

The National Academies of Sciences, Engineering, and Medicine Virtual Workshop

Convened by the National Cancer Policy Forum
in collaboration with the
Computer Science and Telecommunications Board



A WORKSHOP

**Innovation In
Electronic Health Records
for Oncology Care,
Research, and Surveillance**

February 28, 2022 9:30am - 5pm ET
March 1, 2022 9:00am - 12pm ET

The National Academies of SCIENCES
ENGINEERING
MEDICINE

Link to view webcast:

<https://www.nationalacademies.org/event/02-28-2022/innovation-in-electronic-health-records-for-oncology-care-research-and-surveillance-a-workshop>

#NatlCancerForum #CSTB

The National Academies of
SCIENCES • ENGINEERING • MEDICINE





February 28, 2022

Dear Colleagues,

Welcome to the National Academies workshop on *Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance*, convened by the [National Cancer Policy Forum](#) in collaboration with the [Computer Science and Telecommunications Board](#).

The workshop will include an overview of the history and current status of electronic health records (EHRs), strategies to optimize EHR functionality and usability, as well as opportunities for collaboration and innovation in the development, implementation, and use of EHRs to improve oncology care, research, and surveillance. Although this workshop focuses on cancer, it has broad implications for the development and use of EHRs for other areas of medicine.

We welcome your involvement in the workshop. Please use the chatbox on our website (<https://www.nationalacademies.org/event/02-28-2022/innovation-in-electronic-health-records-for-oncology-care-research-and-surveillance-a-workshop>) to ask questions, and please include your name and affiliation when posting questions/comments. 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 event website.

Sincerely,

Mia Levy, MD, PhD
Chief Medical Officer
Foundation Medicine, Inc.

Lawrence N. Shulman, MD, MACP, FASCO
Professor of Medicine
Deputy Director, Clinical Services
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Webcast Information for Attendees

Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance

Joining the Workshop

Live Webstream on Monday, February 28, 2022 from 9:30 am – 5:00 pm ET & Tuesday, March 1, 2022 from 9:00 am – 12:00 pm ET:

<https://www.nationalacademies.org/event/02-28-2022/innovation-in-electronic-health-records-for-oncology-care-research-and-surveillance-a-workshop>

- We welcome your involvement in the workshop. Please use the chatbox on our website (located below the livestream) to ask questions, and please include your name and affiliation.
- This workshop is being webcast and recorded. The webcast and presentation files will be archived on the project webpage.
- Please use the hashtags **#NatlCancerForum** and **#CSTB** to tweet about the workshop.
- Interested in receiving updates from the National Cancer Policy Forum or the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division? Sign up [here](#).

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Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance: A Virtual Workshop

<https://www.nationalacademies.org/event/02-28-2022/innovation-in-electronic-health-records-for-oncology-care-research-and-surveillance-a-workshop>

MONDAY, FEBRUARY 28, 2022 9:30 AM-5:00 PM Eastern Time Zone	
9:30 am	Welcome from the National Cancer Policy Forum <i>Planning Committee Co-chairs:</i> <i>Mia Levy, Foundation Medicine, Inc.</i> <i>Lawrence N. Shulman, University of Pennsylvania Abramson Cancer Center</i>
9:40 am	Session 1: Overview of the Use of EHRs in Oncology Care, Research, and Surveillance <i>Co-moderators:</i> <i>Mia Levy, Foundation Medicine, Inc.</i> <i>Lawrence N. Shulman, University of Pennsylvania Abramson Cancer Center</i> Session Objective: To review the current state and trends of EHRs and discuss the evidence base for the design, development, and use of EHRs in cancer care, research and surveillance. Technical and Contextual Evolution of EHRs <i>Mia Levy, Foundation Medicine, Inc.</i> The Electronic Health Record: From the View of the Oncologist <i>Lawrence N. Shulman, University of Pennsylvania Abramson Cancer Center</i> Patient Perspective <i>Gwen Darien, National Patient Advocate Foundation</i> Integrating Social Determinants of Health in EHRs: Ethical and Social Justice Issues <i>Chanita Hughes-Halbert, USC Norris Comprehensive Cancer Center</i> Quality Improvement and Research Perspective <i>Neal J. Meropol, Flatiron Health</i> Panel Discussion with Speakers
11:10 am	Break
11:20 am	Session 2: Opportunities to Improve the Patient-Facing Aspects of EHRs <i>Co-moderators:</i> <i>Etta D. Pisano, Harvard Medical School/American College of Radiology</i> <i>Robin Yabroff, American Cancer Society</i> Session Objective: To explore opportunities and approaches to improve the patient-facing aspects of EHRs to empower patients and improve patient care and outcomes.

	Impact of EHRs on the Patient-Physician Relationship - Jyoti D. Patel, Northwestern University Integrating Patient Reported Outcomes into Electronic Health Record Systems in Oncology - Ethan Basch, University of North Carolina at Chapel Hill Today's Patient Portal and Sharing of Patient Data Across EHR Systems for Cancer Care and Research - Travis J. Osterman, Vanderbilt University Medical Center Using the EHR to “Nudge” Evidence-based Cancer Care - Samuel U. Takvorian, Penn Medicine Next-generation EHRs to Facilitate Oncology Care - George Hripcsak, Columbia University Panel Discussion with Speakers
12:50 pm	Lunch Break
1:50 pm	Session 3: Opportunities to Optimize the Functionality and Usability of EHRs in Oncology Care Co-moderators: Bradley Malin, Vanderbilt University Medical Center Alex Melamed, Columbia University Medical Center Session Objective: To examine the challenges and opportunities to optimize the functionality and usability of EHRs in clinical workflow to meet the needs of the various users in oncology care. Oncology Care Pathways: Importance and Relation to Current EHRs Functionality and Opportunities for Improvement - Robin Zon, Michiana Hematology Oncology Opportunities for Decision Support through the Use of EHRs - Mary M. Ichiuji, Kaiser Permanente Efficiency of EHR Use and Management in Creating an Ideal Workspace and Presentation of Critical Data for Oncology-specific Care Providers - Shilo Anders, Vanderbilt University Interface Between Electronic Systems and Humans: View From Outside of Medicine - Elizabeth Mynatt, Northeastern University Human Factors Engineering for EHR Design in Oncology Care: The Patient Experience Across the Cancer Care Continuum - Pascale Carayon, University of Wisconsin-Madison An Industry Perspective - Jenna Date, Allscripts Hospital and Health Systems

	Panel Discussion with Speakers
3:25 pm	Break
3:35 pm	Session 4: Roundtable: Innovative Strategies to Improve EHR Data Collection to Support Care Quality and Research Initiatives <i>Co-moderators:</i> Neal J. Meropol, Flatiron Health Lara Strawbridge, Center for Medicare and Medicaid Innovation Session Objective: To discuss new approaches and opportunities to enhance EHR structure, data collection and standardization, interoperability, and EHR integration to improve clinical care and enhance oncology research. Clinician Perspective • Tufia C. Haddad, Mayo Clinic College of Medicine and Sciences Opportunities and Challenges: Entry of Critical Structured Data Into EHRs • Monica Bertagnoli, Brigham & Women's Hospital and Dana-Farber Cancer Institute Researcher Perspective: Opportunities for Improved Research • Jeremy L. Warner, Vanderbilt University Quality Improvement Initiatives: Opportunities for Improved Quality of Care • Barry Russo, The Center for Cancer and Blood Disorders Payer Perspective • Reed V. Tuckson, Black Coalition Against COVID and Tuckson Health Connections, LLC Panel Discussion with Panelists
4:50 pm	Closing Remarks
5:00 pm	Adjourn
TUESDAY, MARCH 1, 2022 9:00 AM-12:00 PM Eastern Time Zone	
9:00 am	Welcome and Overview of Day 2 <i>Planning Committee Co-chairs</i> Mia Levy, Foundation Medicine, Inc. Lawrence N. Shulman, University of Pennsylvania Abramson Cancer Center
9:05 am	Session 5: The Roles of Federal Agencies to Advance Progress in EHRs <i>Co-moderators:</i> Robert W. Carlson, National Comprehensive Cancer Network Nicole F. Dowling, Centers for Disease Control and Prevention Session Objective: To explore current collaborations and initiatives to conceptualize and implement innovations in EHRs, and discuss potential policy incentives for the adoption of improved EHRs in cancer care, research, and surveillance. Potential Role of Science and Technology Policy in Advancement of EHRs • Twee Sim, Office of Science and Technology Policy and the Department of Defense

	Advancing Progress in EHRs: Cancer Surveillance as an Example - Lynne Penberthy, <i>National Cancer Institute</i> Electronic Health Records for Public Health Planning and Research - Lisa C. Richardson, <i>Centers for Disease Control and Prevention</i> Leveraging Electronic Health Records: Expanding Opportunities for Evidence Generation - Paul G. Kluetz, <i>Oncology Center of Excellence, Food and Drug Administration</i> Ready, Set, Go!: Leveraging EHRs for Innovation - Avinash Shanbhag, <i>Office of Technology, Office of the National Coordinator</i> CMMI Perspective - Lara Strawbridge, <i>Center for Medicare and Medicaid Innovation, Centers for Medicare & Medicaid Services</i> Panel Discussion with Speakers
10:35 am	Break
10:45 am	Session 6: Policies to Foster EHR Redesign to Advance Progress in Cancer Care, Research, and Surveillance <i>Co-moderators:</i> Mimi Huizinga, <i>ImmunoGen, Inc.</i> Robert A. Winn, <i>Virginia Commonwealth University Massey Cancer Center</i> Session Objective: To discuss potential policy levers and actionable strategies to enhance innovation in the development, implementation, and use of EHRs in oncology care, research, and surveillance. Panelists (Session Co-moderators) <i>Representing Session 1:</i> Lawrence Shulman <i>Representing Session 2:</i> Etta Pisano <i>Representing Session 3:</i> Bradley Malin <i>Representing Session 4:</i> Lara Strawbridge <i>Representing Session 5:</i> Nicole Dowling Open Discussion
11:50 am	Closing Remarks Mia Levy, <i>Foundation Medicine, Inc.</i> <i>Planning Committee Co-chair</i>
12:00 pm	Adjourn

GLOSSARY OF TERMINOLOGY

Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance

25x5 Initiative – A collaborative effort of clinicians, academics, members of industry, government, payers, professional organizations, and patients to reduce EHR documentation burden by 75% in five years.

American Medical Informatics Association (AMIA) – A non-profit organization dedicated to the development and application of biomedical and health informatics in the support of patient care, teaching, research, and health care administration.

American National Standards Institution (ANSI) - ANSI's facilitates and coordinates the U.S. voluntary standards and conformity assessment system, and safeguards its integrity.

Application Programming Interface (API) – A tool that supports interoperability by allowing different software programs to easily communicate with one other and to share information.

Artificial Intelligence (AI) – The ability of a computer to perform functions that are usually thought of as intelligent human behavior, such as learning, reasoning, problem solving, and decision making. Artificial intelligence uses computer programs that analyze very large amounts of information to learn how to help make decisions or predictions.

American Society of Clinical Oncology (ASCO) – The world's leading professional organization for physicians and oncology professionals caring for people with cancer.

Clinical Data Interchange Standards Consortium (CDISC) – An open, non-profit organization that develops and supports global data standards to improve the quality and interoperability of medical research and healthcare.

Common Oncology Data Elements eXtensions (CodeX) – A member-driven HL7 FHIR Accelerator hosting a growing community working together to enable FHIR-based interoperability that drives substantial improvements for some of the most important challenges and opportunities in patient health.

Computerized Provider Order Entry (CPOE) – A computer application that allows a physician's orders for diagnostic and treatment services (such as medications, laboratory, and other tests) to be entered electronically instead of being recorded on order sheets or prescription pads. The computer compares the order against standards for dosing, checks for allergies or interactions with other medications, and warns the physician about potential problems.

Consolidated Health Informatics (CHI) Initiative – One of the 24 Presidential E-Government initiatives with the goal of adopting vocabulary and messaging standards to facilitate communication of clinical information across the federal health enterprise.

Decision-Support System (DSS) – Computer tools or applications to assist physicians in clinical decisions by providing evidence-based knowledge in the context of patient specific data. Examples include drug interaction alerts at the time medication is prescribed and reminders for specific guideline-based interventions during the care of patients with chronic disease.

Electronic Health Record (EHR) – A digital version of a patient's paper chart. EHRs are real-time, patient-centered records that make information available instantly and securely to authorized users. While an EHR does

contain the medical and treatment histories of patients, an EHR system is built to go beyond standard clinical data collected in a provider's office and can be inclusive of a broader view of a patient's care

Electronic Prescribing (eRx) – A type of computer technology whereby physicians use handheld or personal computer devices to review drug and formulary coverage and to transmit prescriptions to a printer or to a local pharmacy. E-prescribing software can be integrated into existing clinical information systems to allow physician access to patient specific information to screen for drug interactions and allergies.

Enterprise Architecture – A strategic resource that aligns business and technology, leverages shared assets, builds internal and external partnerships, and optimizes the value of information technology services.

Fast Healthcare Interoperability Resources (FHIR) – A Health Level Seven International (HL7) standard for exchanging healthcare information electronically. [See definition of [Health Level Seven International \(HL7\)](#)].

Federal Health Architecture (FHA) – A collaborative body composed of several federal departments and agencies, including the Department of Health and Human Services, the Department of Homeland Security, the Department of Veterans Affairs, the Environmental Protection Agency, the United States Department of Agriculture, the Department of Defense, and the Department of Energy. FHA provides a framework for linking health business processes to technology solutions and standards and for demonstrating how these solution achieve improved health performance outcomes.

Gravity Project – The Gravity Project standardizes data for individual-level components of social determinants of health so it can be documented in and exchanged across digital health and human service platforms.

Health Information Technology (HIT) – The application of information processing involving bot computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making.

Health Information Technology for Economic and Clinical Health Act (HITECH Act) – This Act provides Health and Human Services with the authority to establish programs to improve health care quality, safety, and efficiency through the promotion of health IT, including electronic health records and private and secure electronic health information exchange.

Health Insurance Portability and Accountability Act (HIPAA) – The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's consent or knowledge

Health Level Seven (HL7) – A not-for-profit, ANSI (American National Standards Institute)-accredited standards developing organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services.

Human Factors and Ergonomics (HFE) – Human factors engineering is the application of human factors information to the design of tools, machines, systems, tasks, jobs, and environments for safe, comfortable, and effective human use.

Interoperability – The ability of many different users and different software applications to communicate with one another, exchange data and use the information that has been exchanged. For example, if a patient switches doctors, their medical history can be shared even if the hospital systems or doctors use different computer programs to record their information.

Logical Observation Identifiers Names and Codes (LOINC) – Clinical terminology important for laboratory test orders and results. LOINC is one of a suite of designated standards for use in US Federal Government systems for the electronic exchange of clinical health information.

Machine Learning (ML) – A field of computer science that develops the processes by which computers are taught how to learn and perform certain functions without being specifically programmed to perform those functions. Machine learning involves analyzing very large amounts of information to improve a computer's ability to make decisions or predictions.

Meaningful Use – Sets the specific objectives that eligible professionals and hospitals must achieve to participate in the Centers for Medicare & Medicaid Services EHR Incentive Programs.

Minimal Common Oncology Data Elements (mCODE) – This is a core set of structured data elements for oncology that establishes minimum recommended standards for the structure and content of health record information across use cases and users. The goal of mCODE is to improve the overall quality and consistency of cancer data available to clinicians, patients, researchers, and other stakeholders in the fight against cancer.

National Cancer Database (NCDB) - A joint program of the Commission on Cancer of the American College of Surgeons and the American Cancer Society, NCDB is a nationwide oncology outcomes database for more than 1,500 Commission-accredited cancer programs in the United States and Puerto Rico.

National Program of Cancer Registries (NPCR) – Established by Congress through the Cancer Registries Amendment Act in 1992, and administered by Centers for Disease Control and Prevention, the National Program of Cancer Registries (NPCR) collects data on cancer occurrence (including the type, extent, and location of the cancer), the type of initial treatment, and outcomes. Through NPCR, CDC supports central cancer registries in 46 states, the District of Columbia, Puerto Rico, the U.S. Pacific Island Jurisdictions, and the U.S. Virgin Islands. Together, NPCR and SEER collect information about cancer on the entire US.

Observational Medical Outcomes Partnership (OMOP) – It was a 5-year public-private partnership involving the FDA, multiple pharmaceutical companies, and healthcare providers established to inform the appropriate use of observational healthcare databases for studying the effects (risks and benefits) of medical products. OMOP was transitioned to the [Reagan-Udall Foundation](#) in 2013.

Office of the National Coordinator for Health Information Technology (ONC) – The principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information. The position of National Coordinator was created in 2004, through an Executive Order, and legislatively mandated in the Health Information Technology for Economic and Clinical Health Act of 2009.

Protected Health Information (PHI) – PHI is also sometimes called “personal health information.” As defined by the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, PHI is generally defined as individually identifiable health information in any form.

Personal Health Record (PHR) – A collection of information about a person's health that allows the person to manage and track his or her own health information. A personal health record may include information about allergies, illnesses, surgeries, immunizations, and results of physical exams, tests, and screenings. It may also include information about medicines taken and health habits, such as diet and exercise.

Surveillance, Epidemiology, and End Results (SEER) – Supported by the National Cancer Institute, a coordinated system of population-based cancer registries which collect data on cancer occurrence, the type of initial treatment, and outcomes in 19 geographic areas in the US. The SEER program provides information on

cancer statistics in an effort to reduce the cancer burden among the U.S. population. Together, SEER and NPCR collect information about cancer on the entire US.

Systems Engineering Initiative for Patient Safety (SEIPS) – This is a multidisciplinary initiative applying systems engineering, human factors engineering, and quality engineering approaches.

SMART Health IT – An app platform for healthcare that was launched as a universal application programming interface to transform electronic health records into platforms for substitutable iPhone-like apps.

Systematized Nomenclature of Medicine -- Clinical Terms (SNOMED CT) – This has been designated as a national standard for several purposes (including problem list and public health reporting) in the initial certification criteria for EHRs issued by the Office of the National Coordinator for Health Information Technology.

Trusted Exchange Framework and Common Agreement (TEFCA) – This describes a common set of non-binding, foundational principles for trust policies and practices that can help facilitate exchange among health information networks.

United States Core Data for Interoperability (USCDI) – This is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange.

Value Set Authority Center (VSAC) – This is a value set authoring and repository for value sets. It is the source of truth for value sets for CMS's electronic clinical quality measures. The National Library of Medicine maintains the VSAC and provides downloadable access to the value sets and the Binding Parameter Specification. The VSAC provides users with tools to search existing value sets, create new value sets, and maintain value set content consistent with current versions of the terminologies they use



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**INNOVATION IN ELECTRONIC HEALTH RECORDS FOR
ONCOLOGY CARE, RESEARCH, AND SURVEILLANCE
PLANNING COMMITTEE ROSTER**

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**INNOVATION IN ELECTRONIC HEALTH RECORDS FOR
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Immediate Past President

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Co-Chair

ASCO Telehealth Expert Panel

SPEAKERS, PANELISTS, AND PLANNING COMMITTEE BIOSKETCHES



Shilo Anders, PhD

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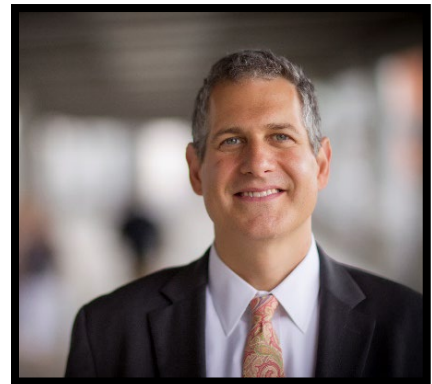
Shilo Anders, PhD, is a Research Associate Professor in the Department of Anesthesiology with secondary appointments in the Departments of Biomedical Informatics and Computer Science at Vanderbilt University. She is a member of the Center for Research and Innovation in Systems Safety (CRISS). Dr. Anders has applied principles of human factors engineering and user centered design as an approach to improve healthcare. She has conducted research on improving system design, individual and team performance, and patient safety and quality. In addition, Dr. Anders' research interests are in applying human factors engineering to (re)design,

develop, and evaluate clinician and patient-facing healthcare technologies.

Ethan Basch, MSc, MD

University of North Carolina at Chapel Hill

Ethan Basch, MSc, MD, is Physician-in-Chief of the North Carolina Cancer Hospital and Chief, Division of Oncology at the University North Carolina, where he is Distinguished Professor in Medical Oncology and Professor of Public Health. He leads a long-standing digital health research program which established that up to half of patients' symptoms go undetected during routine cancer care and in clinical trials, and that patient-reported outcome-based digital strategies substantially improve detection. His team determined that integrating electronic patient-reported symptom monitoring into oncology clinical practice improves clinical outcomes, including survival, and reduces health service utilization. His group created a system for the National Cancer Institute to collect patient-reported adverse events during cancer trials called the 'PRO-CTCAE.' Dr. Basch is involved in efforts to bring patient-reported data into comparative effectiveness research, routine care, and quality improvement. He is a member of the Board of Directors of ASCO, an Associate Editor at *JAMA*, and a prior member of the Board of Scientific Advisors for the NCI and the Methodology Committee of the Patient-Centered Outcomes Research Institute.





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Harvard Medical School

Dana Farber/Brigham and Women's Hospital

Monica M. Bertagnolli, MD, FACS, FASCO, is the Richard E. Wilson Professor of Surgery in the Field of Surgical Oncology at Harvard Medical School, and a member of the Gastrointestinal Cancer and Sarcoma Disease Centers at Dana-Farber/Brigham & Women's Cancer Center, where she collaborates with colleagues in medical oncology, radiation oncology, and pathology to treat cancer patients in a tertiary care setting. Dr. Bertagnolli graduated from Princeton University, and attended medical school at the University of Utah. She trained in surgery at Brigham and Women's

Hospital, and was a research fellow at the Dana Farber Cancer Institute (DF/BWCC). Dr. Bertagnolli has a background in laboratory work focusing upon understanding the role of the inflammatory response in epithelial tumor formation. From 1994-2011, she led gastrointestinal correlative science initiatives within the National Cancer Institute (NCI)-funded Cancer Cooperative Groups, where she facilitated integration of tumor-specific molecular markers of treatment outcome into nation-wide clinical cancer treatment protocols. From 2007-2018, Dr. Bertagnolli served as the Chief of the Division of Surgical Oncology at DF/BWCC. Dr. Bertagnolli has also had numerous leadership roles in multi-institutional cancer clinical research consortia, and currently serves as the Group Chair of the Alliance for Clinical Trials in Oncology, a nation-wide NCI-funded clinical trials group. She is also the Chief Executive Officer of Alliance Foundation Trials, LLC, a not-for-profit corporation that conducts international cancer clinical trials.

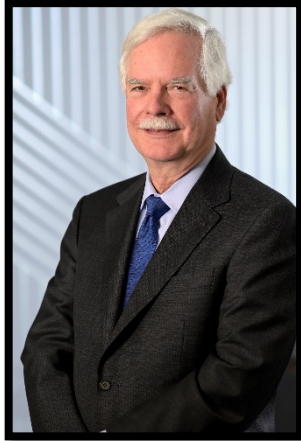
Pascale Carayon, PhD

University of Wisconsin-Madison

Pascale Carayon, PhD, is Professor Emerita in the Department of Industrial and Systems Engineering at the University of Wisconsin-Madison. She is the Founding Director of the Wisconsin Institute for Healthcare Systems Engineering and she led the interdisciplinary Systems Engineering Initiative for Patient Safety (SEIPS) at the University of Wisconsin-Madison. She received her Engineer diploma from the Ecole Centrale de Paris, France, and her PhD in Industrial Engineering from the University of Wisconsin-Madison. She has three decades of research experience analyzing, designing and improving complex work systems such as those in health care. For more than 20 years, her research has focused on patient safety and health care issues such as design of health information technologies and healthy work systems. As an industrial and systems engineer, she is renowned for her groundbreaking contributions in modeling complex system interactions in health care processes that influence patient safety and other outcomes for patients and health care professionals such as clinician well-being. Professor Carayon is an outstanding scholar. She has published more than 400 scientific journal articles and conference papers and was the Editor-in-Chief of *Applied Ergonomics*, a top journal in human factors and ergonomics. She is the editor of the *Handbook of Human Factors and Ergonomics in Health Care and Patient Safety*, which is considered as the definitive textbook on human factors in health care. She is a Fellow of the *Human Factors and Ergonomics Society*, Fellow of



the *International Ergonomics Association*, and member of the editorial boards of *Behaviour and Information Technology*, *Work and Stress*, and *The Journal of Patient Safety*. In 2016, she received the *John M. Eisenberg Patient Safety and Quality Award for Individual Achievement*. Since 2015, Becker's Hospital Review has selected her yearly as one of 50 experts leading the field of patient safety. Dr. Carayon was the co-chair of the National Academies' Committee on Systems Approaches to Improve Patient Care by Supporting Clinician Well-Being. She is a member of the *International Academy of Quality and Safety in Health Care*.



Robert W. Carlson, MD

National Comprehensive Cancer Network

Robert W. Carlson, MD, is the Chief Executive Officer at the National Comprehensive Cancer Network (NCCN). He joined NCCN as CEO in January 2013 following an esteemed history of leadership positions within the organization including, most notably, representative to the NCCN Board of Directors, Founding Chair of the Breast Cancer Guidelines Panel, Founding Chair of the Breast Cancer Risk Reduction Guidelines Panel, and Founding Chair of the Survivorship Guidelines Panel. Prior to his appointment as CEO at NCCN, Dr. Carlson served as Professor of Medicine in the Division of Oncology and Stanford Medical Informatics at Stanford University Medical Center, as well as

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

Gwen Darien, BA

National Patient Advocate Foundation

Gwen Darien, BA, is a longtime patient advocate who has played leadership roles in some of the country's preeminent nonprofit organizations. As executive vice president for patient advocacy and engagement, Ms. Darien leads programs that link PAF's patient service programs to NPAF initiatives, with the goal of improving access to equitable, affordable, quality health care. Called "a bit of a renegade" by *People* magazine, Ms. Darien has long insisted on pushing boundaries while maintaining a safe space for patients. As editor and publisher of *MAMM*, a magazine for women with breast or reproductive cancer, Ms. Darien published features on previously taboo subjects, such as dating after a mastectomy, along with the more expected academic features on news and policy analysis. Her media leadership was recognized by the Avon Foundation, which honored her as one of "the most powerful women in breast cancer." As a three-time cancer survivor herself, Ms. Darien came into cancer advocacy expressly to change the experiences and outcomes for the patients who came after her and to change the public dialogue about cancer and other life-threatening illnesses. With these goals in mind, in 2005 she started the first standalone advocacy entity in a professional cancer



research organization at the American Association for Cancer Research, causing outside observers to note the organization's "progressive commitment to patient advocacy." At AACR, she launched CR magazine – a magazine for people with cancer and those who care for them. Later, she served as the executive director of the Samuel Waxman Cancer Research Foundation; director of The Pathways Project; and executive vice president of programs and services at the Cancer Support Community. In each role, Ms. Darien championed placing patients at the center of health system change, whether it is for research, public policy or direct services. While serving as the chair or on the board of a wide range of program committees and workshop faculties, including the Community Engagement in Genomics Working Group of the National Human Genome Research Institute; a member of the US Pharmacopeia Board of Trustees; and as a member of NASEM's National Cancer Policy Forum, Ms. Darien also writes about her experiences. A recent piece, Transformation: My Experience as a Patient and an Advocate in Three Chapters appeared in the National Academy of Medicine Perspectives. Ms. Darien is a graduate of Sarah Lawrence College, where she also served as an advisor for their Health Advocacy program. She grew up in Milwaukee, but now lives in New York City, where she cooks Persian dishes, collects earrings and improves her friends' personal libraries, one book at a time.



Jenna Date, MS

Allscripts Hospital and Health Systems

Jenna Date, MS, is currently Vice President, Chief Experience Officer at Allscripts Hospital and Health Systems. Her personal mission is to lead design for a compassionate world. At Allscripts, she leads innovation teams to research, envision, and incorporate safe, useful, beautiful, and meaningful healthcare experiences, products and services. She also co-creates a culture of compassion and empathy, with a deep focus on the human experience. Prior to Allscripts, she was an independent design

strategist, helping industry leaders design innovative futures for their customers and organizations with a deep focus in human experience. Ms. Date's 22+ years in the design community has given her a breadth of experience in product, organizational, and service design. She specializes in Human-Centered Design and Product Strategy. Ms. Date has collaborated with global companies and local non-profits, including Eaton Corp., Innovative Systems, Inc., UPMC, Philips/Respironics, BossaNova Robotics, and GE Healthcare. While consulting, Ms. Date directed the masters in Human-Computer Interaction at Carnegie Mellon University, and held an Associate Professor role guiding a series of capstone courses with corporate and non-profit sponsors. She has worked with partners such as GE Healthcare, Cleveland Clinic, Panasonic, Expedia, Bank of America, GE Healthcare, 3M, NASA, and others. Prior to Carnegie Mellon, Ms. Date worked for Siemens Healthcare, MAYA VIZ, and co-founded a boutique design firm, Fit Associates, LLC.

Nicole F. Dowling, PhD

Centers for Disease Control and Prevention

Nicole F. Dowling, PhD, is the Associate Director of Science for the Division of Cancer Prevention and Control, at the Centers for Disease Control and Prevention (CDC). She is responsible for providing leadership, planning, and guidance to division management and staff on scientific policy, research methodology, and priorities for CDC's national cancer programs. Dr. Dowling is an epidemiologist and committed leader in public health science with experience as a Branch Chief, Division Associate Director for Science, Team Lead, and researcher, and with over 20 years working in programs across the agency. Before joining the Division of Cancer Prevention and Control in 2018, She served as the Chief of the Developmental Disabilities Branch, in the National Center on Birth Defects and Developmental Disabilities, where she provided scientific leadership and oversight for CDC's surveillance and research programs for autism and other developmental disabilities, including the Autism and Developmental Disabilities Monitoring Network and the Study to Explore Early Development. Previously, as the Associate Director for Science for the Division of Congenital and Developmental Disorders from 2012-2015, Dr. Dowling worked collaboratively with experts within and outside the division to determine the optimal blood folate level for prevention of neural tube defects. These efforts supported the development of a World Health Organization Guideline for evidence-informed recommendations on blood folate concentrations in women of reproductive age for the prevention of neural tube defects in populations, and the publication detailing the work was awarded a 2015 Charles C. Shepard Science Award. Additional contributions during her career at CDC have included direction of the population research program with the Office of Public Health Genomics, and research to understand the etiology and outcomes of clotting and bleeding disorders with the Division of Blood Disorders. Dr. Dowling completed her undergraduate education at Harvard University and received her PhD in Epidemiology from Emory University.

**Tufia C. Haddad, MD**

Mayo Clinic Cancer Center

Tufia C. Haddad, MD, is an Associate Professor of Oncology at the Mayo Clinic College of Medicine and Science, and a Consultant in the Department of Oncology. Her clinical practice is dedicated to breast cancer. She serves as the Medical Director of Care Anyplace for the Mayo Clinic Center for Digital Health, a portfolio of services inclusive of enterprise-wide Remote Patient Monitoring, Advanced Care at

Home, and Remote Diagnostics. She is an Associate Director of the Mayo Clinic Cancer Center Practice and Chair of Practice Innovation and Platform. She is a member of the Mayo Clinic Informatics/Artificial Intelligence Bioethics Advisory Council. As an oncologist and clinical investigator, she is an active member of the Mayo Clinic Cancer Center Women's Cancer Research Program, and she has received federal funding in support of biomarker discovery and early phase clinical trials in drug-resistant breast cancer. In the field of digital health, her interest is in the transformation of healthcare delivery models and development of advanced clinical decision support

systems with novel and connected health and AI technology solutions. Dr. Haddad has authored over 70 peer-reviewed manuscripts, book chapters, and editorials. Dr. Haddad received her Bachelor of Sciences degree in Biology, magna cum laude, from Marquette University. She completed medical school at Creighton University and is an Alpha Omega Alpha honor society member. Her Internal Medicine residency was completed at the Mayo Clinic (Rochester, Minnesota), and her fellowship in Hematology, Oncology, and Transplantation at the University of Minnesota. She received student humanitarian, individual excellence in medicine, and teaching awards throughout her training, as well as several educational excellence awards while on faculty at the University of Minnesota and the Mayo Clinic College of Medicine and Science. Dr. Haddad was named to the HIMSS Future50 Class of 2021 as a Clinical Leader.

George Hripcsak, MD, MS

Columbia University Irving Medical Center
New York-Presbyterian Hospital

George Hripcsak, MD, MS, is Vivian Beaumont Allen Professor and Chair of Columbia University's Department of Biomedical Informatics and Director of Medical Informatics Services for New York-Presbyterian Hospital/Columbia Campus. He is a board-certified internist with degrees in chemistry, medicine, and biostatistics. Dr. Hripcsak's research focus is on the clinical information stored in electronic health records and on the development of next-generation health record systems. Using nonlinear time series analysis, machine learning, knowledge engineering, and natural language processing, he is developing the methods necessary to support clinical research and patient safety. He leads the Observational Health Data Sciences and Informatics (OHDSI) coordinating center; OHDSI is an international network with 2000 researchers. Dr. Hripcsak is a member of the National Academy of Medicine, the American College of Medical Informatics, the International Academy of Health Sciences Informatics, and the New York Academy of Medicine. He has over 450 publications.



Chanita Hughes-Halbert, PhD

Norris Comprehensive Cancer Center, University of Southern California

Chanita Hughes-Halbert, PhD, is Professor and Vice Chair of Research in the Department of Population and Public Health Sciences and the Associate Director for Cancer Equity at University of Southern California Norris Comprehensive Cancer Center. The goal of her research program is to identify multilevel determinants of minority health and cancer health disparities and to translate this information into sustainable interventions in clinic and community-based settings to improve cancer outcomes

and chronic disease management in diverse populations in local and regional geographic areas. Dr. Hughes-Halbert is a nationally recognized expert in cancer prevention and control among diverse populations and her research is supported by numerous grants from the National Cancer Institute, the National Institutes on Minority Health and Health Disparities, and the Veteran's Affairs Medicine Center. Previously, she was a member of the Board of Scientific Advisors at the National Cancer

Institute and the National Human Genome Research Institute Advisory Council. Dr. Hughes-Halbert is a member of the National Academy of Medicine.

Mimi Huizinga, MD, MPH, FACP

ImmunoGen, Inc.

Mary Margaret (Mimi) Huizinga, MD, MPH, FACP, is Senior Vice President and Head of Medical Affairs at ImmunoGen, a biotechnology company focused on the development of antibody-drug conjugate technology to treat cancer. Previously, Dr. Huizinga served as the Head of US Oncology Medical for Novartis, overseeing the clinical development and medical affairs activities of Novartis oncology portfolio in the US. Dr. Huizinga also built and led the strategic data and digital function at Novartis in the US Oncology business unit, which included real-world evidence, healthcare economics and clinical and value evidence liaisons in addition to constructing a data strategy and platform and supporting all digital marketing. Prior to Novartis, Dr. Huizinga was the Chief Health Information Officer at Premier, Inc, where she led the Applied Sciences division that partnered with healthcare systems and pharmaceutical companies around real world evidence generation. Dr. Huizinga has previously served as the Vice President of Quality at Lifepoint Health, an associate at McKinsey & Company and an Assistant Professor at Johns Hopkins University. She serves as an independent director at HealthMyne, a radiomics company. Dr. Huizinga holds a MD and MPH from Vanderbilt University and is a fellow of the American College of Physicians.



Mary M. Ichiuji, MD

Kaiser Permanente

Mary Mitsuko Ichiuji, MD, is a medical oncologist at Kaiser Permanente (KP). She is the National physician lead for the KP HealthConnect Oncology Beacon Module, created to standardize chemotherapy, enhance safety, and simplify ordering and administration of complex medications. The success of the Beacon Module depends on collaboration among oncologists, nurses, pharmacists and information technologists throughout the organization. Recent efforts have been involved in the implementation and maintenance of KP National Oncology Drug Treatment Pathways. Dr. Ichiuji also serves on the KP National BEACON governance committee, and is a member of the EPIC Oncology Advisory Board. She received her medical degree from the University of California at San Diego.

Paul G. Kluetz, MD

Food and Drug Administration

Paul G. Kluetz, MD, is a Medical Oncologist and Deputy Director of the Oncology Center of Excellence (OCE) at the Food and Drug Administration. In addition to contributing to the strategic leadership and operational oversight of the OCE, he leads several initiatives including creation and direction of the OCE's patient-focused drug development program; OCE's real-world evidence program and support for decentralized trial designs and digital health technology; and initiation and growth of the oncology intra- and extramural research portfolio. He is also active in regulatory review of Oncology products and oversees important oncology drug labeling initiatives. Dr. Kluetz remains clinically active, caring for patients and supervising medical residents at the Georgetown University Hospital.

**Mia Levy, MD, PhD**

Foundation Medicine, Inc.



Mia Levy, MD, PhD, is Chief Medical Officer at Foundation Medicine. She is a practicing medical oncologist specializing in the treatment of breast cancer and a nationally recognized leader in biomedical informatics. She joined Foundation Medicine following an accomplished tenure as director of the Cancer Center at Rush University Medical Center and the System Vice President for Cancer Services at Rush System for Health. Dr. Levy has devoted her career to developing systems to support data-driven decision-making in cancer care and research. She has contributed to more than 90 publications on cancer and led the development of My Cancer Genome, an international knowledge resource for precision medicine that provides accessible information to patients and physicians around cancer-driving mutations, clinical trials, and therapies. She previously served as Associate Professor of Cancer Research, Biomedical Informatics and Medicine, at Vanderbilt University, and as the Director of Cancer Clinical Informatics for the Vanderbilt-Ingram Cancer Center. She is a member of the National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine, and a member of the National Cancer Institute Clinical Trials and Translational Research Advisory Committee.

Bradley Malin, PhD, FACMI, FAIMBE, FIAHSI

Vanderbilt University Medical Center

Bradley Malin, PhD, FACMI, FAIMBE, FIAHSI is the Vice Chair for Research in the Department of Biomedical Informatics at Vanderbilt University Medical Center and the Accenture Professor of Biomedical Informatics, Biostatistics, and Computer Science at Vanderbilt University. He is also Affiliated Faculty in the Center for Biomedical Ethics and Society. He co-directs the Vanderbilt Health Data Science (HEADS) Center, as well as the Center for Genetic Privacy and Identity in Community Settings (GetPreCiSe), an NIH Center of Excellence on Ethical, Legal, and Social Implications Research (CEER). He is one of the Principal Investigators of the Infrastructure Core of the NIH Artificial Intelligence/Machine Learning Consortium to Advance Health Equity and Researcher Diversity (AIM-AHEAD). He currently serves as the co-chair of the Committee on Access, Privacy, and Security of the All of Us Research Program of the U.S. Precision Medicine Initiative and is an appointed member of the Technical Anonymisation Group of the European Medicines Agency and the Board of Scientific Counselors of the National Center of Health Statistics (NCHS) of the Centers for Disease Control and Prevention.



Alexander Melamed, MD, MPH

New York-Presbyterian Hospital
Columbia University Medical Center

Alexander Melamed, MD, MPH, is an Assistant Professor in the Division of Gynecologic Oncology in the Department of Obstetrics and Gynecology at New York-Presbyterian/Columbia University Medical Center. He provides medical and surgical care to women with cancers of the reproductive system including ovarian, uterine, cervical, and vulvar cancer. His research focuses on improving outcomes among people with cancer and promoting the use of robust analytical methods for observational studies in oncology. Dr. Melamed's work has helped to define the role of minimally invasive surgery in gynecologic oncology and identified strategies that reduce unnecessary side effects in the treatment of ovarian cancer, and contributed to a shift in the international standard of care for the treatment of early-stage cervical cancer. Dr. Melamed is the recipient of career development awards from the National Institute of Health's National Center for Advancing Translational Science, the American Society of Clinical Oncology's Conquer Cancer Foundation, and the Department of Defense's Ovarian Cancer Research Program.

Neal J. Meropol, MD
Flatiron Health

Neal J. Meropol, MD, is a medical oncologist, clinical investigator and outcomes researcher who serves as Vice President of Research Oncology at Flatiron Health. In this role, he provides scientific and clinical leadership in leveraging Flatiron's technology platforms to close the gap between research and clinical care. Dr. Meropol's research contributions span drug development and health services research, including evaluation of new agents, predictors of response and outcome, development of tools to overcome barriers to clinical trial participation, and assessment of the economic impact of care. He is the acting chair of the NCI Director's Clinical Trials and Translational Research Advisory Committee (CTAC), and previously served as chair of the National Cancer Institute Gastrointestinal Cancer Steering Committee. Dr. Meropol completed a four-year term as an elected member of the American Society of Clinical Oncology (ASCO) Board of Directors, and currently serves on the ASCO Research Committee. He is a member of the National Academies of Science, Engineering and Medicine's National Cancer Policy Forum. A committed educator, Dr. Meropol served as faculty and chair of the AACR/ASCO Methods in Cancer Clinical Research Vail Workshop, and ASCO Leadership Development Program. He has authored more than 300 manuscripts, book chapters, and editorials related to cancer prevention, treatment, decision making and health economics. Prior to joining Flatiron, he served as Professor and Chief of the Division of Hematology and Oncology at University Hospitals Cleveland Medical Center and Case Western Reserve University, and Associate Director for Clinical Research at the Case Comprehensive Cancer Center



Elizabeth Mynatt, PhD
Northeastern University

Elizabeth Mynatt, PhD, is the Dean of Khoury College of Computer Sciences at Northeastern University. She joined Northeastern University in January 2022 after a 23-year career at Georgia Institute of Technology (Georgia Tech), where she most recently served as Regents' and Distinguished Professor in the College of Computing and executive director of the Institute of People and Technology. She is an internationally

recognized expert in the areas of ubiquitous computing and assistive technologies. Her research contributes to ongoing advances in personal health informatics, computer-supported collaborative work, and human-centered computing. Dr. Mynatt directed the Everyday Computing Lab at Georgia Tech. There she investigated the design of health and information technologies to support breast cancer patients during their journey using personalized mobile technologies. Also, she was one of the leading researchers in the Aware Home Research Initiative that investigated future home

technology designs that enable aging adults to continue to live independently. Dr. Mynatt is also senior investigator with Emory's Cognitive Empowerment Program and Co-Principal Investigator for the NSF AI-CARING Institute, both with the goal of creating longitudinal, interactive AI technologies to empower older adults and their care networks. Dr. Mynatt is a member of the National Academies' Computer Science and Telecommunications Board (CSTB) and the NSF Directorate for Computer, Information Science & Engineering Advisory Committee (CISE AC). She has been recognized as a member of the ACM SIGCHI Academy, and a Sloan and Kavli research fellow. She is the past Chair of the Computing Community Consortium, an NSF-sponsored effort to engage the computing research community in envisioning more audacious research challenges. She has published more than 100 scientific papers, led grants from the NSF and NIH, and chaired the Association for Computing Machinery's Conference on Human Factors in Computing Systems 2010 conference, the premier international conference in human-computer interaction. In 2015 she became a Fellow of the Association of Computing Machinery (ACM) for contributions to human-centered computing and the development of health information technologies. Her article, "*Charting past, present, and future research in ubiquitous computing*," published in 2000, has been cited over 2000 times. She has also been quoted or featured in major publications including the *Washington Post*, *National Geographic*, and *The Wall Street Journal*.

Travis J. Osterman, DO, MS, FAMIA
Vanderbilt University Medical Center

Travis J. Osterman, DO, MS, FAMIA, is a practicing Medical Oncologist, Informatician, and Clinical Director in the Office of the Chief Health Information Officer at Vanderbilt University Medical Center (VUMC). He is also Director of Cancer Clinical Informatics in the Vanderbilt-Ingram Cancer Center. He is board certified in internal medicine, medical oncology, and clinical informatics. He has dual faculty appointments at VUMC in the Department of Biomedical Informatics and the Department of Medicine in the Division of Hematology and Oncology. Dr. Osterman's clinical interest within oncology is lung cancer. He leads the Clinical Cancer Informatics Innovation (C2I2) group whose research focuses on applying clinical informatics methods across the cancer care continuum. His current projects include identifying patients for lung cancer screening, automated clinical trial matching, and using predictive analytics to anticipate toxicity to immunotherapy. As part of this work, his team develops tools used for both research and to directly support patient care. Dr. Osterman is involved several national efforts to improve the availability of oncology-specific EHR data to support quality improvement across oncology practices. He serves on the National Comprehensive Cancer Network (NCCN) Electronic Health Record (EHR) Workgroup and Patient Reported Outcomes (PRO) Workgroup. The focus of these workgroups includes leveraging the EHR to promote innovation and to standardize best practices across cancer centers. He serves on the American Society of Clinical Oncology (ASCO) CancerLinQ Physician Advisory Board, the Minimum Common Oncology Data Elements (mCODE) Workgroup, and the Member and Meeting Publications Editorial Board. He serves on the Epic Adult Oncology Steering Board and chairs Epic's Beacon Community Operations Group. Dr. Osterman also represents VUMC as a founding member on the Oncology Clinical Trial Information Commons (OCTIC) project, which focuses on standardizing how data describing clinical trials are stored.





Jyoti D. Patel, MD, FASCO

Northwestern University

Jyoti D. Patel, MD, is Professor of Medicine at Northwestern University. She graduated from Northwestern University with a degree in English literature and received her medical degree from Indiana University. She completed a residency program at Northwestern University, where she also served as chief medical resident. Dr Patel then went on to complete her medical oncology fellowship at Memorial Sloan-Kettering Cancer Center, NY. In 2003 she returned to Northwestern, where she served as the Thoracic Oncology Program leader of the Robert H. Lurie

Comprehensive Cancer Center of Northwestern University. From 2016-2019 she was Director of Thoracic Oncology at the University of Chicago. In 2020, she returned to Northwestern as Medical Director of Thoracic Oncology of the Lurie Cancer Center, Associate Vice Chair of Clinical Research in the Department of Medicine, and Assistant Director for Clinical Research in the Lurie Cancer Center. Dr. Patel has focused her career on developing therapies for lung cancer. She has authored numerous publications and has served as the principal investigator of multiple clinical trials. She has been instrumental in developing clinical guidelines for the treatment of lung cancer. Dr Patel has held leadership positions on national thoracic cancer committees, including the National Comprehensive Cancer Network, the International Association for the Study of Lung Cancer, and the Alliance for Clinical Trials in Oncology. She has served the American Society of Clinical Oncology in many educational and scientific capacities over the years.

Lynne Penberthy, MD, MPH

National Cancer Institute

Lynne Penberthy, MD, MPH, is the Associate Director for the Surveillance Research Program (SRP), which is within the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI). Dr. Penberthy obtained her MD from the University of Michigan and her MPH in epidemiology at Johns Hopkins. Her career includes a surgical internship in Baltimore, Maryland, at the Sinai Hospital and a preventive medicine residency at Johns Hopkins University. After her residency, she completed her post-doctoral training in epidemiology with the CDC as an epidemic intelligence service (EIS) officer with the Commonwealth of Virginia. She is licensed to practice medicine in the state of Maryland. Prior to her NCI appointment, Dr. Penberthy was the Director of Cancer Research Informatics and Services and Associate Professor of General Internal Medicine at the Virginia Commonwealth University Massey Cancer Center. She directed a team in the development of innovative software with the objectives of using existing data for clinical trials eligibility screening, automated capture of treatment data from oncology practice claims, and the extraction of clinical characteristics from various electronic medical records (EMR) components. Dr. Penberthy was also involved in biobanking and annotation of specimens using clinical data. She has 20 years of experience in cancer surveillance and automation using secondary data. Dr. Penberthy has worked on more than 20 grants and contracts as well as over 30 publications related



to using secondary data and/or informatics tools for cancer surveillance and clinical trials assessment.



Etta D. Pisano, MD

American College of Radiology
Beth Israel Deaconess Medical Center

Etta Pisano, MD, is Chief Research Officer at the American College of Radiology (ACR). In that role, she served in 2020-2021 as the co-Principal Investigator for the ACR's Medical Imaging Data Resource Center, funded by the National Institute of Biomedical Imaging and Bioengineering, which is creating a public archive of imaging and clinical data for COVID-19. She also works with vendors of Artificial Intelligence software to support the testing and validation of those products for FDA approval. She is also currently serving as the Principal Investigator for The Tomosynthesis Mammographic Imaging

Screening Trial, a National Cancer Institute-funded clinical trial under the auspices of the ECOG-ACRIN research base, which will enroll over 128,000 women at 150 sites around the world. She is also currently Professor of Radiology at the University of North Carolina at Chapel Hill and Adjunct Professor of Radiology at the University of Pennsylvania. Prior to her current roles, she has served at the Medical University of South Carolina (MUSC) as Vice President for Medical Affairs and Dean of the College of Medicine and as Vice Dean for Academic Affairs at the University of North Carolina (UNC) School of Medicine, Kenan Professor of Radiology and Biomedical Engineering, Director of the UNC Biomedical Research Imaging Center, and Director of the N.C. Translational and Clinical Sciences Institute, as well as Professor in Residence at Beth Israel-Lahey/Harvard Medical School. She is an expert in breast cancer imaging. Her undergraduate degree in Philosophy is from Dartmouth College and her medical degree is from Duke University. Etta's professional interests center on the development, application and testing of imaging technology for the early detection and diagnosis of breast cancer and other breast problems. She is a member of the National Academy of Medicine.

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 National Center for Chronic Disease Prevention and Health Promotion. As Director, Dr. Richardson oversees operations and provides leadership for DCPC's three national programs, including the largest population-based cancer registry, the National Program of Cancer Registries. Under her leadership the Division has championed efforts to broaden understanding and utilization of cancer data. A key component of this work is making cancer data useful in real time and the real world by modernizing cancer surveillance systems and approaches to data collection. A medical oncologist by training, Dr.



Richardson is a highly sought expert on breast cancer treatment delivery, health disparities and access to cancer care. She has authored or coauthored more than 180 peer-reviewed journal articles examining multi-sectoral approaches to improving cancer care access, delivery, and outcomes.



Barry Russo, MBA

The Center for Cancer and Blood Disorders

Barry Russo, MBA, has been the chief executive officer of The Center for Cancer and Blood Disorders, a private community practice based in Fort Worth, Texas, since 2002. Mr. Russo has over 30 years of healthcare experience. He has worked in academic and community practices as well as academic and community hospitals. The Center for Cancer and Blood Disorders has over 50 providers & 250+ employees at 16 facilities in the Dallas–Fort Worth metroplex, and offers medical oncology, radiation oncology, hematology, gynecologic oncology, breast oncology surgery, stereotactic radiosurgery, integrative medicine, imaging, laboratory services and retail pharmacy. Mr. Russo is a current board member of the Community Oncology Alliance and

Advisory Board for the Cancer Center Business Summit and current member of the Association of Community Cancer Centers, the American Society of Clinical Oncology and Texas Medical Group Management Association. He has an MBA from the University of Dallas and resides in Colleyville, Texas.

Julie Schneider, PhD

Food and Drug Administration

Julie Schneider, PhD, is Associate Director for Research Strategy and Partnerships at the Oncology Center of Excellence (OCE) at the U.S. Food and Drug Administration. In this role, she oversees the OCE Scientific Collaborative, which supports applied research activities addressing topics identified during regulatory review of oncology products. She previously ran the HHS Entrepreneurs-in-Residence Program within the HHS IDEA Lab and worked in several roles at the National Cancer Institute (NCI) focused on developing new research funding opportunities. Julie initially joined the NCI as an AAAS Science and Technology Policy Fellow and obtained her doctoral degree in genetics from the University of Oxford and her bachelor's degree in biology from Yale.

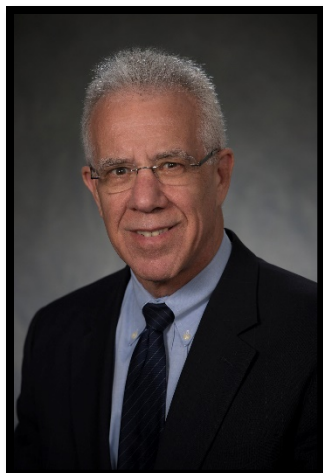


**Avinash Shanbhag, MS**

Office of the National Coordinator for Health Information Technology

Avinash Shanbhag, MS, serves as the Executive Director of the Office of Technology in the Office of National Coordinator for Health Information Technology (ONC) at the Health and Human Services. In this role, he advises the National Coordinator and the Deputy National Coordinator on health information technology matters, provides executive direction and control over ONC's technology portfolio, and fosters health information innovation. Mr. Shanbhag oversees coordination

with federal agencies and industry stakeholders for advancing health information technology (IT) interoperability for improved health care delivery. He leads ONC's standards coordination activities with all the health IT standards development organizations, including administration of the ONC Health IT Certification Program, the Certified Health IT Product Lists and the certification testing tools. He has over 25 years of experience in developing enterprise software systems and managing large scale distributed software systems for healthcare industry. Throughout his over 10-year career with ONC, Mr. Shanbhag has led variety of technology positions, including serving as the Deputy Director of the Office of Technology, Director of the Testing Division and the Director of the Nationwide Health Information Network. During his tenure, he led the creation of the ONC testing and utilities platform to support health IT developers and developed long term vision for nationwide health information network, and successfully transitioned the operations of the network into "eHealth Exchange". Prior to joining ONC, Mr. Shanbhag served as the Director of Core Infrastructure, at the Center for Biomedical Informatics and Information Technology, at the National Cancer Institute. He was responsible for developing and operating the distributed network and semantic services used by all the NCI funded institutions to share research data in a privacy protective manner. He earned a Master's degree in Chemical Engineering from University of Alberta, and a Master's degree in Operations Research from University of Maryland. He also maintains a Service-Oriented Architecture (SOA) certificate and a certificate in Machine Learning from MIT Sloan School of Management.



Lawrence N. Shulman, MD, MACP, FASCO

University of Pennsylvania Abramson Cancer Center

Lawrence N. Shulman, MD, MACP, FASCO, is Professor of Medicine in the Perelman School of Medicine at the University of Pennsylvania, deputy director for Clinical Services at the Abramson Cancer Center, and director of the Center for Global Cancer Medicine. In this capacity, he helps to lead the Cancer Quality program and strategic development of Cancer Services. He is 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. He 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 and Haiti, programs for which he plays a seminal leadership role. He sits on the Vice Chancellor's Advisory Council for Rwanda's University for Global Health Equity. In addition, he helps to lead the development of the national oncology program in Botswana through the Botswana-UPenn Partnership. He is a former member of ASCO's International Affairs Committee and their Task Force on Global Oncology as an Academic Career. He led the World Health Organization's review and revision of their Essential Medicines for Cancer from 2014-2017. He received his MD from Harvard Medical School, and trained in Hematology and Oncology at the Beth Israel Hospital in Boston, MA.

Twee Sim, MD

Office of Science and Technology Policy
Department of Defense

Twee Sim, MD, is a 2021-2022 White House Leadership Development Program Fellow (WHLDP) and serves in the White House Office of Science and Technology Policy (OSTP) as Assistant Director for Transformative Medicine and Health Innovation. As a WHLDP fellow, Dr. Sim takes a systems approach to identify policy levers to advance evidence-based medicine and support innovation in clinical and public health settings, specifically to strengthen the national public health infrastructure in order to support the global public health system. In addition to her role and responsibilities in OSTP, Dr. Sim continues to serve as the Senior Medical Advisor with the Department of Defense's (DoD) Defense Health Agency. At the DoD, Dr. Sim led the development of several Military Health System (MHS) analytics and innovation initiatives, including dashboards and tools to support providers at the point of care and in support of clinical quality policy and initiatives in the areas of HIV, COVID-19, and antimicrobial resistance. Dr. Sim has also contributed significantly to the evaluation of health disparities in the MHS in the areas of maternal and infant morbidity and mortality. Most recently, Dr. Sim was on detail to the HHS Assistant Secretary for Preparedness and Response, where she led the Healthcare Resilience Task Force and Working Group on the COVID-19 Federal Response in coordinating whole-of-government interventions to ensure resiliency of the US health system, workforce and supply chain.



Prior to joining the DoD, Dr. Sim was an Assistant Clinical Professor of Medicine at Harvard Medical School working to advance global medicine and clinical education in the areas of HIV and infectious diseases. Her diverse and extensive background also includes previous roles in public health and private industry sectors in the areas of infectious diseases and information technology. Dr. Sim received her undergraduate degrees in Biophysics/ Biochemistry and Chemical/ Biomedical Engineering. She earned her M.D. from the University of Texas Medical School in San Antonio and completed her training at Temple University in Philadelphia, PA, and Brown University in Providence, RI, where she continues to see patients monthly.



Lara Strawbridge, MPH
Centers for Medicare & Medicaid Services

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

Strawbridge earned her MPH from Johns Hopkins Bloomberg School of Public Health.

Samuel U. Takvorian, MD, MSHP
University of Pennsylvania Perelman School of Medicine

Samuel U. Takvorian, MD, MSHP is an Assistant Professor in the Division of Hematology and Oncology at the University of Pennsylvania Perelman School of Medicine. His research focuses on clinical transformation and innovation in cancer care delivery. He graduated from Harvard Medical School and completed his Internal Medicine residency at Brigham and Women's Hospital in Boston, MA. He served as Chief Fellow while training in Hematology and Oncology at the University of Pennsylvania, where he also earned a Master of Science in Health Policy Research. His interest in health care policy dates back to an AmeriCorps year, leading health advocacy efforts in a community health center to support Massachusetts health reform. His later work at Harvard Business School and the Alliance for Health Reform in Washington, DC inspired him toward a career in health policy and health services research. He remains committed to researching questions pertaining to the value of cancer care, encompassing rigorous measurement of both traditional and patient-reported outcomes, as well as the costs of care, and to improving the implementation of research findings into routine practice. As a Senior Fellow at the Leonard Davis Institute of Health Economics and Innovation Faculty at the Penn Center for Cancer Care Innovation, his work seeks to harness transdisciplinary



insights from the fields of behavioral economics and behavioral science to develop and test potentially transformative models of cancer care delivery. He has received multiple mentorship awards for his commitment to medical education, and was awarded the Jane Alavi Award for clinical excellence during oncology fellowship. He maintains a robust clinical practice in genitourinary oncology.



Reed V. Tuckson, MD, FACP
Black Coalition Against COVID
Tuckson Health Connections, LLC

Reed V. Tuckson, MD, FACP, is Managing Director of Tuckson Health Connections, LLC, a vehicle to advance initiatives that support optimal health and wellbeing through the intersection of health promotion and disease prevention; applied data and analytics; enhanced quality and efficiency in care delivery; and the application of telehealth and biotech innovations. Currently, Dr. Tuckson's focus is on advancing his work as a co-founder of the Black Coalition Against COVID, a multi-stakeholder and interdisciplinary effort working to mitigate the COVID-19 pandemic in Washington, D.C. and nationally by coordinating the four historically Black

medical schools, the National Medical Association (NMA), the Cobb Institute of the NMA, the National Black Nurses Association, the National Urban League, and BlackDoctor.org. Previously, he enjoyed a long tenure as Executive Vice President and Chief of Medical Affairs for UnitedHealth Group, a Fortune 20 Health and wellbeing company. A recognized leader in his field, Dr. Tuckson is honored to have been appointed to leadership roles at the National Institutes of Health; National Academy of Medicine; numerous Federal Advisory Committees; and corporate, non-profit and academic boards. Previously, he served as President of the Charles R. Drew University of Medicine and Science; the Senior Vice President for Professional Standards of the AMA; the Senior Vice President for the March of Dimes Birth Defects Foundation; and the Commissioner of Public Health for Washington, D.C. He has been recognized several times by *Modern Healthcare* magazine's listing of the "50 Most Powerful Physician Executives" in healthcare. He is a graduate of Howard University, Georgetown University School of Medicine, and the Hospital of the University of Pennsylvania's General Internal Medicine Residency and Fellowship Programs, where he was also a Robert Wood Johnson Foundation Clinical Scholar studying at the Wharton School of Business.

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

Jeremy L. Warner MD, MS, FAMIA, FASCO, is an Associate Professor of Medicine and Biomedical Informatics at Vanderbilt University. He is board certified in Medical Oncology, Hematology, and Clinical Informatics. His clinical focus is malignant hematology. Dr. Warner is an Associate Editor of *JCO Clinical Cancer Informatics* and section co-editor of Cancer Informatics for the *IMIA Yearbook*. His primary research goal is to make sense of the structured and unstructured data present in electronic health records and clinical knowledge bases. He is the Deputy Editor of *HemOnc.org*, and Chief



Software Architect of *HemOnc*, an ontology focused on capturing all relevant knowledge pertinent to chemotherapy drugs and regimens. In June 2022, he will transition to Brown University, where he will launch the Center for Cancer Bioinformatics and Data Science.



Robert A. Winn, MD

Virginia Commonwealth University Massey Cancer Center

Robert A. Winn, MD, is Director of Virginia Commonwealth University (VCU) Massey 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, he actively treats veterans each week at the nearby Hunter Holmes McGuire VA Medical Center. Robert holds a B.A. 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

American Cancer Society

Robin Yabroff, PhD, is an epidemiologist and Scientific Vice President, Health Services Research, at the American Cancer Society. She conducts research on the economic burden of cancer; patterns of cancer care, including high cost prescription drugs; health insurance benefit design; and patient, provider, and health system factors associated with quality and value of cancer care. Dr. Yabroff has more than 20 years of



health services research experience 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. Dr. Yabroff has co-authored over 200 peer-reviewed journal articles and has also co-authored invited editorials, commentaries, and book chapters. She is an Associate Editor for the *Journal of the National Cancer Institute*, a founding member of the editorial board of the *Journal of Cancer Survivorship*, and a member of the editorial board of the *JCO Oncology Practice*. Dr. Yabroff has received multiple National Institutes of Health Merit Awards for her research leadership and mentorship. She earned her PhD in epidemiology from the Johns Hopkins School of Public Health and received an MBA from the University of Rochester.



Robin Zon, MD, FACP, FASCO

Michiana Hematology Oncology, PC
ASCO Telehealth Expert Panel

Robin Zon, MD, FACP, FASCO, is Immediate Past President of Michiana Hematology Oncology, PC, and Co-Chair of the American Society of Clinical Oncology (ASCO) Telehealth Expert Panel. Dr. Zon maintains an active certification in medical oncology. She served as past Medical Director of Oncology Research at Memorial Hospital and NCI CCOP Associate and then Principal Investigator until 2013 for the Northern Indiana Cancer Research Consortium, the only NCI designated Community Cancer Oncology Program in the state of Indiana. She has published over 80 articles, many as first or senior author. Dr. Zon

volunteers as a leader for the ASCO and has served as Chair of the Government Relations Committee, Chair of the Clinical Practice Committee, served on the Board of Directors from 2010 to 2013, Chair of the Pathways Taskforce, and Chair of the Oncology Practice Conference, along with many other ASCO related responsibilities. She is a Fellow of the American Society of Clinical Oncology. Dr. Zon serves on the Trinity Oncology Excellence Committee. Additional volunteer activities included being Vice-Chair of the Hoosier Cancer Research Group (formerly Hoosier Oncology Group), and past Board member of RiverBend Cancer Services and the Center for Hospice and Palliative Care. Dr. Zon earned her medical degree from Indiana University School of Medicine, completed her residency at St. Vincent Hospital and Health Care Center in Indianapolis, and a fellowship in medical oncology and hematology at Indiana University Cancer Center. She worked as a Pharmaceutical Research Investigator and Manager of Medical Diagnostic Product Research and Development prior to medical school. Dr. Zon has received the ASCO Distinguished Achievement Award in 2020 and ASCO's National Advocate of the Year Award; she has been called upon by the National Academies of Sciences, the National Cancer Institute and the federal government to offer guidance and share her expertise. Dr. Zon meets local federal government elected officials on a routine basis to promote cancer care policies, most recently regarding funding for NIH/NCI research and telemedicine.



ABOUT THE FORUM



The National Cancer Policy Forum serves as a trusted venue in which experts can identify emerging high-priority policy issues in cancer research and 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. 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.

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Upcoming and Recent Workshops

Advancing Progress in Cancer Prevention and Risk Reduction

June 27-28, 2022

This workshop will consider the current state of knowledge regarding risk factors for cancer and strategies for interventions across multiple levels to reduce cancer risk. Invited presentations and panel discussions may include:

- An overview of the current evidence base for risk factors for cancer, including consideration of how these factors are distributed across populations and influenced by socioeconomic factors.
- Best practices and innovative approaches to implement population-based cancer prevention strategies, including the potential for collaborations with other disease prevention efforts.
- Opportunities to overcome challenges in the delivery of cancer prevention services within communities and health care settings, including consideration of specific strategies for low-resource areas.
- Opportunities to improve implementation of vaccine-based interventions for cancer prevention, as well as for pharmacological and surgical interventions to reduce cancer risk.
- Methods for assessing efficacy of programs and inventions for cancer prevention and risk reduction, including the identification of biomarkers as surrogate endpoints.

[Workshop website](#)

Family Caregiving for People With Cancer and Other Serious Illnesses

May 16-17, 2022

This workshop will examine opportunities to better support family caregivers for people with cancer or other serious illnesses. This collaborative workshop is being convened by the National Cancer Policy Forum, the Roundtable on Quality Care for People with Serious Illness, and the Forum on Aging, Disability, and Independence. The workshop will feature presentations and discussions on topics including:

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

[Workshop website](#)

Innovation in Electronic Health Records for Oncology Care, Research, and Surveillance

February 28 - March 1, 2022

Electronic health records (EHRs) affect clinician and practice efficiency and safety, quality of care, patient satisfaction, and data acquisition. This workshop, convened by the National Cancer Policy Forum in collaboration with the Computer Science and Telecommunications Board, will examine potential opportunities to improve patient care and outcomes to enhance innovation in the development, implementation, and use of EHRs in oncology care, research, and surveillance. Invited presentations and panel discussions will examine:

- Challenges and opportunities to optimize EHRs in oncology care, and governance structures needed to prioritize and implement these improvements.
- Standardization of oncology EHR documentation and data and initiatives to enhance EHR interoperability.
- Opportunities to capture and integrate data on social determinants of health and patient reported outcomes into EHRs to produce real-time or more timely data to guide cancer care, research, and surveillance.
- Use of computing technologies to enhance EHRs.
- Opportunities to align incentives to ensure that EHRs offered by vendors meet the needs of users in oncology.
- Examples of collaborations and innovations in EHRs, and policies to foster redesign of EHRs as a functional component of surveillance systems in oncology care.

[Workshop website](#)

The Role of Companion Animals as Sentinels for Predicting Environmental Exposure Effects on Aging and Cancer Susceptibility in Humans

December 1-3, 2021

Companion animals have a potential role as sentinels of relevant, shared environmental exposures that may affect human aging and cancer. This workshop examined the opportunities and challenges for using this novel translational approach to exposure science as a way to accelerate the knowledge turn in this evolving field.

[Workshop videos and presentations](#)
[Poster session](#)

Promoting Health Equity in Cancer Care

October 25-26, 2021

Significant advancements in the delivery of high-quality cancer care and improvements in patient outcomes have been achieved in recent years; however, such progress has not been evenly distributed across the U.S. population. The National Cancer Policy Forum, in collaboration with the Roundtable on the Promotion of Health Equity, convened a workshop to examine opportunities to improve health equity for patients with cancer.

[Workshop videos and presentations](#)

Upcoming and Recent Workshops

Webinar Series: Addressing Social Needs in Cancer Care

In advance of the workshop, *Promoting Health Equity in Cancer Care*, the Forum convened a webinar series focusing on opportunities to better assess and address the social needs of patients with cancer.

- May 10, 2021: [Food Insecurity among Patients with Cancer](#)
- August 9, 2021: [Housing Insecurity among Patients with Cancer](#)
- September 21, 2021: [Transportation Needs among Patients with Cancer](#)

Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic

July 26-27, 2021

The COVID-19 pandemic has led to dramatic adjustments in cancer care delivery and cancer research. This workshop examined these changes, and considered lessons learned in order to improve the delivery of high-quality cancer care and the conduct of cancer clinical trials in the post-pandemic era.

[Workshop videos and presentations](#)
[Proceedings](#)

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

March 1-2, 2021

The Forum convened a virtual workshop to examine the existing evidence base on how the Patient Protection and Affordable Care Act (ACA) has altered the landscape of cancer prevention and care delivery. Workshop presentations and discussions reviewed the effects of the ACA on people at risk for or living with cancer and provided insight into remaining policy challenges that could inform future efforts to improve the delivery of high-quality cancer care across the care continuum.

[Workshop videos and presentations](#)
[Proceedings](#)

Addressing the Adverse Consequences of Cancer Treatment

November 9-10, 2020

Cancer treatment can lead to an array of significant short- and long-term physical, mental, and socioeconomic consequences for patients and their families. The National Cancer Policy Forum, in collaboration with the Forum on Aging, Disability, and Independence, convened this workshop to examine opportunities to prevent and mitigate the adverse effects of cancer treatment and improve quality of life for cancer survivors and their families.

[Workshop videos and presentations](#)
[Proceedings](#)

WORKSHOP SERIES: OLDER ADULTS

Collaborative series convened by:

National Cancer Policy Forum

Forum on Drug Discovery, Development, and Translation

Forum on Aging, Disability, and Independence

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

January 22, 25, and 27, 2021

Older adults represent the majority of patients diagnosed with cancer and cancer-related deaths. However, the evidence base to guide treatment decision making among older adults with cancer is sparse, primarily because older adults are underrepresented in clinical trials, and trials designed specifically for older adults are rare. This FDA-sponsored workshop examined challenges and opportunities to improve the evidence base for treating older adults with cancer. The workshop examined strategies for improved inclusion of older adults across the drug development continuum.

[Workshop videos and presentations](#)
[Proceedings-in-Brief](#)

Drug Research and Development for Adults Across the Older Age Span

August 5-6, 2020

This workshop convened experts to discuss the lack of evidence about the appropriate use of drugs in older adult populations, which hampers decision making about how to optimize care for older adults. Workshop presentations and discussions highlighted opportunities to better engage older adults in clinical research and strategies to generate evidence-based prescribing information for older adult populations.

[Workshop videos and presentations](#)
[Proceedings](#)

Opportunities and Challenges for Using Digital Health Applications in Oncology

July 13-14, 2020

The National Cancer Policy Forum, in collaboration with the Forum on Cyber Resilience, convened a workshop to examine the role of digital health applications in oncology research and care. Workshop speakers discussed topics such as exemplars of novel digital health applications; regulatory priorities; ethical, security, governance, and payment considerations; and opportunities to improve data availability and use in EHRs and large databases.

[Workshop videos and presentations](#)
[Proceedings](#)

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- Centers for Disease Control and Prevention
- National Institutes of Health/National Cancer Institute
- American Association for Cancer Research
- American Cancer Society
- American College of Radiology
- American Society of Clinical Oncology
- Association of American Cancer Institutes
- Association of Community Cancer Centers
- Bristol-Myers Squibb
- Cancer Support Community
- Flatiron Health
- Merck
- National Comprehensive Cancer Network
- National Patient Advocate Foundation
- Novartis Oncology
- Oncology Nursing Society
- Pfizer Inc.
- Sanofi
- Society for Immunotherapy of Cancer

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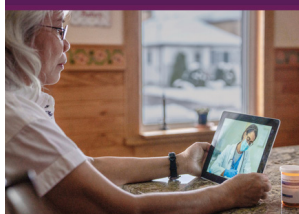


NATIONAL CANCER POLICY FORUM

WORKSHOP PROCEEDINGS AND RELATED PUBLICATIONS

PROCEEDINGS OF A WORKSHOP

Innovation in
Cancer Care and Cancer Research
in the Context of the
COVID-19 Pandemic



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PROCEEDINGS OF A WORKSHOP



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

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PROCEEDINGS OF A WORKSHOP



Addressing the
Adverse Consequences
of Cancer Treatment

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WORKSHOP PROCEEDINGS

2022

The Role of Companion Animals as Sentinels for Predicting Environmental Exposure Effects on Aging and Cancer Susceptibility in Humans: Proceedings of a Workshop (In Process)
Promoting Health Equity in Cancer Care: Proceedings of a Workshop (In Process)
Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic: Proceedings of a Workshop (Prepublication)
Impact of the Affordable Care Act on Cancer Prevention and Cancer Care: Proceedings of a Workshop (Prepublication)

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

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

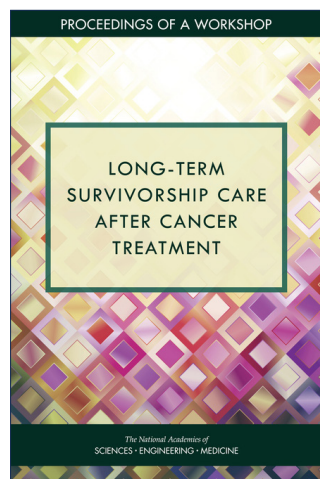
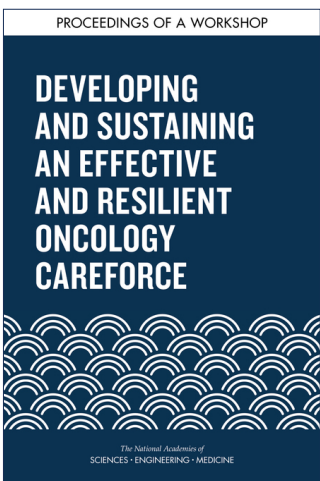
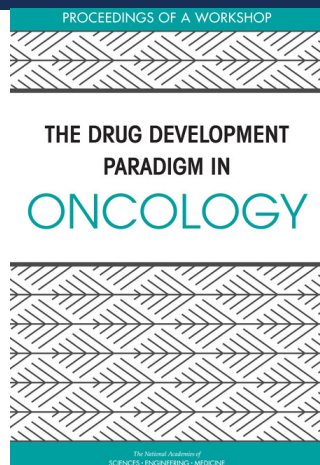
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WORKSHOP PROCEEDINGS

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

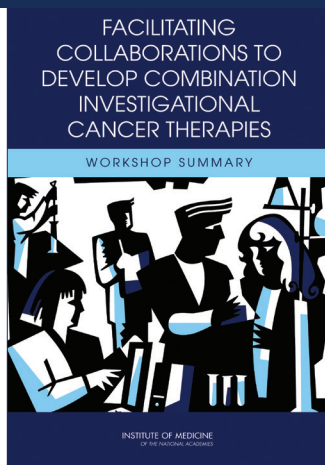
Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer: Workshop Summary
Implementing a National Cancer Clinical Trials System for the 21st Century: Second Workshop Summary
Sharing Clinical Research Data: Workshop Summary
Delivering Affordable Cancer Care in the 21st Century: Workshop Summary
Reducing Tobacco-Related Cancer Incidence and Mortality: Workshop Summary

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



WORKSHOP PROCEEDINGS

2011

Implementing a National Cancer Clinical Trials System for the 21st Century: Workshop Summary
 Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care: Workshop Summary
 The National Cancer Policy Summit: Opportunities and Challenges in Cancer Research and Care
 Nanotechnology and Oncology: Workshop Summary

2010

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

2009

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

2008

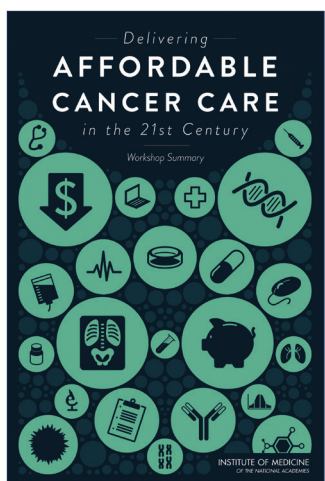
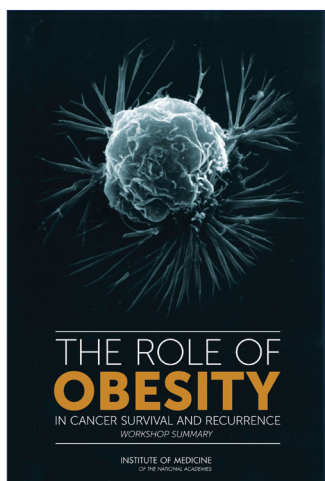
Implementing Colorectal Cancer Screening: Workshop Summary
 Improving the Quality of Cancer Clinical Trials: Workshop Summary

2007

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

2006

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



RELATED WORK

CONSENSUS STUDY REPORTS BUILDING ON NCPF WORK

Childhood Cancer and Function 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:

2021

- Nekhlyudov L., G.B. Campbell., K.H. Schmitz, G.A. Brooks, A.J. Kumar, P.A. Ganz, Von Ah, D. Cancer-related impairments and functional limitations among long-term cancer survivors: Gaps and opportunities for clinical practice. *Cancer*. 2021 Sep 16. doi: 10.1002/cncr.33913. Epub ahead of print. PMID: 34529268.
- Bertagnolli, M.M. and H. Singh. 2021. Treatment of older adults with cancer - addressing gaps in evidence. *New England Journal of Medicine*. <https://www.nejm.org/doi/full/10.1056/NEJMp2106089>
- Housten, A.J., C.M. Gunn, M.K. Paasche-Orlow, and K.M. Basen-Engquist. 2021. Health Literacy Interventions in Cancer: A Systematic Review. *Journal of Cancer Education*. 36(2):240-252. doi: 10.1007/s13187-020-01915-x.

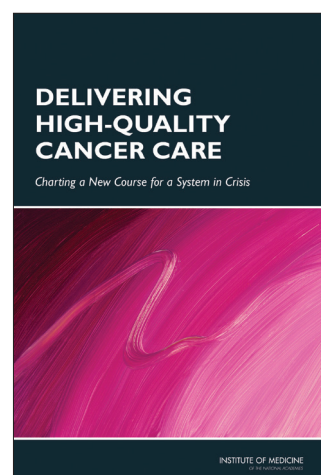
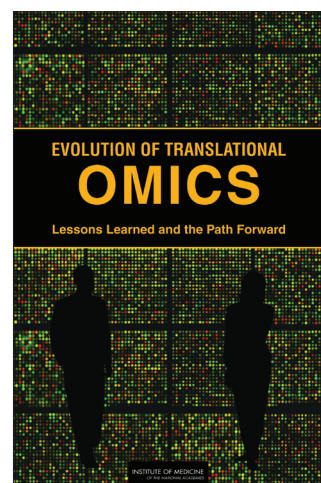
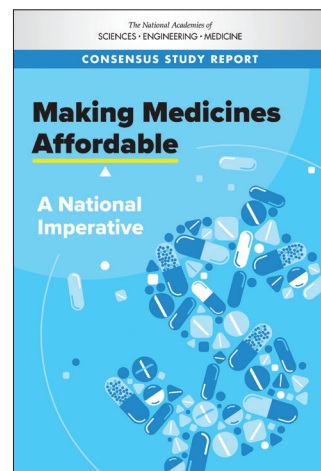
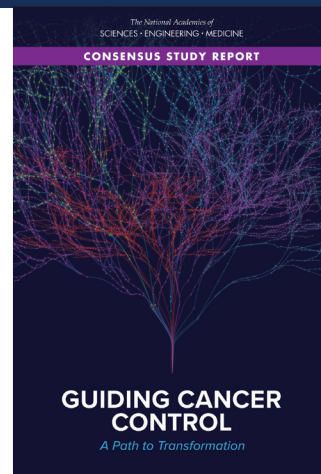
2020

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

2019

- Balogh, E. P., A. B. Bindman, S. G. Eckhardt, S. Halabi, R. D. Harvey, I. Jaiyesimi, R. Miksad, H. L. Moses, S. J. Nass, R. L. Schilsky, S. Sun, J. M. Torrente, and K. E. Warren. 2019. Challenges and opportunities to updating prescribing information for longstanding oncology drugs. *The Oncologist* 24: 1-7. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7066705/>.
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*Accessed date for all articles is February 23, 2022.



2019, continued

- Kline, R. M., G. B. Rocque, E. A. Rohan, K. A. Blackley, C. A. Cantril, M. L. Pratt-Chapman, H. A. Burris, and L. N. Shulman. 2019. Patient navigation in cancer: The business case to support clinical needs. *Journal of Oncology Practice*. Epub ahead of print JOP.1900230. <https://www.ncbi.nlm.nih.gov/pubmed/31509483>.
- Lubejko, B. G., C. Cantril, L. H. Hogg, and L. Kennedy Sheldon. 2019. Novice oncology nurse navigator: Core elements in establishing training needs and building on competencies. *Clinical Journal of Oncology Nursing* 23(4):387-394. <https://www.ncbi.nlm.nih.gov/pubmed/31322621>.
- Nass, S. J., M.B. Cohen, R. Nayar, M.M. Zutter, E. P. Balogh, R. L. Schilsky, H. Hricak, and K.S.J. Elenitoba-Johnson. 2019. Improving cancer diagnosis and care: Patient access to high-quality oncologic pathology. *The Oncologist*. <https://www.ncbi.nlm.nih.gov/pubmed/31366725>.
- Lopez, D., M. L. Pratt-Chapman, E. A. Rohan, L. K. Sheldon, K. Basen-Engquist, R. Kline, L. N. Shulman, and E. J. Flores. 2019. Establishing effective patient navigation programs in oncology. *Supportive Care in Cancer* 27(6):1985-1996. <https://www.ncbi.nlm.nih.gov/pubmed/30887125>.
- Nass, S. J., C. R. Cogle, J. A. Brink, C. P. Langlotz, E. P. Balogh, A. Muellner, D. Siegal, R. L. Schilsky, and H. Hricak. Improving cancer diagnosis and care: Patient access to oncologic imaging expertise. *Journal of Clinical Oncology*. JCO.18.01970. <https://www.ncbi.nlm.nih.gov/pubmed/31050908>.

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- Kline, R. M., N. K. Arora, C. J. Bradley, E. R. Brauer, D. L. Graves, N. Buchanan Lunsford, M. S. McCabe, S. F. Nasso, L. Nekhlyudov, J. H. Rowland, R. M. Schear, and P. A. Ganz. Long-term survivorship care after cancer treatment—summary of a 2017 National Cancer Policy Forum workshop. *Journal of the National Cancer Institute* 110, 110(12):1300-1310. <https://www.ncbi.nlm.nih.gov/pubmed/30496448>.
- Nass, S. J., M. Rothenberg, R. Pentz, H. Hricak, A. Abernethy, K. Anderson, A. W. Gee, R.D. Harvey, S. Piantadosi, M. M. Bertagnolli, D. Schrag, and R. L. Schilsky. Accelerating anticancer drug development—opportunities and trade-offs. *Nature Reviews Clinical Oncology* 15(12):777-786. <https://www.ncbi.nlm.nih.gov/pubmed/30275514>.
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2016

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

2015

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2013

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2012

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

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

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

May 16-17, 2022

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

Statement of Task:

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

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

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

Planning Committee:

Grace B. Campbell, Duquesne University School of Nursing/University of Pittsburgh (Co-chair)
Randall Oyer, Penn Medicine Lancaster General Health (Co-chair)
Allison Applebaum, Memorial Sloan Kettering Cancer Center/Weil Cornell Medical College
Jennifer M. Ballentine, California State University Shiley Haynes Institute for Palliative Care
Cathy Bradley, Colorado School of Public Health/University of Colorado Comprehensive Cancer Center
Julie Bynum, University of Michigan
Jane Carmody, John A. Hartford Foundation
Sara Daminao, Ascension
Pamela S. Hinds, George Washington University
Randall A. Jones, University of Virginia
Rebecca A. Kirch, National Patient Advocate Foundation
Amy Melnick, National Coalition for Hospice and Palliative Care
Clyde W. Oden, Jr., Alameda County Health Care Alliance

Project Staff:

Laurene Graig, Senior Program Officer, Director, Roundtable on Quality Care for People with Serious Illness
Rukshana Gupta, Research Assistant
Siham Idris, Program Assistant
Rachel Austin, Senior Program Assistant
Lori Benjamin Brenig, Research Associate
Tracy Lustig, Senior Program Officer, Director, Forum on Aging, Disability, and Independence
Arzoo Tayyeb, Finance Business Partner
Erin Balogh, Senior Program Officer; Co-Director, National Cancer Policy Forum
Sharyl Nass, Director, Board on Health Care Services; Co-Director, National Cancer Policy Forum

The National Academies of
SCIENCES • ENGINEERING • MEDICINE
HEALTH AND MEDICINE DIVISION

Advancing Progress in Cancer Prevention and Risk Reduction: A Workshop

June 27-28, 2022

Keck Center of the National Academies Room 100
500 Fifth Street, NW
Washington, DC 20001

Workshop website: <https://www.nationalacademies.org/event/06-27-2022/advancing-progress-in-cancer-prevention-and-risk-reduction-a-workshop>

Statement of Task:

A planning committee will organize and host a 1.5-day public workshop that will consider the current state of knowledge regarding risk factors for cancer and strategies for interventions across multiple levels to reduce cancer risk. The workshop will feature invited presentations and panel discussions on topics that may include:

- An overview of the current evidence base for modifiable (e.g., environmental and behavioral) risk factors for cancer, including consideration of how these factors are distributed across populations and influenced by socioeconomic factors.
- Best practices and innovative approaches to implement population-based cancer prevention strategies, including the potential for collaborations with other disease prevention efforts.
- Opportunities to overcome challenges in the delivery of cancer prevention services within communities and health care settings, including consideration of specific strategies for low-resource areas.
- Opportunities to improve implementation of vaccine-based interventions for cancer prevention, as well as for pharmacological and surgical interventions to reduce cancer risk.
- Methods for assessing efficacy of programs and interventions for cancer prevention and risk reduction, including the identification and validation of biomarkers as surrogate endpoints.

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

Planning Committee:

Garnet L. Anderson, Fred Hutchinson Cancer Research Center (Co-chair)
Karen Basen-Engquist, The University of Texas MD Cancer Center (Co-chair)
Gwen Darien, National Patient Advocate Foundation
Nancy E. Davidson, Fred Hutchinson Cancer Research Center/Seattle Cancer Care Alliance
Nicole F. Dowling, Centers for Disease Control and Prevention
Karen M. Emmons, Harvard University
Stanton L. Gerson, Case Comprehensive Cancer Center/National Center for Regenerative Medicine
Katrina Goddard, National Cancer Institute
Julie R. Gralow, American Society of Clinical Oncology
Chanita Hughes-Halbert, University of Southern California Norris Comprehensive Cancer Center
Beth Y. Karlan, Jonsson Comprehensive Cancer Center, University of California, Los Angeles
Scott M. Lippman, Moores Cancer Center, University of California, San Diego
Laura Makaroff, American Cancer Society

Addressing Resistance in Immune Modulator Therapies for Cancer Treatment: A Workshop

November 14-15, 2022

National Academies of Sciences Lecture Room
2101 Constitution Ave, NW
Washington, DC 20001

Statement of Task:

A National Academies of Sciences, Engineering, and Medicine planning committee will plan and host a 1.5-day public workshop that will examine the current challenges related to resistance to immune modulator therapies and discuss potential policy levers that could help to overcome these challenges. The workshop will feature invited presentations and panel discussions on topics that may include:

- An overview of the unique types of immunotherapy resistance based on the causes of resistance, including whether resistance mechanisms vary among different agents, and gaps in current understanding.
- Policy challenges and opportunities to address the problem of resistance, including factors such as:
 - Criteria to move single agents into clinical trials.
 - Criteria to use single agents in combination therapy development (e.g., whether clinical response is necessary).
 - Criteria to assess cancer immunotherapy combinations in early-phase clinical trials.
 - The roles of preclinical modeling and clinical and predictive biomarkers (e.g., companion diagnostics, in vivo imaging) for assessing safety and efficacy.
 - The types of clinical trial designs needed for regulatory approval.
 - Use of big data to aid in determining the dominant drivers of cancer immunotherapy resistance and to predict immunotherapy responses.

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

Planning Committee Pending