. Penberthy's career includes a surgical internship in Baltimore, Maryland, at the Sinai Hospital and a preventive medicine residency at Johns Hopkins University. After her residency, she completed her post-doctoral training in epidemiology with the CDC as an epidemic intelligence service (EIS) officer with the Commonwealth of Virginia. She is licensed to practice medicine in the state of Maryland.

Prior to her NCI appointment, Dr. Penberthy was the Director of Cancer Research Informatics and Services and Associate Professor of General Internal Medicine at the Virginia Commonwealth University Massey Cancer Center. She directed a team in the development of innovative software with the objectives of using existing data for clinical trials eligibility screening, automated capture of treatment data from oncology practice claims, and the extraction of clinical characteristics from various electronic medical records (EMR) components. Dr. Penberthy was also involved in biobanking and annotation of specimens using clinical data. She has 20 years of experience in cancer surveillance and automation using secondary data. Dr. Penberthy has worked on more than 20 grants and contracts as well as over 30 publications related to using secondary data and/or informatics tools for cancer surveillance and clinical trials assessment.

Scott Ramsey, MD, PhD

Fred Hutchinson Cancer Research Center

Scott Ramsey, MD, PhD, is a general internist and health economist. He is a Professor in the Cancer Prevention Program, Public Health Sciences Division at the Fred Hutchinson Cancer Research Center, where he directs Hutchinson Institute for Cancer Outcomes Research, a multidisciplinary team devoted to clinical and economic evaluations of new and existing cancer prevention, screening and treatment technologies. In addition, Dr. Ramsey is a Professor in the Schools of Medicine and Pharmacy at the University of Washington.

Trained in Medicine and economics, Dr. Ramsey's research focuses on economic evaluations in cancer. He has published widely on patterns of care, costs, and cost-effectiveness of treatments for lung, colorectal, and prostate cancer. His research portfolio and interests include: large scale SEER-Medicare/Cancer Registry data linkages, patient reported outcomes, economic modeling of health care interventions, cost-effectiveness analysis, quality of life assessment, patterns of care, health care

utilization, economic burden of disease for patients and society, pragmatic trial design, early technology assessment, and stakeholder engagement.

Dr. Ramsey is co-Chair National Cancer Institute's Cancer Care Delivery Research Steering Committee and an executive office for SWOG. He is past President of the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) and has served on the National Academy of Science's Cancer Policy Forum.

Leslie L. Robison, PhD

St. Jude Children's Research Hospital

As a pediatric epidemiologist, Dr. Robison has had a career-long focus of etiologic and clinical research within pediatric populations, particularly childhood malignancies. For 20 years he was the founding principal investigator of the NIH-funded Childhood Cancer Survivor Study (CCSS), a consortium of 31 pediatric centers in the US and Canada, designed to evaluate long-term outcomes and conduct intervention trials. Beyond the CCSS-related research, he is the Co-Principal Investigator (with Dr. Melissa Hudson) of the St. Jude Lifetime Cohort (SJLIFE), an NCI-funded initiative that is performing prospective clinical assessment of all cancer survivors ever treated at St. Jude Children's Research Hospital. Dr. Robison is an author of more than 800 peer-reviewed manuscripts (*h-index*: 119).

Cleo A. Samuel-Ryals, PhD

University of North Carolina at Chapel Hill

Cleo A. Samuel is an Associate Professor of Health Policy and Management and health services researcher at the University of North Carolina at Chapel Hill (UNC-CH), Gillings School of Global Public Health. Dr. Samuel has extensive expertise in cancer care inequities, palliative and supportive care (e.g., pain management, end-of-life care), and health informatics. She is particularly interested in disentangling the multilevel sources (i.e., patient-, provider-, and health care system-level) of disparities in palliative and supportive cancer care using mixed methods (i.e., quantitative and qualitative data analysis) and addressing such inequities through system-level approaches that leverage health informatics tools.

Prior to arriving at UNC-CH, Dr. Samuel held positions within multiple federal offices/agencies including serving as a Barbara Jordan Health Policy Scholar within the former United States Senate Office of Barack Obama, a Program Specialist within the Office of the National Coordinator for Health Information Technology, and a Health Care Analyst within the Government Accountability Office. In 2019, Dr. Samuel was honored as a '40 Under 40' Leader in Minority Health by the National Minority Quality Forum and Congressional Black Caucus.

Dr. Samuel earned a PhD in Health Policy from Harvard University in 2014 and a Bachelor of Science in Psychology from the University of Miami in 2007.

Mary (Dicey) Jackson Scroggins, MA

International Gynecologic Cancer Society
Pinkie Hugs, LLC

Dicey Jackson Scroggins, a 24-year ovarian cancer survivor and health activist, is the Director of Global Outreach & Engagement for the International Gynecologic Cancer Society; chair of the Advocacy Special Interest Group for the African Organisation for Research and Training in Cancer; and a co-founder of In My Sister's Care, an organization focused on improving gynecologic cancer awareness and care for medically underserved women and on eliminating health disparities. She is also a writer, producer, and founding partner in Pinkie Hugs, LLC—a mother-daughter writing and film production firm specializing in social justice-focused documentaries. The recipient of the 2016 AACR Distinguished Public Service Award and a featured Cancer Health Change Maker (*Cancer Health* magazine, in 2020), Dicey is also a member of the “Community Engagement in Genomics” Working Group of NIH's National Human Genome Research Institute. Her activism is driven by a commitment to global health equity.

Karen Sepucha, PhD

Massachusetts General Hospital

Dr. Sepucha is the director of the Health Decision Sciences Center in the Division of General Internal Medicine at Massachusetts General Hospital (MGH) and an associate professor in Medicine at Harvard Medical School. Her research is focused on developing tools and measures to ensure that patients are well-informed and meaningfully involved in significant medical decisions. Dr. Sepucha oversees efforts to promote shared decision making in primary and specialty care at MGH and across Partners Health Care. In this work, she has overseen the delivery of more than 50,000 patient decision aids and training of more than 1,000 clinicians in shared decision making communication skills. Her recent research has focused on the development of survey instruments to measure the quality of decisions. The decision quality instruments have been used in national surveys of medical decisions and have been adapted for use in national patient experience surveys. Two performance measures based on these surveys have been endorsed by the National Quality Forum. Dr. Sepucha has been active in local, national and international efforts to improve decision quality, including the International Patient Decision Aids Standards collaboration. She has a Ph.D. in Engineering-Economic Systems and Operations Research from Stanford University, with a focus in decision sciences.

Lawrence N. Shulman, MD, MACP, FASCO

University of Pennsylvania

Lawrence N. Shulman, MD is Professor of Medicine at the Perelman School of Medicine, University of Pennsylvania, where he is the Deputy Director for Clinical Services of the Abramson Cancer Center, and Director of the Center for Global Cancer Medicine. In this capacity, he leads the Cancer Quality program and strategic development of Cancer Services across the University of Pennsylvania Health System's 6 hospitals and affiliated practices.

He received his MD from Harvard Medical School, and trained in Hematology and Oncology at the Beth Israel Hospital in Boston, MA. A specialist in the treatment of patients with breast cancer, his research includes development of new cancer therapies, and implementation of cancer treatment programs in

low-resource settings.

Dr. Shulman is currently Chair of the Commission on Cancer and serves on the National Cancer Policy Forum of the National Academies. He is the former Chair of the American Society of Clinical Oncology Quality of Care Committee and the Commission on Cancer's Quality Integration Committee.

Dr. Shulman serves as Senior Oncology Advisor to the non-profit organization Partners In Health (PIH). He sits on the Vice Chancellor's Advisory Council for Rwanda's University for Global Health Equity. Through the Botswana-UPenn Partnership, he is developing a national oncology program in Botswana. Dr. Shulman was a member of ASCO's International Affairs Committee and their Task Force on Global Oncology. He co-led the World Health Organization's review and revision of their Essential Medicines for Cancer from 2014-2017, and had a leadership role in the development of their Monograph on Essential Medical Devices for Cancer, published in 2017.

Thomas J. Smith MD, FACP, FASCO, FAAHPM

Johns Hopkins Medical Institutions

Dr. Smith is an oncologist and palliative care specialist with a lifelong interest in better symptom management and improving access to high quality affordable care. As an oncologist he specialized in comprehensive multi-disciplinary breast cancer for 25 years. With the late Dr. Chris Desch he helped start the Rural Cancer Outreach Program (RCOP) of Virginia Commonwealth University's Massey Cancer Center. This brought state of the art cancer care including clinical trials and palliative care to 5 rural hospitals in Virginia. The RCOP improved care dramatically, saved patients millions of travel miles, and ensured that indigent patients could receive care near their home. As an oncologist, he worked to remove the financial incentives for giving chemotherapy, and to standardize guidelines for care.

With Patrick Coyne and others, he helped start the Thomas Palliative Care Unit and Program at VCU-MCV in the late 1990s, one of the first academic palliative care programs in the country. He and colleagues showed that palliative care improved symptoms, allowed patients and families to choose the care they wanted, did not cost more than usual care, and even improved survival.

Currently, he is the Director of Palliative Medicine for Johns Hopkins Medicine, charged with integrating palliative care into all the Johns Hopkins venues. The PC consult service sees over 1500 new patients a year, and a research agenda with "Scrambler Therapy" for chemotherapy induced neuropathy, neuromyelitis optica spectrum disorder pain, and central pain; palliative care for patients on Phase I drug trials; palliative care for patients undergoing Whipple procedures; and auricular point acupuncture for cancer pain, among others.

Dr. Smith has been recognized in "Best Doctors in America" for many years and is a Fellow in the American College of Physician, the American Society of Clinical Oncology and the American Academy of Hospice and Palliative Medicine. He received the ACS Trish Greene Award for "outstanding research that benefits cancer patients and their families", and in 2018 was recognized as a "Visionary in Palliative Care" by AAHPM. In 2019 he received the Project on Death in America (PDIA) Palliative Medicine National Leadership Award, and the Walther Foundation- ASCO award for excellence in supportive oncology. In 2020 he received the Ellen Stovall Award from the National Coalition of Cancer Survivors that recognizes individuals, organizations, or other entities who demonstrate innovation in improving

cancer care for patients in America. He has published over 400 articles, editorials and reviews, and helped write the test questions for the ABIM hospice and palliative medicine exam.

Dr. Smith is also a prostate cancer survivor, experiencing first hand surgery, recurrence, “salvage” radiation therapy and androgen deprivation therapy with many significant side effects. He knows all too well the experience of living and working while waiting for the other shoe to drop. He and his late colleague Terry Langbaum pointed out the trials of “metastatic cancer survivorship” in an opinion piece published in the New England Journal of Medicine, hopefully stimulating research into this area.

Lara Strawbridge, MPH

Centers for Medicare & Medicaid Services

Lara Strawbridge is the Director of the Division of Ambulatory Payment Models in the Patient Care Models Group in the Center for Medicare and Medicaid Innovation (CMMI). In this role, Ms. Strawbridge leads CMS’s efforts on physician specialty models, such as the Oncology Care Model and the Radiation Oncology Model, and Part B drug issues. Prior to taking on the Division Director role, Ms. Strawbridge led the Oncology Care Model and also previously worked in CMMI’s Research and Rapid-Cycle Evaluation Group. Ms. Strawbridge began her career in health policy and research at the Institute of Medicine and previously was a teacher in Hertfordshire, England, and Washington, DC. Ms. Strawbridge earned her MPH from Johns Hopkins Bloomberg School of Public Health.

Emily S. Tonorezos, MD, MPH

National Cancer Institute

Emily S. Tonorezos, MD, MPH, is Director of the [Office of Cancer Survivorship](#), part of the Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI). In this position, Dr. Tonorezos leads NCI’s efforts to address the challenges facing cancer survivors and their families -- to prevent or mitigate adverse effects and to improve the health and well-being of cancer survivors from the time of diagnosis through the remainder of their lives.

Dr. Tonorezos came to NCI from Memorial Sloan Kettering Cancer Center and the Weill Cornell Medical College, where she worked in General Internal Medicine as Director of the Adult Long-Term Follow-Up Program for survivors of childhood and young adult cancers. Her research focuses on cardiometabolic consequences of cancer therapy, childhood and young adult cancer survivorship, diet and nutrition, and care coordination for this population. She serves on the National Academy of Sciences, Engineering and Medicine Committee on Childhood Cancer and Disability; the Cancer Survivorship Committee, the Adolescent and Young Adult Task Force, and the Clinical Guideline Committee for the American Society of Clinical Oncology (ASCO); and the Metabolic Syndrome Guideline Committee for the Children’s Oncology Group (COG). She is currently co-leader of the International Guideline Harmonization Group for the metabolic syndrome and led a recent international effort to develop recommendations for adult survivors of heritable retinoblastoma.

Joseph Unger, PhD, MS

SWOG Statistics and Data Management Center

Dr. Joseph Unger is a health services researcher and biostatistician. He uses big data strategies to understand more about cancer patients' treatment outcomes and disparities, and has generated novel insights about the scientific, clinical, and population impact of clinical trials. He has been at the forefront of efforts to link Medicare claims data to clinical-trial records to address novel research questions. Dr. Unger also has extensive expertise in the design and analysis of prospective clinical trials that examine disease symptoms and treatment side effects, patient quality of life and delivery of cancer care. He has a particular research focus about barriers to clinical trial participation. His research has revealed that factors such as annual household income and having multiple simultaneous health conditions, or comorbidities, can affect patients' participation in clinical trials, and has highlighted how structural and clinical barriers are the predominant reasons most patients most adult cancer patients are unable to participate in clinical trials.

Robert A. Winn, MD

VCU Massey Cancer Center

Robert Winn, M.D., was appointed director of VCU Massey Cancer Center on December 2, 2019. In this position, he oversees a cancer center designated by the National Cancer Institute that provides outstanding cancer care, conducts groundbreaking research to discover new treatments for cancer and offers high-quality education, training and community outreach programs.

His current basic science research, which has been supported by multiple National Institutes of Health and Veterans Affairs Merit awards, focuses on the cellular pathways that drive the development and progression of lung cancer and the role of cell division arrest in lung cancer.

Winn is committed to community-engaged research centered on eliminating health disparities. He is a principal investigator on several community-based projects funded by the NIH and National Cancer Institute, including the All of Us Research Program, a NIH precision medicine initiative. He has received national and international acclaim for his efforts to empower underserved patient populations, improve health care delivery and ensure equal access to cancer care.

Winn's previous faculty appointments include serving as director of the University of Illinois Cancer Center from 2015 to 2019 and as associate vice chancellor of health affairs for community-based practice at the University of Illinois Hospital and Health Science System from 2013 to 2019.

Melisa L. Wong, MD, MAS

University of California, San Francisco

Melisa Wong, MD, MAS is a geriatric oncology clinician-investigator dually trained in medical oncology and aging research and a current National Institute on Aging Paul B. Beeson Emerging Leaders in Aging Scholar. She is an Assistant Professor in the Divisions of Hematology/Oncology and Geriatrics at the University of California, San Francisco (UCSF). Dr. Wong's research aims to understand changes in functional status during cancer treatment in older adults and to improve cancer care among older adults by aligning treatments with individualized goals for function, quality of life, longevity, and other priorities.

She completed her medical education at UCSF as well as her internal medicine residency, hematology/oncology fellowship, aging research fellowship, and master's degree in clinical research. Dr. Wong's research program has been supported by the National Institute on Aging; National Cancer Institute; Women Who Conquer Cancer, The ASCO Foundation; UCSF Clinical and Translational Science Institute; UCSF Claude D. Pepper Older Americans Independence Center; UCSF Helen Diller Family Comprehensive Cancer Center; and the Mount Zion Health Fund.

Robin Yabroff, PhD

American Cancer Society

Robin Yabroff, PhD, is an epidemiologist and Scientific Vice President, Health Services Research, at the American Cancer Society. She conducts research on the economic burden of cancer; patterns of cancer care, including high cost prescription drugs; health insurance benefit design; and patient, provider, and health system factors associated with quality and value of cancer care.

Dr. Yabroff has more than 20 years of health services research experience. Prior to joining the American Cancer Society, she held positions within the Office of Health Policy, Assistant Secretary for Planning and Evaluation (ASPE) in the US Department of Health and Human Services, the Health Services and Economics Branch of the National Cancer Institute, and the faculty of the Lombardi Cancer Center, Georgetown University. She earned her PhD in epidemiology from the Johns Hopkins School of Public Health and received an MBA from the University of Rochester.

Dr. Yabroff has co-authored over 150 peer-reviewed journal articles and has also co-authored invited editorials, commentaries, and book chapters. She is an Associate Editor for the *Journal of the National Cancer Institute*, a founding member of the editorial board of the *Journal of Cancer Survivorship*, and a member of the editorial board of the *Journal of Oncology Practice*. Dr. Yabroff has received multiple National Institutes of Health Merit Awards for her research leadership and mentorship.

Yousuf Zafar, MD, MHS, FASCO

Duke University

Dr. Zafar is a gastrointestinal medical oncologist and Associate Professor of Medicine, Public Policy, and Population Health Science at the Duke Cancer Institute and Duke-Margolis Center for Health Policy. He serves as Chief Quality & Innovation Officer at the Duke Cancer Institute. Dr. Zafar also serves as Clinical Associate Director of Duke Forge (Health Data Science Center). Dr. Zafar's work has focused on identifying and intervening upon the financial burden of cancer care. His research explores ways to improve cancer care delivery with a primary focus on improving the value of cancer treatment from both patient-focused and policy perspectives.

Dr. Zafar speaks internationally on his research and cancer care delivery. He has over 100 publications in peer-reviewed journals including the *New England Journal of Medicine*, the *Journal of Clinical Oncology*, and *JAMA Oncology*. His research has been funded by the National Institutes of Health and the American Cancer Society, among others. His work has been covered by national media outlets including *New York Times*, *Forbes*, *Wall Street Journal*, *NPR*, and *Washington Post*. He is a Fellow of the American Society of Clinical Oncology.



ABOUT THE FORUM



The National Cancer Policy Forum serves as a trusted venue in which experts can identify emerging high-priority policy issues in cancer research and care and work collaboratively to examine those issues through convening activities focused on opportunities for action. The Forum provides a continual focus within the National Academies on cancer, addressing issues in science, clinical medicine, public health, and public policy that are relevant to the goal of reducing the cancer burden, through prevention and by improving the care and outcomes for those diagnosed with cancer. Forum activities inform stakeholders about critical policy issues through published reports and often inform consensus committee studies. The Forum has members with a broad range of expertise in cancer, including patient advocates, clinicians, and basic, translational, and clinical scientists. Members represent patients, federal agencies, academia, professional organizations, nonprofits, and industry.

The Forum has addressed a wide array of topics, including:

- enhancing collaborations to accelerate research and development;
- improving the quality and value of care for patients who have been diagnosed with or are at risk for cancer;
- developing tools and technologies to enhance cancer research and care; and
- examining factors that influence cancer incidence, mortality, and disparities.

nationalacademies.org/NCPF

To receive updates on the National
Cancer Policy Forum, visit

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Upcoming and Recent Workshops

WORKSHOP SERIES ON OLDER ADULT POPULATIONS

Collaborative series convened by:

National Cancer Policy Forum

Forum on Drug Discovery, Development, and Translation

Forum on Aging, Disability, and Independence

Improving the Evidence Base for Treatment Decision Making for Older Adults with Cancer

January 22, 25, and 27, 2021

Older adults represent the majority of patients diagnosed with cancer and the majority of cancer-related deaths. However, the evidence base to guide treatment decision making among older adults with cancer is sparse, primarily because older adults are underrepresented in clinical trials, and trials designed specifically for older adults are rare. This workshop will examine challenges and opportunities to improve the evidence base for treating older adults with cancer, including clinical trial design and analysis strategies, incorporation of geriatric assessments and patient reported outcomes in clinical trials, and the potential for real world data collection from clinical practice to fill evidence gaps.



Workshop website:

<https://www.nationalacademies.org/our-work/improving-the-evidence-base-for-treatment-decision-making-for-older-adults-with-cancer-a-workshop>

This workshop follows an earlier workshop on Drug Research and Development for Adults Across the Older Age Span, held in 2019. This workshop convened stakeholders to discuss the lack of evidence about the appropriate use of drugs in older adult populations, hampering decision making about how to optimize care for older adults. Workshop presentations and discussions highlighted opportunities to better engage older adults in clinical research and strategies to generate evidence-based prescribing information for older adult populations.



Workshop website:

<https://www.nationalacademies.org/event/08-05-2020/drug-research-and-development-for-older-adult-populations-a-workshop>

Addressing the Adverse Consequences of Cancer Treatment

November 9-10, 2020

Cancer care is associated with significant physical, mental, and socioeconomic consequences. This workshop, convened by the National Cancer Policy Forum in collaboration with the Forum on Aging, Disability, and Independence, will examine the array of short- and long-term toxicities and adverse effects that patients may experience as a result of cancer treatment and consider opportunities to improve quality of life for cancer

survivors and their families.

Workshop presentations and discussions will focus on topics such as:

- An overview of the array of adverse consequences of cancer treatment across the lifecourse, including physical, psychosocial, and socioeconomic consequences
- Opportunities to improve informed and goal-concordant care, especially in light of evidence gaps on the long-term consequences of cancer treatment
- Opportunities to redesign cancer treatment to screen for and reduce toxicities
- Improving the evidence base for addressing the adverse consequences of cancer treatment
- System-level redesign and policy change to improve survivorship care
- Participant recommendations for the path forward



Workshop website:

<https://www.nationalacademies.org/event/11-09-2020/addressing-the-adverse-consequences-of-cancer-treatment-a-workshop>

Opportunities and Challenges for Using Digital Health Applications in Oncology

The National Cancer Policy Forum, in collaboration with the Forum on Cyber Resilience, convened a workshop to examine the role of digital health applications in oncology research and care. Workshop speakers discussed topics such as:

- Exemplars of novel digital health applications, including an emphasis on patient-facing technologies
- Regulatory priorities
- Ethical, security, governance, and payment considerations
- Opportunities to improve data availability and use in EHRs and large databases
- Participant reactions and recommendations for the path forward




Workshop videos and presentation files:

<https://www.nationalacademies.org/event/07-13-2020/opportunities-and-challenges-for-using-digital-health-applications-in-oncology-a-workshop>

Recent Workshops and Publications



Advancing Progress in the Development and Implementation of Effective, High-Quality Cancer Screening

Evidence-based screening approaches have contributed to improved patient outcomes, and research continues to develop and evaluate potential new strategies for early cancer detection. However, there are a number of challenges related to ensuring effective, high-quality screening. This workshop examined current issues in cancer screening, including principles and methods of cancer screening; key gaps in the evidence base for cancer screening, as well as statistical and methodologic challenges; validation and implementation of novel screening technologies; patient access to high-quality cancer screening and follow-up care; and shared decision making and communication in cancer screening.

-  Workshop videos and presentation files:
<https://www.nationalacademies.org/event/03-02-2020/advancing-progress-in-the-development-and-implementation-of-effective-high-quality-cancer-screening-a-workshop>


Applying Big Data to Address the Social Determinants of Health in Oncology

This workshop, held in collaboration with the Committee on Applied and Theoretical Statistics, examined social determinants of health (SDOH) in the context of cancer and considered opportunities to effectively leverage big data to improve health equity and reduce disparities.

-  Workshop videos and presentation files:
<https://www.nationalacademies.org/event/10-21-2019/applying-big-data-to-address-the-social-determinants-of-health-in-oncology-a-workshop>
-  Proceedings:
<https://www.nap.edu/catalog/25835/applying-big-data-to-address-the-social-determinants-of-health-in-oncology>

Health Literacy and Communications Strategies in Oncology

This workshop, held in collaboration with the Roundtable on Health Literacy, examined opportunities, methods, and strategies to improve the communication of cancer information in a clinic visit, across a health care organization, and among the broader community.

-  Workshop videos and presentation files:
<https://www.nationalacademies.org/event/07-15-2019/health-literacy-and-communication-strategies-in-oncology-a-workshop>




-  Proceedings:
<https://www.nap.edu/catalog/25664/health-literacy-and-communication-strategies-in-oncology-proceedings-of-a>

-  Workshop Overview:
<https://www.nap.edu/resource/25664/interactive/>

-  Workshop highlight videos are available at:
www.youtube.com/watch?v=M1NjXeG_cgs and
www.youtube.com/watch?v=9iyPsTZ7RNw

Developing and Sustaining an Effective and Resilient Oncology Careforce

Advances in cancer research, screening and diagnostic practices, and cancer treatment have led to improved outcomes for patients with cancer and a growing population of cancer survivors, but they have also increased the complexity of cancer care. Demographic trends, new payment models, growing emphasis on interprofessional practice, the widespread adoption of technologies in clinical practice, and a shift to the outpatient care delivery all have a profound effect on the cancer careforce. This workshop examined opportunities to better support the oncology careforce and improve the delivery of high-quality cancer care.

-  Workshop videos and presentation files:
<https://www.nationalacademies.org/our-work/developing-and-sustaining-an-effective-and-resilient-oncology-careforce-a-workshop>
-  Proceedings:
<https://www.nap.edu/catalog/25533/developing-and-sustaining-an-effective-and-resilient-oncology-careforce-proceedings>
-  Workshop Overview:
<https://www.nap.edu/resource/25533/interactive/>

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- Cancer Support Community
- CEO Roundtable on Cancer
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LONG-TERM SURVIVORSHIP CARE AFTER CANCER TREATMENT

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WORKSHOP PROCEEDINGS

2020

Opportunities and Challenges for Using Digital Health Applications in Oncology: Proceedings of a Workshop (In Process)

Advancing Progress in the Development and Implementation of Effective, High-Quality Cancer Screening: Proceedings of a Workshop (In Process)

Reflections on Sharing Clinical Trial Data: Challenges and a Way Forward: Proceedings of a Workshop

Applying Big Data to Address the Social Determinants of Health in Oncology: Proceedings of a Workshop

Health Literacy and Communication Strategies in Oncology: Proceedings of a Workshop

Enhancing Scientific Reproducibility Through Transparent Reporting: Proceedings of a Workshop

2019

Developing and Sustaining an Effective and Resilient Oncology Careforce: Proceedings of a Workshop

Advancing Progress in the Development of Combination Cancer Therapies with Immune Checkpoint Inhibitors: Proceedings of a Workshop

Improving Cancer Diagnosis and Care: Clinical Application of Computational Methods in Precision Oncology: Proceedings of a Workshop

2018

Improving Cancer Diagnosis and Care: Patient Access to Oncologic Imaging and Pathology Expertise and Technologies: Proceedings of a Workshop

Establishing Effective Patient Navigation Programs in Oncology: Proceedings of a Workshop

Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop

2017

The Drug Development Paradigm in Oncology: Proceedings of a Workshop

Cancer Care in Low-Resource Areas: Cancer Treatment, Palliative Care, and Survivorship Care: Proceedings of a Workshop

Implementation of Lung Cancer Screening: Proceedings of a Workshop

Incorporating Weight Management and Physical Activity Throughout the Cancer Care Continuum: Proceedings of a Workshop

2016

Policy Issues in the Clinical Development and Use of Immunotherapy for Cancer Treatment: Proceedings of a Workshop

Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection: Workshop Summary

Appropriate Use of Advanced Technologies for Radiation Therapy and Surgery in Oncology: Workshop Summary

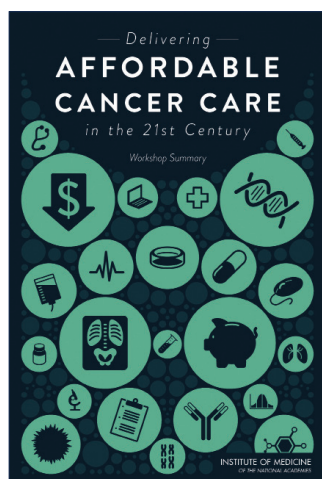
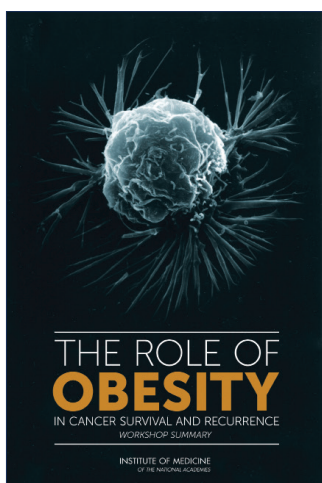
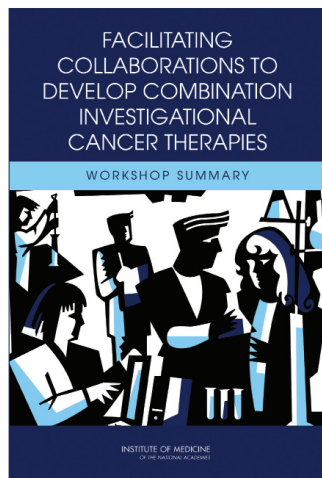
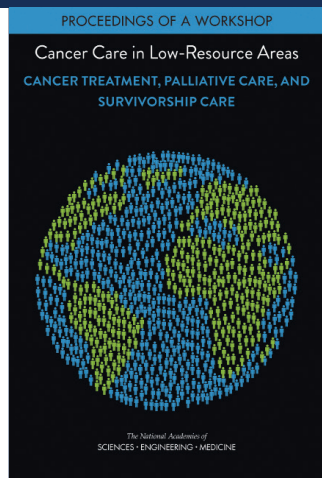
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WORKSHOP PROCEEDINGS

2015

Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop by the Institute of Medicine and the American Cancer Society

Policy Issues in the Development and Adoption of Biomarkers for Molecularly Targeted Cancer Therapies: Workshop Summary

Assessing and Improving the Interpretation of Breast Images: Workshop Summary

Role of Clinical Studies for Pets with Naturally Occurring Tumors in Translational Cancer Research: Workshop Summary

2014

Ensuring Patient Access to Affordable Cancer Drugs: Workshop Summary

Contemporary Issues for Protecting Patients in Cancer Research: Workshop Summary

2013

Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer: Workshop Summary

Implementing a National Cancer Clinical Trials System for the 21st Century: Second Workshop Summary

Sharing Clinical Research Data: Workshop Summary

Delivering Affordable Cancer Care in the 21st Century: Workshop Summary

Reducing Tobacco-Related Cancer Incidence and Mortality: Workshop Summary

2012

The Role of Obesity in Cancer Survival and Recurrence: Workshop Summary

Informatics Needs and Challenges in Cancer Research: Workshop Summary

Facilitating Collaborations to Develop Combination Investigational Cancer Therapies: Workshop Summary

2011

Implementing a National Cancer Clinical Trials System for the 21st Century: Workshop Summary

Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary

The National Cancer Policy Summit: Opportunities and Challenges in Cancer Research and Care

Nanotechnology and Oncology: Workshop Summary

2010

Genetic Testing (with the National Research Council): Summary of a Workshop

Extending the Spectrum of Precompetitive Collaboration in Oncology Research: Workshop Summary

A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care: Workshop Summary

Policy Issues in the Development of Personalized Medicine in Oncology: Workshop Summary

2009

Assessing and Improving Value in Cancer Care: Workshop Summary

Ensuring Quality Cancer Care Through the Oncology Workforce: Sustaining Care in the 21st Century: Workshop Summary

Multi-Center Phase III Clinical Trials and the NCI Cooperative Group Program: Workshop Summary

2008

Implementing Colorectal Cancer Screening: Workshop Summary

Improving the Quality of Cancer Clinical Trials: Workshop Summary

2007

Cancer-Related Genetic Testing and Counseling: Workshop Proceedings

Cancer in Elderly People: Workshop Proceedings

Implementing Cancer Survivorship Care Planning: Workshop Summary

2006

Effect of the HIPAA Privacy Rule on Health Research: Proceedings of a Workshop

Developing Biomarker-Based Tools for Cancer Screening, Diagnosis, and Treatment: Workshop Summary

RELATED WORK

CONSENSUS STUDY REPORTS BUILDING ON NCPF WORK

Guiding Cancer Control:

A Path to Transformation (2019)

Report: nap.edu/catalog/25438

Making Medicines Affordable:

A National Imperative (2017)

Report: nap.edu/catalog/24946

Biomarker Tests for Molecularly Targeted

Therapies: Key to Unlocking Precision Medicine (2016)

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Ovarian Cancers: Evolving Paradigms in Research and Care (2016)

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Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013)

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Evolution of Translational Omics: Lessons Learned and the Path Forward (2012)

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A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program (2010)

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Evaluation of Biomarkers and Surrogate Endpoints in Chronic Disease (2010)

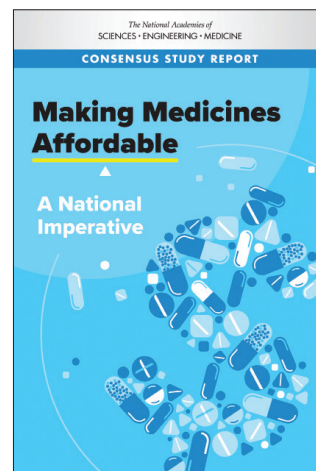
Report: nap.edu/catalog/12869

Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research (2009)

Report: nap.edu/catalog/12458

Cancer Biomarkers: The Promises and Challenges of Improving Detection and Treatment (2007)

Report: nap.edu/read/11892



INDIVIDUALLY AUTHORED PUBLICATIONS BUILDING ON NCPF WORK

Independent, individually authored articles* in the literature arising from NCPF workshops—and consensus studies building on the work of NCPF—include:

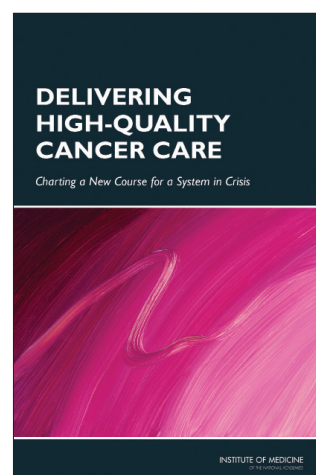
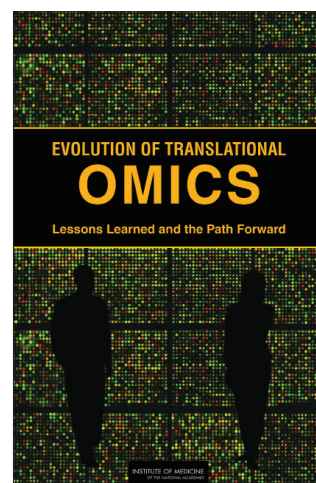
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Forum on Aging, Disability and Independence

The National Academies of Sciences, Engineering, and Medicine convenes a forum of relevant stakeholders from the federal sector, academia, industry, professional associations, and advocacy groups that provides a structured environment to define and discuss issues within the long-term services and supports system that affect an individual's ability to live independently. This Forum provides a neutral venue for broad ranging discussions for coordination and integration of aging and disability stakeholders. With the ultimate goal to serve all individuals with respect to long-term supports and services preferences regardless of age or disability, the Forum will (in its dialogue and discussion at meetings) highlight capacities in which aging and disability network coordination is strong; examine the historic challenges faced by aligning the aging and disability networks; define the scope of the challenges; explore new approaches for resolving problem areas; elevate the visibility and perspectives of the many relevant stakeholders; and set the stage for future policy actions.

The populations of interest to the forum include both individuals who are aging with a disability, and individuals who develop disabilities as they age. Broad areas of examination may include areas such as integrating support systems; participant direction; person-centered planning; assistive technologies; workforce, education, and training; research and evaluation; and public policies. The forum serves as a platform for disparate communities who possess knowledge about disability and/or aging to share information and offer lessons learned in order to broaden their impact and sphere of influence to improve individuals' abilities to live independently.

Sponsor/s: AARP; Administration for Community Living; American Geriatrics Society; Consumer Technology Association Foundation; LeadingAge; National Institute on Aging; National Institute on Disability, Independent Living and Rehabilitation Research; PHI; The Gerontological Society of America; The John A Hartford Foundation

Forum Members:

Stephen, Ewell, *Chair*, Executive Director, Consumer Technology Association
Rebecca, Stoeckle, *Chair*, Vice President and Director of Health and Technology, Education Development Center
James, C. Appleby, Chief Executive Officer, The Gerontological Society of America
John, Auerbach, President and Chief Executive Officer, Trust for America's Health
Julie, Bynum, Professor of Internal Medicine, University of Michigan
Margaret, L. Campbell, Campbell & Associates Consulting
Bruce, A. Chernof, President and Chief Executive Officer, The SCAN Foundation
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Thomas, E. Edes, Director, Geriatrics & Extended Care Operations, Department of Veterans Affairs
Robert, Espinoza, Vice President of Policy, PHI
Donna, Fick, Elouise Ross Eberly Endowed Professor, Penn State University College of Nursing
Terry, Fulmer, President, The John A. Hartford Foundation
Kathy, Greenlee, Former Assistant Secretary for Aging and Administrator, Greenlee Global LLC
Robert, Jarrin, Managing Director, The Omega Concern, LLC
Susan, Jenkins, Director, Administration for Community Living
Janni, Lehrer-Stein, Independent Consultant, Disability Policy and Advocacy
Sarah, Ruiz, Associate Director, National Institute on Disability, Independent Living and Rehabilitation Research
Katie, Smith Sloan, President and CEO, LeadingAge
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Rukshana Gupta, Senior Program Assistant
Sharyl Nass, Director, Board on Health Care Services

Website: www.nationalacademies.org/ADIForum

Improving the Evidence Base for Treatment Decision Making for Older Adults with Cancer: A Collaborative Workshop

National Cancer Policy Forum

Forum on Drug Discovery, Development, and Translation

Forum on Aging, Disability, and Independence

Workshop Dates: January 22, 25, 27, 2021

Sponsor: Food and Drug Administration

Statement of Task

An ad hoc planning committee will plan and host a 1.5-day public workshop to examine challenges and opportunities to improve the evidence base for treating older adults with cancer. The workshop will feature invited presentations and panel discussions on topics such as:

- The root causes that limit enrollment of older adults in clinical trials for oncology (and other disciplines such as cardiology and pulmonology), and strategies to mitigate those barriers;
- Strategies for inclusion of older adults in early phase studies (e.g., pharmacokinetic, pharmacodynamic, and in vitro studies that describe dose-response, concentration-response, and drug-drug and drug-disease interactions) that can inform the development of later phase studies;
- Clinical trial design and analysis strategies that could encourage and facilitate enrollment of older adults in cancer clinical trials (e.g., decentralization of clinical trial sites, broadening eligibility criteria, and offering caregiver support);
- Opportunities to incorporate geriatric assessments and patient reported outcomes into clinical trial designs; and
- Strategies to collect real world data via observational studies or registries to improve the collection of postmarket safety and efficacy data on newly approved drugs.

The planning committee will develop the agenda for the workshop sessions, select and invite speakers and panelists, 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.

Planning Committee

Monica Marie Bertagnolli, MD, Brigham and Women's Hospital (*Chair*)

Garnet Anderson, PhD, Fred Hutchinson Cancer Research Center

Gwen Darien, BA, National Patient Advocate Foundation

R. Donald Harvey, PharmD, BCOP, FCCP, FHOPA, Emory University School of Medicine

Samir N. Khleif, MD, Georgetown University Medical Center

Heidi Klepin, MD, Wake Forest School of Medicine

Larissa Nekhlyudov, MD, MPH, Harvard University Medical School/Brigham & Women's Hospital

Randall A. Oyer, MD, Penn Medicine Lancaster General Health

Rebecca D. Pentz, PhD, Emory University School of Medicine

Barbara Radziszewska, PhD, MPH, National Institute on Aging



Eric H. Rubin, MD, Merck Research Laboratories

Ishwaria Subbiah, MD, MS, The University of Texas MD Anderson Cancer Center

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Lori Benjamin Brenig, Research Associate, National Cancer Policy Forum

Annalee Gonzales, Administrative Assistant, Board on Health Care Services

Micah Winograd, Senior Finance Business Partner, Health and Medicine Division

Carolyn Shore, Director, Forum on Drug Discovery, Development and Translation

Tracy A. Lustig, Director, Forum on Aging, Disability, and Independence

Sharyl Nass, Director, National Cancer Policy Forum; Senior Director, Board on Health Care Services



The Impact of the Affordable Care Act on Cancer Prevention and Care: A Workshop

Workshop Dates: March 1-2, 2021

Statement of Task

A National Academies of Sciences, Engineering, and Medicine planning committee will organize and host a 1.5-day public workshop to examine the impact of the Patient Protection and Affordable Care Act (ACA) on cancer prevention and care (early detection, diagnosis, treatment, and survivorship).

The workshop will feature invited presentations and panel discussions on topics that may include:

- The effects of ACA provisions such as:
 - Coverage for certain preventive care services without patient cost sharing;
 - Prohibition of exclusions for preexisting conditions;
 - Coverage of children up to age 26 on a parent's health insurance plan; and
 - State-based Medicaid expansions.
- The impact of new organizational infrastructure (e.g., the Patient-Centered Outcomes Research Institute and Centers for Medicare and Medicaid Innovation), and their relevance to cancer research.
- The effects of payment reform demonstration projects (such as accountable care organizations and the oncology medical home pilot) on patient outcomes and the quality and efficiency of oncology care delivery; as well as the viability and sustainability of alternative payment models.
- Remaining evidence gaps and policy challenges and their impact on patients with cancer.
- Lessons learned from the design and implementation of the ACA that could inform future health care reform efforts.

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.

Planning Committee Pending

The National Academies of
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*Board on Health Sciences Policy
Board on Health Care Services*

**Changing the Culture of Data Management and Sharing:
A Collaborative Workshop**

April 2021: Exact Dates To Be Announced

In response to a request from the NIH Office of Science Policy, a planning committee of the National Academies of Sciences, Engineering, and Medicine will convene a two-day virtual public workshop to discuss the challenges and opportunities for researchers, institutions, and funders to establish effective data management and sharing practices. The objective of the workshop is to examine strategies, resources, and promising practices for developing and evaluating data management and sharing plans, as well as to discuss how researchers can effectively share scientific data over the course of the data life cycle.

Input will be sought from a variety of perspectives, including researchers, data repository managers, funding institutions, publishers, research participants, and other stakeholders to include a diversity of biomedical research fields and disciplines. With an emphasis on illustrative case studies, real world examples, and promising practices, potential topics may include:

- Addressing overarching strategies for managing and sharing data, taking into consideration diverse needs (e.g., human vs non-human data, type and size, data generators vs data users);
- Assessing value of shared data and the development and evaluation of data management and sharing plans, which may include discussions of:
 - best practices for repositories to collect the metrics needed to make such assessments,
 - the extent to which data value was anticipated and planned for prior to generating or sharing data, and
 - how this might inform prospective planning for sharing;
- Monitoring and evaluating data management and sharing practices, including discussion of appropriate metrics for timelines of data availability and life cycles of different types of scientific data; and
- Considering educational and other resource needs for responsible data sharing practices.

The workshop planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate or select moderators for the discussions. At the end of each workshop day, key points from individual speakers will be summarized and shared with the audience by a moderator. The workshop website will contain presentations from the speakers who provide the National Academies with permission to share their slides and the video of the webcast from the workshop.

Planning Committee Pending