Health Literacy and Communication Strategies in Oncology: A Workshop

July 15 - 16, 2019
July 15, 2019

Dear Colleagues,

Welcome to the National Academies of Sciences, Engineering, and Medicine workshop on Health Literacy and Communication Strategies in Oncology. This meeting is hosted by the National Cancer Policy Forum, in collaboration with the Roundtable on Health Literacy.

The goals of this workshop are to identify opportunities to improve communication of information about cancer and to support the health literacy needs of patients and families in cancer care. The workshop will examine strategies to accomplish these goals at the level of patient-clinician interactions, within health care systems, and within the broader community. Presentations will examine communication strategies for diverse populations, including individuals with low health literacy; best practices to improve communication across the cancer care continuum; media and public health strategies to deliver accurate information about cancer; and strategies for health care systems and insurers to improve communication and support individuals’ health literacy needs.

We encourage attendees to participate actively and suggest opportunities to improve communication and meet patients’ health literacy needs across the continuum of cancer care. 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 be available at http://www.nationalacademies.org/hmd/Activities/Disease/NCPF/2019-JULY-15.aspx

Sincerely,

Karen Basen-Engquist, PhD, MPH
Planning Committee Co-Chair
Annie Laurie Howard Research Distinguished Professor
Director, Center for Energy Balance in Cancer Prevention & Survivorship
Professor of Behavioral Science
The University of Texas MD Anderson Cancer Center

Michael Paasche-Orlow, MD, MA, MPH
Planning Committee Co-Chair
Professor
Boston University School of Medicine

The National Academies of
SCIENCES • ENGINEERING • MEDICINE
# Health Literacy and Communication Strategies in Oncology

**A National Cancer Policy Forum Workshop**

In Collaboration with the Roundtable on Health Literacy

**Keck Center of the National Academies**

500 Fifth Street, NW - Room 100

Washington, DC 20001

**July 15, 2019**

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<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>7:30 am</td>
<td>Registration and Breakfast</td>
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| 8:00 am    | **Session 1: Overview of Health Literacy and Communication Strategies in Oncology**  
**Moderator:** Karen Basen-Engquist, The University of Texas MD Anderson Cancer Center  
**Welcome and Workshop Overview**  
**Planning Committee Co-Chairs:**  
- Karen Basen-Engquist, The University of Texas MD Anderson Cancer Center  
- Michael Paasche-Orlow, Boston University School of Medicine  
**Keynote Presentation: Leveraging Media for Cancer Education**  
- Elmer Huerta, Medstar Washington Hospital Center  
**Cultural Competency and Best Practices for Communication with Multicultural Populations**  
- Marjorie Kagawa Singer, University of California, Los Angeles Fielding School of Public Health  
**Panel Discussion**  
Include speakers and  
- Deborah Collyar, Patient Advocates in Research  
- Ivis Sampayo, SHARE Cancer Support |
| 9:45 am    | Break                                                                   |
| 10:00 am   | **Session 2: Strategies and Best Practices to Improve Communication Across the Cancer Care Continuum**  
**Moderator:** Randall Oyer, Penn Medicine Lancaster General  
**Strategies for Communicating about Prevention and Screening**  
- Cathy Meade, Moffitt Cancer Center  
**Strategies to Improve Patient-Clinician Communication in Oncology Care**  
- Anthony Back, University of Washington School of Medicine  
**Communication with Adolescents and Young Adult Cancer Populations**  
- Gwendolyn Quinn, New York University Langone Health  
**Strategies for Communicating Health Information in Survivorship Care**  
- Frank Penedo, University of Miami |
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<tr>
<td>12:15 pm</td>
<td>Lunch Break</td>
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| 1:15 pm      | Session 3: Communication Strategies to Build Public Trust and Counter Inaccurate Information about Cancer  
Moderator: Nicole Dowling, Centers for Disease Control and Prevention  
Overcoming the Challenge of Online Health Misinformation in Cancer Communication  
  Wen-Ying Sylvia Chou, National Cancer Institute  
Opportunities for Local and State Governments to Promote Effective Public Health Communication about Cancer  
  Shalewa Noel-Thomas, Washington, DC Department of Health  
Strategies to Convey Accurate and Accessible Cancer Information to the Public  
  Richard Wender, American Cancer Society  
21st Century Media Strategies to Engage and Inform the Public about Cancer  
  Lisa Fitzpatrick, Grapevine Health (“Dr. Lisa on the Street”)  
Ensuring Responsible Media Communication about Cancer and Strategies to Build Public Trust  
  Ivan Oransky, Medscape  
Panel Discussion  
Include speakers and  
  James Hamblin, The Atlantic |
| 3:00 pm      | Break                                                                |
| 3:45 pm      | Session 4: Current and Future Research Strategies for Health Communication in Oncology  
Moderator: Lisa Kennedy Sheldon, Oncology Nursing Society  
The National Cancer Institute’s Portfolio of Research on Health Literacy and Communication in Oncology and Priorities For Future Research  
  April Oh, National Cancer Institute  
Communicating Effectively about Cancer Genetics with Patients of Low Health Literacy  
  Galen Joseph, University of California, San Francisco  
Visual Design Strategies to Increase Effectiveness of Cancer Communication  
  Allison Lazard, University of North Carolina at Chapel Hill  
The Role of Health Insurance Literacy in Reducing Patients’ Financial Toxicity  
  Mary Politi, Washington University School of Medicine in St. Louis  
Panel Discussion |
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<tr>
<td>5:30 pm</td>
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<td>Evening Reception</td>
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<td>7:30 am</td>
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<td>8:00 am</td>
<td>Session 5: Procedures, Policies, and Programs to Assess and Address Health Literacy Needs of Patients and Families</td>
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<td>Moderator: Michael Paasche-Orlow, Boston University School of Medicine</td>
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<td>Strategies and Policies for Health Care Organizations to Address the Needs of Patients and Families with Low Health Literacy</td>
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<td>Urmimala Sarkar, University of California, San Francisco</td>
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<td>Development of Patient Navigation Programs and Their Role in Promoting Health Literacy</td>
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<td>Mandi Pratt-Chapman, George Washington University Cancer Institute</td>
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<td>Clinic-Based Programs to Improve Symptom Management and Patient-Clinician Communication</td>
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<td>Heidi Donovan, University of Pittsburgh School of Nursing</td>
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<td>Policies and Incentives for Health Insurance Organizations to Promote Health Literacy and Effective Communication</td>
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<td>Kim Parson, Humana</td>
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<td>10:00 am</td>
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<td>Session 6: Stakeholder Perspectives and Priorities for the Path Forward</td>
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<td>Moderator: Cathy Meade, Moffitt Cancer Center</td>
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<td>Wen-Ying Sylvia Chou, National Cancer Institute</td>
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<td>Gwen Darien, National Patient Advocate Foundation</td>
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<td>Darci Graves, Centers for Medicare &amp; Medicaid Services</td>
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<td>Claire Saxton, Cancer Support Community</td>
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<td>Robert Winn, University of Illinois at Chicago</td>
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<td>11:30 am</td>
<td>Workshop Wrap Up</td>
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Workshop Notes

- This workshop is being webcast and recorded. Please identify your name and affiliation prior to asking questions at the microphone.

- The workshop webpage and live webcast are available at: [http://nationalacademies.org/hmd/Activities/Disease/NCPF/2019-JULY-15.aspx](http://nationalacademies.org/hmd/Activities/Disease/NCPF/2019-JULY-15.aspx) (presentations and the webcast will also be archived at this address)

- Please use hashtags #NatlCancerForum and #HealthLitRT to tweet about the workshop.

- Interested in receiving updates from the National Cancer Policy Forum or the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine? [http://nationalacademies.org/hmd/Global/Media%20Room/Updates.aspx](http://nationalacademies.org/hmd/Global/Media%20Room/Updates.aspx)

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## WORKSHOP PLANNING COMMITTEE MEMBERS

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<thead>
<tr>
<th>Name</th>
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<tr>
<td>Karen Basen-Engquist, PhD, MPH</td>
<td>Co-Chair</td>
<td>The University of Texas MD Anderson Cancer Center</td>
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<tr>
<td>Annie Laurie Howard Research</td>
<td>Director, Center for Energy Balance in Cancer Prevention &amp; Survivorship</td>
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<td>Distinguished Professor</td>
<td>Professor of Behavioral Science</td>
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<td>Michael Paasche-Orlow, MD, MA, MPH</td>
<td>Co-Chair</td>
<td>Boston University School of Medicine</td>
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<td>Professor of Medicine</td>
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<td>Garnet Anderson, PhD</td>
<td>Beth Karlan, MD</td>
<td>University of California, Los Angeles</td>
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<td>Senior Vice President and Director</td>
<td>Professor and Vice Chair</td>
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<tr>
<td>Public Health Sciences Division</td>
<td>Women's Health Research</td>
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<tr>
<td>Fred Hutchinson Cancer Research Center</td>
<td>Department of Obstetrics and Gynecology</td>
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<td>Affiliate Professor</td>
<td>David Geffen School of Medicine</td>
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<td>Department of Biostatistics</td>
<td>Director, Cancer Population Genetics</td>
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<td>University of Washington</td>
<td>Jonsson Comprehensive Cancer Center</td>
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<td>Edward J. Benz Jr., MD</td>
<td>Lisa Kennedy Sheldon, PhD, APRN, AOCNP®, FAAN</td>
<td>Oncology Nursing Society</td>
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<tr>
<td>President and Chief Executive Officer, Emeritus</td>
<td>Chief Clinical Officer</td>
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<td>Dana-Farber Cancer Institute</td>
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<td>Richard and Susan Smith Distinguished Professor of Medicine, Genetics, and Pediatrics</td>
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<td>Harvard Medical School</td>
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<td>Nicole F. Dowling, PhD</td>
<td>Cathy Meade, PhD, RN, FAAN</td>
<td>Moffitt Cancer Center</td>
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<td>Associate Director for Science</td>
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<td>Division of Cancer Prevention and Control</td>
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<td>National Center for Chronic Disease Prevention and Health Promotion</td>
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<td>Centers for Disease Control and Prevention</td>
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<td>Christine Gunn, PhD</td>
<td>Randall A. Oyer, MD</td>
<td>Penn Medicine Lancaster General</td>
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<td>Assistant Professor, Medicine</td>
<td>Medical Director, Oncology</td>
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<td>Boston University School of Medicine</td>
<td>Ann B. Barshinger Cancer Institute</td>
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<td>Robert A. Winn, MD</td>
<td>University of Illinois at Chicago</td>
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<td>VHA National Program Manager, Prevention Policy</td>
<td>Professor of Medicine</td>
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<td>Division of Pulmonary, Critical Care, Sleep, and Allergy</td>
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<td>University of Illinois Hospital &amp; Health Sciences System</td>
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<td>Office of Nursing Services</td>
<td>Associate Vice Chancellor, Community-Based Practice</td>
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<td>Department of Veterans Affairs</td>
<td>Director, University of Illinois Cancer Center</td>
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<td>Linda House, RN, BSN, MSM</td>
<td>American Cancer Society</td>
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<td>President</td>
<td>Senior Scientific Director</td>
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<td>Cancer Support Community</td>
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<td>Ashley Housten, OTD, MSCI</td>
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<td>Washington University School of Medicine in St. Louis</td>
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<td>Anthony (Tony) Back, MD</td>
<td>Professor, Department of Medicine, Division of Oncology, University of Washington School of Medicine</td>
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<tr>
<td>James Hamblin, MD</td>
<td>Writer and Senior Editor, The Atlantic</td>
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<td>Founder and President, Patient Advocates in Research</td>
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<td>Research Professor/Professor Emerita, Department of Community Health Sciences, Department of Asian American Studies, Fielding School of Public Health, University of California, Los Angeles</td>
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<td>Lisa Fitzpatrick, MD, MPH, MPA</td>
<td>Founder, Promoting Pratical Health, Inc., Milken Institute School of Public Health, George Washington University</td>
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<td>Shalewa Noel-Thomas, PhD, MPH</td>
<td>Bureau Chief, Cancer and Chronic Disease Prevention Bureau, Washington, DC Department of Health</td>
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<td>Darci Graves, MPP, MA</td>
<td>Special Assistant to the Director, Office of Minority Health, Centers for Medicare &amp; Medicaid Services</td>
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<td>Nina O'Connor, MD, FAHAHPM</td>
<td>Chief, Palliative Care, University of Pennsylvania Health System, Chief Medical Officer, Penn Medicine Hospice, Associate Professor of Clinical Medicine, University of Pennsylvania Perelman School of Medicine</td>
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<td>Associate Center Director, Patient-Centered Initiatives and Health Equity, George Washington University Cancer Institute</td>
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<td>Ivan Oransky, MD</td>
<td>Vice President, Editorial, Medscape, Co-founder, Retraction Watch, President, Association of Health Care Journalists, Distinguished Writer in Residence, Arthur Carter Journalism Institute, Clinical Assistant Professor of Medicine, New York University</td>
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<td>Livia Wan M.D. Endowed Chair, Vice-Chair of Research, Obstetrics and Gynecology, Professor, Population Health and Center for Medical Ethics, New York University Langone Health</td>
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<td>Kim Parson, BA</td>
<td>Consultant, Humana</td>
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<td>Senior Director, Education and Outreach, Cancer Support Community</td>
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<td>Sylvester Professor of Psychology and Medicine, Associate Director, Cancer Survivorship &amp; Translational Behavioral Sciences, Miller School of Medicine, Sylvester Comprehensive Cancer Center, Co-leader, Cancer Control Research Program, University of Miami</td>
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We are grateful for the support of our sponsors, which is crucial to the work of the Forum.
The National Cancer Policy Forum serves as a trusted venue in which experts can identify emerging high-priority policy issues in cancer research and care and work collaboratively to examine those issues through convening activities focused on opportunities for action. The Forum provides a continual focus within the National Academies on cancer, addressing issues in science, clinical medicine, public health, and public policy that are relevant to the goal of reducing the cancer burden, through prevention and by improving the care and outcomes for those diagnosed with cancer. Forum activities inform stakeholders about critical policy issues through published reports and often inform consensus committee studies. The Forum has members with a broad range of expertise in cancer, including patient advocates, clinicians, and basic, translational, and clinical scientists. Members represent patients, federal agencies, academia, professional organizations, nonprofits, and industry.

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

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

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

October 28-29, 2019

The collection and analysis of big data is expected to transform the field of cancer research and improve cancer care. Analyses of big data have the potential to elucidate ways in which the social determinants of health contribute to cancer incidence and outcomes, and may also identify promising avenues for intervention. However, not all individuals and communities may benefit equally from these advances: concerns remain about whether applications of big data research will reduce existing health disparities in oncology, or whether they might inadvertently exacerbate these disparities.

This workshop will examine the social determinants of health in the context of cancer, and consider opportunities to effectively leverage big data to improve health equity and reduce disparities. The workshop will feature invited presentations and discussion on topics such as:

- The impact of social determinants of health on cancer incidence and outcomes
- Opportunities to leverage big data and analytic methods in oncology
- Examples of novel data sources and methodologies
- Data policy and ethical considerations
- Stakeholder engagement and collaboration to improve health equity
- Research gaps and a research agenda


Advancing Progress in Cancer Prevention and Risk Reduction

March 2-3, 2020

Cancer prevention is considered the most cost-effective long-term strategy for cancer control. In the United States, approximately 42 percent of cancer diagnoses and 45 percent of cancer deaths are related to modifiable behavioral and environmental risk factors such as: cigarette smoking, excess body weight, physical inactivity, alcohol consumption, and exposure to ultraviolet radiation, chemicals, and pollutants. These risk factors do not uniformly affect populations—many modifiable risk factors are influenced by socioeconomic factors that contribute to significant disparities in cancer incidence and outcomes.

This workshop will provide a venue for the cancer community to examine the current state of knowledge on modifiable risk factors in cancer and to discuss contextually-appropriate approaches for cancer prevention and risk reduction. Workshop presentations and discussion will focus on:

- Best practices and innovative approaches to implement population-based cancer prevention and risk reduction strategies
- 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
- Strategies to improve implementation of vaccine-based interventions for prevention, as well as for interventions for risk reduction (e.g., surgery and pharmacologic approaches)
- Methods for assessing effectiveness of cancer prevention and risk reduction efforts

Workshop website forthcoming

Save the Date: Future Workshops

July 13-14, 2020

November 9-10, 2020
Health Literacy and Communication Strategies in Oncology

This workshop, held in collaboration with the Roundtable on Health Literacy, will examine opportunities, methods, and strategies to improve the communication of cancer information in a clinic visit, as patients and families navigate the health care system, and within the broader community. Workshop presentations and discussion will review procedures, policies, and programs to support health literacy needs of patients and families; best practices to improve communication across the cancer continuum; opportunities to build public trust and counter inaccurate information about cancer; and ongoing research to improve health communication in oncology care.

Workshop videos and presentation files:

Updating Labels for Generic Oncology Drugs

In March 2019, participants examined the challenges and opportunities to update oncology drugs labels that are inconsistent with the current evidence base and use in clinical practice. Discussions focused on what information sources should be considered for labeling updates, evidentiary standards for labeling updates, and evidence considerations for special populations like pediatric oncology. This project was sponsored by the FDA and held in collaboration with the Forum on Drug Discovery, Development, and Translation.

Workshop presentation files:

Developing and Sustaining an Effective and Resilient Oncology Careforce

The landscape of cancer care is undergoing rapid change. Advances in cancer research, screening and diagnostic practices, and cancer treatment have led to improved outcomes for patients with cancer and a growing population of cancer survivors, but they have also increased the complexity of cancer care. Demographic trends, new care delivery and payment models, the widespread adoption of technologies in clinical practice, and increasing family caregiving responsibilities have had a profound effect on the cancer careforce. This workshop examined opportunities to better support the oncology careforce and improve the delivery of high-quality cancer care.

Workshop videos and presentation files:

The Clinical Application of Computational Methods in Precision Oncology

Precision oncology therapies, which target specific abnormalities in a patient’s cancer, are changing the nature of cancer treatment by enabling clinicians to select therapies that are most likely to benefit individual patients. Increasingly, oncologists are formulating cancer treatment plans using results from complex tests that characterize the molecular underpinnings of an individual patient’s cancer. These advances depend on the use of computational methods to analyze large-scale datasets derived from genomic tests and other omics technologies. This workshop examined the challenges and opportunities in the development of computational methods for precision medicine to improve cancer diagnosis and care.

Workshop videos and presentation files:

Advancing Progress in the Development of Combination Cancer Therapies with Immune Checkpoint Inhibitors

Immune checkpoint inhibitors, like those that target PD-1 and PD-L1 proteins, have changed the standard of care for multiple types of cancer and represent a majority share of new cancer drug applications to the FDA. There has been growing interest in combining checkpoint inhibitors with other therapies to further improve efficacy. Several challenges impede optimal development of combination therapies with checkpoint inhibitors, such as prioritizing combinations for testing, identifying patients who are most likely to benefit, assessing endpoints for safety and clinical benefit, overcoming resistance to therapy, and developing cancer site-agnostic indications. This workshop examined the opportunities to improve the development of combination cancer therapies that include immune checkpoint inhibitors.

Workshop videos and presentation files:
FORUM SPONSORS

- Centers for Disease Control and Prevention
- National Institutes of Health/National Cancer Institute
- American Association for Cancer Research
- American Cancer Society
- American College of Radiology
- American Society of Clinical Oncology
- Association of American Cancer Institutes
- Association of Community Cancer Centers
- Bristol-Myers Squibb
- Cancer Support Community
- CEO Roundtable on Cancer
- Flatiron Health
- Helsinn Therapeutics (U.S.), Inc.
- LIVESTRONG Foundation
- Merck
- National Comprehensive Cancer Network
- Novartis Oncology
- Oncology Nursing Society
- Pfizer Inc.

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Fred Hutchinson Cancer Research Center

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Dana-Farber Cancer Institute

William Bailey, Pharm.D.
Helsinn Therapeutics (U.S.), Inc.

Karen Basen-Engquist, Ph.D., M.P.H.
The University of Texas MD Anderson Cancer Center

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University of Colorado Cancer Center

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Perelman School of Medicine, University of Pennsylvania

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Bristol-Myers Squibb

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Lori Hoffman Högg, M.S., R.N., CNS, AOCN
Department of Veterans Affairs

Linda House, R.N., BSN, MSM
Cancer Support Community

Hedvig Hricak, M.D., Ph.D.
Memorial Sloan Kettering Cancer Center

Roy A. Jensen, M.D.
The University of Kansas Cancer Center

Lisa Kennedy Sheldon, Ph.D., APRN-BC, AOCNP, FAAN
Oncology Nursing Society

Samir Khleif, M.D.
Georgetown University

Ronald M. Kline, M.D., FAAP
Centers for Medicare & Medicaid Services

Michelle M. Le Beau, Ph.D.
The University of Chicago Comprehensive Cancer Center

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Rush University Cancer Center

J. Leonard Lichtenfeld, M.D., MACP
American Cancer Society

Neal Meropol, M.D.
Flatiron Health

Martin J. Murphy, Ph.D., D.Med.Sc.
CEO Roundtable on Cancer

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Lancaster General Health

Richard Pazdur, M.D.
Food and Drug Administration

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American Society of Clinical Oncology

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University of Pennsylvania Abramson Cancer Center

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Novartis Oncology

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University of Iowa Holden Comprehensive Cancer Center

Robert A. Winn, M.D.
University of Illinois Health Cancer Center

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Sharyl Nass, Ph.D.
Forum Director and Director,
Board on Health Care Services

Erin Balogh, M.P.H.
Senior Program Officer

Emily Zevon, Sc.D.
Associate Program Officer

Natalie Lubin, B.A.
Research Assistant

Annalee Gonzales, B.A.
Administrative Assistant

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Senior Program Assistant

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WORKSHOP PROCEEDINGS

2019

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

2018

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

2017

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

2016

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

2015

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

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#NatlCancerForum

The National Academies of Sciences Engineering Medicine
WORKSHOP PROCEEDINGS

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: Workshop Summary (2013 and 2011)
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
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: Workshop Proceedings
Nanotechnology and Oncology: Workshop Summary

2010
Direct to Consumer Genetic Testing (with the National Research Council): Summary of a Workshop
Extending the Spectrum of Precompetitive Collaboration in Oncology Research: Workshop Summary
A Foundation for Evidence-Driven Practice: A Rapid Learning System for Cancer Care: Workshop Summary
Policy Issues in the Development of Personalized Medicine in Oncology: Workshop Summary

2009
Assessing and Improving Value in Cancer Care: Workshop Summary
Ensuring Quality Cancer Care Through the Oncology Workforce: Sustaining Care in the 21st Century: Workshop Summary
Multi-Center Phase III Clinical Trials and the NCI Cooperative Group Program: Workshop Summary

2008
Implementing Colorectal Cancer Screening: Workshop Summary
Improving the Quality of Cancer Clinical Trials: Workshop Summary

2007
Cancer-Related Genetic Testing and Counseling: Workshop Proceedings
Cancer in Elderly People: Workshop Proceedings
Implementing Cancer Survivorship Care Planning: Workshop Summary

2006
Effect of the HIPAA Privacy Rule on Health Research: Proceedings of a Workshop
Developing Biomarker-Based Tools for Cancer Screening, Diagnosis, and Treatment: Workshop Summary
RELATED WORK

Consenus Study Reports building on NCPF work

Biomarker Tests for Molecularly Targeted Therapies: Key to Unlocking Precision Medicine (2016) Report: nap.edu/catalog/21860
Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013) Report: nap.edu/catalog/18359

Individually authored publications building on NCPF work

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

2019


2018


*access date for all articles: January 31, 2019

2016


2015


2014


2013


2012


2011


2010

ABOUT THE ROUNDTABLE ON HEALTH LITERACY

The Roundtable on Health Literacy brings together leaders from academia, industry, government, foundations and associations, and representatives of patient and consumer interests. The mission of the Roundtable is to inform, inspire, and activate a wide variety of stakeholders to implement and share evidence-based health literacy practices and policies with the goal of improving health and well-being.

MEMBERS

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Northwell Health

Lori Hall  
Eli Lilly and Company

Linda Harris  
Office of Disease Prevention and Health Promotion

Nicole Holland  
Tufts University School of Dental Medicine

Ellen Markman  
Stanford University

Michael M. McKee  
University of Michigan Medical School

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Merck Sharpe & Dohme Corp.

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Health Literacy Media

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Boston Medical Center

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Health Literacy Partners

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The Board on Population Health and Public Health Practice (BPH) focuses on areas and issues affecting the public’s health. In studies ranging from core principles and needs in the field to specific issues such as vaccine safety, pandemic preparedness issues, smoking cessation, health disparities, and reducing environmental and occupational hazards, BPH considers the best ways to ensure the health of the public. In order to improve the health of groups, communities, and populations, the Board explores topics such as cardiovascular and infectious disease prevention and control interventions and the capacity of federal, state, and local agencies to protect the health of the public.

ABOUT THE ROUNDTABLE
The Roundtable on Health Literacy envisions a society in which the demands of the health and health care systems are respectful of and aligned with people’s skills, abilities, and values. The mission of the roundtable is to inform, inspire, and activate a wide variety of stakeholders to support the development, implementation, and sharing of evidence-based health literacy practices and policies. The goal is to improve the health and well-being of all people.

ROUNDTABLE STAFF
Melissa G. French, M.S., Director, Roundtable on Health Literacy
Alexis Wojtowicz, Research Associate, Roundtable on Health Literacy
Rose Marie Martinez, Sc.D., Senior Board Director

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THE NATIONAL ACADEMIES
The nation turns to the National Academies of Sciences, Engineering, and Medicine for independent, objective advice on issues that affect people’s lives worldwide.
Applying Big Data to Address the Social Determinants of Health in Oncology  
Workshop Hosted by the National Cancer Policy Forum  
In Collaboration with the Board on Mathematical Sciences and Analytics  

October 28-29, 2019  
NAS Lecture Room  
2101 Constitution Ave., N.W.  
Washington, D.C. 20418

Statement of Task

An ad hoc committee will plan and host a 1.5-day public workshop that will examine health equity and the social determinants of health in the context of cancer, and consider opportunities to effectively use big data and convergence science to improve health outcomes and reduce disparities. The workshop will feature invited presentations and panel discussions on topics that may include:

- The impact of social determinants of health on cancer incidence and outcomes  
- Ways to capture precise and meaningful data on social determinants of health in oncology (social omics)  
- Potential biomarkers of environmental and social factors that may affect cancer incidence and care outcomes (e.g., microbiome, exposome, and epigenome)  
- The potential advantages and limitations of various methods for identifying geographic populations and communities at risk (e.g., state, county, zip code, city ward, or congressional district)  
- Potential opportunities to reduce bias in capturing big data and applying computational methods to inform cancer care  
- Examples of how community engagement and big data could be used to inform policies to promote health equity in oncology

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

<table>
<thead>
<tr>
<th>Robert A. Winn, MD (Chair)</th>
<th>Kenneth Anderson, MD</th>
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<tbody>
<tr>
<td>Professor of Medicine</td>
<td>Kraft Family Professor of Medicine</td>
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<tr>
<td>Division of Pulmonary, Critical Care, Sleep, and Allergy</td>
<td>American Cancer Society Clinical Research Director</td>
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<td>University of Illinois at Chicago</td>
<td>Jerome Lipper Multiple Myeloma Center</td>
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<tr>
<td>Associate Vice Chancellor, Community-Based Practice</td>
<td>Harvard Medical School</td>
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<tr>
<td>Director, University of Illinois Cancer Center</td>
<td>Dana-Farber Cancer Institute</td>
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<td>University of Illinois Hospital &amp; Health Sciences System</td>
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<th>Garnet Anderson, PhD</th>
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<td>Public Health Sciences Division</td>
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<td>Fred Hutchinson Cancer Research Center</td>
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<td>Affiliate Professor, Department of Biostatistics</td>
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<td>University of Washington</td>
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<td>Name</td>
<td>Position and Affiliation</td>
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<tr>
<td>Karen Basen-Engquist, PhD, MPH</td>
<td>Associate Director for Science, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention</td>
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<tr>
<td>Annie Laurie Howard Research</td>
<td>Distinguished Professor, Center for Energy Balance in Cancer Prevention &amp; Survivorship, The University of Texas MD Anderson Cancer Center</td>
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<td>Ronald Kline, MD, FAAP</td>
<td>Medical Officer, Patient Care Models Group, Center for Medicare and Medicaid Innovation, Centers for Medicare &amp; Medicaid Services</td>
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<tr>
<td>Otis Brawley, MD, MACP, FASCO, FACE</td>
<td>Bloomberg Distinguished Professor, Department of Epidemiology, Bloomberg School of Public Health, Department of Oncology, School of Medicine, Johns Hopkins University</td>
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<tr>
<td>Rebecca Miksad, MD</td>
<td>Senior Medical Director, Flatiron Health</td>
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<tr>
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<td>Associate Director for Science, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention</td>
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<tr>
<td>Timothy Rebbeck, PhD</td>
<td>Director, Center for Global Cancer Prevention, Vincent L. Gregory Professor of Cancer Prevention, Harvard T.H. Chan School of Public Health, Professor, Division of Population Sciences, Dana-Farber Cancer Institute</td>
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<tr>
<td>Stanton L. Gerson, MD</td>
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<tr>
<td>Lori Hoffman Högg, MS, RN, CNS, AOCN®</td>
<td>VHA National Program Manager, Prevention Policy, National Center for Health Promotion and Disease Prevention, National Oncology Clinical Advisor, Office of Nursing Services, Department of Veterans Affairs</td>
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<tr>
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<td>Robin Yabroff, PhD</td>
<td>Senior Scientific Director, Health Services Research, American Cancer Society</td>
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Sharyl Nass, PhD – Director, National Cancer Policy Forum and Board on Health Care Services

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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 inventions 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.
Garnet Anderson, PhD
University of Washington

Garnet Anderson is the Senior Vice President and Director of the Fred Hutchinson Cancer Research Center’s Public Health Sciences Division and an affiliate professor of biostatistics at the University of Washington School of Public Health and Community Medicine. Dr. Anderson’s research focuses on women’s health. She helps lead the design and analysis of large-scale trials to give women new ways to prevent and fight disease and improve their quality of life.

Anthony (Tony) Back, MD
University of Washington School of Medicine

Anthony Back is a Professor at the University of Washington School of Medicine, Division of Oncology. He is Co-Director of the Cambia Palliative Care Center of Excellence with Dr. Randy Curtis. His research on patient-physician communication has been funded by the National Cancer Institute, Robert Wood Johnson Foundation, Gordon and Betty Moore Foundation, Arnold P. Gold Foundation and many others. He was a faculty scholar for the project on Death and America. He co-founded VitalTalk as a 501c3 foundation with Dr. Robert Arnold and Dr. James Tulsky, to use a startup entrepreneurship approach to disseminating clinician-skills training for serious illness. He created the first online video illustrations of communication skills, created the first smartphone teaching app for this purpose, and the first video blog, still ongoing at vitaltalkconversations.com. For over a decade, he has been a senior teacher at the Upaya Institute’s Being with Dying contemplative practice program, and the Resilient program for the American Society of Clinical Oncology Professional Development program. Currently, he is the principal investigator for Care.Lab, a national initiative funded by the John A. Hartford Foundation, which aims to scale up innovations for serious illness.

Karen Basen-Engquist, PhD, MPH
The University of Texas MD Anderson Cancer Center

Karen Basen-Engquist is a Professor of Behavioral Science, an Annie Laurie Howard Research Distinguished Professor, and Director of the Center for Energy Balance in Cancer Prevention and Survivorship at The University of Texas MD Anderson Cancer Center.

Dr. Basen-Engquist’s research focuses on cancer survivors and the role of health behavior interventions in decreasing the severity of late effects, improving physical functioning, optimizing quality of life and reducing risk of chronic diseases. In addition, she studies intervention methods for behavior change and innovative real-time methods for assessing symptoms and behavior in cancer patients and survivors.
Dr. Basen-Engquist recently completed an R01 study funded by the National Cancer Institute (NCI) to investigate the mechanisms of exercise adoption and maintenance in endometrial cancer survivors, using a social cognitive theory model that tests the social, physiological and behavioral predictors of exercise adherence. Additionally, 2 NCI-funded pilot studies evaluated the benefits of exercise for advanced colon cancer patients and cancer survivors with chemotherapy induced heart failure. She currently directs a prevention program funded by the Cancer Prevention & Research Institute of Texas (CPRIT) to increase physical activity among medically underserved breast cancer survivors.

Through activities at the Center, Dr. Basen-Engquist endeavors to expand energy balance research by facilitating collaboration among investigators and expanding research in 4 broad areas – the effect of exercise, nutrition, and weight control on outcomes in cancer survivors and people at increased risk of cancer; biological mechanisms underlying relationships between energy balance and cancer; dissemination and implementation research related to energy balance interventions; and basic biobehavioral mechanisms underlying exercise, eating behavior and weight loss.

**Edward J. Benz Jr., MD**
Dana-Farber Cancer Institute and Harvard Medical School

Edward J. Benz Jr. is the President and CEO Emeritus at Dana-Farber Cancer Institute and the Richard and Susan Smith Distinguished Professor of Medicine, Genetics, and Pediatrics at Harvard Medical School. Dr. Benz began his faculty career at Yale University in 1979, rising to the rank of Professor of Medicine and Human Genetics in 1987. He served as Chief of the Hematology Section and Vice Chair of the Department of Internal Medicine from 1987-1993, after which he served as the Jack D. Meyers Professor and Chair of the Department of Medicine at the University of Pittsburgh (1993-1995) and Sir William Osler Professor, Director of the Department of Medicine and Physician in Chief at Johns Hopkins University. He was President of Dana-Farber from 2000-2016. Dr. Benz is an internationally recognized hematologist who is an active National Institutes of Health-funded Investigator. He is an expert in inherited anemias. His laboratory studies focus on the molecular regulation and functions of membrane cytoskeletal proteins that were originally discovered in the red blood cell. He has authored more than 300 peer reviewed articles, reviews, chapters, and abstracts. He is Co-editor of “Hematology: Principles and Practice,” which received the First Place Award for Textbooks from the British Medical Journal and of the “Oxford Textbook of Medicine,” for which he and his colleagues received the Royal Society of Authors Textbook Award. He was an Associate Editor of the *New England Journal of Medicine* from 2002-2016.

Dr. Benz has been appointed as a Fellow in the American Association for the Advancement of Sciences, and has been elected to membership in the National Academy of Medicine (formerly the Institute of Medicine) of the National Academy of Sciences, the American Academy of Arts and Sciences, the American Society of Clinical Investigation, and the Association of American Physicians. He is a past President of the American Society of Hematology, the American Society of Clinical Investigation, the Association of American Cancer Institutes, the American Clinical and Climatological Association, and the Friends of the National Institute of Nursing. In recognition of his efforts to achieve the ideal working environment, Dana Farber created the Edward J. Benz Jr. People and Culture Award and its Office of Faculty development renamed its award for advancement of women faculty the Edward J. Benz Jr. Award. In 2016 he was received the Innovator in Health Care Award from the Network for Excellence in health Innovations.
Dr. Benz received his training at Brigham and Women’s Hospital, the National Institutes of Health, Boston Children’s Hospital, Yale, Princeton, and Harvard Medical School, where he received the Soma Weiss and Leon Resnick Awards for student research. He is board certified in internal medicine and hematology.

Wen-Ying Sylvia Chou, PhD, MPH, MS
National Cancer Institute

Wen-Ying Sylvia Chou is a Program Director in the Health Communication and Informatics Research Branch of the Behavioral Research Program at the National Cancer Institute. Her research interests include social media and health, health related misinformation online, health literacy, patient-provider communication at the end of life, and mixed methods research. Trained as a sociolinguist, she has expertise in qualitative analyses of health care interactions. She has led a number of NIH initiatives on the role of technology and social media in various areas of health, including funding initiatives on the impact of the changing communication landscape on substance use and addiction as well as cancer prevention and control. Dr. Chou has more than 75 scientific publications, many of which have documented health-related internet use, the impact of social media use, and the utility of qualitative and mixed methods approaches to clinical communication.

Dr. Chou began her career at the NCI as a Cancer Prevention (postdoctoral), having obtained her MS and PhD in Linguistics from Georgetown University. She holds a bachelor’s degree in Music (piano performance) from Santa Clara University and a master’s degree in Public Health from the Interdisciplinary MPH program at University of California, Berkeley.

Deborah Collyar, BS
Patient Advocates in Research

Deborah Collyar is the founder and president of Patient Advocates in Research (PAIR). PAIR is an international communication network of patient advocates who work with research communities, advocacy organizations, and patients. The network includes multiple diseases including cancers, rare diseases, and infectious diseases. In her current role, Ms. Collyar educates people about research and shares real patient experiences throughout the research process while helping to translate discoveries into clinical use. Deborah also founded the Clinical Trial Information Project (CTIP), which helped cancer patients understand research studies and access open clinical trials. CTIP prompted the National Cancer Institute to redesign its information system.

Ms. Collyar has authored an eBook called DCIS Dilemmas: Discussions About Ductal Carcinoma in Situ and Research Behind It and a blog called One Health of a Life, in addition to articles on patient advocacy and communication. She is also an editorial board member for the DIA Global Forum online monthly magazine, and reviews for several journals.

Ms. Collyar volunteers with the Alliance for Clinical Trials in Oncology as the vice chair of the Publications Committee, and as a member of the Ethics, Health Outcomes, Experimental Therapeutics, and Patient Advocacy Committees. She was the first patient advocate in the NCI Clinical Trials Network (NCTN) and is
a leader in public trial results summaries. She is also faculty in the AACR/ASCO Vail Methods in Clinical Research Workshop and the SITC Immunotherapy Winter School.

Gwen Darien, BA
National Patient Advocate Foundation

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

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

While serving as the chair or on the board of a wide range of program committees and workshop faculties, including the Community Engagement in Genomics Working Group of the National Human Genome Research Institute and as a member of PCORI’s Patient Engagement Advisory Panel, Gwen also writes about her experiences as an advocate and cancer survivor. Her recent piece, Transformation: My Experience as a Patient and an Advocate in Three Chapters, appeared in the National Academy of Medicine Perspectives. Gwen is a graduate of Sarah Lawrence College, where she also served as an advisor for their Health Advocacy program.
Heidi Donovan, PhD, RN
University of Pittsburgh School of Nursing

Heidi Donovan is a Professor in the Department of Health & Community Systems at the University of Pittsburgh School of Nursing. She is the Director of the Magee Family CARE Center at the University of Pittsburgh Medical Center, which provides support and leads research for patients and caregivers impacted by gynecological cancers. Her NIH funded research has focused on symptom management and the development and testing of theoretically-guided psycho-educational interventions to improve outcomes for patients with cancer and their family caregivers. She serves on the Patient Centered Outcomes Research and Cancer Prevention and Control Committees of the Gynecologic Oncology Group and is on the Medical Advisory Board of the National Ovarian Cancer Coalition.

Nicole F. Dowling, PhD
Centers for Disease Control and Prevention

Nicole Dowling is the Associate Director for Science with the Division of Cancer Prevention and Control, in the National Center for Chronic Disease Prevention and Health Promotion, 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 joined the CDC in 2000 and served from 2015 to early 2018 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 population research 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. She has authored and co-authored more than 65 peer-reviewed journal articles. Nicole completed her undergraduate education at Harvard University and received her PhD in Epidemiology from Emory University.
Lisa Fitzpatrick, MD, MPH, MPA
Grapevine Health and George Washington University

Lisa Fitzpatrick is Founder of Promoting Practical Health, Inc., where Grapevine Health started. Lisa is also a Lecturer at the Milken Institute School of Public Health at George Washington University. Lisa is an infectious diseases physician and CDC-trained medical epidemiologist. Her career has spanned research, clinical medicine, global health, community health education and patient advocacy. She recently served as the medical director for Washington, DC’s Medicaid program. Dr. Fitzpatrick began her career as a medical epidemiologist at the Centers for Disease Control and Prevention (CDC) where she held several leadership positions. She has served as a U.S. Diplomat and an epidemiologist for the CDC, and also served as a member of the CDC’s elite Epidemic Intelligence Service. Dr. Fitzpatrick is also a professorial lecturer for the George Washington University Milken Institute School of Public Health, an Aspen Institute Health Innovator fellow and member of the Aspen Institute Global Leadership Network. She has a Master’s in Public Health from the University of California-Berkeley School of Public Health and Masters in Public Administration from the Harvard Kennedy School of Government.

Darci Graves, MPP, MA
Centers for Medicare & Medicaid Services

Darci Graves serves as Special Assistant to the Director of the Office of Minority Health at the Centers for Medicare & Medicaid Services. In this role, she assists in the coordination and implementation of priority office-wide programs, policies, and products. In addition, she provides subject matter expertise in areas such as culturally and linguistically appropriate services, cancer, health disparities, and health equity.

Ms. Graves holds graduate degrees in Communications, Religion and Sociology, and Public Policy and has nearly 20 years of professional and academic experience in the fields of cultural and linguistic competence and health education. Darci began her career as a faculty member at the University of Missouri-Kansas City School of Medicine, where she aided in the development, implementation, and management of diversity, spirituality, communications, and geriatrics curricula. Since then, she has continued to write and work in the area of cultural and linguistic competency as it relates to topics including public safety, disaster preparedness and response, language access, and domestic violence.

As a photographer, writer, and lifelong student, Darci is committed to sharing her journey and insights. Her life philosophy is that thought-provoking and inquisitive individuals can enhance the quality of people’s lives through a commitment to respectful understanding, a lifetime of learning, and a profound sense of community. This philosophy has served as the underpinning to her personal, academic, and professional careers.
Christine Gunn, PhD
Boston University School of Medicine

Christine Gunn is an Assistant Professor of Medicine at the Boston University School of Medicine. She is a health services researcher focused on risk communication, decision-making, and the utilization of evidence-based care. She has conducted an array of research on how patients and providers negotiate the experience of being at risk for cancer and its impact on the utilization of health services. She is particularly interested in studying how health literacy impacts health decision-making and behaviors. Dr. Gunn has received funding from AcademyHealth through the New Investigator Small Grant Program to examine women’s perceptions of the Massachusetts breast density notification legislation and its influence on their intentions for future screening. She is the recipient of a K07 career development award from the National Cancer Institute. This award uses community-engaged methods to develop and test a breast cancer screening decision aid in partnership with women with low health literacy. Dr. Gunn has extensive experience in qualitative research methods, surveys, and mixed methods approaches to studying risk and prevention behaviors.

James Hamblin, MD
The Atlantic

James Hamblin is a writer and senior editor at The Atlantic. He hosts the video series *If Our Bodies Could Talk*, for which he was a finalist in the Webby awards for Best Web Personality. He is a past Yale University Poynter Fellow in journalism, and he has lectured at Harvard Medical School, Wharton Business School, Columbia Mailman School of Public Health, and SXSW, among others. His writing and videos have been featured in The New York Times, Politico, NPR, The Guardian, Elle, Mother Jones, The Washington Post, The Awl, The Los Angeles Times, and Marketplace, among others. Time magazine named him among the 140 people to follow on Twitter, Greatist named him among the most influential people in health media, and BuzzFeed called him "the most delightful MD ever."

After medical school at Indiana University, he did three years of residency before joining The Atlantic to develop a health section and write.

Lori Hoffman Högg, MS, RN, CNS, AOCN®
Department of Veterans Affairs

Lori Hoffman Högg, MS, RN CNS, AOCN®, is the VHA National Program Manager for Prevention Policy in the National Center for Health Promotion and Disease Prevention, which is field-based, in Durham, North Carolina. She is also the National Oncology Clinical Advisor for the Office of Nursing Services, Department of Veterans Affairs in Washington, D.C. She develops recommendations for evidence based standards for prevention and practice, along with developing policy and guidance documents and educational priorities for staff and Veterans. She held membership on the NCI’s National Quality Cancer Care Committee and is serving a second 3 year appointment as a member of the National Cancer Policy Forum. She graduated from the Robert Packer Hospital School of...
Nursing in Sayre, Pennsylvania and completed her graduate work at the State University of New York’s Health Science Center in Syracuse, New York. She previously served as Cancer Program Director at the Albany, N.Y. Stratton VA Medical Center; Administrator of the Breast Center, through a joint appointment in the Divisions of General Surgery and Radiology, at the Cleveland Clinic Foundation in Ohio; and other advanced practice and staff roles in both academic medical centers and private practice. She’s published a number of book chapters, peer reviewed articles, has been honored as a Kizer Grant Money recipient for her commitment to lead innovation and performance excellence and received the Distinguished Federal Government Service Award for demonstrating high standards in government and community service. Her research interests include development of nursing-sensitive quality measures for breast cancer using the National Oncology Nursing Society’s “Putting Evidence into Practice” resources. This work received international recognition for best research awarded at the International Society of Nurses in Cancer Care (ISNCC). Additional interests include initiatives for lung cancer screening, cancer survivorship and life sustaining treatment/goals of care conversation projects. Nationally recognized for her clinical and leadership expertise, she’s presented at national conferences on timely access to care and quality initiatives within the continuum of cancer care. She’s served as an Editorial Review Board Member for the Clinical Journal of Oncology Nursing and held Clinical Associate Faculty positions in the Graduate Program in Nursing of the Sage Colleges; Clinical Instructor of Nursing, Frances Payne Bolton School of Nursing, Case Western Reserve University; and Clinical Faculty, Breen School of Nursing, Ursuline College. She is past president of the Capital District Chapter of the Oncology Nursing Society.

Lori represented the Commonwealth of Pennsylvania as the State Representative for the American Cancer Society’s Nurse of Hope Program where she represented over 100,000 volunteers. Responsibilities included Public and Professional Education, Prevention and Detection, Research Updates, Crusade efforts, and Public Relations: Radio and Television appearances, along with Local, State and National Conferences. She also served on the New York State Department of Health’s Comprehensive Cancer Control Plan Task Force. Lori continues to advocate for cancer patients and their families in her community through ACS volunteer work on medical advisory and health resource councils.

Linda House, RN, BSN, MSM
Cancer Support Community

Linda House is the President of the Cancer Support Community (CSC). She has a long-standing history with the Cancer Support Community. First she served as a local, affiliate volunteer and now, as President of the headquarters office. In her current role, Linda oversees several areas of CSC including the Research and Training Institute, the Cancer Policy Institute, strategic growth and development and marketing and communications while maintaining high engagement with CSC’s affiliates and service delivery functions. Linda joined CSC after many years working in the cancer care environment, including over a decade of direct patient care in the acute oncology and hospice care setting.

Immediately prior to joining CSC, Linda served as Executive Director of St. Vincent Cancer Care in Indianapolis where she led a team of individuals to provide care across the full cancer continuum. Prior to that, Linda was Senior Director of Advocacy and Professional Relations for Lilly Oncology working with patient and professional organizations on programs and broad issues related to cancer care.

Linda serves in a variety of advisory roles in the national cancer community and is also an active volunteer with a number of organizations in her local community.
Ashley Housten, OTD, MSCI
Washington University School of Medicine in St. Louis

Ashley Housten is an assistant professor in the Division of Public Health Sciences at Washington University School of Medicine in St. Louis. Her research program has focused on investigating the role of health literacy in decision-making among diverse and underserved populations. Specifically, she is interested in identifying challenges and opportunities for strengthening patient-provider communication related to decision-making, with an emphasis on understanding how individuals access and apply health information. Dr. Housten has funding from the National Institute on Minority Health and Health Disparities (NIMHD) to conduct an investigation of women’s perceptions of the benefits and harms of breast cancer screening mammography. Participants are racially/ethnically diverse (i.e., Latina [English- and Spanish-speaking], Black, non-Latina White) women ages 40-49 years with varying levels of health literacy. The goal of this project is to develop and pilot decision support tools specifically designed to enhance the way we communicate with women about breast cancer screening when recommendations are divergent. Dr. Housten has presented her research at the Society for Medical Decision Making, Preventing Overdiagnosis, the International Conference on Communication in Healthcare, and the Health Literacy Annual Research Conference. She is a member of the International Patient Decision Aid Standards Collaboration Health Literacy 2.0 Review Working Group.

Elmer Huerta, MD, MPH
Medstar Washington Hospital Center

Elmer Huerta is currently Director of the Cancer Preventorium, Washington Cancer Institute, MedStar Washington Hospital Center in Washington, DC. Noticing that his patients with advanced cancer knew more about soap operas and soccer than cancer prevention, he has dedicated more than 30 years to promote disease prevention and early detection to the public using the media. His radio and television programs reach Spanish-Speaking people in the United States and Latin America. At his Cancer Preventorium, founded in 1994, he has seen over 37,000 people, mostly poor and uninsured Latinos for prevention and early detection consultations.

Through his educational work, Dr. Huerta—author of the best sellers “Health Information Made Easy,” “Confronting Cancer” and “100 Questions About your Health”—has developed a high degree of respect and trust in the Hispanic community at the local, national, and international level. He is senior medical contributor for CNN en Espanol.

Dr. Huerta was appointed by President Clinton as member of the National Cancer Advisory Board in 1998 and was elected in 2007 as the first-ever Latino National President of the American Cancer Society.

Dr. Huerta received the 2004 Innovations in Prevention Award by the Secretary of the Department of Health and Human Services and the 2013 White House Public Health and Prevention Champion of Change Award.

Dr. Huerta was selected as one of the 100 Most Influential Hispanics in the United States in 2008.
Galen Joseph, PhD
University of California, San Francisco

Galen Joseph is an Associate Professor in the Department of Anthropology, History and Social Medicine at the University of California, San Francisco. She is also a member of the Helen Diller Family Comprehensive Cancer Center. Her research examines the evolving social and ethical implications of genomic medicine and the socio-cultural and institutional dimensions of inequities in cancer care. As an anthropologist, Dr. Joseph specializes in ethnographic approaches, but she uses a range of mixed qualitative and quantitative methods and community-based participatory research to investigate issues affecting vulnerable and medically underserved populations across the cancer continuum and in the translation of new genomic technologies to clinical settings and clinical research. Dr. Joseph is particularly interested in identifying and addressing the challenges of effectively communicating with low-health literacy and limited-English-proficiency (LEP) populations in both clinical and community settings. She is the author of numerous publications, and has been funded by the NIH, Susan G. Komen for the Cure, Avon Foundation and other funders. Prior to joining UCSF, she received her PhD in Cultural Anthropology from the University of California, Santa Cruz, and completed a post-doctoral fellowship in Migration, Globalization and Citizenship at Yale University’s Center for International & Area Studies.

Marjorie Kagawa-Singer, PhD, MA, MN, RN
University of California, Los Angeles Fielding School of Public Health

Marjorie Kagawa-Singer is a Research Professor/Professor Emerita in the Department of Community Health Sciences and Department of Asian American Studies at the University of California, Los Angeles Fielding School of Public. For the past 45 years, her career, as a clinician and researcher, has been focused on reducing, and ultimately eliminating cancer health disparities in communities of color. Marjorie’s approach is to more effectively identify fundamental cultural processes of both the dominant society and those of groups who bear the undue burden of cancer health disparities along the entire continuum of cancer care, from prevention to end of life. Marjorie’s theoretical approach is to demonstrate how culture impacts health outcomes by emphasizing the multi-level, multi-dimensional elements that constitute cultural worldviews and how the interactions of individuals, social, and health system structures promote or constrain the health outcomes for diverse communities.
cultural groups. Methodologically, she uses a mixed paradigm and mixed method approach of inductive qualitative and deductive quantitative strategies, utilizing Community Based Participatory principles. She has worked mainly with the highly heterogeneous Asian American and Native Hawaiian and Pacific Islander population groups. However, her work has also encompassed the major groups of color including African Americans, and Hispanic/Latino/as and Native Americans.

**Beth Karlan, MD**  
*University of California, Los Angeles*

Beth Karlan is Professor and Vice Chair of Women's Health Research in the Department of Obstetrics and Gynecology at the David Geffen School of Medicine, University of California, Los Angeles. She is also Director of Cancer Population Genetics at the Jonsson Comprehensive Cancer Center at UCLA. Dr. Karlan's research focuses on ovarian and other women's cancers, as well as inherited cancer susceptibility. She has authored over 350 research publications and is an American Cancer Society Clinical Research Professor. She is Editor-in-Chief of the scientific journals *Gynecologic Oncology* and *Gynecologic Oncology Reports*. In 2012, Dr. Karlan was appointed by the White House to serve on the National Cancer Advisory Board and in 2015 she was elected to membership in the National Academy of Medicine. Dr. Karlan is a Fellow of the American Society of Clinical Oncology.

**Lisa Kennedy Sheldon, PhD, APRN, AOCNP®, FAAN**  
*Oncology Nursing Society*

Lisa Kennedy Sheldon is the Chief Clinical Officer at the Oncology Nursing Society (ONS). She drives the vision and clinical strategy of the organization to support oncology nurses, advanced practice nurses and researchers, and transform cancer care. Dr. Sheldon has practiced as a nurse for more than 40 years. She continues to practice as an oncology nurse practitioner (AOCNP®) at St. Joseph Hospital in Nashua, NH, and served as the writer for their successful Magnet application. At the national level, Dr. Sheldon serves on the National Cancer Policy Forum. Dr. Sheldon holds a PhD in Nursing from the University of Utah and completed a postdoctoral fellowship at Dana-Farber Cancer Institute. Dr. Sheldon's program of research has focused on interprofessional studies on communication and psychosocial issues in cancer care. As experienced faculty and former tenured Associate Professor at the University of Massachusetts-Boston, she taught nursing for over 20 years at the undergraduate, masters and doctoral levels as well as RN-BS programs. Dr. Sheldon has received numerous honors and awards including induction as a fellow in the American Academy of Nursing. She has served in numerous leadership positions including Co-Chair of the Global Nursing Caucus, President of the Theta Alpha chapter of Sigma Theta Tau International. The author of numerous articles on nursing, cancer care and health issues, Dr. Sheldon has served as the Editor of the *Clinical Journal of Oncology Nursing* and authored three books including *Communication for Nurses: Talking with Patients*, now in its third edition.
Allison Lazard, PhD  
University of North Carolina at Chapel Hill

Allison Lazard is an Assistant Professor in the School of Media and Journalism and an Associate Member of the Lineberger Comprehensive Cancer Center at the University of North Carolina at Chapel Hill. Her research revolves around a core interest in how visual and interactive design influences the perception and impact of health messages. Dr. Lazard often collaborates with public health and medical experts in multidisciplinary efforts to develop and evaluate design strategies for complex communication topics, including: tobacco control, cancer prevention, and cancer survivorship support.

Cathy Meade, PhD, RN, FAAN  
Moffitt Cancer Center

Cathy Meade is a Senior Member in the Division of Population Science, Health Outcomes and Behavior at the Moffitt Cancer Center. She describes herself as a “community-minded researcher.” She is a national leader in the field of health disparities, health literacy, and cancer communications, and interested in the role that culture and literacy play in the development and design of behavioral interventions. She was one of the first nurse investigators to conduct studies in the area of patient understanding and health literacy whereby mismatches were identified between patients’ reading levels and the reading levels of health information. She was a member of the Institute of Medicine’s Health Literacy Committee, which produced the 2004 report titled Health Literacy: A Prescription to End Confusion. Her current research spans cancer prevention to survivorship, and aims to bring information, services and scientific advancements ‘right back to the community’ in ways that are understandable and meaningful. This entails the use of community-based participatory methods that build sustained and trustworthy community partnerships for improved health. A key outcome of her work has been development of the Tampa Bay Community Cancer Network, a community-academic network established in 2005, which serves as a springboard to address community concerns about cancer prevention. For example, initiatives to improve colorectal cancer screening in community clinics, promote early diagnosis and timely use of cancer services using patient navigators, and increase Hispanic farmworker knowledge and Pap test using health ambassadors to name a few.

Shalewa Noel-Thomas, PhD, MPH  
Washington, DC Department of Health

Shalewa Noel-Thomas serves as the Bureau Chief for the Cancer and Chronic Disease Prevention Bureau at Washington, DC Department of Health. In this capacity she oversees the Chronic Disease Division, Cancer Programs Division, the Cancer Registry and the Tobacco Control Program. She has a background in public health leadership, health disparities, community-based participatory research, public health program development, and workforce development and training. Prior to joining DC Health, Dr. Noel-Thomas served as the Director of the Office of Minority Health and Health Disparities at the Maryland Department of Health where she directed multiple programs designed to address health disparities. She also served as Clinical Assistant
Professor in the Department of Behavioral Science and Community Health at the University of Florida where she directed a HRSA-funded Public Health Training Center and developed and taught graduate courses. Dr. Noel-Thomas’ work in health disparities began when she worked at the Moffitt Cancer Center as the Center Coordinator and Outreach Co-Director for the Tampa Bay Community Cancer Network, an NCI-funded program focused on eliminating cancer health disparities. Dr. Noel-Thomas received her undergraduate degree from Florida A&M University, and her master’s and doctorate degrees in Public Health from the University of South Florida.

**Nina O’Connor, MD, FAAHPM**
University of Pennsylvania

Nina is the Chief of Palliative Care for the University of Pennsylvania Health System and the Chief Medical Officer for Penn Medicine Hospice. She attended Yale University and completed medical school, residency, and a faculty development fellowship at the University of Virginia. She later completed a fellowship in Hospice and Palliative Medicine at the University of Pennsylvania. She joined the faculty at Penn in 2013 and quickly assumed leadership for the palliative care program at the Hospital of the University of Pennsylvania. She founded the palliative care program at Penn Presbyterian Medical Center and served as program director for the Hospice and Palliative Medicine Fellowship for several years. Her interests include integration of palliative care into cancer care, barriers to hospice, and serious illness communication training. She is currently partnering Harvard’s Ariadne Labs to implement the Serious Illness Care Program in all sites of Penn Medicine’s Abramson Cancer Center. Dr. O’Connor is a Fellow of the American Academy of Hospice and Palliative Medicine.

**April Oh, PhD, MD, MPH**
National Cancer Institute

April Oh is a Program Director in the Health Communication and Informatics Research Branch at the National Cancer Institute. She has a portfolio of research grants in multilevel health communication interventions in cancer prevention and control including physical activity, eating behaviors, HPV vaccination communication, neighborhood and policy effects and community health promotion, mobile health, technology applications to promote behavior change, advance equity and improve public health. Dr. Oh also has scientific and programmatic interests in dissemination and implementation science research and serves as Program Director for NCI’s Speeding Research Tested Interventions into Practice training program and works as a programmatic liaison to the Implementation Science Team at NCI. She previously served as Senior Policy Advisor to the U.S. Surgeon General. Dr. Oh holds a doctoral degree in public health (community health sciences) from the University of Illinois at Chicago, a master’s degree in public health from the University of Michigan, and bachelor’s degree in public health from the University of North Carolina at Chapel Hill.
Ivan Oransky, MD
Medscape and New York University

Ivan Oransky is vice president of editorial at Medscape, Distinguished Writer in Residence at NYU’s Carter Journalism Institute, and co-founder of RetractionWatch. Ivan is also president of the Association of Health Care Journalists and a Clinical Assistant Professor of Medicine at the New York University School of Medicine. Formerly, he was global editorial director of MedPage Today, executive editor at Reuters Health, the managing editor for online at Scientific American, and deputy editor of The Scientist.

He received his bachelor’s degree from Harvard University, where he was executive editor of The Harvard Crimson, his medical degree from New York University, and completed an internship at Yale before leaving medicine to be a full-time journalist. A 2012 TEDMED speaker, he is the recipient of the 2015 John P. McGovern Medal for excellence in biomedical communication from the American Medical Writers Association, and in 2017 was awarded an honorary doctorate in civil laws from The University of the South (Sewanee). Ivan, who holds an appointment at the NYU School of Medicine as a clinical assistant professor of medicine, has also taught at the City University of New York Graduate School of Journalism and has written for publications from Nature to the New York Times.

Randall A. Oyer, MD
Penn Medicine Lancaster General

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

Dr. Oyer is a member of the Cancer Service Line Executive Committee and the Cancer Service Line Quality Committee at the Abramson Cancer Center- University of Pennsylvania, Philadelphia.

Dr. Oyer is also a member of the Board of Directors, and Treasurer of the Association of Community Cancer Centers, Rockville, Maryland. Dr. Oyer is an ex-officio Commissioner of the American College of Surgeons Commission on Cancer, representing the Association of Community Cancer Centers.
Michael Paasche-Orlow, MD, MA, MPH
Boston University School of Medicine

Michael Paasche-Orlow is a Professor of Medicine at the Boston University School of Medicine. Dr. Paasche-Orlow is a general internist and an internationally recognized expert in the field of health literacy. Dr. Paasche-Orlow’s work has brought attention to the role health literacy plays in racial and ethnic disparities, self-care for patients with chronic diseases, care transitions, end-of-life decision making, and the ethics of research with human subjects. Dr. Paasche-Orlow is the Director of the Boston University School of Medicine General Internal Medicine Academic Post-Doctoral Fellowship Program and is the Associate Section Chief for Research for the Section of General Internal Medicine. Dr. Paasche-Orlow is the director of HARC, the Health Literacy Annual Research Conference and is the founding editor of the journal Health Literacy Research and Practice. Dr. Paasche-Orlow is a member of the Roundtable on Health Literacy of the National Academies of Sciences, Engineering, and Medicine.

Kim Parson, BA
Humana

Kim Parson is a consultant at Humana, a Member Engagement Marketing organization. She helps teams develop and test new clinical communication strategies to improve people’s engagement in their health, leading to improved health outcomes and lower costs for members, employers, and Humana.

Kim leads enterprise health literacy efforts at Humana, serves on the steering committee for Health Literacy Kentucky, and was a member of the National Academy of Medicine Roundtable on Health Literacy from 2013-2017.

Frank J. Penedo, PhD
University of Miami

Frank J. Penedo an internationally recognized expert in cancer survivorship and psychosocial oncology, is the Associate Director for Cancer Survivorship and Translational Behavioral Sciences at the University of Miami, Miller School of Medicine and Sylvester Comprehensive Cancer Center. Dr. Penedo is the Sylvester Professor of Psychology and Medicine and co-leads the Cancer Control Research Program. He received his PhD in clinical health psychology at the University of Miami and completed his clinical residency at the University of Pittsburgh Western Psychiatric Institute, and an NIH post-doctoral fellowship in psychosocial oncology and behavioral medicine at University of Miami Department of Psychology and Sylvester. From 2000 until 2012, he held a faculty position in the Department of Psychology at the University of Miami. In 2012, he joined the Feinberg School of Medicine at Northwestern University in Chicago and was awarded the inaugural Roswell Park endowed chair in the Department of Medical Social Sciences. At Northwestern, he served as leader of the cancer control and survivorship research program and director of survivorship at the Robert H. Lurie Comprehensive Cancer Center. At the Lurie Cancer Center, he created and served as
the first director of the Cancer Survivorship Institute, a behavioral translational research and clinical care institute. He rejoined Sylvester and Department of Psychology at the University of Miami in 2018. His work evaluates the role of sociocultural, bio behavioral, and psychosocial mechanisms underlying disease activity and health outcomes, and the efficacy of evidence-based psychosocial interventions in promoting optimal chronic disease management and health outcomes in cancer. His work also involves translational research evaluating the impact of symptom and toxicities, monitoring and management in ambulatory oncology, patient reported outcomes in survivorship care, precision oncology and phase 1 trials, as well as the implementation of evidence-based behavioral interventions delivered within health systems and the community to improve patient and system level outcomes. Dr. Penedo has served as President of the International Society of Behavioral Medicine, and his research and mentoring has been recognized by numerous awards from prestigious societies in his field. He is a fellow of the Society of Behavioral Medicine and the Academy of Behavioral Medicine Research, has served in numerous NIH study sections and as associate editor for multiple journals in his field. He is the author of more than 200 articles in cancer survivorship and chronic disease management and has been continuously funded by the NIH for the past 15 years.

Mary Politi, PhD
Washington University School of Medicine in St. Louis

Mary Politi is a health psychologist and an Associate Professor in the Division of Public Health Sciences, Department of Surgery, at Washington University School of Medicine in St. Louis. Her work aims to help patients and the public understand health information, explore what is important to them when making health decisions, and collaborate to make evidence-informed decisions that meet their needs. She also works with health care professionals, public health advocates, and members of the public interested in training in shared decision-making and patient engagement in health care. Her research includes a focus on eliminating health disparities by engaging communities with unmet health needs and including them in both research and dissemination efforts.

Mandi Pratt-Chapman, MA
George Washington University Cancer Institute

Mandi Pratt-Chapman is Associate Center Director, Patient-Centered Initiatives and Health Equity for the George Washington University Cancer Institute. Her research focuses on patient navigation, cancer survivorship and health equity for lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) communities. She led the development of national, consensus-based core competencies for Oncology Patient Navigators and a corresponding online training to provide navigators access to free training to build core competencies. She chaired the Oncology Patient Navigator – Certified Generalist process. She served as co-PI for the National Cancer Survivorship Resource Center (2010-2015) and has co-authored four holistic clinical practice guidelines on breast, prostate, colorectal and head and neck cancer survivorship care with American Cancer Society expert panels. She was PI or Co-PI for four Patient Centered Outcomes Research Institute-funded projects to inform health services standards for cancer survivorship; catalyze dissemination
and implementation of evidence-based cancer survivorship and patient navigation practices; and build community-driven research in lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities in Washington, DC. She also served as PI for a pioneering health equity initiative, the TEAM training, which has trained 36 organizations from across the U.S. on systems change approaches to improve health equity. Her personal mission is to make evidence-based cancer control strategies available to more people as quickly as possible.

Gwendolyn P. Quinn, PhD
New York University Langone Health

Gwendolyn P. Quinn is the Livia Wan M.D. Endowed Chair and Vice-Chair of Research in Obstetrics and Gynecology and Professor in the department of Population Health and the Center for Medical Ethics at NYU Langone Health School of Medicine. She is the chair of the promotion and tenure committee and a member of the faculty senate. Dr. Quinn received her PhD in educational psychology from Florida State University and did a post-graduate fellowship in public health and has post-graduate certification in Program Evaluation and Biomedical Ethics. Her research focuses on improving patient/family/physician communication through understanding the barriers and benefits of health care use from multi-stakeholder perspectives. Her current research and training efforts are in the areas of: Reproductive Health, Sexuality, and Fertility Preservation, Quality of Life issues in Pediatric, Adolescent & Young Adult and LGBTQ+ Cancer Populations, and Cancer Clinical Trials (including minority barriers to participation); and training researchers to conduct research with high risk populations.

Ivis Sampayo, BA
SHARE Cancer Support

Ivis Sampayo is a two time breast cancer survivor and the Senior Director of Programs at SHARE Cancer Support. She joined the organization in May 1996, as the first LatinaSHARE Director where she used her knowledge of the NYC Latino community to develop programs that would enrich the Spanish community. Ivis’ strong background in grassroots leadership helped her to develop our LatinaSHARE program into one of the first Latino programs to provide various breast and ovarian cancer services in Spanish. Through her management and advocacy skills, the LatinaSHARE program has seen growth of services and specific programs for the Latino communities, including the Novela project which provides awareness and education about breast cancer, as well as the breaking of myths about this disease within this community. This Novela was presented as a poster abstract at the 2011 San Antonio Breast Cancer Symposium, which was a first for SHARE. In her current position at SHARE, as the Senior Director of Programs, she initiates and develops various programs in both English and Spanish. Through her leadership, supervision, and mentoring, the program department has developed various Webinars, Radio Blogs, support services, community outreach, helpline support and advocacy opportunities. Under her leadership, SHARE has increased its services and outreach to various communities, including the African American communities, the Latino communities and the Japanese communities. SHARE now has been able to provide peer support outside of NYC through Ivis’ commitment, leadership and perseverance. Ivis is a board member of NBCC and is involved in various local and national committees. She has won local and national recognition as well as various awards through her work at SHARE.
Urmimala Sarkar, MD, MPH
University of California, San Francisco and Zuckerberg San Francisco General Hospital

Urmimala Sarkar is Associate Professor of Medicine at the University of California, San Francisco in the Division of General Internal Medicine, Associate Director of the UCSF Center for Vulnerable Populations, and a primary care physician at Zuckerberg San Francisco General Hospital’s Richard H. Fine People’s Clinic. Dr. Sarkar’s research focuses on innovating for health equity. Her research employs new tools, such as digital/mobile health and social media to address and improve the safety and quality of outpatient care. She has expertise in medical errors and patient safety, diabetes, and cancer prevention and survivorship. This research incorporates collaboration with a range of expertise, including design thinking/usability testing, human factors engineering, data science, health services research, and implementation science.

She has conducted studies which explore the impact of health communication (health literacy, English proficiency) and health information technology on patient safety. Her prior studies on internet-based patient portals demonstrate digital disparities by race/ethnicity and health literacy. Her social media studies use mixed-methods approaches to understand patient perspectives about physician quality and about cancer screening behaviors. Her ongoing work employs varied health information technologies to detect and ameliorate adverse events among outpatient chronic disease populations. She is currently funded by the Agency for Healthcare Research and Quality (AHRQ) and the National Cancer Institute, and the Gordon and Betty Moore Foundation, among others.

Claire Saxton, MBA
Cancer Support Community

Claire Saxton is the Senior Director for Education & Outreach at the Cancer Support Community (CSC). She is responsible for CSC’s national patient education and outreach programs. She launched CSC’s award-winning Frankly Speaking About Cancer Clinical Trials education program and has produced cancer patient & caregiver education in 7 languages and a variety of print, digital, and in-person formats. Claire has 25+ years of experience in nonprofit management, and a wealth of experience in patient education and advocacy. Claire came to CSC from the Urology Care Foundation, where she managed national patient education programs and disease awareness campaigns with partners including the National Football League and coalitions of patient advocacy organizations.

As Executive Director of the Bladder Cancer Advocacy Network, Claire expanded their educational programming and developed the first National Bladder Cancer Awareness Day. While the Executive Director of the Breast Cancer Resource Center in Austin, Texas, she doubled their patient advocacy and outreach programs. Claire began her work in health advocacy while part of the team that opened the National Domestic Violence Hotline in 1996.
Claire holds an MBA from the University of Oregon and an undergraduate degree from Rice University. She is inspired by the everyday courage of patients, survivors and their loved ones she has met throughout her career.

Richard Wender, MD
American Cancer Society

Richard Wender, Chief Cancer Control Officer of the American Cancer Society, helps lead the only comprehensive cancer control organization in the world. He drives the effort to transform the face of cancer in the United States and around the globe, by developing strategies for access to care, patient navigation, and health equity.

Prior to joining the Society’s staff in 2013, he provided extensive volunteer leadership at the organization’s state and local levels. In 2006, he was elected national president of the Society, becoming the first primary care physician to serve in this capacity.

Dr. Wender worked for more than three decades as a family physician in the department of family and community medicine at Thomas Jefferson University in Philadelphia. From 2002 until 2013, he served as alumni professor and chair of the department.

Dr. Wender has led numerous initiatives designed to improve preventive care and chronic disease management. He currently serves as chair of the National Colorectal Cancer Roundtable.

Robert A. Winn, MD
University of Illinois at Chicago

Dr. Robert A. Winn is an accomplished physician-scientist and a proponent of the “bench to community” model of research. He is committed to developing methods to ensure equal access to cutting-edge medical treatments and eliminate health disparities in Illinois and beyond.

As the Associate Vice Chancellor for Community-Based Practice, Dr. Winn oversees management of the UI Health Mile Square Health Center, a 13-site Federally Qualified Health Center network. His vision for Mile Square is to build a 21st Century model of community-based health care providers that reflects the mission of the academic health center and develops meaningful research programs that, if adopted, can enhance the overall well-being of the community.

As Director of the UI Cancer Center, Dr. Winn works tirelessly to bridge the gap between basic science and community-based health care. He is a principal investigator on several community-based NIH- and NCI-funded projects including U54 ChicagoCHEC, U54 Cher Chicago, the P20 GUIDE Project, and the UG3 All of Us Precision Medicine Initiative.

Dr. Winn’s basic science research, which has been supported by multiple NIH and VA Merit awards, focuses on the translational aspects of the role the proliferation pathways and cellular senescence play in lung cancer. He has received national and international acclaim for his efforts to empower underserved
patient populations, improve health care delivery, and ensure equal access to cutting-edge medical treatments.

Dr. Winn received his medical degree from the University of Michigan Medical School in Ann Arbor. He completed his medical residency at Rush Presbyterian St. Luke’s Medical Center in Chicago, and a Pulmonary/Critical Care Medicine fellowship at the University of Colorado School of Medicine. He is a member of the National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine.

Robin Yabroff, PhD, MBA
American Cancer Society

Robin Yabroff is an epidemiologist with more than 20 years of health services research experience. Currently, she is the Senior Scientific Director of Health Services Research at the American Cancer Society. Previously, she was with the Office of Health Policy, Assistant Secretary for Planning and Evaluation (ASPE) in the US Department of Health and Human Services and also worked for more than 10 years in the Health Services and Economics Branch within the National Cancer Institute (NCI). Prior to her position at the NCI, she was a member of the faculty of the Lombardi Cancer Center, Georgetown University. She earned her PhD in epidemiology from the Johns Hopkins School of Public Health and received an MBA from the University of Rochester. Her areas of expertise are related the economic burden of cancer, medical financial hardship, high cost prescription drugs, and patient and provider factors associated with quality of care.

Dr. Yabroff has co-authored over 140 peer-reviewed journal articles and other publications and is an associate editor for the Journal of the National Cancer Institute and on the editorial board of the Journal of Cancer Survivorship. She served as a guest editor for the Medical Care journal supplement, Health Care Costing: Data, Methods, Future Directions, and the Journal of the National Cancer Institute journal supplement, Comparing Cancer Care and Economic Outcomes Across Health Systems: Challenges and Opportunities. Dr. Yabroff received multiple NIH Merit Awards for her research leadership and most recently led a multi-institutional collaborative effort to improve publicly available data for estimating the burden of cancer in the US, the Medical Expenditure Panel Survey (MEPS): Experiences with Cancer Survivorship Supplement.