

Enabling 21st Century Applications for Cancer Surveillance through Enhanced Registries and Beyond A National Cancer Policy Forum Workshop



A WORKSHOP

NATIONAL ACADEMIES Sciences
Engineering
Medicine

Enabling 21st Century Applications for
Cancer Surveillance Through
Enhanced Registries and Beyond

Monday, July 29 • 8:30AM – 5:30PM ET
Tuesday, July 30 • 8:30AM – 11:30AM ET

*The Keck Center – Room 100
500 5th Street, NW
Washington, DC 20001*

Link to view the live webcast:

[Enabling 21st Century Applications for Cancer Surveillance through
Enhanced Registries and Beyond: A Workshop | National Academies](#)

July 29, 2024

Dear Colleagues,

Welcome to the National Academies of Sciences, Engineering, and Medicine workshop, *Enabling 21st Century Applications for Cancer Surveillance through Enhanced Registries and Beyond*. This workshop is being convened by the National Cancer Policy Forum.

The intent of the workshop is to examine opportunities to enhance and modernize cancer surveillance to improve cancer research, care, and outcomes for all patients. Workshop presentations and discussions will provide an overview of the current state of cancer surveillance; lessons learned from U.S. and international cancer surveillance efforts; data collection methods and technological advances; opportunities to support the cancer surveillance workforce and infrastructure; and policy opportunities to advance cancer surveillance. We hope the workshop will spur progress toward envisioning and implementing a cancer surveillance system of the future that delivers high-quality comprehensive data collection, timely reporting, and analysis for improving equitable care and patient outcomes.

We welcome your involvement in the workshop. Please use the microphones in the room or the chat box on our [website](#) to ask questions, and please mention your name and affiliation. The proceedings of the workshop will be published by the National Academies Press and may incorporate your comments and ideas. Archived presentations and videos from the workshop will also be available on the website.

We look forward to your involvement in this workshop.

Sincerely,

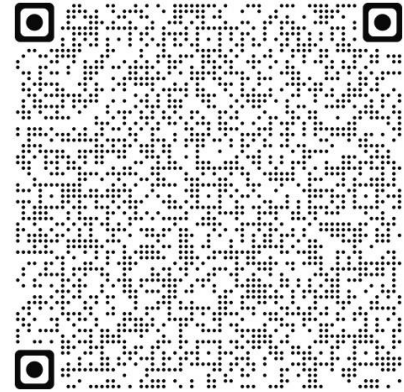
Lisa C. Richardson, MD, MPH
Director
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Robin Yabroff, PhD, MBA
Scientific Vice President
Health Services Research
Department of Surveillance and Health Equity
Science
American Cancer Society

Enabling 21st Century Applications for Cancer Surveillance through Enhanced Registries and Beyond July 29-30, 2024

National Cancer Policy Forum

[Workshop Website](#)
Keck Center Room 100
500 Fifth Street, NW
Washington, DC 20001



WORKSHOP AGENDA

MONDAY, JULY 29, 2024 EASTERN TIME ZONE	
8:00 am	Breakfast and Registration (30 minutes)
8:30 am	Welcome and Introductory Remarks (15 minutes) Lisa Richardson, Centers for Disease Control and Prevention Robin Yabroff, American Cancer Society
8:45 am	Session 1: Overview of the Current State of Cancer Surveillance (1 hour, 45 minutes) <i>Co-Moderators:</i> Lisa Richardson, Centers for Disease Control and Prevention Nadia Howlader, National Cancer Institute <i>Session objectives</i> - To review the current state of cancer surveillance in the United States. Examine the history of cancer surveillance; infrastructure and processes of surveillance; ongoing challenges and implications of the current system of cancer surveillance on research, patient care, and health outcomes, including health inequities; and future opportunities to strengthen population health through cancer surveillance. The Importance of Cancer Surveillance for Improving Patient Care (8-10 minutes) - Kelly Shanahan, Metavivor Charting the Course: The Evolution of Cancer Surveillance in the United States and Vision for the Future (8-10 minutes) - Douglas Lowy, National Cancer Institute Opportunities and Challenges to Improve Cancer Surveillance and Registries Perspective from the National Cancer Institute's Surveillance, Epidemiology, and End Results Program (8-10 minutes) - Lynne Penberthy, National Cancer Institute Perspective from the Centers for Disease Control and Prevention (8-10 minutes) - Vicki Benard, Centers for Disease Control and Prevention Perspective from the National Cancer Database (8-10 minutes) - Bryan Palis, American College of Surgeons (<i>participating virtually</i>) - Lawrence Shulman, University of Pennsylvania Perspective from the North American Association of Central Cancer Registries (8-10 minutes) - Betsy Kohler, North American Association of Central Cancer Registries Panel Discussion (45 minutes)

10:30 am	Break (15 minutes)
10:45 am	Session 2: Lessons Learned from U.S. and International Cancer Surveillance Efforts (1 hour, 45 minutes) <i>Co-Moderators:</i> Scarlett Lin Gomez, University of California, San Francisco Larissa Nekhlyudov, Brigham & Women's Hospital, Dana-Farber Cancer Institute, and Harvard Medical School <i>Session objective</i> - To examine U.S. and international cancer surveillance efforts and consider potential strategies for improving cancer surveillance, including opportunities for multidisciplinary collaboration and applying lessons learned from other surveillance efforts (e.g., childhood cancer registries). Lessons Learned from U.S.-Based Cancer Surveillance Efforts Challenges and Opportunities from a Surveillance, Epidemiology, and End Results Registry Perspective (8-10 minutes) - Scarlett Lin Gomez, University of California, San Francisco Challenges and Opportunities from a National Program of Cancer Registries Perspective (8-10 minutes) - Wendy Aldinger, Pennsylvania Cancer Registry Challenges and Opportunities from the Curators and Users of Registry Data Perspectives - Stephen Schwartz, Fred Hutchinson Cancer Center (8-10 minutes) - Jessica Chubak, Kaiser Permanente Washington Health Research Institute (<i>participating virtually</i>) (8-10 minutes) Lessons Learned from International Surveillance and Registries - Craig Earle, Canadian Partnership Against Cancer (8-10 minutes) - Volker Arndt, German Cancer Research Center (<i>participating virtually</i>) (8-10 minutes) Panel Discussion (45 minutes) Session speakers and: - Sarah Greene, Cancer Research Advocate
12:30 pm	Lunch (1 hour)
1:30 pm	Session 3: Challenges and Opportunities: Data Collection Methodologies and Technological Advances in Cancer Surveillance (2 hours) <i>Co-Moderators:</i> Lawrence Shulman, University of Pennsylvania Peter Paul Yu, Hartford HealthCare Cancer Institute & Memorial Sloan Kettering Cancer Center <i>Session objective</i> - To examine opportunities and challenges in surveillance data collection methodologies and discuss current and future tools for automation and analytics. Panel Discussion <i>Introductory Remarks</i> (4-5 minutes) - Peter Paul Yu, Hartford HealthCare Cancer Institute & Memorial Sloan Kettering Cancer Center <i>Flatiron Health Database and Infrastructure</i> (4-5 minutes) - Emily Castellanos, Flatiron Health <i>National Cancer Database</i> (4-5 minutes) - Bryan Palis, American College of Surgeons (<i>participating virtually</i>)

	<i>Reconceptualization of data entry and storage in Electronic Health Records</i> (4-5 minutes) • Lawrence Shulman, University of Pennsylvania <i>Lessons learned from COVID-19 & Cancer Consortium</i> (4-5 minutes) • Jeremy Warner, Brown University <i>Centers for Disease Control and Prevention Electronic Pathology Implementation Project</i> (4-5 minutes) • Sandy Jones, Centers for Disease Control and Prevention <i>Common data models: CodeX's minimal Common Oncology Data Elements</i> (4-5 minutes) • Su Chen, MITRE <i>Data Linkages in Cancer Surveillance Models</i> (4-5 minutes) • Elizabeth Shenkman, University of Florida <i>Interoperable Electronic Health Records in Cancer Surveillance</i> (4-5 minutes) • Peter Stetson, Memorial Sloan Kettering Cancer Center (<i>participating virtually</i>) <i>Innovations and Applications of Artificial Intelligence and Large Language Models</i> (4-5 minutes) • Peter Clardy, Google Health
3:30 pm	Break (15 minutes)
3:45 pm	Session 4: The Infrastructure and Workforce Supporting Cancer Surveillance (1 hour, 45 minutes) <i>Co-Moderators:</i> Bryan Palis, American College of Surgeons (<i>participating virtually</i>) Lisa Richardson, Centers for Disease Control and Prevention <i>Session objective</i> • To examine the workforce and resources necessary for effective cancer surveillance. National Cancer Registrars Association Perspectives: Cancer Registry Professionals and their Influence on Cancer Surveillance (8-10 minutes) • Nadine Walker, National Cancer Registrars Association The CAP Cancer Protocols: Harnessing Structured Data to Optimize Cancer Surveillance (8-10 minutes) • Samantha Spencer, College of American Pathologists (CAP) Use of Electronic Health Records and Health Information Exchanges to Streamline Registry Processes (8-10 minutes) • Mary Charlton, University of Iowa College of Public Health Vision for the 21st Century Cancer Surveillance Workforce (8-10 minutes) • Kevin Ward, Rollins School of Public Health, Emory University Panel Discussion (1 hour, 5 minutes) Session speakers and: • Emily Castellanos, Flatiron Health • Jackie Gerhart, Epic
5:30 pm	Adjourn and Reception

**TUESDAY, JULY 30, 2024
EASTERN TIME ZONE**

8:00 am	Breakfast and Registration (30 minutes)
8:30 am	Session 5: Panel Discussion on Policy Opportunities for Advancing Progress (1 hour, 45 minutes) <i>Co-Moderators:</i> Robin Yabroff, American Cancer Society Cathy Bradley, Colorado School of Public Health <i>Session objective</i> - To discuss policy opportunities for advancing progress in cancer surveillance and perspectives on achieving the vision for the future. Panel Discussion <i>Policy Opportunities from the Centers for Disease Control and Prevention</i> (4-5 minutes) - Sandy Jones, Centers for Disease Control and Prevention <i>Policy Opportunities from the National Cancer Institute</i> (4-5 minutes) - Lynne Penberthy, National Cancer Institute <i>Policy Opportunities to Support Resource Needs to Conduct High-Quality Cancer Surveillance in the U.S.</i> (4-5 minutes) - Micky Tripathi, Office of the National Coordinator for Health Information Technology <i>How Payment Models Impact Changes in Quality Cancer Care</i> (4-5 minutes) - Nancy Keating, Harvard University <i>Advances in Data Linkages</i> (4-5 minutes) - Michaela Dinan, Yale University <i>Policy Opportunities from the Vendor Perspective</i> (4-5 minutes) - Jackie Gerhart, Epic <i>Policy Opportunities from Technological Innovations</i> (4-5 minutes) - Andrew Hantel, Dana-Farber Cancer Institute and Harvard University <i>Privacy, Security, and Ethics of Cancer Registry Data</i> - Deven McGraw, Citiizen (4-5 minutes) - Aaron Goldenberg, Case Western Reserve University (4-5 minutes)
10:15 am	Break (15 minutes)
10:30 am	Session 6: Improving Cancer Surveillance—Enhanced Registries and Beyond (1 hour) <i>Co-Moderators:</i> Lisa Richardson, Centers for Disease Control and Prevention Robin Yabroff, American Cancer Society Session 1: Lisa Richardson and Nadia Howlader Session 2: Scarlett Lin Gomez and Larissa Nekhlyudov Session 3: Lawrence Shulman and Peter Paul Yu Session 4: Bryan Palis (<i>participating virtually</i>) and Lisa Richardson Session 5: Robin Yabroff and Cathy Bradley
11:30 am	Adjourn

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Planning Committee Roster

Lisa C. Richardson, MD, MPH (Co-Chair)

Director
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Robin Yabroff, PhD, MBA (Co-Chair)

Scientific Vice President
Health Services Research
American Cancer Society

Cathy Bradley, PhD

Professor
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Paul A. Bunn, Jr. Endowed Chair in
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Deputy Director
University of Colorado Cancer Center
Dean
Colorado School of Public Health

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Nadia Howlader, PhD

Cancer Epidemiologist and Program Director
Surveillance Research Program
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National Institute of Health

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Professor of Pulmonary Disease and
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Lipman Chair in Oncology
Virginia Commonwealth University
School of Medicine
President
Association of American Cancer Institutes

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Speaker, Panelist, and Moderator Roster

Wendy Aldinger, RHIA, ODS

Manager
Pennsylvania Cancer Registry

Volker Arndt, MD, MPH

Associate Professor
Epidemiological Cancer Registry Baden-Württemberg &
Unit of Cancer Survivorship
Division of Clinical Epidemiology and Aging Research
German Cancer Research Center (DKFZ)

Vicki Benard, PhD

Chief, Cancer Surveillance Branch
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

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Colorado School of Public Health

Emily Castellanos, MD, MPH

Medical Director
Flatiron Health

Mary Charlton, PhD

Director
Iowa Cancer Registry
Professor
Department of Epidemiology
College of Public Health
University of Iowa

Su Chen, MD

Clinical Science Principal
MITRE
Co-Chair
CodeX HL7 FHIR Accelerator

Jessica Chubak, PhD, MBHL

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Kaiser Permanente Washington
Health Research Institute
Affiliate Professor
Department of Epidemiology
University of Washington

Peter Clardy, MD

Pulmonary and Critical Care physician
Senior Staff Clinical Specialist Lead
Clinical Enterprise Team
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Associate Professor, Epidemiology
Yale School of Public Health
Co-leader, Cancer Prevention and Control Program
Yale Comprehensive Cancer Center
Yale School of Medicine

Craig Earle, MD, MSc, FRCPC

Chief Executive Officer
Canadian Partnership Against Cancer

Jackie Gerhart, MD

Chief Medical Officer
Epic

Aaron Goldenberg, PhD, MPH

Professor, Vice Chair, and Director of Research
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School of Medicine
Member
Population and Cancer Prevention Program
Case Comprehensive Cancer Center
Director
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Bioethics Center for Community Health
AND Genomic Equity (CHANGE)
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Advisor | Advocate | Consultant

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HMS Center for Bioethics
Instructor in Medicine
Harvard Medical School

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Surveillance Research Program
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Executive Director
North American Association of Central Cancer Registries

Douglas Lowy, MD

Principal Deputy Director
National Cancer Institute
National Institutes of Health

Deven McGraw, JD, MPH, LLM

Chief Regulatory & Privacy Officer
Citizen

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Editor-in-Chief
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Robin Yabroff, PhD, MBA

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Peter Paul Yu, MD, FACP, FASCO

Physician-in-Chief
Hartford HealthCare Cancer Institute
Clinical Member
Memorial Sloan Kettering Cancer Center

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Speaker, Panelist, Moderator, and Planning Committee Biosketches



Wendy Aldinger, RHIA, ODS
Pennsylvania Cancer Registry

Wendy Aldinger is the Manager of the Pennsylvania Cancer Registry where she oversees the daily operations of the registry. Ms. Aldinger has been with the cancer registry for over 30 years. She earned her Bachelor of Science degree in Health Information Management from York College of Pennsylvania. Ms. Aldinger also maintains the Registered Health Information Administrator (RHIA) and Oncology Data Specialist (ODS) certifications. She is currently the President of the Board of Directors of the North American Association of Central Cancer Registries (NAACCR) and is a member of several state and local cancer registry and health information associations.



Volker Arndt, MD, MPH
German Cancer Research Center (DKFZ)

Volker Arndt, MD, MPH, is Director of the Epidemiological Cancer Registry Baden-Wuerttemberg and head of the Unit of Cancer Survivorship within the Division of Clinical Epidemiology and Aging Research at the German Cancer Research Center Heidelberg. He is associate professor at the Heidelberg University and member of the Board of Directors at the International Association of Cancer Registries (IACR) as well as of the steering committee of the European Network of Cancer Registration and the advisory boards “Long-term cancer survivorship” and “Quality and interconnectedness in cancer care” within the German Cancer Plan. He works with partners at the national and international level to improve the utility of cancer registration data on items relevant for cancer survivorship by implementation of recurrence, risk of long-term and late effects, and survival. He has authored or coauthored more than 300 peer-reviewed journal articles with a focus on outcome in cancer patients and survivors.



Vicki Benard, PhD
Centers for Disease Control and Prevention

Vicki Benard, PhD, is an epidemiologist with more than 25 years’ experience working in CDC’s Division of Cancer Prevention and Control. As the Chief of the Cancer Surveillance Branch, she leads the National Program of Cancer Registries capturing cancer incidence data from 46 states, the District of Columbia, and 3 territories. Her focus is on providing cancer data to measure progress, drive action, prevent cancers, and improve treatment for all people.

Dr. Benard did her undergraduate work in statistics and math at the University of South Alabama and earned her doctorate in biometry and epidemiology from the Medical University of South Carolina. She first joined DCPC in 1998 as a contractor working with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to conduct a needs assessment of epidemiologic capacity in cancer control. Two years later, she became a staff epidemiologist. Much of her research has examined cervical cancer control and screening practices within the NBCCEDP, and she is well published on these issues.



Cathy Bradley, PhD
Colorado School of Public Health

Cathy J. Bradley, PhD, is the Dean of the Colorado School of Public Health and the Deputy Director of the University of Colorado Cancer Center. Dr. Bradley is a health economist and holds the Paul A. Bunn, Jr. Endowed Chair in Cancer Research. Prior to joining the University of Colorado, she was the founding Chair of the Department of Healthcare Policy and Research, at the Virginia Commonwealth University School of Medicine.

Dr. Bradley received a Bachelor's degree from Old Dominion University and a Master's of Public Administration and PhD in Health Policy and Administration from the University of North Carolina Gillings School of Public Health.

Dr. Bradley's research focuses on decisions made at the intersection of work, health insurance, and cancer, and seeks to explain how when faced with a serious and expensive path to treat illness such as cancer, many workers remain employed to keep employer-based health insurance, despite needs for treatment and convalescence. This research has extended to families and caregivers and their financial consequences. Within this realm, Dr. Bradley concentrates on policies that reduce disparate outcomes and financial burden among people who must make these stark choices. She is also an expert in Medicaid and using administrative datasets to explore research questions related to health disparities. Since 1998, she has been continuously funded as a principal investigator by the National Institutes of Health, and has received funding from the American Cancer Society, the Commonwealth Fund, and other state and international agencies.

Dr. Bradley served on national advisory committees including the National Academies of Science, Engineering, and Medicine National Cancer Policy Forum and formerly served on the National Advisory Committee to the Agency for Healthcare Quality & Research. She currently serves on the Patient-Centered Outcomes Research Institute (PCORI) Methods Committee. She is also an Associate Editor for *Journal of the National Cancer Institute*, on the Editorial Board of the *Journal of Cancer Survivorship*, and was formerly an Associate Editor of *Health Economics*.

Dr. Bradley has received numerous awards and honors including the Women in Science, Dentistry, and Medicine Professional Achievement Award in Leadership, the Distinguished Faculty Award at Michigan State University, and the Distinguished Faculty Scholar Award at Virginia Commonwealth University.



Emily Castellanos, MD, MPH
Flatiron Health

Emily Castellanos is a board-certified medical oncologist and hematologist who serves as medical director at Flatiron Health, where she leverages her clinical and research expertise to develop innovative approaches to real world evidence generation and inform product strategy. She has a special interest in integrated approaches to real-world data, such as clinico-genomics, clinico-claims, or imaging data, as well as novel approaches to real world study design. Emily also maintains a clinical practice specializing in breast malignancies at Fox Chase Cancer Center.

Emily earned her BS with distinction in biological sciences from Stanford University. She then received her medical degree from Vanderbilt University Medical Center, where she remained for her clinical training. She completed her residency in internal medicine, and after serving as chief resident she remained at Vanderbilt for her hematology/oncology fellowship. Prior to coming to Flatiron, she served on the faculty in the division of hematology/oncology at Vanderbilt University Medical Center and earned her MPH with a focus on health policy.



Mary Charlton, PhD

University of Iowa College of Public Health

Dr. Mary Charlton is a Professor in the Department of Epidemiology at the University of Iowa College of Public Health, the Director of the statewide Iowa Cancer Registry, Co-Leader of the Cancer Epidemiology and Population Science Program in the Holden Comprehensive Cancer Center, and President of the Iowa Cancer Consortium. She has conducted numerous studies of cancer risk factors, outcomes and disparities in access and quality of cancer care, particularly among rural populations. One current focus area of her research is to engage providers, administrators, and staff in community hospitals/clinics in research designed to address the challenges of providing high-quality, comprehensive cancer care in rural areas. Another related area of her research focuses on expanding the role of traditional cancer surveillance systems and streamlining data collection and monitoring processes to better facilitate quality improvement and research endeavors.



Su Chen, MD

MITRE

Dr. Su Chen, MD, is a Clinical Science Principal at MITRE. She is an intrepid emergency medicine physician, computer scientist, and clinical informaticist with systems leadership experience in healthcare information systems optimization. Su is currently co-chairs the CodeX HL7® FHIR® Accelerator, a not-for-profit member community advancing open clinical specialty data exchange standards in cancer, genomics, cardiovascular health, and beyond. She serves on the Executive Committee and the Technical Review Group mCODE® (minimal Common Oncology Data Elements), an open standard for cancer data exchange. Prior to joining MITRE, Su served as Director of Clinical IT in a nationwide health system, Steward Health Care, and Chief Medical Information Officer and Urgent Care Medical Director of the Greater New Bedford Community Health Care Center.



Jessica Chubak, PhD, MBHL

Kaiser Permanente Washington Health Research Institute

Jessica Chubak, PhD, is a Senior Investigator at Kaiser Permanente Washington Health Research Institute in Seattle, Washington and Affiliate Professor in the Department of Epidemiology at the University of Washington. Her research focuses primarily on cancer screening and cancer survivorship, with an emphasis on modifiable exposures and receipt of health services. She has a strong interest in epidemiologic methods, including methods for using electronic health data. Before completing her PhD in Epidemiology in 2007 from the University of Washington, Dr. Chubak was a Fulbright Scholar at the University of Otago in New Zealand, where she received a Masters of Bioethics and Health Law.



Peter Clardy, MD
Google Health

Dr. Peter Clardy is a pulmonary / critical care physician, clinical educator and medical technologist. He is a senior staff clinical specialist at [Google Health](#). Dr. Clardy's team develops, evaluates, and implements AI solutions in healthcare, working with internal Google teams including DeepMind, Research, and Cloud to create tools that help providers organize and understand medical information, simplify workflows and improve patient outcomes. He and his team have developed and deployed Google's first clinician facing search and summarization tools, and are platforming Google's most recent generative AI models for use in healthcare and life sciences.

Dr. Clardy is the former Deputy Editor of the Pulmonary and Critical Care section of UpToDate, an online reference for clinicians, and his clinical interests include sepsis, acute respiratory distress syndrome, quality improvement, and intersection of clinical reasoning and cognitive error. He previously served as the Director of Medical Critical Care at Beth Israel Deaconess Medical Center, the Program Director for the Massachusetts General Hospital / Beth Israel Deaconess Medical Center / Harvard Fellowship in Pulmonary and Critical Care Medicine, Associate Dean for Medical Education at Harvard Medical School, and as the Chair of the Departments of Medicine and Medical Education at Mount Auburn Hospital. Dr. Clardy helped to coordinate the COVID-19 pandemic response at Mount Auburn Hospital, where he worked clinically as an intensivist in the medical and surgical intensive care units until 2022.



Michaela A. Dinan, PhD
Yale School of Public Health

Dr. Michaela Dinan is a health services researcher with expertise in health policy and disparities research specializing in the adoption and impact of emerging medical technology in cancer. Dr. Dinan obtained her PhD in Health Policy and Management from the UNC Gillings School of Global Public Health in 2011. She joined the faculty at Duke University in 2013 and has maintained a continuously funded, independent program of research with four current, active RO1-equivalent grants as PI. She has over 95 peer-reviewed published manuscripts in top journals including JAMA, JAMA internal medicine, JAMA oncology, and the Journal of Clinical Oncology. She is an internationally recognized researcher for her work in cancer survivorship, outcomes, and disparities with numerous oral presentations and invited lectures at national and international meetings. Dr. Dinan recently conceived of and led the first linkage of population-level datasets such as SEER-Medicare with physical tumor samples and

custom genomic analysis, thereby allowing for "next-generation" cancer epidemiology in combination with modern in-depth biologic and genomic analysis. Dr. Dinan joined the YSPH faculty in the Department of Epidemiology in January 2021. She is also a member of the Cancer Outcomes, Public Policy and Effectiveness Research Center and co-leads the Cancer Prevention and Control Program for the Yale Cancer Center.



Craig Earle, MD, MSc, FRCPC
Canadian Partnership Against Cancer

Dr. Craig Earle is Chief Executive Officer at the Canadian Partnership Against Cancer, a medical oncologist at Sunnybrook's Odette Cancer Centre in Toronto, a Senior Scientist at ICES, and a Professor of Medicine at the University of Toronto. Dr. Earle originally trained and practiced in Ottawa, after which he spent 10 years – 1998 to 2008 – in Boston at Harvard Medical School, Dana-Farber Cancer Institute and the Harvard School of Public Health. From 2008 to 2017 he was Director of Health Services Research and Head of Clinical Translation at the Ontario Institute for Cancer Research.



Jackie Gerhart, MD
Epic

Jackie Gerhart, MD is a family medicine physician and clinical informaticist at Epic in Verona, WI. She earned her medical degree from Mayo Clinic College of Medicine in Rochester, MN, and is an Associate Professor at the University of Wisconsin-Madison, where she practices in urgent care. Her passion is to reduce barriers to medical care through the best use of technology. She enjoys advocating to align policy with practice to improve clinician well-being and empower patients. At Epic she focuses on healthcare innovation including practical uses of AI to help patients get well and stay well. She is the lead clinical researcher for Epic Research, and her team partners with federal agencies to review real-world evidence and advance medicine.



Aaron Goldenberg, PhD, MPH
Case Western Reserve University

Dr. Aaron Goldenberg, PhD MPH is a Professor and Vice-Chair in the Department of Bioethics at Case Western Reserve University. He is also Director of the CWRU Bioethics Center for Community Health and Genomic Equity. Dr. Goldenberg has a background in bioethics, health behavior/health education, public health ethics, and public health genetics. He also has expertise in qualitative and quantitative research design and analysis and has focused his work on the ethical, legal, and social issues (ELSI) associated with the integration of new genomic technologies into research, clinical and public health settings. Dr. Goldenberg's research program has been grounded by a number of major project areas, including: 1) the ethical and social implications of storing and using of biological specimens and data for future research; 2) implications of genetics and gene-environment interactions for racial/ethnic minorities and other communities

experiencing health disparities; and 3) ethical implications of expanding newborn screening programs, gene targeted therapies, and rare disease. Dr. Goldenberg is also a member of the Population and Cancer Prevention program for the Case Comprehensive Cancer Center and has recently collaborated on a community-based project to increase traditional and genomic screening for prostate cancer risk in the greater Cleveland area. Dr. Goldenberg is also Co-chair for the Ethical, Legal, and Policy Subcommittee for the Association for Public Health Laboratories and a member of the Institutional Review Board for the NIH's All of Us Research Program.



Scarlett Lin Gomez, PhD, MPH
University of California, San Francisco

Scarlett Lin Gomez is Professor and Vice Chair for Faculty Development in the Department of Epidemiology and Biostatistics and Co-Leader of the Cancer Control Program of the Helen Diller Family Comprehensive Cancer Center, at the University of California, San Francisco. She is Director of the Greater Bay Area Cancer Registry, a participant in the NCI SEER (Surveillance, Epidemiology, End Results) program and the California Cancer Registry. Her research focuses primarily on cancer health disparities and aims to understand the multilevel drivers, particularly the structural and social determinants of health, of those disparities.



Sarah M. Greene, MPH
Cancer Research Advocate

Sarah Greene, MPH, is a consultant, researcher, and cancer survivor with expertise in learning health systems, health communication, electronic health data, and patient-centered care. Much of her career has been focused on building productive, sustainable multi-site networks that conducted applied research on cancer, aging, and communication. She applies a versatile skillset and intellectual curiosity in the areas of digital health, evidence mobilization, and community engagement, and is a recognized national leader in understanding how to bridge research and healthcare delivery using a learning health systems approach. Ms. Greene's perspectives are deeply informed by her recent experience with a cancer diagnosis and successful treatment. Recent consulting clients have included the National Academy of Medicine, Trillium Health Partners, the National Cancer Institute, and Kaiser Permanente. Prior to consulting, she was the inaugural Executive Director of the Health Care Systems Research Network (HCSRN), a consortium of embedded research

centers, where she led all of the organization's activities. Ms. Greene also served as an Associate Director at PCORI, providing intellectual and organizational leadership for PCORI's National Patient-Centered Clinical Research Network, PCORnet®. Throughout her career, Ms. Greene has frequently led strategic planning and change management initiatives and complements these skills with strong technical capabilities including literature synthesis, survey design, evaluation, and qualitative analysis. An accomplished writer and speaker with more than 170 publications and presentations, she has shared her work at the National Academy of Medicine, American College of Cardiology, American Medical Informatics Association, and AcademyHealth, among many other organizations. Ms. Greene received both her MPH and a BA in Psychology and Italian from Indiana University and resides in Seattle.



Andrew Hantel, MD
Dana-Farber Cancer Institute and Harvard University

Andrew Hantel, MD, is a faculty member in the Divisions of Leukemia and Population Sciences at Dana-Farber Cancer Institute and the Harvard Medical School Center for Bioethics and an Instructor in Medicine at Harvard Medical School (HMS). He received his MD from Loyola University Chicago; trained in internal medicine, adult hematology/oncology, and medical ethics at the University of Chicago; and completed a post-doctoral fellowship in population sciences at the Dana-Farber/Harvard Cancer Center. Dr. Hantel's clinical care focuses on inpatients with leukemia and related blood cancers. His research program leverages health services and care delivery methods to address ethical dilemmas in cancer discovery and delivery. He has received research funding from multiple sources including the National Institutes of Health, American Society for Clinical Oncology,

and the American Cancer Society. His current work focuses on cancer health equity in the contexts of research participation, artificial intelligence, and climate change.



Nadia Howlader, PhD
National Cancer Institute

Dr. Nadia Howlader has nearly two decades of experience working on clinical studies, cancer epidemiology, and population statistics and modeling. Her research focuses on breast cancer, non-Hodgkin lymphoma, and lung cancer occurrences and outcomes. For about 15 years, Dr. Howlader has been working at the National Cancer Institute (NCI) applying innovative analytic tools and leading congressionally mandated reports on the national cancer burden. She utilizes diverse data systems—including the SEER cancer registries, death certificates, Medicare claims, healthcare provider, and laboratory data—to address high-impact research questions. She also leads NCI efforts to harmonize data systems, create new data elements, and validate these new data sources to enhance SEER registry data. Additionally, as Program Director Dr. Howlader manages NCI grant portfolios in cancer surveillance, health disparities, and biostatistical methods.

Dr. Howlader received her M.S. in Biostatistics from the University of Washington, and her Ph.D. in Epidemiology from the George Washington University. She publishes regularly in highly-ranked journals such as the New England Journal of Medicine, the Journal of the American Medical Association, the Journal of Clinical Oncology, the Journal of the National Cancer Institute, and the American Journal of Epidemiology. She regularly presents to diverse audiences of policymakers, professionals, and academics. Dr. Howlader is a recipient of the 2011 NIH Merit award.



Sandy Jones
Centers for Disease Control and Prevention

Mrs. Sandy Jones is a Public Health Advisor with the Cancer Surveillance Branch, in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention in Atlanta, GA. She joined the Cancer Surveillance Branch in 2004 to lead the develop and implement standardized cancer pathology reporting to cancer registries. She provides informatics expertise to laboratories and cancer registries on cancer pathology and biomarker reporting. Serves as Co-Chair of the North American Association of Central Cancer Registries (NAACCR) Pathology Reporting WG and provides guidance on maintaining the NAACCR Electronic Pathology Reporting Guidelines to support reporting of narrative and structured College of American Pathologists (CAP) electronic Cancer

Protocols. Mrs. Jones provides technical assistance on real-time reporting of cancer pathology and biomarker data and coordinates with the Association of Public Health Laboratories to utilize the APHL Informatics Messaging Services cloud platform for secure data exchange. She provides technical input on the development of software, eMaRC Plus, to process cancer pathology and biomarker reports. She works closely with laboratory information system vendors to test and implement standardized cancer data exchange with cancer registries. She provided input on the development of the HL7 FHIR Cancer Pathology Data Sharing Implementation Guide for reporting pathology data to EHRs and Cancer Registries. Her collaboration with the DHHS Office of the National Coordinator for Health Information Technology and the National Cancer Institute contributed to the development of the United States Core Data for Interoperability (USCDI) Cancer Dataset.



Nancy L. Keating, MD, MPH
Harvard University

Nancy L. Keating, MD, MPH, is Professor of Health Care Policy and Medicine at Harvard Medical School and a primary care physician at Brigham and Women's Hospital. She is Program Leader of the Dana-Farber/Harvard Cancer Center's Cancer Care Delivery Research Program.

Dr. Keating's research studies care delivery for individuals with cancer, including access to care, quality of care, and how we pay for and deliver care. She served as currently Clinical Lead of the Evaluation Team for the Center for Medicare and Medicaid Service's Oncology Care Model, an alternate payment and delivery model for oncology practices administering chemotherapy. The evaluation assessed spending, quality of care, health care utilization, and patients' experiences for patients receiving chemotherapy in approximately 200

participating practices compared with non-participating practices. In other work, she is studying the impact of financial integration of oncology practices into systems and hospitals and its impact on care delivery. In ongoing work, she is assessing the reliability and consistency of quality and equity measurement across oncology practices caring for individuals with cancer. Previous work has examined cancer screening in the US, including screening behavior following changes in guidelines as well as assessing the impact on state breast density notification laws on supplemental breast cancer screening. She has also studied patient, physician, and health system factors contributing to the variations in the intensity of end-of-life care for individuals with advanced cancer and she has studied interventions to improve patients' understanding of the goals of chemotherapy and to improve patients' discussions with their clinicians about their preferences and goals of care.

Dr. Keating received her MD degree from the University of Chicago Pritzker School of Medicine, and her MPH degree from the Harvard TH Chan School of Public Health. In 2022, she was awarded the John M. Eisenberg Award for Career Achievement in Research by the Society of General Internal Medicine. She is an elected member of the American Society for Clinical Investigation and the Association of American Physicians. Dr. Keating has been continuously funded by the National Institutes of Health as principal investigator for more than twenty years. She co-leads a T32 training grant, Training in Oncology Population Sciences, or TOPS. She currently serves as an Associate Editor at the Journal of the National Cancer Institute, a member of the editorial board of Annals of Internal Medicine and the Journal of Geriatric Oncology, and she is member of the National Comprehensive Cancer Center Senior Oncology Guideline Panel.



Betsy A. Kohler, MPH
North American Association of Central Cancer Registries

Ms. Betsy Kohler has almost 40 years of experience in cancer surveillance at the state, national and international levels. As Executive Director for the North American Association of Central Cancer Registries (NAACCR), she works with the major cancer surveillance organizations in the US and Canada on data collection and standardization policies and procedures, integration of cancer data systems, promotion of cancer surveillance data for research and monitoring of progress for cancer control objectives and inequities. Formerly as Director of Cancer Epidemiology at the NJ Department of Health and Senior Services I served as PI on the NJ Surveillance Epidemiology and End Results (SEER) contract and the CDC co-operative agreement for the National Program of Cancer Registries and directed both the cancer registry and a robust research program. In

addition, she served as a member of the National Coordinating Council on Cancer Surveillance (now the High-Level Strategic Group), and the Comprehensive Cancer Control National Partners, and on the Editorial board of Cancer in Five Continents Vol. X (IACR/WHO). I am currently serving on the Board of Directors of the International Association of Cancer Registries and as an Advisor to the National Firefighters Registry. Betsy earned a Master's degree in Public Health with a concentration in cancer epidemiology and biostatistics.



Douglas Lowy, MD
National Cancer Institute

Dr. Douglas Lowy is the Principal Deputy Director of the National Cancer Institute (NCI), National Institutes of Health (NIH), and Chief of the Laboratory of Cellular Oncology in the Center for Cancer Research at NCI. He received his medical degree from New York University School of Medicine and trained in internal medicine at Stanford University and dermatology at Yale. Dr. Lowy's research includes the biology of papillomaviruses and the regulation of normal and neoplastic growth. The papillomavirus research is carried out in close collaboration with Dr. John Schiller, and they were involved in the initial development, characterization, and clinical testing of the preventive virus-like particle-based HPV vaccines that are now used in the three FDA-approved HPV vaccines. Dr. Lowy's growth regulation research is now focused primarily on the DLC family of tumor suppressor genes and their mechanism of action. In response to the COVID-19 epidemic, he has led the SARS-CoV-2 serology research effort at NCI. Dr. Lowy is a member of the

National Academy of Sciences (NAS) and of the Institute of Medicine of the NAS. For their HPV vaccine research, he and Dr. Schiller have received numerous honors, including the 2007 Federal Employee of the year Service to America Medal from the Partnership for Public Service, the 2011 Albert B. Sabin Gold Medal Award, the 2012 National Medal of Technology & Innovation (awarded in 2014), and the 2017 Lasker-DeBakey Clinical Medical Research Award.



Deven McGraw, JD, MPH, LLM
Citizen

Deven McGraw is the Chief Regulatory and Privacy Officer for Citizen, a platform for patients to gather and manage their health information, divested from Invitae in 2023 (Deven co-founded Citizen prior to its acquisition by Invitae in 2021.) From 2015-2017, she directed U.S. health privacy and security as Deputy Director, Health Information Privacy at the HHS Office for Civil Rights and Chief Privacy Officer (Acting) of the Office of the National Coordinator for Health IT. Widely recognized for her expertise in health privacy, she directed the Health Privacy Project at the Center for Democracy & Technology for six years, testifying before Congress on health privacy issues on multiple occasions and leading the privacy and security policy work for the HITECH Health IT Policy Committee. She also is currently serving on the following bodies: Health IT Advisory Committee (appointed by

GAO); Data and Surveillance Workgroup of the CDC's Advisory Committee to the Director on CDC's Data Modernization; Board of Directors of Manifest MedEx, the largest health information exchange in California.; and the National Academy of Medicine Artificial Intelligence Code of Conduct Steering Committee. She previously was the Chief Operating Officer of the National Partnership for Women and Families and, before joining federal government service, advised health industry clients on HIPAA compliance and data governance while a partner at Manatt, Phelps & Phillips, LLP. Deven graduated magna cum laude from Georgetown University Law Center and has a Master of Public Health from Johns Hopkins University.



Larissa Nekhlyudov, MD, MPH, FASCO

Brigham and Women's Hospital, Dana-Farber Cancer Institute, Harvard Medical School

Dr. Larissa Nekhlyudov is a Professor of Medicine at Harvard Medical School and is a practicing primary care physician at the Brigham & Women's Hospital in Boston, Massachusetts. She is also the Clinical Director, Internal Medicine for Cancer Survivors at the Dana-Farber Cancer Institute where she offers clinical care for long term survivors of childhood and adult cancers. Dr. Nekhlyudov is particularly interested in improving the care of cancer survivors and the interplay between primary and oncology care. Her publications (including journal articles, book chapters, and two books), as well as her broad-ranging educational programs, have promoted global awareness among health care providers about the ongoing needs of cancer patients across the care continuum. Dr. Nekhlyudov has been at the forefront of the field of cancer survivorship, nationally and internationally, by leading

and participating in the development of policies, clinical guidelines, educational programs, and research.

Dr. Nekhlyudov is an active member of the American Society of Clinical Oncology, the National Comprehensive Cancer Network, and is an Executive Member of the Cancer and Primary Care Research International Network (Ca-PRI). She is a member of the National Academies of Sciences, Engineering and Medicine (NASEM) National Cancer Policy Forum. Dr. Nekhlyudov has served on several NASEM activities including the *Committee on the Quality of Cancer Care: Addressing the Challenges of an Aging Population* and the *Committee on Diagnosing and Treating Adult Cancers* and the planning committees for *Long-Term Survivorship Care after Cancer Treatment: A Workshop* and *Improving the Evidence Base for Treatment Decision-Making for Older Adults with Cancer: A Virtual Workshop*, and *Developing a Multidisciplinary and Multispecialty Workforce for Patients with Cancer, from Diagnosis to Survivorship, among others*. During her tenure as the Inaugural National Cancer Institute (NCI)-AcademyHealth Visiting Scholar, she developed a framework for quality survivorship care that has now been adapted by the NCI Office of Cancer Survivorship and has led to numerous national and international initiatives. Throughout her career, Dr. Nekhlyudov has been dedicated to teaching and mentoring students, residents, fellows, and faculty. She has also been committed to empowering cancer survivors and caregivers through educational programs as well as volunteer guidance for numerous local and national cancer advocacy organizations.

Dr. Nekhlyudov received her M.D. from the Mount Sinai School of Medicine and completed residency training at Yale-New Haven Hospital/Yale Primary Care Residency Program. She completed the Harvard Medical School Fellowship in General Medicine and Primary Care and received a Master of Public Health degree from the Harvard School of Public Health. Dr. Nekhlyudov has been on faculty at Harvard Medical School since 1999.



Bryan E. Palis, MA

American College of Surgeons

Bryan Palis is employed by the American College of Surgeons as the Senior Manager of Statistics and Analytics for the National Cancer Database (NCDB). Having worked at the College for over 22 years as a statistician, his expertise with data analysis, modeling, and interpretation has been applied to the NCDB on a range of projects from staging and outcomes studies to infrastructure assessments. The work has facilitated development of the Rapid Cancer Reporting System aimed to reduce lag time for data availability and report in real-time adherence with standardized metrics for patient care. Recently, Bryan served as co-Chair of the CoC Recurrence Task Force charged with assessing completeness and accuracy of data to differentiate new primary and recurrent diseases. Additionally, Bryan has been involved with feasibility assessments as part of a broader effort to enable

external data linkages. All of these works have culminated in the publication of peer-reviewed studies leveraging the framework of cancer surveillance system. Bryan received his Master's degree from Loyola University Chicago.



Lynne Penberthy, MD, MPH
National Cancer Institute

Dr. Lynne Penberthy is the Associate Director for the Surveillance Research Program (SRP), which is within the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI) since 2013. Dr. Penberthy obtained her MD from the University of Michigan and her MPH in epidemiology at Johns Hopkins. Dr. Penberthy's career includes a surgical internship in Baltimore, Maryland, at the Sinai Hospital and a preventive medicine residency at Johns Hopkins University. After her residency, she completed her post-doctoral training in epidemiology with the CDC as an epidemic intelligence service (EIS) officer with the Commonwealth of Virginia. She is licensed to practice medicine in the state of Maryland. Dr. Penberthy has a long history of focus on informatics and automation and has been involved in biobanking both in her academic role as well as at NCI.

In addition to her role as SEER program director, she is the lead for the National Childhood Cancer Registry (NCCR) development and implementation under the Childhood Cancer Data Initiative (CCDI). The latter is a population-based system based on cancer registries but brings in a multitude of other data sources to support research on childhood cancer.



Lisa C. Richardson, MD, MPH
Centers for Disease Control and Prevention

Lisa C. Richardson, MD, MPH, is Director of the Division of Cancer Prevention and Control (DCPC), the largest unit within the Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion. As director of DCPC, she works with partners at the national, state, and local levels to break down barriers to good health and create opportunities for everyone to live a long and healthy life. Under her leadership, DCPC's four foundational programs, the National Breast and Cervical Cancer Early Detection Program, National Program of Cancer Registries, National Comprehensive Cancer Control Program, and Colorectal Cancer Control Program, have helped the cancer control community better understand, prevent and control cancer in all populations. Dr. Richardson also provides guidance for the Division's

research agenda that includes the National Cancer Prevention and Control Research Network. A medical oncologist by training, she has authored or coauthored more than 150 peer-reviewed journal articles examining multi-sectoral approaches to improving cancer care access, delivery, and outcomes.



Susan M. Schneider, PhD, RN, AOCN®, FAAN

Duke University

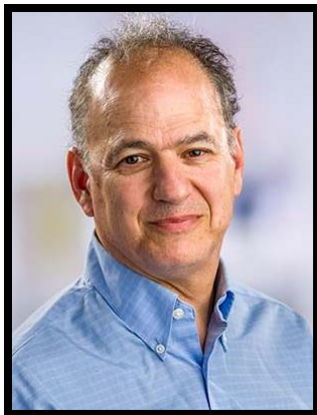
Dr. Susan Schneider earned PhD, MS, and BSN degrees in Nursing. She received numerous awards, including the Excellence in Cancer Nursing Research Award and Excellence in Cancer Nursing Education Award from the Oncology Nursing Society. She is a Fellow in the American Academy of Nursing. Currently, she is an Associate Professor Emerita at Duke University.

Dr. Schneider has over 35 years of experience as a clinical nurse, advanced practice nurse, and researcher caring for individuals with cancer. In these roles, she has both implemented and conducted clinical trials at three comprehensive cancer centers. She has expertise in conducting phase I pharmaceutical trials and has been a primary investigator for funded supportive care trials.

As a researcher, she focused on developing interventions to manage symptom distress in order to improve cancer patients' quality of life and increase survival. Such interventions hold significant potential for enhancing an individual's ability to adhere to treatment regimens and cope with the disease. She has received funding from the National Institutes of Health, the American Cancer Society, and the Oncology Nursing Society Foundation.

Dr. Schneider has devoted her teaching career to the development of oncology nurse leaders. Examples of her program development skills include obtaining funding for innovative models of educating advanced practice oncology nurses at two universities. Dr. Schneider is a past President of the Oncology Nursing Society and served on the Biden Cancer Initiative Board.

Dr. Schneider uses her extensive clinical knowledge to advocate for quality care for the cancer population. As a support group leader, she assists individuals with metastatic cancer to make decisions about clinical trials and supportive care. As a leader of a professional organization, she is an experienced advocate for funding for cancer research and patient access to care.



Stephen M. Schwartz, PhD, MPH

Fred Hutchinson Cancer Center

Dr. Stephen M. Schwartz is an epidemiologist and Co-Principal Investigator of the Fred Hutchinson Cancer Center's Cancer Surveillance System, a population-based cancer registry that is part of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. His research covers a broad range of molecular, biochemical, environmental, and lifestyle factors that can affect the development and outcome of cancer. A major objective of his research is to determine the influence of genetics on disease risk, either alone or in combination with lifestyle and environmental risk factors. His projects include studies of risk factors for human papillomavirus-related cancers and testicular germ-cell tumors, and of molecular markers for outcomes among patients with head and neck cancer. He also studies the health and well-being of adolescent and young-adult cancer survivors, particularly issues involving fertility preservation.



Kelly Shanahan, MD
Metavivor

In 2008, Kelly Shanahan had everything going for her: a busy and successful ob-gyn practice; a precocious 9 year old daughter; and a well used passport from traveling all over the world with her family to attend conferences, with a liberal dose of vacation on the side. When she was diagnosed with stage IIB breast cancer, she considered it a mere bump in the road.

And for five years, breast cancer was an aside, something to put in the past medical history section of forms. Even when she developed sudden back pain, Kelly never thought it could be breast cancer rearing its ugly head – a pulled muscle, a herniated disc maybe, but not what it turned out to be: metastatic breast cancer in virtually every bone in her body, with a fractured vertebrae and an about to break left femur. Kelly was diagnosed in 2013, on her 53rd birthday.

Neuropathy from the chemo cost her career, but she has found a new purpose in advocacy. Kelly is on the board of METAvivor, a member of the Metastatic Breast Cancer Alliance, a Komen Advocate in Science, on the symptom intervention committee of the Alliance for Clinical Trials in Oncology, a grant reviewer, and research advocate. She is passionate about getting patients to the table in the design, implementation, and follow up of clinical trials, especially as she is now enrolled in a clinical trial and has a LOT of feedback!

Follow her on Twitter @stage4kelly.

Kelly Shanahan is a mother, a wife, a daughter, a doctor, a woman LIVING with metastatic breast cancer.



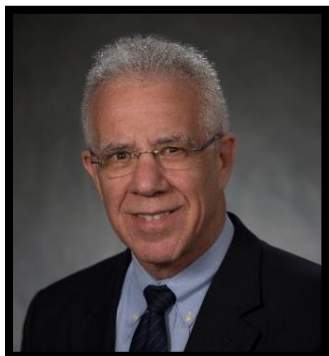
Elizabeth Shenkman, PhD
University of Florida

Elizabeth Shenkman, PhD is the Chair of the Department of Health Outcomes and Biomedical Informatics, the Co-Director of the University of Florida (UF) Clinical and Translational Science Institute (CTSI) and the Advisor to the UF Health Cancer Center. Dr. Shenkman is a health outcomes researcher with a research focus on: 1) determining which combinations of health care delivery, community, and patient factors influence quality and outcomes of care; and 2) developing and testing corresponding evidence-based strategies to reduce disparities in health outcomes among underserved populations.

Dr. Shenkman leads the Patient Centered Outcomes Research Institute-funded OneFlorida+ Clinical Research Network, which is comprised of 17 different health system partners caring for over 17 M Floridians or approximately 60% of the population in the 3rd largest state in the US along with 2 M Georgians and 1.1 M Alabamans. The University of California-Irvine and the University of Arkansas Medical Sciences recently joined OneFlorida+. The patients receiving care in this network include vulnerable populations who are rarely or minimally included in traditional clinical trials (e.g., those of lower socioeconomic status, racial and ethnic minorities, children, and older adults). A hallmark of OneFlorida+ is its centralized Data Trust, which contains linked health care claims, electronic health record, tumor registry, vital statistics, and census data from its health system partners for cohort discovery, study feasibility determination, and to augment primary data collection activities. Dr. Shenkman facilitates investigators' access to OneFlorida+ clinical settings and the Data Trust for a wide range of interventional trials and observational studies.

Dr. Shenkman is also an MPI for the NIH Office of the Director-funded All of Us Precision Medicine cohort initiative in collaboration with the University of Miami, Emory University and Morehouse School of Medicine. In that capacity, she is responsible for overseeing community engagement and recruitment and retention efforts focused on rural and underserved populations in North Florida.

Dr. Shenkman's research is funded by PCORI, the Agency for Health Care Research and Quality, NIH, and the National Cancer Institute. Her work is published in such journals as Pediatrics, Health Services Research, Clinical Epidemiology, Pediatric Blood and Cancer, and the American Journal of Public Health. Dr. Shenkman is an elected member of the Society for Pediatric Research and the American Pediatric Society.



Lawrence N. Shulman, MD, MACP, FASCO
University of Pennsylvania

Lawrence N. Shulman, MD, is Professor of Medicine at the Perelman School of Medicine, the Associate Director for Special Projects at the Abramson Cancer Center at the University of Pennsylvania, and Director of the Center for Global Cancer Medicine. He received his MD from Harvard Medical School and trained in Hematology and Oncology at the Beth Israel Hospital in Boston, MA.

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

A specialist in the treatment of patients with breast cancer, his research includes development of new cancer therapies, and implementation of cancer treatment programs in low-resource settings. In this regard, Dr. Shulman serves as Senior Oncology Advisor to the non-profit organization Partners In Health (PIH). The PIH mission includes the establishment of national cancer treatment programs with the Ministries of Health in Rwanda, Lesotho, and Haiti, programs for which he plays a seminal leadership role.



Samantha Spencer, MD
College of American Pathologists

Samantha Spencer, MD, serves as the Senior Director, Standards & Guidelines at the College of American Pathologists (CAP) with expertise in clinical informatics, structured data capture, standardized cancer reporting, and clinical product management. Dr. Spencer is the staff lead for the CAP Council on Informatics and Pathology Innovation, which oversees the work of the Cancer, Pathology Electronic Reporting, Informatics, Artificial Intelligence, and Digital and Computational Pathology Committees. Over the years she has worked on several consultative projects, collaborative activities, and grants with groups such as the CDC-NPCR, American College of Surgeons, American Joint Committee on Cancer, WHO-IARC, NAACCR, NCI-SEER, American Society of Clinical

Oncology, Cancer Care Ontario, the California Cancer Registry, major EHR and LIS vendors, and most importantly pathologist users of the CAP Cancer Protocol cancer reporting templates. Dr. Spencer currently leads the CAP contract work supporting FDA efforts to promote the work of the SHIELD Initiative (Systemic Harmonization and Interoperability Enhancement for Laboratory Data), a collaborative public-private stakeholder community developing and promoting laboratory IVD test data standardized representation and exchange. She also oversees and supports the CAP Pathology and Laboratory Quality Center for Evidence-based Guidelines.

Before joining the CAP in 2010, Dr. Spencer was a practicing emergency and internal medicine physician with an interest and work in quality practice improvement. She is board-certified in Clinical Informatics and Emergency Medicine, with a certificate in Product Strategy.



Peter Stetson, MD, MA, FAMIA
Memorial Sloan Kettering Cancer Center

Pete Stetson is the Chief Health Informatics Officer at Memorial Sloan Kettering Cancer Center. His role at MSK is to lead digital strategy and ensure impact and value delivery for MSK's digital health solutions. As part of the core leadership team of DigITs (Digital Informatics & Technology Solutions), Dr. Stetson oversees emerging digital health program development, clinical and nursing informatics, consumer and population health informatics, and clinical and translational research informatics. Pete also continues to work as a Hospitalist, an Informatics researcher, and teaches and mentors in Informatics.



Micky Tripathi, PhD, MPP
U.S. Department of Health and Human Services

Micky Tripathi is the National Coordinator for Health Information Technology at the U.S. Department of Health and Human Services, where he leads the formulation of the federal health IT strategy and coordinates federal health IT policies, standards, programs, and investments.

Dr. Tripathi has over 20 years of experience across the health IT landscape. He most recently served as Chief Alliance Officer for Arcadia, a health care data and software company focused on population health management and value-based care, the project manager of the Argonaut Project, an industry collaboration to accelerate the adoption of FHIR, and a board member of HL7, the Sequoia Project, the CommonWell Health Alliance, and the CARIN Alliance.

Dr. Tripathi served as the President and Chief Executive Officer of the Massachusetts eHealth Collaborative (MAeHC), a non-profit health IT advisory and clinical data analytics company. He was also the founding President and CEO of the Indiana Health Information Exchange, a statewide HIE partnered with the Regenstrief Institute, an Executive Advisor to investment firm LRVHealth, and a Fellow at the Berkman-Klein Center for Internet and Society at Harvard University.

He holds a PhD in political science from the Massachusetts Institute of Technology, a Master of Public Policy from Harvard University, and an AB in political science from Vassar College. Prior to receiving his PhD, he was a Presidential Management Fellow and a senior operations research analyst in the Office of the Secretary of Defense in Washington, DC, for which he received the Secretary of Defense Meritorious Civilian Service Medal.



Nadine R. Walker, MS, ODS-C
National Cancer Registrars Association

Nadine Walker is the Senior Director of Professional Practice at the National Cancer Registrars Association (NCRA) and brings more than 30 years of experience as a certified cancer registry professional. Walker has worked at community hospitals and academic-teaching healthcare facilities in New Jersey as part of the cancer leadership team building quality, patient-centered cancer programs. Walker was also responsible for coordinating and managing the American College of Surgeons (ACoS) Commission on Cancer program accreditations and Cancer Registry operations. Walker is dedicated to the professional growth and advocacy for cancer registry professionals.

In her current role at NCRA, Walker is responsible for the direction, management, and delivery of NCRA products and services that are tied to the organization's strategic development and cancer registrars' professional practice. She has previously served on NCRA's Board of Directors as its President and has also served as NCRA's inaugural liaison to the American College of Surgeons Cancer Surgery Standards Program (CSSP).

Walker earned her master's degree in health science from Rutgers University and her Master of Human Services degree from Lincoln University (PA). She also holds the NCRA Oncology Data Specialist (ODS) credential.



Kevin C. Ward, PhD, MPH
Rollins School of Public Health, Emory University

Kevin Ward is a cancer epidemiologist at the Rollins School of Public Health at Emory University in Atlanta, Georgia with a focus in cancer surveillance. He is the Director of the Georgia Center for Cancer Statistics (GCCS) and the current Principal Investigator of the National Cancer Institute's SEER Registry in Georgia. In partnership with the Georgia Department of Public Health, his Center operates the population-based Georgia Cancer Registry (GCR) and has done so since 1995. The GCR is supported by both the CDC's National Program of Cancer Registries and the NCI's SEER Program and data from the registry is used to develop strategies and policies for cancer prevention and control in our state. Kevin has worked with this Center for over 25 years and has extensive experience, both nationally and internationally, in all aspects of cancer registry development, cancer surveillance and the use of cancer registries for cancer control and research purposes. Kevin

has served on the Executive Board of the North American Association of Central Cancer Registries (NAACCR) since 2019 and has chaired the registry certification process in North America since 2009.



Jeremy L. Warner, MD, MS, FAMIA, FASCO
Brown University

Jeremy L. Warner MD, MS, FAMIA, FASCO is a Professor of Medicine and Professor of Biostatistics at Brown University, Associate Director of Data Science for the Legorreta Cancer Center, and Director of the Brown/Lifespan Center for Clinical Cancer Informatics and Data Science (CCIDS). His clinical specialty is malignant hematology, and he practices at Rhode Island Hospital. His primary research goal is to make sense of the structured and unstructured data present in electronic health records and clinical knowledge bases to directly improve outcomes for people living with cancer. He is the Chief Technology Officer of HemOnc.org LLC, which hosts the largest freely available wiki of anticancer regimens (HemOnc.org) and the derivative HemOnc knowledgebase. He is one of the founders of the

COVID-19 and Cancer Consortium (CCC19) and directs the CCC19 Research Coordinating Center. He is the Editor-in-Chief of JCO Clinical Cancer Informatics.



Robert A. Winn, MD
Virginia Commonwealth University

Robert A. Winn, MD, is the Director of Virginia Commonwealth University (VCU) Massey Comprehensive Cancer Center. He is also senior associate dean for cancer innovation at the VCU School of Medicine, and professor at the Division of Pulmonary Disease and Critical Care Medicine at VCU. His current basic science research focuses on the translational aspects of the role that proliferation pathways and cellular senescence play in lung cancer. As a pulmonologist, Robert 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. Robert is the president-elect of the Association of American Cancer Institutes (AACI); Chair of the National Cancer Policy Forum of the National Academies of Sciences,

Engineering, and Medicine; and a member of the Board of Directors for the American Cancer Society and LUNgevity Foundation. Robert holds a BA from the University of Notre Dame and an MD from the University of Michigan Medical School in Ann Arbor. He completed an internship and residency in internal medicine at Rush-Presbyterian-St. Luke's Medical Center in Chicago and a fellowship in pulmonary and critical care medicine at the University of Colorado Health Sciences Center in Denver.



Robin Yabroff, PhD, MBA
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 the quality and value of cancer care.

Dr. Yabroff has more than 25 years of health services research experience and currently has adjunct positions within the Department of Medicine, Johns Hopkins University, and the Rollins School of Public Health, Emory University. 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 350 peer-reviewed journal articles and 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. She was recognized as a Fellow of the American Society of Clinical Oncology (FASCO) in 2024.



Peter Paul Yu, MD, FACP, FASCO

Hartford HealthCare Cancer Institute & Memorial Sloan Kettering Cancer Center

Peter Paul Yu MD FACP FASCO is Physician-In-Chief Hartford HealthCare Cancer Institute and Clinical Member Memorial Sloan Kettering Cancer Center. Dr. Yu served as President 2014-2015 of the American Society of Clinical Oncology, during which time ASCO launched 2 journals, JCO Global Oncology and JCO Clinical Cancer Informatics, for which he is Associate Editor. Dr. Yu serves on the external advisory board for the California Cancer Registry, Fred Hutchinson Institute for Cancer Outcomes Research, and the Epic Systems Adult Oncology Steering Board.

As SVP Hartford HealthCare Dr. Yu directs strategic planning and provides operational oversight for all cancer related activities inclusive of patient care, research and post-graduate medical education. Hartford HealthCare provides oncologic care for a third of Connecticut's population.

The Memorial Sloan Cancer Alliance is a strategic partnership with Hartford HealthCare created to accelerate the transfer of knowledge from academia to clinical practice. In 2016, Dr. Yu was jointly recruited to lead this work at Hartford HealthCare.



National Cancer Policy 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 cancer 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 the cancer community and the public about critical policy issues through workshops and published reports. The forum has members with a broad range of expertise in cancer, including patient advocates, clinicians, and basic, translational, and clinical scientists. Forum 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.



Upcoming and Recent Workshops

Cancer Engineering: The Convergence of Engineering and Health to Advance Cancer Research and Care

Collaborative workshop convened by:

National Cancer Policy Forum
Board on Mathematical Sciences and Analytics
Board on Life Sciences

May 20–21, 2025

The concept of cancer engineering involves the application of engineering principles to solve challenges across cancer research and cancer care. This multidisciplinary approach brings together the fields of biology, engineering, and health care to devise innovative solutions that enhance the effectiveness, accessibility, and affordability of cancer care. This workshop will consider opportunities to improve patient outcomes through the convergence of engineering with oncology practice, research, and policy.

[Learn more and register here](#)

Addressing the Impact of Tobacco and Alcohol Use on Cancer-Related Health Outcomes

Collaborative workshop convened by:

National Cancer Policy Forum
Forum on Mental Health and Substance Use Disorders

March 17–18, 2025

The use of both alcohol and tobacco has independent and synergistic health effects, including links to many different cancers. There is a clear need to better understand the impact of dual use on cancer incidence and outcomes, to improve public education, and to develop oncology clinical practice guidelines for patients who use alcohol and tobacco. This workshop will examine the current state of the science and explore strategies to reduce tobacco and alcohol use to lower cancer risk and improve health outcomes.

[Learn more and register here](#)

Examining Clinical Guidelines for the Adoption of Genomic Testing

Collaborative workshop convened by:

Roundtable on Genomics and Precision Health
National Cancer Policy Forum

October 29, 2024

Clinical practice guidelines can impact adoption of new technologies into routine medical care. This workshop will examine how guidelines for genomic testing are developed by various organizations, with a focus on exploring inconsistencies across guidelines and opportunities for a possible path forward for more consistent clinical guidelines for genomics to improve patient care.

Website pending

Opportunities and Challenges for the Development and Adoption of Multicancer Detection Tests

October 28–29, 2024

Cancer screening is considered a key cancer control strategy because patients who are diagnosed with earlier stages of disease often have better treatment options and improved health outcomes. However, effective screening tests are lacking for most cancers. The development of minimally invasive approaches to screen for multiple tumor types at once could address this unmet need, but the clinical utility of multicancer detection (MCD) testing has yet to be established.

[Learn more and register here](#)

Enabling 21st Century Applications for Cancer Surveillance Through Enhanced Registries and Beyond

July 29–30, 2024

Population-based cancer surveillance has a pivotal role in assessing the nation's progress in cancer control. Cancer surveillance helps inform research and care interventions aimed at reducing the burden of cancer on patients and communities, including the ability to identify health disparities in cancer outcomes. Surveillance data are crucial for identifying emerging trends in health outcomes and opportunities to improve the quality of cancer care. However, challenges with the current approach to cancer surveillance in the United States include delays and gaps in data collection, as well as inadequate infrastructure and workforce to keep pace with the informatics and treatment-related advances in cancer. The National Cancer Policy Forum will convene a public workshop to examine opportunities to enhance and modernize cancer surveillance in order to improve cancer research, care, and outcomes for all patients.

[Learn more and register here](#)

Toward a Framework to Improve Diversity and Inclusion in Clinical Trials

Collaborative workshop convened by:

Forum on Drug Discovery, Development, and Translation
National Cancer Policy Forum

May 20, 2024

This workshop aimed to explore opportunities to improve racial and ethnic diversity in clinical trials with a focus on system-level change and collective efforts across organizations and sectors that no one entity can effectively take on alone.

[Workshop videos and presentations](#)

Recent Workshops

Biological Effectors of Social Determinants of Health in Cancer: Identification and Mitigation

March 20–21, 2024

Biological effectors of social determinants of health (SDOH) interact and impact cancer risk, treatment outcomes, and health equity. This workshop considered opportunities to advance health equity in cancer by identifying promising avenues for future research, as well as policies and interventions aimed at mitigating the negative impacts of the SDOH in cancer.

[Workshop videos and presentations](#)

Optimizing Public–Private Partnerships for Clinical Cancer Research

Collaborative workshop convened by:

National Cancer Policy Forum

Forum on Drug Discovery, Development, and Translation

October 17–18, 2023

Public–private partnerships (PPPs) have the potential to more effectively leverage public funding and resources, increase the breadth and depth of research, and affect a more rapid translation from basic discoveries to public health applications. Industry, government, nonprofit, and academic organizations could each make important and unique contributions to this endeavor. This workshop examined opportunities to enhance and foster PPPs for clinical cancer research and considered lessons learned from examples of public–private collaborations in oncology or other fields that have helped to advance clinical research and improve patient outcomes.

[Workshop videos and presentations](#)

Assessing and Advancing Progress in the Delivery of High-Quality Cancer Care

Collaborative workshop co-hosted by:

National Cancer Policy Forum

American Society of Clinical Oncology

October 5–6, 2023

2023 marked the 10-year anniversary of the Institute of Medicine report *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* and the ability of the cancer care delivery system to provide high-quality cancer care to all patients remains elusive. This workshop provided an opportunity for the cancer care community to discuss persistent barriers to achieving excellent and equitable cancer care for all and additional actions that could be taken to implement the 2013 recommendations. Workshop presentations and discussions also identified aspects of cancer care that have changed over the past decade and where new strategies are needed to improve the quality of care.

[Workshop videos and presentations](#)

Developing a Multidisciplinary and Multispecialty Workforce for Patients with Cancer, from Diagnosis to Survivorship

Collaborative workshop convened by:

National Cancer Policy Forum

Global Forum on Innovation in Health Professional Education

July 17–18, 2023

Patients living with and beyond cancer often require care from a wide range of clinicians as they navigate cancer diagnosis, treatment, and survivorship care. A multispecialty and multidisciplinary workforce is critical to ensuring that all patients with cancer receive high-quality care. This workshop examined opportunities to improve equitable access to multispecialty, multidisciplinary care for patients living with and beyond cancer.

[Workshop videos and presentations](#)

The Impact of the Dobbs Decision on Cancer Care Webinar Series

The National Cancer Policy Forum hosted a webinar series to discuss the downstream effects of the U.S. Supreme Court ruling *Dobbs v. Jackson Women's Health Organization* on access to reproductive health care in the context of cancer care.

- **How Abortion Restrictions Affect Patients and Care Delivery, July 11, 2023**
- **Health System and Workforce Effects, July 25, 2023**
- **Ethical, Legal, and Social Implications, August 31, 2023**

[Webinar series website](#)

The Potential Contribution of Cancer Genomics Information to Community Investigations of Unusual Patterns of Cancer

Collaborative workshop convened by:

National Cancer Policy Forum

Roundtable on Genomics and Precision Health

April 13, 2023

This workshop examined the opportunities to apply genomic and epigenomic biomarkers of environmental exposures associated with unusual patterns of cancer, particularly in pediatric populations. The workshop was sponsored by the Division of Environmental Health Science and Practice in the National Center for Environmental Health at the Centers for Disease Control and Prevention (CDC) and was convened to provide background information to assist the CDC in revising its [Guidelines for Examining Unusual Patterns of Cancer and Environmental Concerns](#).

[Workshop videos and presentations](#)

[Proceedings](#)

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American Cancer
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American College of
Radiology

American Society of
Clinical Oncology

Association of American
Cancer Institutes

Association of
Community Cancer
Centers

Cancer Center at Illinois

Flatiron Health

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Cancer Network

National Patient
Advocate Foundation

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Society

Partners In Health

Pfizer Inc.

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University of Pennsylvania

Rohit Bhargava, Ph.D.
Cancer Center at Illinois

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NATIONAL CANCER POLICY FORUM

WORKSHOP PROCEEDINGS AND RELATED PUBLICATIONS



WORKSHOP PROCEEDINGS

2024

Biological Effectors of Social Determinants of Health in Cancer: Identification and Mitigation (In Progress)
Optimizing Public-Private Partnerships for Clinical Cancer Research (In Progress)
Assessing and Advancing Progress in the Delivery of High-Quality Cancer Care
Developing a Multidisciplinary and Multispecialty Workforce for Patients with Cancer, from Diagnosis to Survivorship
Incorporating Integrated Diagnostics into Precision Oncology Care: Proceedings of a Workshop
Addressing Treatment Resistance in the Development of Cancer Immune Modulator Therapeutics: Proceedings of a Workshop

2023

The Potential Contribution of Cancer Genomics Information to Community Investigations of Unusual Patterns of Cancer: Proceedings of a Workshop
Advancing Progress in Cancer Prevention and Risk Reduction: Proceedings of a Workshop
Realizing the Potential of Genomics across the Continuum of Precision Health Care: Proceedings of a Workshop

2022

Family Caregiving for People with Cancer and Other Serious Illnesses: A Workshop
Innovation in Electronic Health Records for Cancer Care, Research, and Surveillance: A Workshop
Promoting Health Equity in Cancer Care: Proceedings of a Workshop
The Role of Companion Animals as Sentinels for Predicting Environmental Exposure Effects on Aging and Cancer Susceptibility in Humans: Proceedings of a Workshop
Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic: Proceedings of a Workshop
Impact of the Affordable Care Act on Cancer Prevention and Cancer Care: Proceedings of a Workshop

2021

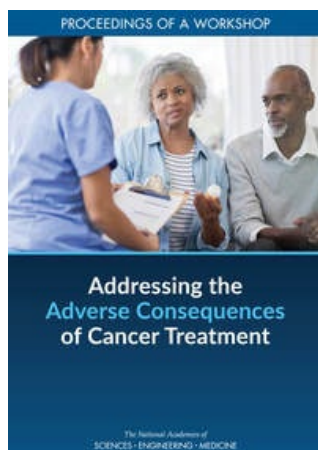
Addressing the Adverse Consequences of Cancer Treatment: Proceedings of a Workshop
Opportunities and Challenges for Using Digital Health Applications in Oncology: Proceedings of a Workshop
Improving the Evidence Base for Treatment Decision Making for Older Adults with Cancer: Proceedings of a Workshop— in Brief
Advancing Progress in the Development and Implementation of Effective, High-Quality Cancer Screening: Proceedings of a Workshop
Drug Research and Development for Adults Across the Older Age Span: Proceedings of a Workshop

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National Cancer Policy Forum, visit:

nationalacademies.org/NCPF

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WORKSHOP PROCEEDINGS

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 in Biomedical Research Through Transparent Reporting: Proceedings of a Workshop

2019

Developing and Sustaining an Effective and Resilient Oncology Careforce: Proceedings of a Workshop
 Advancing Progress in the Development of Combination Cancer Therapies with Immune Checkpoint Inhibitors: Proceedings of a Workshop
 Improving Cancer Diagnosis and Care: Clinical Application of Computational Methods in Precision Oncology: Proceedings of a Workshop

2018

Improving Cancer Diagnosis and Care: Patient Access to Oncologic Imaging and Pathology Expertise and Technologies: Proceedings of a Workshop
 Establishing Effective Patient Navigation Programs in Oncology: Proceedings of a Workshop
 Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop

2017

The Drug Development Paradigm in Oncology: Proceedings of a Workshop
 Cancer Care in Low-Resource Areas: Cancer Treatment, Palliative Care, and Survivorship Care: Proceedings of a Workshop
 Implementation of Lung Cancer Screening: Proceedings of a Workshop
 Incorporating Weight Management and Physical Activity Throughout the Cancer Care Continuum: Proceedings of a Workshop

2016

Policy Issues in the Clinical Development and Use of Immunotherapy for Cancer Treatment: Proceedings of a Workshop
 Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection: Workshop Summary
 Appropriate Use of Advanced Technologies for Radiation Therapy and Surgery in Oncology: Workshop Summary

2015

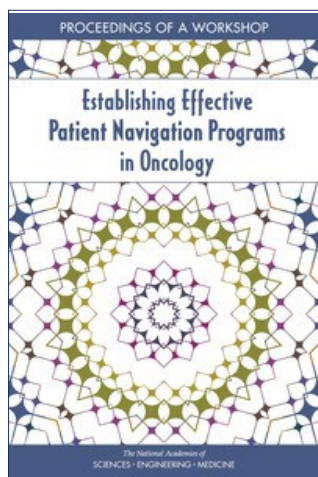
Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop by the Institute of Medicine and the American Cancer Society
 Policy Issues in the Development and Adoption of Biomarkers for Molecularly Targeted Cancer Therapies: Workshop Summary
 Assessing and Improving the Interpretation of Breast Images: Workshop Summary
 Role of Clinical Studies for Pets with Naturally Occurring Tumors in Translational Cancer Research: Workshop Summary

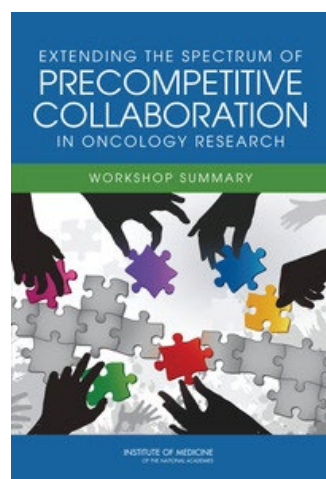
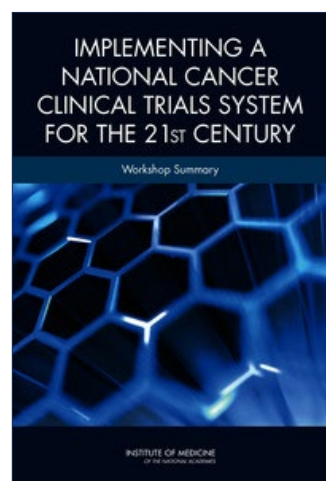
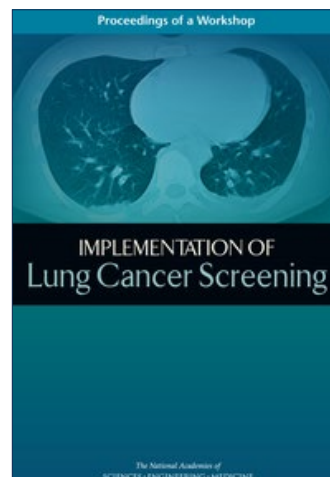
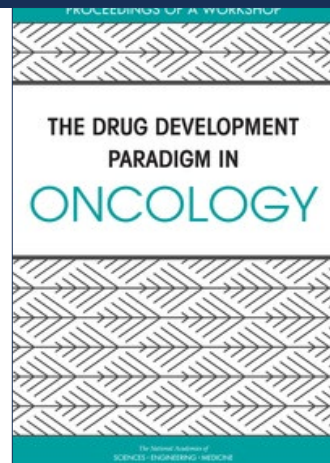
2014

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





WORKSHOP PROCEEDINGS

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

Direct-to-Consumer Genetic Testing (with the National Research Council): Summary of a Workshop
Extending the Spectrum of Precompetitive Collaboration in Oncology Research: Workshop Summary
A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care: Workshop Summary
Policy Issues in the Development of Personalized Medicine in Oncology: Workshop Summary

2009

Assessing and Improving Value in Cancer Care: Workshop Summary
Ensuring Quality Cancer Care Through the Oncology Workforce: Sustaining Care in the 21st Century: Workshop Summary
Multi-Center Phase III Clinical Trials and the NCI Cooperative Group Program: Workshop Summary

2008

Implementing Colorectal Cancer Screening: Workshop Summary
Improving the Quality of Cancer Clinical Trials: Workshop Summary

2007

Cancer-Related Genetic Testing and Counseling: Workshop Proceedings
Cancer in Elderly People: Workshop Proceedings
Implementing Cancer Survivorship Care Planning: Workshop Summary

2006

Effect of the HIPAA Privacy Rule on Health Research: Proceedings of a Workshop
Developing Biomarker-Based Tools for Cancer Screening, Diagnosis, and Treatment: Workshop Summary

RELATED WORK

CONSENSUS STUDY REPORTS BUILDING ON NCPF WORK

Childhood Cancer and Functional Impacts Across the Care Continuum (2021)

Report: nap.edu/catalog/25944

Diagnosing and Treating Adult Cancers and Associated Impairments (2021)

Report: nap.edu/catalog/25956

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

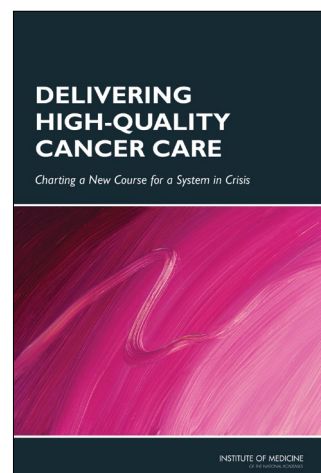
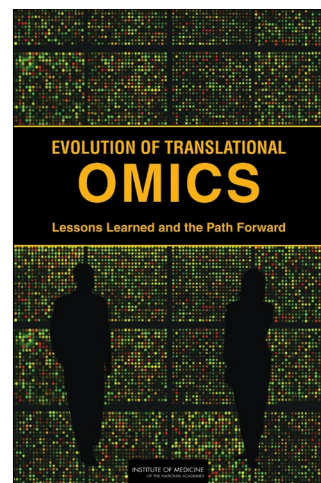
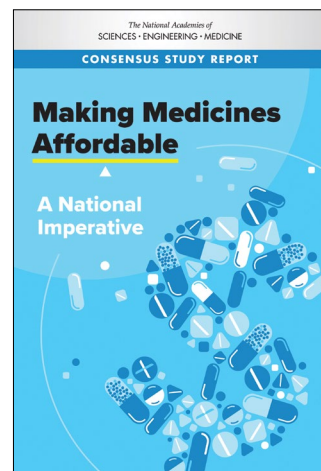
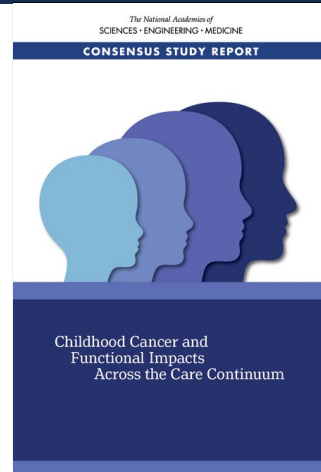
Independent, individually authored articles arising from NCPF workshops—and consensus studies building on NCPF work—include:

2024

- Peterson, D. E., N. L. Stout, L. N. Shulman, J. Perkins, G. LeMarier, and L. Nekhlyudov. 2024. Gaps in access to medically necessary dental care for patients living with and beyond cancer: We must do better. *Journal of Clinical Oncology*. <https://doi.org/10.1200/JCO.24.00162>.

2022

- Bono, K. and N. L. Keating. 2022. Addressing social determinants of health: Now is the time. *Journal of the National Cancer Institute*. <https://academic.oup.com/jnci/advance-article/doi/10.1093/jnci/djac137/6705076?searchresult=1>.
- Bradley, C. J., S. Kitchen, S., Bhatia, J., Bynum, G. Darien, J. L. Lichtenfeld, R. Oyer, L. N. Shulman, and L. Kennedy Sheldon. 2022. Policies and practices to address cancer's long-term adverse consequences. *Journal of the National Cancer Institute*. 114(8):1065-1071. <https://academic.oup.com/jnci/article-abstract/114/8/1065/6570605?redirectedFrom=fulltext>.
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- Hyer, R. N. 2022. Insights for oncology trials garnered from the rapid development of an mRNA COVID-19 vaccine. *Cancer Journal* 28(2):146-150. https://journals.lww.com/journalppo/Fulltext/2022/03000/Insights_for_Oncology_Trials_Garnered_From_the.12.aspx.
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- Nekhlyudov, L., L. A. Fleisher, and P. B. Jacobsen. 2022. Telemedicine across the cancer care continuum: Evidence and opportunities for clinical care, research, and policy. *Cancer Journal* 28(2):121-124. https://journals.lww.com/journalppo/Abstract/2022/03000/Telemedicine_Across_the_Cancer_Care_Continuum_.8.aspx.



2022, continued

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Upcoming Workshop

Opportunities and Challenges for the Development and Adoption of Multicancer Detection Tests: A Workshop

October 28-29, 2024

Keck Center Room 100
500 Fifth Street, NW
Washington, DC 20001

Workshop Background

Cancer screening is considered a key cancer control strategy because patients who are diagnosed with earlier stages of disease often have better treatment options and improved health outcomes. However, effective screening tests are lacking for most cancers. The development of minimally invasive approaches to screen for multiple tumor types at once could address this unmet need, but the clinical utility of multicancer detection (MCD) testing has yet to be established. This workshop will examine the state of the science for the clinical use of MCD testing and feature presentations and panel discussions on topics such as:

- Examples of current and emerging MCD tests.
- Challenges and opportunities to validate MCDs and determine their clinical utility for detecting cancer and reducing cancer-specific mortality.
- Strategies for cancer care downstream of MCD testing, such as follow-up diagnostic testing and treatment decision-making.
- Limitations of MCDs, including the burden on patients and health care systems from false-positive test results, overdiagnosis, and overtreatment.
- Research and policy gaps for assessing MCDs and their impact on cancer care and outcomes and health equity.

Planning Committee

Beth Y. Karlan, University of California, Los Angeles (Co-Chair)

Lawrence N. Shulman, University of Pennsylvania (Co-Chair)

Justin E. Bekelman, University of Pennsylvania

Philip E. Castle, National Cancer Institute

Ruth Etzioni, Fred Hutchinson Cancer Center

Chanita Hughes-Halbert, University of Southern California

Elena Martinez, University of California, San Diego

Etta Pisano, American College of Radiology

Robert Winn, Virginia Commonwealth University

[Workshop Website](#)

Upcoming Workshop

Examining Clinical Guidelines for the Adoption of Genomic Testing: A Workshop October 29, 2024

Roundtable on Genomics and Precision Health
National Cancer Policy Forum

Workshop Background

Clinical practice guidelines are used as clinical decision support tools to promote best practices among those working in laboratories or health care settings. For genomic testing, they aim to standardize the application of genomic data in medical care through their recommendations. Clinical guidelines are most often developed by professional societies and there are multiple types of clinical guidelines. Furthermore, guidelines produced by different organizations can be incongruous even when using the same type of evidence. The lack of consistency in clinical guidelines can lead to gaps in the adoption of genomic testing across the health care ecosystem, creating challenges for clinicians, patients, payers, and genetic test developers.

To better understand the challenges and opportunities associated with consistent clinical practice guidelines for genomics, the Roundtable on Genomics and Precision Health will host a public workshop in collaboration with the National Cancer Policy Forum to examine how guidelines are developed and how groups could collaborate to create more compatibility.

The workshop's presentations and discussions may focus on:

- Exploring the processes and methodologies used by different professional societies, organizations, and collaborations to gather evidence and develop clinical guidelines for appropriate genomic testing.
- Understanding how clinicians, payers, test developers, laboratory partners, and others decide which guideline(s) to follow and how they use these guidelines in practice.
- Examining elements that are consistent and those that differ across clinical guidelines for genomics and how these areas impact access, coverage, and equity in care for patients and how they affect clinicians, payers, test developers, laboratories, and others.
- Discussing opportunities for a possible path forward for more compatible clinical guidelines for genomics to improve patient care.

Planning Committee

Mylynda Massart, UPMC Primary Care Precision Medicine Center (Co-Chair)

Victoria Pratt, Representing Association for Molecular Pathology; Agena Biosciences (Co-Chair)

Trish Brown, CVS Health

Pranil Chandra, PathGroup

W. Gregory Feero, Representing Journal of American Medical Association; Geisel School of Medicine;
Maine Dartmouth Family Medicine Residency Program

Gabriel Lazarin, Myriad Genetics

Funda Meric-Bernstam, MD Anderson Cancer Center

Rebecca Morgan, Evidence Foundation; McMaster University; Case Western Reserve University

Wanda Nicholson, George Washington University Milken Institute School of Public Health

Mary Nix, Agency for Healthcare Research and Quality

Pim Suwannarat, Mid-Atlantic Permanente Medical Group

Workshop Website Pending

Upcoming Workshop

Addressing the Impact of Tobacco and Alcohol Use on Cancer-Related Health Outcomes: A Workshop

March 17-18, 2025

National Cancer Policy Forum
Forum on Mental Health and Substance Use Disorders

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

Workshop Background

The use of both alcohol and tobacco has independent and synergistic health effects, including links to many different cancers. There is a clear need to better understand the impact of dual use on cancer incidence and outcomes, to improve public education, and to develop oncology clinical practice guidelines for patients who use alcohol and tobacco. This workshop will examine the current state of the science and explore strategies to reduce tobacco and alcohol use to lower cancer risk and improve health outcomes.

This workshop will feature presentations and panel discussions on topics such as:

- The effects of tobacco and alcohol use—including synergistic effects—on cancer incidence and outcomes.
- Risk factors for tobacco and alcohol use and their influence on disparities in outcomes.
- Clinical practice guidelines, including in the context of cancer treatment, for tobacco cessation and interventions to help patients reduce alcohol use.
- Strategies for data collection and research to address evidence gaps.
- Lessons from tobacco control that could be applied to encourage reduction in alcohol use.
- Impact of recent tobacco policy changes and ways to further advance progress in tobacco control.

Planning Committee Pending

[Workshop Website](#)

Upcoming Workshop

Cancer Engineering: The Convergence of Engineering and Health to Advance Cancer Research and Care: A Workshop

May 20-21, 2025

National Cancer Policy Forum
Board on Mathematical Sciences and Analytics
Board on Life Sciences

Keck Center Room 100
500 5th Street, NW
Washington, DC 20001

Workshop Background

The concept of cancer engineering involves the application of engineering principles to solve challenges across cancer research and cancer care. This multidisciplinary approach brings together the fields of biology, engineering, and health care to devise innovative solutions that enhance the effectiveness, accessibility, and affordability of cancer care. This workshop will consider opportunities to improve patient outcomes through the convergence of engineering with oncology practice, research, and policy.

This workshop will feature presentations and panel discussions on topics such as:

- Strategies to break down disciplinary silos and promote convergence in engineering and cancer research and care.
- Consideration of technologies and interventions that apply engineering approaches to accelerate cancer research and to improve care and outcomes for patients with cancer.
- Examples of the challenges and opportunities to translate advances from engineering into technologies that enable precision cancer research and care.
- Strategies to ensure that advances in cancer engineering are equitable, inclusive, and address health disparities.
- Approaches to facilitate broad access to the output of cancer engineering to promote the delivery of high-quality care, particularly in community-based settings of care.
- Opportunities to develop and expand the cancer engineering workforce, including leadership development, multidisciplinary education and training, collaborative research approaches, and use of dissemination and implementation science strategies.

Planning Committee Pending

[Workshop Website](#)