National Cancer Policy Forum Virtual Workshop



Live Webcast:

Day I: Monday, March I, 2021 from II:00 am - 5:00 pm ET
 Day 2: Tuesday, March 2, 2021 from II:00 am - 2:00 pm ET

#NatlCancerForum

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Webcast Information for Attendees

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

Joining the Workshop

Monday, March 1, 2021 from 11:00 am - 5:00 pm ET

https://www.nationalacademies.org/event/03-01-2021/the-impact-of-the-affordable-care-act-on-cancer-prevention-and-cancer-care-a-virtual-workshop-part-1

Tuesday, March 2, 2021 from 11:00 am - 2:00 pm ET

https://www.nationalacademies.org/event/03-02-2021/the-impact-of-the-affordable-care-act-on-cancer-prevention-and-cancer-care-a-virtual-workshop-part-2

- 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 the 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 here.
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Impact of the Affordable Care Act on Cancer Prevention and Cancer Care: A Virtual Workshop

AGENDA

MARCH I, 2021 Eastern Time Zone https://www.nationalacademies.org/event/03-01-2021/the-impact-of-the-afforact-on-cancer-prevention-and-cancer-care-a-virtual-workshop-part-1 II:00 am Welcome from the National Cancer Policy Forum Randall A. Oyer, Lancaster General Penn Medicine	dable-care-
https://www.nationalacademies.org/event/03-01-2021/the-impact-of-the-afforact-on-cancer-prevention-and-cancer-care-a-virtual-workshop-part-1 I 1:00 am Welcome from the National Cancer Policy Forum	dable-care-
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Randall A. Over, Lancaster General Penn Medicine	
Transaction General Ferrit Tedicine	
Deborah Schrag, Harvard Medical School and Dana-Farber Cancer Institute	9
Workshop Planning Committee Co-Chairs	
II:15 am Session I: Coverage of Preventive Services	
Moderators:	
Nicole F. Dowling, Centers for Disease Control and Prevention	
Roy A. Jensen, University of Kansas Cancer Center	
What evidence is there that the ACA has increased utilization of	cancer
preventive services? (10 minutes)	
 Lindsay Sabik, University of Pittsburgh 	
What evidence is there that the ACA has decreased inequities in cancer screening and surveillance? (10 minutes)	coverage of
 Folasade (Fola) P. May, University of California, Los Angeles 	
What are the remaining barriers to coverage of preventive servic ACA has not addressed? (10 minutes)	es that the
Stacey A. Fedewa, American Cancer Society	
Panel Discussion (15 minutes)	
12:00 pm Transition Break	
I 2:05 pm Session 2: Coverage for Cancer Services for Individuals Insured by Marketplace/Health Exchanges and Non-Exclusion of Preexisting Moderators:	
Robert Winn, Virginia Commonwealth University Massey Cancer Center	
Gwen Darien, National Patient Advocate Foundation	
Patient/Consumer Advocacy Perspectives on ACA Expansions	
 Freddie White-Johnson, Mississippi Network for Cancer Control at Eliot Fishman, Families USA 	nd Prevention
ACA Marketplace/Health Exchanges	
Sherry Glied, New York University	

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	Non-Exclusion of Preexisting Conditions
	Katie Keith, Georgetown University
	Panel Discussion
1:05 pm	Break
1:20 pm	Session 3: Medicaid Expansion and Non-Expansion
	Moderators:
	Robin Yabroff, American Cancer Society Nicole Huberfeld, Boston University
	Tricole Fluberfeld, Boston Oniversity
	Framing Remarks and Overview of Session (5 minutes)
	Robin Yabroff, American Cancer Society
	Overview Presentation of Data on Medicaid Expansion Increasing Access to Care (10 minutes)
	Nicole Huberfeld, Boston University School of Law
	Evidence that Medicaid Expansion Has Improved Health Outcomes (10 minutes)
	Kosali Simon, Indiana University
	Overview of State Medicaid Expansions and Non-Expansions (10 minutes) • Trish Riley, National Academy for State Health Policy
	State Health Policy Perspectives
	Mike Herndon, Oklahoma Healthcare Authority
	Dave Richard, North Carolina Medicaid Program
	Panel Discussion
2:45 pm	Transition Break
2:50 pm	Session 4: ACA Provisions Affecting Adolescent and Young Adult Populations
	Moderator: Nicole F. Dowling, Centers for Disease Control and Prevention
	Elyse R. Park, Harvard Medical School/Mass General and Anne Kirchhoff, University of Utah
	Shreya Roy, Oregon Health and Science University
	Panel Discussion
3:25 pm	Transition Break
3:30 pm	Session 5: Impact of Organizations Created by the ACA on Cancer-Relevant
	Research Moderators:
	Moderators:

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	FORUM
	Cathy J. Bradley, University of Colorado Comprehensive Cancer Center
	Cleo A. Samuel-Ryals, University of North Carolina, Chapel Hill
	CMS Innovation Center Priorities (15 minutes)
	Lara Strawbridge, Centers for Medicare and Medicaid Services
	Barbara L. McAneny, New Mexico Oncology Hematology Consultants, Ltd.
	Patient-Centered Outcomes Research Institute Priorities (15 minutes)
	Steve Clauser, Patient-Centered Outcomes Research Institute
	Ellen V. Sigal, Friends of Cancer Research
	Coordination across Federal Agencies, Unfinished Business and Priorities for the New Administration (10 minutes)
	Melinda B. Buntin, Vanderbilt University School of Medicine
	Panel Discussion (45 minutes)
4:55 pm	Wrap Up Day I Remarks Information about the March 2nd Session
5:00 pm	Adjourn
	MARCH 2, 2021
	Eastern Time Zone
	w.nationalacademies.org/event/03-02-2021/the-impact-of-the-affordable-care-
	w.nationalacademies.org/event/03-02-2021/the-impact-of-the-affordable-care- icer-prevention-and-cancer-care-a-virtual-workshop-part-2
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act-on-can	Cer-prevention-and-cancer-care-a-virtual-workshop-part-2 Welcome and Overview of Day 2 Session 6: Reflections on Progress, Challenges, and Next Steps for Health
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	 Cathy J. Bradley, University of Colorado Comprehensive Cancer Center Nicole Huberfeld, Boston University Roy A. Jensen, University of Kansas Cancer Institute Cleo A. Samuel-Ryals, University of North Carolina, Chapel Hill Lara Strawbridge, Centers for Medicare & Medicaid Services
1:50 pm	Closing Remarks
2:00 pm	Adjourn



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Robin Yabroff, PhD

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Chair, PCORI Engagement, Dissemination and
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Freddie White-Johnson, MPPA

Program Director Mississippi Network for Cancer Control and Prevention

Robert Winn, MD

Director, VCU Massey Cancer Center Senior Associate Dean, Cancer Innovation Professor, Internal Medicine School of Medicine Virginia Commonwealth University

Robin Yabroff, PhD

Scientific Vice President Health Services Research American Cancer Society



SPEAKERS, PANELISTS, MODERATORS, AND PLANNING COMMITTEE BIOSKETCHES

Georges C. Benjamin, MD

American Public Health Association

Georges C. Benjamin, MD, is a well-known health policy leader, practitioner and administrator. He currently serves as the executive director of the American Public Health Association, the nation's oldest and largest organization of public health professionals. He is also a former secretary of health for the state of Maryland.

Dr. Benjamin is a graduate of the Illinois Institute of Technology and the University Of Illinois College Of Medicine. He is board-certified in internal medicine, a Master of the American College of Physicians, a fellow of the National Academy of Public Administration, a fellow emeritus of the American College of Emergency Physicians, and a member of the National Academy of Medicine. He serves on several nonprofit boards such as Research! America, the Truth Foundation and, the Reagan-Udall Foundation. He is a former member of the National Infrastructure Advisory Council, a council that advises the President on how best to assure the security of the nation's critical infrastructure.

Donald Berwick, MD, MPP, FRCP, KBE

Institute for Healthcare Improvement

Donald Berwick, MD, MPP, FRCP, KBE, is President Emeritus and Senior Fellow at the Institute for Healthcare Improvement (IHI), an organization he co-founded and led as President and CEO for 19 years. He is one of the nation's leading authorities on health care quality and improvement. In July, 2010, President Obama appointed Dr. Berwick to the position of Administrator of the Centers for Medicare and Medicaid Services (CMS), which he held until December, 2011. A pediatrician by background, Dr. Berwick has served as Clinical Professor of Pediatrics and Health Care Policy at the Harvard Medical School, Professor of Health Policy and Management at the Harvard School of Public Health, and as a member of the staffs of Boston's Children's Hospital Medical Center, Massachusetts General Hospital, and the Brigham and Women's Hospital. He has also served as vice chair of the U.S. Preventive Services Task Force, the first "Independent Member" of the Board of Trustees of the American Hospital Association, and chair of the National Advisory Council of the Agency for Healthcare Research and Quality. He is an elected member of the American Philosophical Society, the American Academy of Arts and Sciences, and the National Academy of Medicine (formerly the Institute of Medicine). Dr. Berwick served two terms on the IOM's governing Council, was a member of the IOM's Global Health Board, and currently chairs the NAM Board on Health Care Services. He served on President Clinton's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry. His numerous awards include the 2007 William B. Graham Prize for Health Services Research, the 2006 John M. Eisenberg Patient Safety and Quality Award, and the 2007 Heinz Award for Public Policy. In 2005, he was appointed Honourary Knight Commander of the British Empire by Her Majesty Queen Elizabeth II, the highest honor in the UK for non-



UK citizens. He is the author or co-author of over 200 scientific articles and six books. He also serves now as Lecturer in the Department of Health Care Policy at Harvard Medical School.

Cathy J. Bradley, PhD

University of Colorado

Cathy J. Bradley, PhD, is the Associate Dean for Research in the Colorado School of Public Health and the Deputy Director of the University of Colorado 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.

Melinda B. Buntin, PhD

Vanderbilt University School of Medicine

Melinda B. Buntin, PhD is the Mike Curb Professor of Health Policy and founding chair of the Department of Health Policy at Vanderbilt University School of Medicine.

She was previously Deputy Director of Health, Retirement and Long-Term Analysis at the Congressional Budget Office where she evaluated legislative proposals and directed studies related to health care financing, including reports on prescription drugs under Part D, beneficiaries dually eligible for Medicare and Medicaid, and care coordination demonstrations. Prior to that, Dr. Buntin was deputy director of RAND Health's Economics, Financing, and Organization Program, director of Public Sector Initiatives for RAND Health, and co-director of the Bing Center for Health Economics. Her research at RAND focused on insurance benefit design, health insurance markets, provider payment, and the care use and needs of the elderly.

Dr. Buntin's work at Vanderbilt is focused on health care delivery and costs, with an emphasis on improving the value created by the health care system. She is also co-leading the Vanderbilt Policies 4 Action Research Hub, which is conducting research on ways to improve the health and education outcomes of low-income children. Dr. Buntin is an elected member of the National Academy of Medicine for which she currently serves on the Board on Health Care Services, and of the National Academy of Social Insurance. She is also the deputy editor of the new JAMA Health Forum, which launched in January 2020.

Dr. Buntin has an AB from Princeton and a PhD in Health Policy with a concentration in economics from Harvard.



Robert W. Carlson, MD

National Comprehensive Cancer Network

Robert W. Carlson, MD, is the Chief Executive Officer at the National Comprehensive Cancer Network (NCCN). He joined NCCN as CEO in January 2013 following an esteemed history of leadership positions within the organization including, most notably, Representative to the NCCN Board of Directors, Chair of the Breast Cancer Guidelines Panel, Member and Founding Chair of the Breast Cancer Risk Reduction Guidelines Panel, and Chair of the Survivorship Guidelines Panel.

Prior to his appointment as CEO at NCCN, Dr. Carlson served as Professor of Medicine in the Division of Oncology and Stanford Medical Informatics at Stanford University Medical Center, as well as Medical Director of inpatient oncology and hematology at Stanford Cancer Institute in California.

Dr. Carlson is a graduate of Stanford University Medical School, and he completed his internship and junior residency in internal medicine at Barnes Hospital Group in St. Louis before returning to Stanford University to complete his senior residency. He earned a Bachelor of Science with distinction from Stanford University, specializing in biological sciences. Dr. Carlson is board certified in Medical Oncology and Internal Medicine.

Steve Clauser, PhD, MPA

Patient-Centered Outcomes Research Institute

Steve Clauser, PhD, MPA, is the Program Director of the Healthcare Delivery and Disparities Research program at the Patient-Centered Outcomes Research Institute (PCORI). He is responsible for developing PCORI's research program that evaluates comparisons among alternative health system strategies to improve patient outcomes in a broad range of clinical and organizational domains.

Clauser is a health services and outcomes researcher with over 25 years of research management experience. His past research has focused on developing measures of patient reported outcomes, care experiences, and clinical effectiveness for use by health care organizations to track, assess, and improve the quality of care they provide to adults with cancer and other chronic diseases. Before coming to PCORI, Clauser held the positions of associate director for the National Cancer Institute's (NCI) Community Oncology Research Program, as well as chief of NCI's Outcomes Research Branch. He also was co-director of NCI's Community Cancer Centers Program, where he developed and managed a variety of research projects related to system strategies to improve cancer care delivery, including methods to increase adherence to evidence based practice and models of multidisciplinary treatment planning for patients requiring multi-modal cancer treatment. He has expertise in a broad range of research methodologies used for assessing patient reported outcomes and quality improvement programs.

Before NCI, Clauser served in a number of senior research management positions at the Centers for Medicare and Medicaid Services. His most recent position was director of the

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Quality Measurement and Health Assessment Group in the Office of Clinical Standards and Quality, where he directed CMS quality measurement research initiatives in support of Medicare's consumer quality reporting programs in managed care organizations, hospitals, nursing homes, home health agencies, and renal dialysis centers. He also served as director, operations policy directorate, in the Office of the Assistant Secretary for Health Affairs, where he directed the CHAMPUS Reform program to improve primary care for military dependents and retirees.

Clauser received his BA from Michigan State University, PhD from the University of Minnesota, and MPA from the Hubert H. Humphrey Institute in Minneapolis.

Gwen Darien, BA

National 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 PAF'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 cancer 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 <u>Community Engagement in Genomics Working Group</u> of the National Human Genome Research Institute; a member of the US Pharmacopeia Board of Trustees; and as the chair of PCORI's Patient Engagement Advisory Panel, Gwen also writes about her experiences. A recent piece, <u>Transformation: My Experience as a Patient and an Advocate in Three Chapters</u> 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. She grew up in Milwaukee, but now lives in New York City, where she cooks Persian dishes, collects earrings and improves her friends' personal libraries, one book at a time.

Nicole F. Dowling, PhD

Centers for Disease Control and Prevention

Nicole F. Dowling, PhD, is the Associate Director of Science at the Centers for Disease Control and Prevention. She is responsible for providing leadership, planning, and guidance to division management and staff on scientific policy, research methodology, and priorities for CDC's national cancer programs.

Dr. Dowling is an epidemiologist and committed leader in public health science with experience as a Branch Chief, Division Associate Director for Science, Team Lead, and researcher, and with over 20 years working in programs across the agency. Before joining the Division of Cancer Prevention and Control in 2018, She served as the Chief of the Developmental Disabilities Branch, in the National Center on Birth Defects and Developmental Disabilities, where she provided scientific leadership and oversight for CDC's surveillance and research programs for autism and other developmental disabilities, including the Autism and Developmental Disabilities Monitoring Network and the Study to Explore Early Development. Previously, as the Associate Director for Science for the Division of Congenital and Developmental Disorders from 2012-2015, Dr. Dowling worked collaboratively with experts within and outside the division to determine the optimal blood folate level for prevention of neural tube defects. These efforts supported the development of a World Health Organization Guideline for evidence-informed recommendations on blood folate concentrations in women of reproductive age for the prevention of neural tube defects in populations, and the publication detailing the work was awarded a 2015 Charles C. Shepard Science Award.

Additional contributions during her career at CDC have included direction of the population research program with the Office of Public Health Genomics, and research to understand the etiology and outcomes of clotting and bleeding disorders with the Division of Blood Disorders. Dr. Dowling completed her undergraduate education at Harvard University and received her PhD in Epidemiology from Emory University.

Stacey Fedewa, PhD, MPH

American Cancer Society

Stacey Fedewa, PhD, MPH, is an epidemiologist and Scientific Director in the Screening and Risk Factors Surveillance Team within the Data Sciences Department at the American Cancer Society (ACS). She is responsible for cancer screening and early detection research and examines disparities and access to cancer screening and the quality of it. She also examines how health policies and public health recommendations influence screening utilization and early detection. Fedewa's work has been used to inform national roundtables on colorectal cancer screening, HPV vaccination, and lung cancer. She has published over a 100 scientific articles, 4



book chapters, and several invited editorials. Fedewa received a BS and MPH from the University of Michigan and PhD from Emory University.

Eliot Fishman, PhD

Families USA

As Senior Director of Health Policy, Eliot Fishman leads Families USA's policy analysis and advocacy agenda development at the state and federal levels, working with the policy department and other members of senior leadership. In this capacity, he leads Families USA's analytical and policy development work regarding universal coverage, transformation of health care delivery and payment, and achieving equity in health care access and outcomes. He directs major initiatives defending Medicaid at the national and state level and seeking to leverage system transformation to drive health equity.

Prior to joining Families USA, he served at the Centers for Medicare and Medicaid Services (CMS) from 2013 to 2017. In that role, he led the federal government's work with states on Medicaid waivers and federal policy on the Children's Health Insurance Program (CHIP), and Medicaid and CHIP quality measurement, eligibility, and enrollment. CMS named Eliot its Executive of the Year in 2016 for his work leading Medicaid waiver negotiations regarding expansion, delivery system reform, and provider payment innovation. Prior to his work at CMS, Eliot served as Director of the Office of Policy in the New Jersey Department of Health, where he directed a large, complex portfolio including the Center for Health Statistics, Institutional Review Board, Office of Healthcare Quality Assessment, Office of Planning & Development for Senior Services, New Jersey Health Information Technology Commission, New Jersey Commission on Brain Injury Research and New Jersey Commission on Spinal Cord Research. He led the development of a pilot program in which over half of the state's newborns were automatically enrolled in health insurance before hospital discharge through the state's birth registry. He also was a Principal at Health Management Associates, a consulting firm specializing in health policy issues for low-income people, where he led a national practice focused on implementation of two major new programs for people with complex needs in the Affordable Care Act: Medicaid Health Homes program and the new Medicare-Medicaid Financial Alignment initiative. Before that, he worked as a Vice President in the Metropolitan Jewish Health System, a large, non-profit integrated delivery system in New York, where he developed a multi-million dollar portfolio of new programs and services from proposal stage into staffing and implementation in an integrated health and long-term care delivery system. He also has published extensively on health policy and health reform.

Sherry Glied, PhD

New York University

Since 2013, Sherry Glied has been Dean of New York University's Robert F. Wagner Graduate School of Public Service. From 1989-2013, she was Professor of Health Policy and Management at Columbia University's Mailman School of Public Health. From July 2010-August 2012, Glied served as Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services. She had previously served as Senior Economist on the President's Council of Economic Advisers in 1992-1993, under Presidents Bush and Clinton, and participated in the



Clinton Health Care Task Force. She has been elected to the National Academy of Medicine, the National Academy of Social Insurance, and served as a member of the Commission on Evidence-Based Policymaking.

Glied's principal areas of research are in health policy reform and mental health care policy. She is the author of *Chronic Condition* (Harvard University Press, 1998); *Better But Not Well: Mental Health Policy in the U.S. since 1950*, with Richard Frank (Johns Hopkins University Press, 2006) and co-editor, with Peter C. Smith, of *The Oxford Handbook of Health Economics* (Oxford University Press, 2011).

Glied is an economist. She holds a BA (Yale), an MA (University of Toronto), and a PhD (Harvard University).

Mike Herndon, DO

Oklahoma Health Care Authority

Mike Herndon, DO, is Chief Medical Officer at the Oklahoma Health Care Authority (OHCA), the administrator of SoonerCare (Oklahoma Medicaid). Prior to serving in this position, Dr. Herndon worked 20 years in private practice.

At OHCA, Dr. Herndon has led several significant agency initiatives. He designed and directed the agency's Disease Management Program and managed the Adult Medicaid Quality Grant, among others. Dr. Herndon developed and implemented the SoonerCare Pain Management Program, designed to assist practices with the application of evidence-based and standard-of-care treatment strategies for SoonerCare members treated for chronic pain.

Dr. Herndon is also a member of the Oklahoma Perinatal Quality Improvement Collaborative's leadership team. This is just one of numerous medical and civic committees and boards on which he has served, including two years as chairman of the Oklahoma Foundation for Medical Quality. A trusted expert in his field, Dr. Herndon currently serves as chair of the Oklahoma Prevention Leadership Collaborative Prescription Drug Planning Workgroup, an initiative of Governor Mary Fallin to reduce prescription drug abuse in Oklahoma. Dr. Herndon has served on the PCORI Board of Governors for over 2 years.

Additionally, Dr. Herndon is founder of two free community health clinics in the Oklahoma City area—the Hope Center in Edmond, Okla., and the Lighthouse Medical Clinic in Oklahoma City.

Dr. Herndon earned his medical degree from the Oklahoma State University College of Osteopathic Medicine and is board certified in family medicine.

Nicole Huberfeld, JD

Boston University

Nicole Huberfeld, JD, is an endowed Edward R. Utley Professor of Health Law, Ethics & Human Rights at Boston University. Her work is at the intersection of health law and constitutional law. She researches the law's impact on vulnerable populations through governance and policy choices

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made in health care, public health, and social programs, with particular interest in Medicaid and health reform. She is co-author of two casebooks and many book chapters, journal articles, and commentaries, including a five-year study of the early implementation of the ACA (What Is Federalism in Healthcare For?, Stanford Law Review, 2018, with Gluck). Her work has been cited in judicial opinions by the U.S. Supreme Court and other federal and state courts. In 2019, Huberfeld won the Excellence in Teaching Award (for teaching in the Core) at BUSPH. She has been quoted by media outlets such as New York Times, Bloomberg, NPR, Congressional Quarterly, Washington Post, National Law Journal, Mother Jones, Politico, Univision, Modern Healthcare, and Vice News.

Mimi Huizinga, MD, MPH, FACP

Novartis Oncology

Mary Margaret ("Mimi") Huizinga, MD, MPH, FACP, is the Vice President and Head, US Oncology Medical at Novartis. Dr. Huizinga leads clinical development and medical affairs for oncology in the US. Previously, she was VP of Strategic Data and Digital for US Oncology at Novartis where she supported the broader digital, data and real world evidence needs and Novartis's goal to go big on data and digital. Prior to joining Novartis, Dr. Huizinga was the Chief Health Information Officer at Premier, Inc., ensuring that Premier's products and services met the evolving needs of healthcare systems, and led Premier's Applied Science division. Dr. Huizinga also oversaw a collaborative of over 40 integrated delivery networks that were participating in alternative payment models. She led the development of a benchmarking approach that helped systems prioritize efforts to achieve success in these programs. Dr. Huizinga was named a core faculty in three of CMS's learning action networks for Pioneer ACOs, Next Generation ACOs and ESCOs (ESRD Seamless Care Organization). She was a member of various National Quality Forum (NQF) and PCPI committees.

Previously, she was the Medical Director for the Center of Health Promotion and Disease Management at Vanderbilt University where she promoted population health and shared data strategies and was a leader in informatics. Dr. Huizinga was the Vice President for Quality at LifePoint Hospitals and led the Hospital Engagement Network. At LifePoint, her efforts lead to a cultural change movement and have significantly reduced mortality, readmissions and patient harm while improving employee satisfaction. Dr. Huizinga has also worked as an Associate at McKinsey & Company's Washington, DC, office and as a faculty member at The Johns Hopkins University. She is a board-certified internist, a Fellow of the American College of Physicians and a part-time Assistant Professor of Medicine at The Johns Hopkins University School of Medicine.

Roy A. Jensen, MD

The University of Kansas Cancer Center

Dr. Jensen was appointed the director of The University of Kansas Cancer Center in 2004. As a result of a broad-based university, community and regional effort, The University of Kansas Cancer Center was designated as a cancer center by the National Cancer Institute in July 2012. Dr. Jensen is currently Professor of Pathology and Laboratory Medicine, Professor of Anatomy and Cell Biology, Professor of Cancer Biology, and the William R. Jewell, M.D. Distinguished Kansas Masonic Professor, at the University of Kansas Medical Center. Prior to his



appointment at Kansas, Jensen was a member of the Vanderbilt-Ingram Cancer Center and a faculty member in Pathology, Cell Biology, and Cancer Biology for 13 years.

Dr. Jensen graduated from Vanderbilt University School of Medicine in 1984, and remained there to complete a residency in Anatomic Pathology and a Surgical Pathology fellowship with Dr. David Page. Following his clinical training he accepted a postdoctoral fellowship at the National Cancer Institute in the laboratory of Dr. Stuart Aaronson. After joining the faculty at Vanderbilt University, Dr. Jensen's research interests focused on understanding the function of BRCA1 and BRCA2 and their role in breast neoplasia; and in the characterization of premalignant breast disease at both the morphologic and molecular levels. He currently has over 150 scientific publications and has lectured widely on the clinical and molecular aspects of breast cancer pathology.

Dr. Jensen has served on numerous grant review panels, study sections, and site visit teams for the NIH, the Department of Defense-Breast Cancer Research Program, the Medical Research Council of Canada, the California Breast Cancer Research Program, and the Susan G. Komen Breast Cancer Foundation. Jensen serves on the Science Policy and Governmental Affairs Committees for the American Association for Cancer Research (AACR) and the Federation of American Societies for Experimental Biology. In addition, he is a member of the AACR Pathology Task Force and AACR Publications Committee. He is a member of the Science Policy Working Group of the American Society for Investigative Pathology, and co-chaired the research committee for C-Change. In 2013, he was elected to the Board of Directors for the Association of American Cancer Institutes (AACI) and served as the president of AACI from 2018-2020. Jensen was chair of NCI's Subcommittee A from 2018-2020 and also served on the Director's Working Group for the Board of Scientific Advisors to the National Cancer Institute. Finally, he is the Chair of the University of Oklahoma Stephenson Cancer Center External Advisory Board.

Katie Keith, JD, MPH

Georgetown University

Katie Keith, JD, MPH, is an associate research professor at Georgetown University's Center on Health Insurance Reforms and teaches courses on the Affordable Care Act and LGBT health law and policy at Georgetown University Law Center. She provides "Following the ACA" rapid response analysis for *Health Affairs* where she is a contributing editor. She has written widely on topics that include the health insurance marketplaces, enforcement, and nondiscrimination, and her research and analysis has been featured in state and national media outlets across the country.

Katie also maintains an active consulting practice advising nonprofit and foundation clients. Her work includes an emphasis on implementation of the Affordable Care Act and its impact on underserved populations, such as the LGBT community. She is a co-founder and steering committee member of Out2Enroll, a national initiative to connect LGBT people with coverage options, and an appointed consumer representative to the National Association of Insurance Commissioners where she represents the interests of consumers in front of state insurance



regulators from all 50 states and DC. She also serves as a Scholar with the O'Neill Institute for National and Global Health Law.

Prior to joining the Georgetown faculty, Keith served as a health policy intern to Senator John D. Rockefeller (D-WV), an editor for *Global Health Governance*, and a Peace Corps volunteer in Ghana in West Africa. Keith received her law degree from the Georgetown University Law Center and holds a Master's in Public Health from Johns Hopkins University.

Anne C. Kirchhoff, PhD, MPH

University of Utah

Anne C. Kirchhoff, PhD, MPH is a tenured Associate Professor of Pediatrics at the University of Utah School of Medicine and a Huntsman Cancer Institute Investigator in the Cancer Control and Population Sciences Research Program. As a health services researcher, her program primarily concerns evaluating patient outcomes related to healthcare access and cancer late effects, and developing interventions for childhood, adolescent and young adult cancer survivors, with a focus on addressing the social and financial consequences of cancer. Dr. Kirchhoff leads a range of studies from interventions at Huntsman Cancer Institute and Primary Children's Hospital to statewide analyses of survivor outcomes using the Utah Population Database. Her research interests also include using large, population-based surveys to examine socioeconomic outcomes of cancer survivors. Dr. Kirchhoff has a strong history of funding as a Principal Investigator from both institutional grant support and external funding via the NIH and foundations, including a ongoing NCI R01 to develop and test insurance educational materials for adolescents and young adults with cancer.

Folasade (Fola) P. May, MD, PhD, MPhil

University of California, Los Angeles Veterans Health Administration

Dr. Folasade P. May is an Assistant Professor of Medicine at the University of California Los Angeles (UCLA), Director of the May Health Services Research Lab at UCLA, Director of Quality Improvement in Gastroenterology at UCLA Health and a gastroenterologist in the Veterans Health Administration. She graduated from Yale University with a degree in Molecular, Cellular, and Developmental Biology and then matriculated to the University of Cambridge (UK) where she obtained a Masters in Epidemiology. She attended Harvard Medical School and trained in internal medicine at Massachusetts General Hospital before relocating to Los Angeles, California where she completed a fellowship in gastroenterology and a PhD in Health Policy and Management from the UCLA Fielding School of Public Health.

Her research addresses challenges in access to preventive services nationally and internationally. In the UCLA Kaiser Permanente Center for Health Equity, the team engages in work to improve population health strategies, increase access to cancer screening and to eliminate health disparities at UCLA Health, in Federally Qualified Health Centers, and in the Veterans Affairs. She is passionate about improving awareness about preventive health and health equity and is involved in advocacy at the state and national level to develop and encourage policy to improve health care delivery and access to care. Dr. May is also an Assistant director of the Specialty



Training and Advanced Research training program at UCLA and a Director of Grants and Postgraduate Research for the UCLA Global Health Program

Barbara L. McAneny, MD, FASCO, MACP

New Mexico Oncology Hematology Consultants Ltd American Medical Association

Barbara L. McAneny, MD, a board-certified medical oncologist/hematologist from Albuquerque, N.M., became the 173rd president of the American Medical Association in June 2018. She has been a member of the AMA Board of Trustees since June 2010, serving as its chair in 2015-2016.

Dr. McAneny is a fellow and former member of the board of directors of the American Society of Clinical Oncology (ASCO), and a past president of the New Mexico Medical Society (NMMS), the Greater Albuquerque Medical Association and the New Mexico chapter of the American College of Physicians. In addition, she has served as a member of the Community Oncology Alliance Board of Trustees and on the board of directors of the Cancer Center Business Summit. She became the delegate to the AMA from ASCO in 2002, and was elected to the AMA Council on Medical Service in 2003, serving as its chair in 2009–2010.

Dr. McAneny is the founder and current chair of the board of the National Cancer Care Alliance, a group of independent practices collaborating to use innovation to deliver high-quality, high-value cancer care and to develop new alternative payment models based on sound data driven principles. Prior to this, she was a founding member of Oncology Circle, a group of oncology practices using data to promote best practices.

Dr. McAneny's interest in using data to improve practice sustainability began when she was appointed to the Centers for Medicare & Medicaid Service's Practicing Physicians Advisory Council, where she served from 2002 to 2006. In 2012, Dr. McAneny received a \$19.8 million grant from the Centers for Medicare & Medicaid Innovation to demonstrate how oncology practices could use triage pathways to dramatically lower costs while improving outcomes. This award, named COME HOME (for Community Oncology Medical Home), later was incorporated into Medicare's Oncology Care Model. Innovative Oncology Business Solutions Inc., the company she created to manage the award, is now assisting physician practices in developing the process changes needed for MACRA.

Dr. McAneny also co-founded New Mexico Oncology Hematology Consultants Ltd. in 1987 with Clark Haskins, MD. A managing partner since 1999 and currently CEO, she built New Mexico Cancer Center as the first physician-owned multi-disciplinary cancer center in the state with clinics in Albuquerque and Gallup. She also founded the New Mexico Cancer Center Foundation, which provides grants to help patients with nonmedical expenses.

Dr. McAneny graduated magna cum laude from the University of Minnesota in 1973 and with honors from the University of Iowa College of Medicine in 1977. She completed her residency in internal medicine at the University of Iowa in 1980 and her fellowship in hematology/oncology



at the University of New Mexico in 1983. She is married to Steven Kanig, MD, a nephrologist and chair of the New Mexico AMA delegation.

Neal J. Meropol, MD

Flatiron Health

Neal J. Meropol, MD is a medical oncologist, clinical investigator and outcomes researcher who serves as Vice President and Head of Medical and Scientific Affairs at Flatiron Health. In this role, he leads efforts and engages partners to leverage Flatiron's technology platforms and provider network to gain insights from real world data that accelerate research and improve quality of care for cancer patients. Prior to joining Flatiron, he served as Professor and Chief of the Division of Hematology and Oncology at University Hospitals Cleveland Medical Center and Case Western Reserve University, and Associate Director for Clinical Research at the Case Comprehensive Cancer Center.

Dr. Meropol's research contributions span drug development and health services research, including evaluation of new agents, predictors of response and outcome, development of tools to overcome barriers to clinical trial participation, and assessment of the economic impact of care. He is an appointed member to the NCI Director's Clinical Trials and Translational Research Advisory Committee (CTAC), and served two terms as Chair of the National Cancer Institute Gastrointestinal Cancer Steering Committee. Dr. Meropol completed a four-year term as an elected member of the American Society of Clinical Oncology (ASCO) Board of Directors. A committed educator, Dr. Meropol served as faculty and chair of the AACR/ASCO Methods in Clinical Research Vail Workshop, and ASCO Leadership Development Program. He has authored more than 300 manuscripts, book chapters, and editorials related to cancer prevention, treatment, decision making, and health economics.

Dr. Meropol received his undergraduate degree from Princeton University in Philosophy, and MD from Vanderbilt University. He was a resident in Internal Medicine at Case Western Reserve University, and completed hematology and medical oncology fellowships at the University of Pennsylvania. He spent a sabbatical at the Leonard Davis Institute of Health Economics at the Wharton School of the University of Pennsylvania.

Randall A. Oyer, MD

Penn Medicine Lancaster General

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 (Cancer Genetics) 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 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.

Elyse R. Park, PhD, MPH, FAPOS

Massachusetts General Hospital/Harvard Medical School

Dr. Park is a clinical health psychologist and health services researcher who focuses on understanding and improving health-related behaviors among cancer survivors and populations at risk for cancer. A Professor of Psychiatry at Massachusetts General Hospital/Harvard Medical School, her research is conducted at the MGH Mongan Institute, Health Policy Research Center. She is Associate Director of the MGH Cancer Center Survivorship Program and the Director of the MGH Division of Clinical Research's Qualitative and Mixed Methods Unit. Over the past decade she has conducted research on the health behaviors, mental health care utilization, and health insurance coverage of childhood cancer survivors. She conducted a national survey and documented underinsurance, lack of understanding of the ACA, and financial distress among childhood survivors. This is critical, as young survivors often face continued health care challenges and require preventive healthcare and ongoing care to monitor and treat long-term effects of their cancer and treatment. She received funding from the American Cancer Society to develop a patient-navigation intervention to assist childhood survivors to learn how to access and utilize their health insurance coverage. This intervention is being piloted, with outcomes to increase health literacy and decrease financial distress among cancer survivors.

Lori Pierce, MD

American Society of Clinical Oncology University of Michigan

Dr. Lori Pierce attended Duke University School of Medicine and completed a Radiation Oncology residency and chief residency at the Hospital of the University of Pennsylvania. She then was appointed as a Senior Investigator at the National Cancer Institute, National Institutes of Health in Bethesda, MD from 1990-1992. In 1992, Dr. Pierce joined the faculty of the University of Michigan where she is currently Professor with tenure in Radiation Oncology. Since coming to Michigan, she has served as residency director and clinical director in the Department of Radiation Oncology. In August 2005, Dr. Pierce was appointed by the University of Michigan Board of Regents to be Vice Provost for Academic and Faculty Affairs, a position she still holds.

Dr. Pierce has dedicated her career to the treatment of breast cancer patients. Her research focuses on the use of radiotherapy in the multi-modality treatment of breast cancer, with emphasis on intensity modulated radiotherapy in node positive breast cancer, the use of radiosensitizing agents, and the outcomes of women treated with radiation for breast cancer who are carriers of a BRCA1/2 breast cancer susceptibility gene. She serves as Director of the Michigan Radiation Oncology Quality Consortium (MROQC), a quality consortium of radiation oncology practices across the state of Michigan that seeks to establish best practices in the treatment of breast and lung cancers. This initiative is funded by Blue Cross Blue Shield of Michigan and Blue Care Network. She is a previous member of the NCI Breast Cancer Steering



Committee and previously served on the Steering Committee for the Early Breast Cancer Trialists' Collaborative Group at the University of Oxford. She continues to serve on many U.S. breast cancer boards and committees and was recently selected to be a member of the Breast Cancer Research Foundation Scientific Advisory Board.

Dr. Pierce has published over 200 manuscripts and book chapters and has received numerous teaching awards from the University of Michigan and multiple national organizations. Honors include receipt of the European Society of Therapeutic Radiology and Oncology travel award, the American Medical Association Women Physician Mentor Award, the American Association for Women Radiologists' Marie Curie Award, the Conquer Cancer Foundation Endowed Women Who Conquer Cancer Mentorship Award, and selection as a Susan G. Komen for the Cure Scholar. Most recently, Dr. Pierce was elected to the National Academy of Medicine, Class of 2018. She was also selected as the 2019 Woman of the Year by the United Way of Washtenaw County in Michigan. In 2018, she was elected president-elect of the American Society of Clinical Oncology, the largest organization of oncology professionals in the world, and is currently serving as president.

Dave Richard, BA

North Carolina Department of Health and Human Services

Dave Richard is the Deputy Secretary, NC Medicaid, where he leads North Carolina's \$14 billion Medicaid and NC Health Choice programs for the state's Department of Health and Human Services (DHHS). Richard's vision for Medicaid is to ensure a sustainable, personcentered and innovative Medicaid program for more than two million North Carolinians who use Medicaid. As the programs undergo transformation to even better fit the needs of state and its residents, he is committed to the fundamental goal of improving the health and well-being of all residents. Richard believes the right way to achieve success is to work closely with stakeholders in all aspects of Medicaid.

Prior to leading Medicaid, Richard was the Deputy Secretary for DHHS Behavioral Health and Developmental Disability Services and the State Operated Healthcare Facilities divisions. He joined DHHS in May 2013 as the Director of the Division of Mental Health, Intellectual and Developmental Disabilities and Substance Abuse Services. Richard joined DHHS after leading The Arc of North Carolina, an advocacy and service organization for people with intellectual and developmental disabilities, as its Executive Director for 24 years. Richard has a bachelor's degree in education from Louisiana State University.

Trish Riley, MS

National Academy for State Health Policy

Trish Riley is Executive Director of the National Academy for State Health Policy and president of its corporate Board. She helped build NASHP as CEO from 1988-2003.

Previously, she was a Distinguished Fellow in State Health Policy at George Washington University and taught in the graduate program at the Muskie School of Public Service, University of Southern Maine. From 2003-2011 she served as Director of the Governor's Office of Health



Policy and Finance, leading the effort to develop a comprehensive, coordinated health system in Maine including access to affordable health insurance. She was the principal architect of Dirigo Health Reform and served as the state's liaison to the federal government and Congress, particularly during deliberations around national health reform. She chaired the Governor's Steering Committee to develop a plan to implement the Affordable Care Act in Maine. Riley has also held appointive positions under five Maine governors – directing the aging office, Medicaid and state health agencies, and health planning and licensing programs.

Riley has published and presented widely about state health reform. She served as a member of the Kaiser Commission on Medicaid and the Uninsured, and serves at the Institute of Medicine's Board on Health Care Services, the National Academy for Social Insurance where she cochaired the Study Panel on Medicaid and the Culture of Health, Board of Directors of Maine's Co-Op insurance plan. She was a founding member of the Medicaid and CHIP Payment and Access Commission (MACPAC), served on the Institute of Medicine's Subcommittee on Creating an External Environment for Quality and was a member of the Board of Directors of the National Committee on Quality Assurance. Riley holds a BS & MS from the University of Maine.

Shreya Roy, PhD

Oregon Health & Science University

Shreya Roy, PhD, is the Assessment and Evaluation Research Associate at the Oregon Center for Children and Youth with Special Health Needs, the state's Title V block grant agency for children and youth with special health care needs (CYSHCN) at the Institute of Development & Disability, Oregon Health & Science University (OHSU). Her research interests include mixed-methods designs for program and policy evaluation. She is currently involved in projects which support Oregon children with medical complexity and their families to transition from pediatric to adult healthcare.

Lindsay Sabik, PhD

University of Pittsburgh

Dr. Lindsay Sabik is an Associate Professor in the Department of Health Policy and Management in the University of Pittsburgh Graduate School of Public Health, a Member of the UPMC Hillman Cancer Center, and Director of the Workgroup on Cancer Health Services Research within the Pitt Health Policy Institute. Dr. Sabik is a health economist and health services researcher focused on investigating the impact of state and federal policies on healthcare access, utilization, and health outcomes among historically underserved populations, with a focus on cancer care. Recent projects examining the role of state health policy in access to cancer screening, timely diagnosis, and treatment have been funded by the National Cancer Institute, the Agency for Healthcare Research and Quality, and the American Cancer Society. She received her PhD in Health Policy, with a focus in health economics, from Harvard University.

Cleo Samuel-Ryals, PhD

University of North Carolina, Chapel Hill



Cleo A. Samuel-Ryals 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. She is also the Director of the Centering Racial Equity in Data Science (CREDS) Initiative at the UNC Lineberger Comprehensive Cancer Center. Dr. Samuel-Ryals 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-Ryals 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-Ryals was honored as a '40 Under 40' Leader in Minority Health by the National Minority Quality Forum and Congressional Black Caucus.

Dr. Samuel-Ryals 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.

Deborah Schrag, MD, MPH

Dana-Farber Cancer Institute Harvard Medical School

Deb Schrag, MD, MPH, is Chief of the Division of Population Sciences at Dana Farber Cancer Institute and Professor of Medicine at Harvard Medical School in Boston, MA. She is a health services researcher and gastrointestinal medical oncologist with focus on colorectal cancer. Her research focuses on improving the quality, effectiveness and cost-effectiveness of cancer care delivery. She leads the Harvard Program in Cancer Care Delivery Research, is the PI of several multi-center trials and leads efforts to develop data standards to characterize outcomes of cancer treatment at population-scale. She has performed foundational work in patient-reported outcomes and building phenomic data standards to systematically measure outcomes from electronic health records. Dr. Schrag is an Associate Editor of the Journal of the American Medical Association, a fellow of the American Society of Clinical Oncology and a former Board of Director, a past member of the National Cancer Policy Forum and an elected member of the American Association of Physicians.

Kathleen Sebelius, BA, MPA

Former Secretary, Department of Health and Human Services Sebelius Resources LLC

Kathleen Sebelius has been engaged in health policy for decades in the public and private sectors. She served in President Obama's cabinet at HHS Secretary and was elected statewide four times in Kansas as Governor and Insurance Commissioner.

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Currently, Sebelius is the CEO of Sebelius Resources LLC. She serves on the boards of directors of Devoted Health, Exact Sciences, Myovant Sciences, and several private health sector interests. She continues policy work with the Kaiser Family Foundation and co-leads the Health Strategy Group for the Aspen Institute.

Sebelius lives in Lawrence, Kansas, with her husband, Gary. They have two married sons and four grandchildren.

Ellen V. Sigal, PhD

Friends of Cancer Research

Ellen V. Sigal, PhD, is Chairperson and Founder of Friends of Cancer Research (*Friends*), an advocacy organization based in Washington, DC working to accelerate policy change, support groundbreaking science, and deliver new therapies to patients.

Dr. Sigal also serves in a variety of prominent leadership roles including: Chair of the Reagan-Udall Foundation for the FDA, the Board of the Foundation for the National Institutes of Health, and the Board of the COVID-19 Evidence Accelerator – a partnership between the Reagan-Udall Foundation and Friends of Cancer Research with participation from the FDA. Dr. Sigal has been appointed twice to the Board of Governors of the Patient-Centered Outcomes Research Institute as a representative of patients and health consumers.

Additionally, Dr. Sigal was named to President-Elect Biden's Cancer Moonshot Blue Ribbon Panel, to the Parker Institute for Immunotherapy Advisory Group, and the inaugural board of advisors for the George Washington University Milken Institute of Public Health.

Kosali Simon, PhD

Indiana University
National Bureau of Economic Research

Dr. Kosali Simon joined O'Neill as a professor in 2010. In 2016 she was named a Herman B. Wells Endowed Professor, becoming only the third recipient of this honor at Indiana University. In 2019 she was appointed Associate Vice Provost (AVP) for Health Sciences at IUB. Simon is a nationally known health economist who specializes in applying economic analysis in the context of health insurance and health care policy. Her current research mainly focuses on the impact of health insurance reform on healthcare and labor market outcomes, and on the causes and consequences of the opioid crisis. She is also active in national leadership roles in her profession, serving on several boards and in editorial positions. A summary of her recent research appears in the 2018 National Bureau of Economic Research Reporter.

Simon is a research associate of the National Bureau for Economic Research, a group with which she has been affiliated since 2002. She serves as a member of the governing body of the Association for Public Policy Analysis and management (APPAM). From 2009-2016, she served

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as a board member of the American Society of Health Economists; from 2014-2017 she served as a board member of the American Economic Association (AEA)'s Committee on the Status of Women in Economics (CSWEP), and directed the national mentoring program for female assistant professors in economics. She also served a three-year term with the nation's largest health philanthropy, the Robert Wood Johnson Foundation (RWJF); in 2013, she was selected to the National Advisory Committee of RWJF Health Policy Scholars Program, a committee composed of 13 nationally recognized experts in social science and health policy. In 2007, Simon was recognized for her early contributions to health services research as the recipient of the John D. Thompson Prize for Young Investigators.

Related to editorial roles, she is Editor for the Journal of Health Economics, Co-Editor of Journal of Human Resources and editorial board member for the American Journal of Health Economics and the Journal of Policy Analysis and Management. She is former Associate Editor of Health Economics (2009-2018) and former co-editor of Journal of Policy Analysis and Management (2010-2015).

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, D.C. Ms. Strawbridge earned her MPH from Johns Hopkins Bloomberg School of Public Health.

Freddie White-Johnson, MPPA

Mississippi Network for Cancer Control and Prevention

Freddie White-Johnson is the Program Director for the Mississippi Network for Cancer Control and Prevention at the University of Southern Mississippi. The network is designed to build on an established community and institutional capacity in order to eliminate cancer health disparities by conducting community-based participatory education, training, and research. She recognized that the traditional healthcare system was more oriented toward treatment than prevention, and because of that, she spearheaded the development of a stakeholder collaboration that led to the founding of the Fannie Lou Hamer Cancer Foundation in 2004, which is a 501(c)3 nonprofit community-based organization. She is responsible for raising more than \$100,000 to purchase five acres of land in Ruleville, Mississippi, which will be used to build the foundation's headquarters. In April 2014, she secured \$300,000 from the state of Mississippi to help with the construction of the foundation; and in July 2014, she made history when she created and launched the first civil rights historic license plate in the state of Mississippi in commemoration of a civil rights leader, Fannie Lou Hamer, who died from untreated breast



cancer. This license plate was approved by the Mississippi legislature and signed into law on April 22, 2015.

White-Johnson served as a member of the Advisory Panel on Patient Engagement from August 2017 to August 2020.

Robert Winn, MD

Virginia Commonwealth University

Robert Winn, MD, 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.

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 200 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 *JCO Oncology Practice*. Dr. Yabroff has received multiple National Institutes of Health Merit Awards for her research leadership and mentorship.



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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Workshops and Publications

Impact of the Affordable Care Act on Cancer Prevention and Cancer Care

March 1-2, 2021

This workshop will examine the evidence base on how the Patient Protection and Affordable Care Act (ACA) has altered the landscape of cancer prevention and care delivery. The workshop will feature invited presentations and discussions on topics such as:

- The effects of coverage expansions under the ACA on access to cancer care, patient outcomes, and health disparities.
- The impact of new organizational infrastructure and their relevance to cancer research.
- The effects of payment reform demonstration projects 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.

Workshop website here.



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, examined the array of short- and long-term toxicities and adverse effects that patients may experience as a result of cancer treatment and considered opportunities to improve quality of life for cancer survivors and their families.

Workshop videos and presentation files here.

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 — sponsored by the Food and Drug Administration — examined challenges and opportunities to improve the evidence base for treating older adults with cancer. Presentations and panel discussions examined the root causes that limit enrollment of older adults in cancer clinical trials and strategies for improved inclusion of older adults across the drug development continuum.

Workshop videos and presentations here.

Drug Research and Development for Adults Across the Older Age Span

August 5-6, 2020

This workshop follows an earlier event on on the same topic, held in 2019. Stakeholders were convened 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 videos and presentations here.

Proceedings here.

Workshops and Publications

Opportunities and Challenges for Using Digital Health Applications in Oncology

July 13-14, 2020

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 patient-facing technologies; regulatory priorities; ethical, security, governance, and payment considerations; and opportunities to improve data availability and use in EHRs and large databases.

Workshop videos and presentation files here.



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

March 2-3, 2020

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 here.

Proceedings here.

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

October 28-29, 2019

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 here.

Proceedings here.

Health Literacy and Communications Strategies in Oncology

July 15-16, 2019

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 here.

Proceedings here.

Workshop overview here.

Workshop highlight videos here and here.

Developing and Sustaining an Effective and Resilient Oncology Careforce

February 11-12, 2019

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 here.

Proceedings here.

Workshop overview here.

FORUM SPONSORS

- Centers for Disease Control and Prevention
- National Institutes of Health/National Cancer Institute
- American Association for Cancer Research
- American Cancer Society
- American College of Radiology
- American Society of Clinical Oncology
- Association of American Cancer Institutes
- Association of Community Cancer Centers
- Bristol-Myers Squibb
- Cancer Support
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- CEO Roundtable on Cancer
- · Flatiron Health
- Merck
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- Oncology Nursing Society
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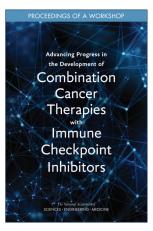
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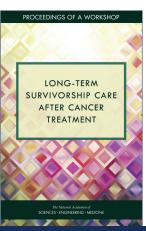
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WORKSHOP PROCEEDINGS AND RELATED PUBLICATIONS







WORKSHOP PROCEEDINGS

2021

Improving the Evidence Base for Treatment Decision-Making for Older Adults with Cancer: Proceedings in Brief (In Process)

Drug Research and Development for Adults Across the Older Age Span: Proceedings of a Workshop

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

Addressing the Adverse Consequences of Cancer Treatment: Proceedings of a Workshop (In Process)

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

2020

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

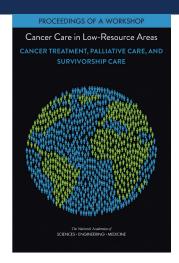
2017

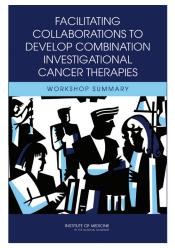
The Drug Development Paradigm in Oncology: Proceedings of a Workshop

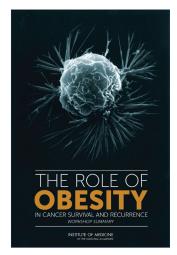
Cancer Care in Low-Resource Areas: Cancer Treatment, Palliative Care, and Survivorship Care: Proceedings of a Workshop

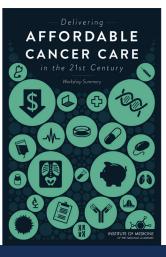
Implementation of Lung Cancer Screening: Proceedings of a Workshop

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









WORKSHOP PROCEEDINGS

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

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

 $\hbox{Multi-Center Phase III Clinical Trials and the NCI Cooperative Group Program: Workshop Summary} \\$

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)

Report: nap.edu/catalog/21860

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

Report: nap.edu/catalog/21841

Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013) Report: nap.edu/catalog/18359 Evolution of Translational Omics: Lessons Learned and the Path Forward (2012)
Report: nap.edu/catalog/13297

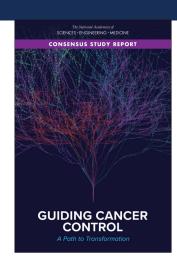
A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program (2010) Report: nap.edu/catalog/12879

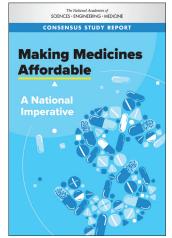
Evaluation of Biomarkers and Surrogate Endpoints in Chronic Disease (2010) Report: nap.edu/catalog/12869

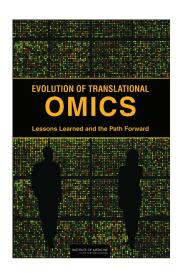
Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research (2009)

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:

2020

- Housten, A.J., C.M. Gunn, M.K. Paasche-Orlow, and K.M. Basen-Engquist. 2020. Health Literacy Interventions in Cancer: A Systematic Review. J Canc Educ. In Press.
- Schilsky, R.L., S. Nass, M.M. Le Beau, and E.J. Benz, Jr. 2020. Progress in Cancer Research, Prevention and Care. N Engl
 J Med. https://www.nejm.org/doi/full/10.1056/NEJMp2007839?query=featured_home.
- Shulman, L. N., L. K. Sheldon, and E. J. Benz. 2020. The Future of Cancer Care in the United States—Overcoming Workforce Capacity Limitations. JAMA Oncology. doi:10.1001/jamaoncol.2019.5358 https://jamanetwork.com/journals/jamaoncology/article-abstract/2758839
- Panagiotou, O. A., L. Hoffman-Högg, H. Hricak, S. N. Khleif, M. A. Levy, D. Magnus, M. J. Murphy, B. Patel, R. A. Winn, S. J. Nass, C. Gatsonis, and C. R. Cogle. 2020. Clinical Application of Computational Methods in Precision Oncology: A Review. JAMA Oncol. https://jamanetwork.com/journals/jamaoncology/article-abstract/2765757
- Takvorian, S. U., E. Balogh, S. Nass, V. L. Valentin, L. Hoffman-Hogg, R. A. Oyer, R. W. Carlson, N. J. Meropol, L. K. Sheldon, and L. N. Shulman. 2019. Developing and Sustaining an Effective and Resilient Oncology Careforce: Opportunities for Action. J Natl Cancer Inst. https://pubmed.ncbi.nlm.nih.gov/31868912/

2019

- Balogh, E. P., A. B. Bindman, S. G. Eckhardt, S. Halabi, R. D. Harvey, I. Jaiyesimi, R. Miksad, H. L. Moses, S. J. Nass,
 R. L. Schilsky, S. Sun, J. M. Torrente, and K. E. Warren. 2019. Challenges and opportunities to updating prescribing information for longstanding oncology drugs. The Oncologist 24: 1-7. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7066705/.
- Takvorian, S. U., E. Balogh, S. Nass, V. L. Valentin, L. Hoffman-Högg, R. A. Oyer, R. W. Carlson, N. J. Meropol, L. K. Sheldon, and L. N. Shulman. 2019. Developing and sustaining an effective and resilient oncology careforce: Opportunities for action, Journal of the National Cancer Institute, djz239, https://doi.org/10.1093/jnci/djz239 https://academic.oup.com/jnci/advance-article/doi/10.1093/jnci/djz239/5685814.
- Kline, R. M., G. B. Rocque, E. A. Rohan, K. A. Blackley, C. A. Cantril, M. L. Pratt-Chapman, H. A. Burris, and L. N. Shulman. 2019. Patient navigation in cancer: The business case to support clinical needs. Journal of Oncology Practice. Epub ahead of print JOP.1900230. https://www.ncbi.nlm.nih.gov/pubmed/31509483.
- Lubejko, B. G., C. Cantril, L. H. Hogg, and L. Kennedy Sheldon. 2019. Novice oncology nurse navigator: Core elements in establishing training needs and building on competencies. Clinical Journal of Oncology Nursing 23(4):387-394. https://www.ncbi.nlm.nih.gov/pubmed/31322621.

2019, continued

- Nass, S. J., M.B. Cohen, R. Nayar, M.M. Zutter, E. P. Balogh, R. L. Schilsky, H. Hricak, and K.S.J. Elenitoba-Johnson. 2019. Improving cancer diagnosis and care: Patient access to high-quality oncologic pathology. The Oncologist. https://www.ncbi.nlm.nih.gov/pubmed/31366725.
- Lopez, D., M. L. Pratt-Chapman, E. A. Rohan, L. K. Sheldon, K. Basen-Engquist, R. Kline, L. N. Shulman, and E. J. Flores. 2019. Establishing effective patient navigation programs in oncology. Supportive Care in Cancer 27(6):1985-1996. https://www.ncbi.nlm.nih.gov/pubmed/30887125.
- Nass, S. J., C. R. Cogle, J. A. Brink, C. P. Langlotz, E. P. Balogh, A. Muellner, D. Siegal, R. L. Schilsky, and H. Hricak. Improving cancer diagnosis and care: Patient
 access to oncologic imaging expertise. Journal of Clinical Oncology, JCO.18.01970. https://www.ncbi.nlm.nih.gov/pubmed/31050908.

2018

- Kline, R. M., N. K. Arora, C. J. Bradley, E. R. Brauer, D. L. Graves, N. Buchanan Lunsford, M. S. McCabe, S. F. Nasso, L. Nekhlyudov, J. H. Rowland, R. M. Schear, and P. A. Ganz. Long-term survivorship care after cancer treatment—summary of a 2017 National Cancer Policy Forum workshop. Journal of the National Cancer Institute 110, 110(12):1300-1310. https://www.ncbi.nlm.nih.gov/pubmed/30496448.
- Nass, S. J., M. Rothenberg, R. Pentz, H. Hricak, A. Abernethy, K. Anderson, A. W. Gee, R.D. Harvey, S. Piantadosi, M. M. Bertagnolli, D. Schrag, and R. L. Schilsky. Accelerating anticancer drug development—opportunities and trade-offs. Nature Reviews Clinical Oncology 15(12):777-786. https://www.ncbi.nlm.nih.gov/pubmed/30275514.
- Demark-Wahnefried, W., K. H. Schmitz, C. M. Alfano, J. R. Bail, P. J. Goodwin, C. A. Thomson, D. W. Bradley, K. S. Courneya, C. A. Befort, C. S. Denlinger, J. A. Ligibel, W. H. Dietz, M. R. Stolley, M. L. Irwin, M. M. Bamman, C. M. Apovian, B. M. Pinto, K. Y. Wolin, R. M. Ballard, A. J. Dannenberg, E. G. Eakin, M. M. Longjohn, S. D. Raffa, L. L. Adams-Campbell, J. S. Buzaglo, S. J. Nass, G. M. Massetti, E. P. Balogh, E. S. Kraft, A. K. Parekh, D. M. Sanghavi, G. S. Morris, and K. Basen-Engquist. 2018. Weight management and physical activity throughout the cancer care continuum. CA: A Cancer Journal for Clinicians 68(1):64-89. https://www.ncbi.nlm.nih.gov/pubmed/29165798.

2017

- Basen-Engquist, K., C. M. Alfano, M. Maitin-Shepard, C. A. Thomson, K. H. Schmitz, B. M. Pinto, K. Stein, D. S. Zucker, K. L. Syrjala, E. Fallon, C.
 Doyle, and W. Demark-Wahnefried. 2017. Agenda for translating physical activity, nutrition, and weight management interventions for cancer survivors into clinical and community practice. Obesity (Silver Spring) 25(Suppl 2):S9-S22. https://www.ncbi.nlm.nih.gov/pubmed/29086526.
- Smith, G. L., P. A. Ganz, J. E. Bekelman, S. J. Chmura, J. J. Dignam, J. A. Efstathiou, R. Jagsi, P. A. Johnstone, M. L. Steinberg, S. B. Williams, J. B. Yu, A. L. Zietman, R. R. Weichselbaum, and Y.-C. Shih. 2017. Promoting the appropriate use of advanced radiation technologies in oncology: Summary of a National Cancer Policy Forum workshop. International Journal of Radiation Oncology Biology Physics 97(3):450-461. https://www.ncbi.nlm.nih.gov/pubmed/28011046.

2016

• Kirch, R., G. Reaman, C. Feudtner, L. Wiener, L. A. Schwartz, L. Sung, and J. Wolfe. 2016. Advancing a comprehensive cancer care agenda for children and their families: Institute of Medicine workshop highlights and next steps. CA: A Cancer Journal for Clinicians 66(5):398-407. https://www.ncbi.nlm.nih.gov/pubmed/27145249.

2015

Nass, S. J., L. K. Beaupin, W. Demark-Wahnefried, K. Fasciano, P. A. Ganz, B. Hayes-Lattin, M. M. Hudson, B. Nevidjon, K. C. Oeffinger, R. Rechis, L. C. Richardson, N. L. Seibel, and A. W. Smith. 2015. Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine workshop. Oncologist 20(2):186-195. https://www.ncbi.nlm.nih.gov/pubmed/25568146.

2014

- Bertagnolli, M. M., R. Canetta, and S. J. Nass. 2014. Expanding public-private collaborations to enhance cancer drug development: A Report of the Institute of Medicine's workshop series, "Implementing a National Cancer Clinical Trials System for the 21st Century." Oncologist 19(11):1179-1185. https://www.ncbi.nlm.nih.gov/pubmed/25326161.
- Balogh, E. P., C. Dresler, M. E. Fleury, E. R. Gritz, T. J. Kean, M. L. Myers, S. J. Nass, B. Nevidjon, B. A. Toll, G. W. Warren, and R. S. Herbst. 2014. Reducing tobacco-related cancer incidence and mortality: Summary of an Institute of Medicine workshop. Oncologist 19(1):21-31. https://www.ncbi.nlm.nih.gov/pubmed/24304712.
- Ferrell, B. R., T. J. Smith, L. Levit, and E. Balogh. 2014. Improving the quality of cancer care: Implications for palliative care. Journal of Palliative Medicine 17(4):393-399. https://www.ncbi.nlm.nih.gov/pubmed/24548217.

2013

- Ramsey, S. D., P. A. Ganz, V. Shankaran, J. Peppercorn, and E. Emanuel. 2013. Addressing the American health-care cost crisis: Role of the oncology community. Journal of the National Cancer Institute 105(23):1777-1781. https://www.ncbi.nlm.nih.gov/pubmed/24226096.
- Balogh, E. P., P. B. Bach, P. D. Eisenberg, P. A. Ganz, R. J. Green, J. C. Gruman, S. J. Nass, L. N. Newcomer, S. D. Ramsey, J. E. Schottinger, and Y. T.
 Shih. 2013. Practice-changing strategies to deliver affordable, high-quality cancer care: Summary of an Institute of Medicine workshop. Journal of Oncology Practice 9(6s):54s-59s. https://www.ncbi.nlm.nih.gov/pubmed/29431037.

2012

- Demark-Wahnefried, W., E. A. Platz, J. A. Ligibel, C. K. Blair, K. S. Courneya, J. A. Meyerhardt, P. A. Ganz, C. L. Rock, K. H. Schmitz, T. Wadden, E. J. Philip, B. Wolfe, S. M. Gapstur, R. Ballard-Barbash, A. McTiernan, L. Minasian, L. Nebeling, and P. J. Goodwin. 2012. The role of obesity in cancer survival and recurrence. Cancer Epidemiology, Biomarkers & Prevention 21(8):1244-1259. https://www.ncbi.nlm.nih.gov/pubmed/22695735.
- LoRusso, P. M., R. Canetta, J. A. Wagner, E. P. Balogh, S. J. Nass, S. A. Boerner, and J. Hohneker. 2012. Accelerating cancer therapy development: The importance of combination strategies and collaboration. Summary of an Institute of Medicine workshop. Clinical Cancer Research 18(22):6101-6109. https://www.ncbi.nlm.nih.gov/pubmed/23065428.

2011

- Nass, S. J., E. Balogh, and J. Mendelsohn. 2011. A national cancer clinical trials network: Recommendations from the Institute of Medicine. American Journal of Therapeutics 18(5):382-391. https://www.ncbi.nlm.nih.gov/pubmed/21326081.
- Balogh, E. P., P. A. Ganz, S. B. Murphy, S. J. Nass, B. R. Ferrell, and E. Stovall. 2011. Patient-centered cancer treatment planning: Improving the quality of oncology care. Summary of an Institute of Medicine workshop. Oncologist 16(12):1800-1805. https://www.ncbi.nlm.nih.gov/pubmed/22128118.

2010

• Altshuler, J. S., E. Balogh, A. D. Barker, S. L. Eck, S. H. Friend, G. S. Ginsburg, R. S. Herbst, S. J. Nass, C. M. Streeter, and J. A. Wagner. 2010. Opening up to precompetitive collaboration. Science Translational Medicine 2(52):52cm26. https://www.ncbi.nlm.nih.gov/pubmed/20926831.

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Board on Health Sciences Policy Board on Health Care Services

Changing the Culture of Data Management and Sharing: A Workshop

April 28-29, 2021

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:
 - o 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
 - o 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.



Cancer Research and Care in the Context of the COVID-19 Pandemic: A Workshop on Lessons Learned National Cancer Policy Forum

July 26-27, 2021 Virtual

Project Overview

A National Academies of Sciences, Engineering, and Medicine planning committee will organize and host a 1.5-day virtual, public workshop that will examine changes in cancer research and care that occurred in response to the COVID-19 pandemic, and consider lessons learned from that experience in order to improve the conduct of cancer research and the delivery of high-quality cancer care in the post-pandemic era. The workshop will feature invited presentations and panel discussions on topics that may include:

- A review of practice changes, such as increased use of telehealth, that were implemented in response to the pandemic, and their impact on cancer research and care.
- Opportunities and strategies to retain and build on beneficial changes that
 - Advance the delivery of high-quality cancer care (e.g., by improving patient-centeredness, accessibility, equity, and affordability).
 - o Improve the conduct of clinical cancer research (e.g., by facilitating inclusive, community-based clinical trials, leveraging digital tools and technologies).
- Policy and regulatory modifications that would be needed to continue beneficial changes in practice.

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