NATIONAL ACADEMIES Sciences Engineering Medicine

The Potential Contribution of Cancer Genomics Information to Community Investigations of Unusual Patterns of Cancer: A Virtual Workshop

Thursday, April 13, 2023
8:30 am – 3:00 pm ET

Collaborative workshop convened by:
National Cancer Policy Forum
Roundtable on Genomics and Precision Health

Link to view live webcast:

https://www.nationalacademies.org/event/04-13-2023/the-potential-contribution-of-cancer-genomics-information-to-community-investigations-of-unusual-patterns-of-cancer-a-workshop

Roundtable on GENOMICS and PRECISION HEALTH

NATIONAL CANCER POLICY FORUM

NATIONAL ACADEMIES Sciences Engineering Medicine

April 13, 2023

Dear Colleagues,

Welcome to the National Academies of Sciences, Engineering, and Medicine workshop on *The Potential Contribution of Cancer Genomics Information to Community Investigations of Unusual Patterns of Cancer*. This workshop is being convened by the National Cancer Policy Forum, in collaboration with the Roundtable on Genomics and Precision Health. We would like to extend our gratitude to our sponsor, The Division of Environmental Health Science and Practice in the National Center for Environmental Health at the Centers for Disease Control and Prevention.

This workshop is an opportunity for the cancer community to discuss the current state of the science on the identification of genomic and epigenomic biomarkers of environmental exposures associated with cancers, with emphasis on pediatric cancers. Workshop speakers are also encouraged to share their input on information to assist the CDC in revising their Cancer Cluster Guidelines.

We welcome your involvement in the workshop. Please use the chat box on our website (https://www.nationalacademies.org/event/04-13-2023/the-potential-contribution-of-cancer-genomics-information-to-community-investigations-of-unusual-patterns-of-cancer-a-workshop) to ask questions, and please mention your name and affiliation. The proceedings of the workshop will be published by the National Academies Press and may incorporate your comments and ideas. Archived presentations and videos from the workshop will also be available on the website.

We look forward to this important workshop.

Sincerely,

Roberta Ness
Workshop Planning Committee Chair

NATIONAL CANCER POLICY FORUM

Guidance for Attendees

The Potential Contribution of Cancer Genomics Information to Community Investigations of Unusual Patters of Cancer: A Virtual Workshop

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Joining the Public Chat

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

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THANK YOU!!

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

Collaborative workshop convened by:
National Cancer Policy Forum
Roundtable on Genomics and Precision Health

THURSDAY, APRIL 13, 2023

8:30 am **Introductory Session**

Welcome and Opening Remarks
Roberta Ness, *Planning Committee Chair*

Centers for Disease Control and Prevention Workshop Priorities
Stephanie Foster, *Centers for Disease Control and Prevention*

8:50 am **Opening Keynote Address**
Overview of Pediatric Cancers and Environmental Exposures
Catherine Metayer, *University of California, Berkeley*

9:15 am **Session 1: Novel Approaches to Improve Identification of Genomic and Epigenomic Biomarkers and Environmental Exposures**
Moderator: Carmen Marsit, Emory University

DNA Methylation Biomarkers of Environmental Exposures
Christine Ladd-Acosta, *Johns Hopkins Bloomberg School of Public Health*

Genomic Methods to Understand the Genetic Origins of Pediatric Cancers
Jinghui Zhang, *St. Jude Children's Research Hospital*

Using Cancer Mutational Signatures to Explore Etiology of Pediatric Cancer
Ludmil Alexandrov, *University of California, San Diego*

Panel Discussion with Keynote and Speakers

10:15 am **Session 2: Statistical and Epidemiological Approaches to Identify Linkages of Genomic Biomarkers to Cancer Clusters**
Moderators: Wei-Ting Hwang, University of Pennsylvania Perelman School of Medicine
Sharon Plon, Texas Children's Hospital

The Role of Central Cancer Registries in the Investigation of Unusual Patterns of Cancer
Recinda Sherman, *North American Association of Central Cancer Registries*

Epidemiological Approaches for Assessing Reports of Cancer Clusters and Environmental Exposures
Melissa Bondy, *Stanford University*

Genomic Ancestry Inference to Decompose Genetic and Environmental Contributions to Cancer Disparities
King Jordan, *Georgia Institute of Technology*

Panel Discussion

11:15 am **BREAK**

11:30 am **Session 3: Environmental Exposures and Pediatric Cancer**
Moderators: Mark Purdue, National Institutes of Health
Kim Nichols, St. Jude Children's Research Hospital

Current Epidemiologic Evidence on Environmental Exposures and Pediatric Cancer
Michael Scheurer, *Baylor College of Medicine*

Using Molecular Epidemiology to Investigate Environmental Exposures and Pediatric Cancer
Joseph Wiemels, *University of Southern California*

The Exposome and Pediatric Cancer
Lauren Petrick, *Mount Sinai and Sheba Medical Center*

Panel Discussion

12:30 pm **Session 4: Strategies for Communication about Environmental Exposures and Cancer Risk**
Moderator: Alejandro Sweet-Cordero, University of California, San Francisco

Enhancing Communication and Engagement with Communities about Cancer Clusters
Trevor Schaefer, *Trevor's Trek Foundation*

Communicating What We Do Know in Community Cancer Investigations
Julia Brody, *Silent Spring Institute, Brown University*

Promoting Culturally Sensitive Risk Communication with the Community
Monica Ramirez-Andreotta, *University of Arizona*

Panel Discussion

1:30 pm **BREAK**

1:45 pm **Session 5: Lessons Learned and Future Considerations**
Moderator: Roberta Ness, Planning Committee Chair

Panelists:

- **Jack Taylor,** *National Institute of Environmental Health Sciences*
- **Logan Spector,** *University of Minnesota*
- **Trevor Schaefer,** *Trevor's Trek Foundation*
- **Jerald A. Fagliano,** *Drexel University*

2:45 pm **Closing Remarks**
Roberta Ness*, Planning Committee Chair*

3:00 pm **ADJOURN**

NATIONAL CANCER POLICY FORUM

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

Planning Committee Roster

Roberta Ness, MD
Planning Committee Chair

Wei-Ting Hwang
Professor of Biostatistics
Department of Biostatistics, Epidemiology, and Informatics
Center for Clinical Epidemiology and Biostatistics
Perelman School of Medicine
University of Pennsylvania

Carmen J. Marsit, PhD
Executive Associate Dean for Faculty Affairs and Research Strategy
Rollins Distinguished Professor of Research
Rollins School of Public Health
Gangarosa Department of Environmental Health
Emory University

Kim E. Nichols, MD
Director, Division of Cancer Predisposition
Department of Oncology
St. Jude Children's Research Hospital

Sharon E. Plon, MD, PhD, FACMG
Dan L Duncan Professorship
Departments of Pediatrics/Hematology-Oncology
Molecular and Human Genetics
Assistant Dean School of Medicine
Baylor College of Medicine
Chief, Cancer Genetics Clinic
Texas Children's Hospital

Mark P. Purdue, PhD
Senior Investigator
Occupational and Environmental Epidemiology Branch
Division of Cancer Epidemiology and Genetics
National Institutes of Health

E. Alejandro Sweet-Cordero, MD
Chief, Division of Pediatric Oncology
Director, Molecular Oncology Initiative
Benioff Professor of Children's Health
Professor of Pediatrics
University of California, San Francisco

NATIONAL CANCER POLICY FORUM

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

Speaker Roster

Ludmil B. Alexandrov, PhD
Associate Professor, Cellular and Molecular Medicine
Associate Professor, Bioengineering
Moores Cancer Center
University of California, San Diego

Melissa L. Bondy, PhD
Chair and Professor, Epidemiology and Population Health
Stanford Medicine Discovery Professor
Associate Director, Population Sciences
Stanford Cancer Institute
Co-Director, Center for Population Health Sciences
Stanford University

Julia Brody, PhD
Executive Director and Senior Scientist
Silent Spring Institute

Jerry Fagliano, PhD, MPH
Clinical Professor and Chair
Department of Environmental and Occupational Health
Dornsife School of Public Health
Drexel University

King Jordan, PhD
Professor, School of Biological Sciences
Director, Bioinformatics Graduate Program
Georgia Institute of Technology

Christine Ladd-Acosta, PhD
Associate Professor and Director, Genetics
Department of Epidemiology
Associate Director for Epigenomics
ECHO-DAC
Vice Director, Wendy Klag Center for Autism and Developmental Disabilities
Johns Hopkins Bloomberg School of Public Health
Johns Hopkins University

Catherine Metayer, MD, PhD
Faculty, Epidemiologist
School of Public Health
University California, Berkeley

Lauren Petrick, PhD
Associate Professor, Dept. of Environmental Public Health
Head, Untargeted Metabolomics
Senator Frank R. Lautenberg Environmental Health Sciences Laboratory
Icahn School of Medicine
Mount Sinai
Director, Center for Metabolomics and Molecular Phenotyping
The Bert Strassburger Metabolic Center
Sheba Medical Center, Tel-Hashomer, Israel

Mónica Ramírez-Andreotta, MPA, PhD
Associate Professor
Department of Environmental Science
Mel and Enid Zuckerman College of Public Health
Division of Community, Environment & Policy
Global Change - Graduate Interdisciplinary Program
University of Arizona

Michael E. Scheurer, PhD, MPH, FACE
Professor, Baylor College of Medicine
Sidney L. and Donald F. Faust Chair of Pediatric Cancer Epidemiology
Texas Children's Hospital

Trevor Schaefer
Executive Director/Co-Founder
Trevor's Trek Foundation

Recinda Sherman, MPH, PhD, CTR
Program Manager, Data Use & Research
North American Center for Cancer Registries

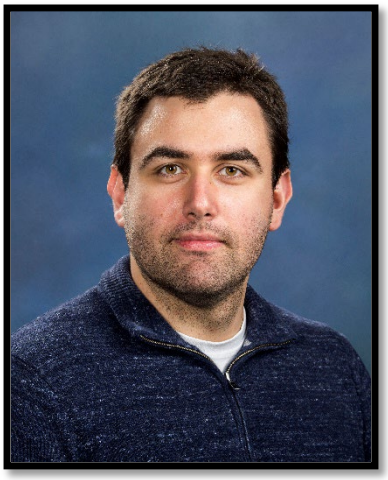
Logan G. Spector, Ph.D.
Professor, Suzanne Holmes Hodder Chair in Pediatric Cancer Research
Director, Division of Epidemiology/Clinical Research
Department of Pediatrics
University of Minnesota

Jack A. Taylor, MD, PhD
NIH Scientist Emeritus
Epidemiology Branch and Epigenetic & Stem Cell Biology Laboratory
National Institute of Environmental and Health Sciences
National Institutes of Health

Joseph Leo Wiemels, PhD
Professor, Center for Genetic Epidemiology
Associate Director, Shared Resources
Norris Comprehensive Cancer Center
University of Southern California

Jinghui Zhang, PhD
Member/Chair
Endowed Chair of Bioinformatics
Department of Computational Biology
St Jude Children's Research Hospital

SPEAKERS AND PLANNING COMMITTEE BIOSKETCHES



Ludmil B. Alexandrov, Ph.D.
University of California, San Diego

Ludmil Alexandrov is an Associate Professor in the Department of Cellular and Molecular Medicine as well as the Department of Bioengineering at University of California San Diego. He earned his Bachelor of Science degree in Computer Science from Neumont University and received his Master's of Philosophy in Computational Biology as well as his Ph.D. in Cancer Genetics from the University of Cambridge. Dr. Alexandrov's research has been focused on understanding the mutational processes in cancer.

In 2013, he developed the first comprehensive map of the mutational signatures in human cancer. More recently, Ludmil mapped the signatures of clock-like mutational processes operative in normal somatic cells, demonstrated that mutational signatures have the potential to be used for targeted cancer therapy, and identified the mutational signatures associated with tobacco smoking.

Dr. Alexandrov has 132 publications in peer-reviewed journals from which 26 publications in *Nature*, *Science*, or *Cell* and another 48 publications in *Nature Genetics*, *Nature Medicine*, *Nature Biotechnology*, *Nature Cancer*, *Cancer Cell*, *Cell Genomics*, *Science Translational Medicine*, *PNAS*, or *Nature Communications*. In 2014, Ludmil Alexandrov was recognized by Forbes magazine as one of the "30 brightest stars under the age of 30". In 2015, he was awarded the Prize for Young Scientists in Genomics and Proteomics by Science magazine and SciLifeLab, and he also received a Harold M. Weintraub Award by the Fred Hutchinson Cancer Center. In 2016, Dr. Alexandrov was awarded the Carcinogenesis Young Investigator Award by Oxford University Press. In 2018, he was awarded the Balfour Prize Lecture of the Genetics Society, an Alfred P. Sloan Research Fellowship in Computational & Evolutionary Molecular Biology, and an Early Career Award by The International Academy for Medical and Biological Engineering. In 2019, Dr. Alexandrov was awarded a Packard Fellowship for Science and Engineering and was named as an Abeloff V Scholar. In 2020, Dr. Alexandrov was awarded an Outstanding New Environmental Scientist (ONES) Award by National Institute of Environmental Health Sciences. Ludmil is currently one of six co-investigators leading the Mutographs of Cancer project, a $25 million Cancer Grand Challenge initiative to identify the unknown cancer-causing factors.

Melissa Bondy, Ph.D.
Stanford University

Dr. Melissa Bondy is chair of the Department of Epidemiology and Population Health, Co-Director of the Center for Population Health Sciences, and the Associate Director for Population Sciences at Stanford. She is an internationally recognized cancer epidemiologist with a multi-disciplinary focus on translational research with a strong interest in health disparities, and environmental exposures. Her research focus is in genetic and molecular epidemiology, and is at the forefront of developing innovative ways to assess the roles of heredity and genetic susceptibility in the etiology of cancer and outcomes, primarily brain and breast cancer. In the last year she had led COVID-19 research. She is President of the American College of Epidemiology, Scientific Director of Susan G. Komen's Share For Cures Study, and recently completed her service on the National Cancer Institute's Board of Scientific Advisors, and is a member of many NCI Cancer Center's External Advisory Boards.

Julia Brody, Ph.D.
Silent Spring Institute

Julia Brody, Ph.D., is the executive director and a senior scientist at Silent Spring Institute, a scientific research organization that studies environmental factors and breast cancer. Her current research focuses on reporting back to people who participate in environmental health studies to inform them about their own chemical exposures. As part of the emerging field of environmental health literacy, she is also studying what Americans know about endocrine disrupting compounds (EDCs). Her interest in returning exposure results grew out of the Cape Cod Breast Cancer and Environment Study, an investigation of higher incidence in the region. The study included the first comprehensive assessment of exposure to EDCs in homes. In 2017, Dr. Brody published a critical review in Environmental Research analyzing 158 epidemiological studies of environmental pollutants and breast cancer published in the preceding 10 years. She earned her Ph.D. at the University of Texas at Austin.

Jerald A. Fagliano, Ph.D.
Drexel University

Dr. Jerald Fagliano is a Clinical Professor and Chair of the Department of Environmental and Occupational Health at the Dornsife School of Public Health at Drexel University. He earned a Master of Public Health degree in environmental health from Yale University, and a Ph.D. in occupational and environmental epidemiology from The Johns Hopkins University. His interests are in drinking water quality, children's environmental health, climate change, and public health practice. At Drexel, he teaches the integrated core

course in public health for master's degree students and a course on the public health impacts of global climate change. Prior to joining Drexel in 2015, Dr. Fagliano was the senior environmental epidemiologist at the New Jersey Department of Health for 30 years, where he led programs conducting disease and injury tracking, public health assessments of hazardous waste sites, investigations of disease clusters, and surveillance of worker health and safety.

Wei-Ting Hwang, Ph.D.
University of Pennsylvania Perelman School of Medicine

Dr. Hwang's research focus on statistical methods for early-phase oncology trials, analysis of survival, longitudinal and spatial data, the discovery and evaluation of cancer biomarkers. She has extensive experience in the applications of clinical and translational cancer research including psychosocial and environmental health research on cancer. One of Dr. Hwang's main research efforts has been devoted to the development of chimeric antigen receptor (CAR) therapy. As the leading statistical investigator in the cellular therapy program at Penn, Dr. Hwang was the trial statistician for many early-phase CAR trials including the ones that led to the first FDA-approved cell-based therapy, Kymriah. She continues to provide her statistical insights for the design and analysis of this drug development process and to develop innovative solutions to challenges that are unique to cellular CAR therapy. Dr. Hwang has also provided a leadership role in several institutional Biostatistics Cores including multiple P01s, SPORE, and P42 Penn Superfund Research (SRP) Center that studies the effects of asbestos. In addition, she is the Associate Director of Biostatistics for Penn's Center of Excellence in Environmental Toxicology (CEET) and has led several population science projects that evaluate the environmental exposomes and lung cancer outcomes in our Abramson Cancer Center (ACC) catchment area. She is a member of ACC's clinical trials scientific review and monitoring committee and ACC Biostatistics Core. She is also a co-PI on a NIH-funded U01 award that focused on the analytical validation of a biomarker of Friedreich's Ataxia.
Dr. Hwang has been recognized for her statistical contribution by many peer-reviewed publications and appointments to several national and international committees. She is an elected fellow of American Statistical Association (ASA).

King Jordan, Ph.D.
Georgia Institute of Technology

Dr. I. King Jordan is Professor in the School of Biological Sciences and Director of the Bioinformatics Graduate Program at the Georgia Institute of Technology. Members of Dr. Jordan's laboratory at Georgia Tech conduct bioinformatics research with an emphasis on human population genomics and genetic ancestry inference in support of health equity. His group also develops bioinformatics software for large-scale genome sequence and functional genomic analyses. In addition to his research and development efforts, Dr. Jordan is actively engaged in bioinformatics and genomics capacity building, with a focus on global health in Africa and Latin America. He was named a Fulbright Scholar to Colombia, and he is the Co-Founder and Director of the PanAmerican Bioinformatics Network.

Christine Ladd-Acosta, Ph.D.
Johns Hopkins Bloomberg School of Public Health

Dr. Ladd-Acosta is Associate Professor and Director of Genetics in the Department of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. In addition, she is Associate Director for Epigenomic Analyses at the Environmental influences on Child Health Outcomes Data Analysis Center (ECHO-DAC) and Vice Director of the Wendy Klag Center for Autism and Developmental Disabilities. Her research focuses on applying epigenomic and genomic epidemiology approaches to improve population health, with a particular concentration on child and neurodevelopmental health outcomes. Her findings have been recognized with a "best original article" award by Environmental Research and with results reported in multiple publications declared as top 20 advances in autism research by the Interagency Autism Coordinating Committee (IACC).

Carmen Joseph Marsit, Ph.D.
Emory University

Carmen J. Marsit, Ph.D.. is Executive Associate Dean for Faculty Affairs and Research Strategy, Rollins Distinguished Professor of Research, Professor in the Gangarosa Department of Environmental Health and Department of Epidemiology at the Rollins School of Public Health of Emory University, and member of the Emory Winship Cancer Institute. He leads a multi-disciplinary research program focused on understanding the impacts of the environment on maternal and child health and human cancer utilizing the tools of genomics, epigenomics, and

bioinformatics to uncover mechanisms underlying the impact of the environment on health within epidemiologic studies. Dr. Marsit was the recipient of a NIMH Biobehavioral Research Award for Innovative New Scientists. His current projects are examining the impacts of maternal structural, psychosocial, and chemical exposures on the transcriptomes and epigenomes of the placenta in populations in the United States and in Thailand. He also has an extensive record of research in the utilization of epigenetic biomarkers to understand the etiology and outcomes of human exposure related cancers. Dr. Marsit serves as Director of the NIEHS-funded Emory HERCULES Exposome Research Center and Training Program in the Environmental Health Sciences and Toxicology and was the founding Director of the Emory-Georgia Clean Air Research and Education Program in the Republic of Georgia. Dr. Marsit received his B.S. in Biochemistry from Lafayette College and his Ph.D. in the Biological Sciences in Public Health from the Graduate School of Arts and Sciences at Harvard University.

Catherine Metayer, M.D., Ph.D.
University of California, Berkeley

Dr. Metayer received her medical degree from the University of Bordeaux II in France, and her Ph.D. in Epidemiology from Tulane University, School of Public Health in New Orleans. She is currently Professor at the UC Berkeley, School of Public Health, Division of Epidemiology. Prior to joining UC Berkeley, Dr. Metayer was a scientist at the US National Cancer Institute, Division of Cancer Epidemiology and Genetics. Her work primarily focuses on environmental, dietary, and genetic risk factors of childhood leukemia and testicular cancer, which disproportionately affect the Latinx communities in California. She is the Director of the Center for Integrative Research on Childhood Leukemia and the Environment (CIRCLE), and the immediate past Chair of the Childhood and Cancer Leukemia International Consortium (CLIC). She collaborates with researchers at the intersection of various omics including genetics, epigenetics, metabolomics, and adductomics.

Roberta B. Ness, M.D., M.P.H.

Roberta B. Ness, M.D., M.P.H., a recognized expert in public health, is former dean of The University of Texas School of Public Health, one of the largest such Schools in the nation. Dr. Ness's international acclaim is demonstrated by membership in the most esteemed professional society in the U.S., the National Academies of Science as well as the American Society for Clinical Investigation, Delta Omega Honorary, and the American Epidemiologic Society. She is former president of the top two professional societies in her field, a fellow of the American College of Physicians, and associate editor or on the editorial board of numerous scientific journals. Other honors include a 1996 Leadership Award from the Family Health Council; 2006 Laureate Award from the American College of Physicians; 2008 Distinguished Professor of Women's Health from the Society for General Internal Medicine; 2011 Presidential appointment to the Mickey Leland Center for Environmental Research; 2013 Petersdorf Lectureship from the American Association of Medical Colleges; and 2014 Athena Swan lectureship at Oxford University. She has received two of the most prestigious lifetime achievement awards in her field: the 2013 Snow Award from the American Public Health Association, and 2017 Lillienfeld Award from the American College of Epidemiology.

Dr. Ness received her M.D. from Cornell University and her M.P.H. from Columbia University. In over 450 peer review publications, she established the leading paradigm in the field of women's health research, termed "gender based biology", and helped to unravel the cause of diseases from preeclampsia to ovarian cancer. Also named one of America's foremost experts in innovative thinking, Dr. Ness is author of four books and a popular on-line course setting out a systematic, novel method for how to maximize personal creativity. She has delivered over 150 keynote lectures to America's top universities, R&D intensive corporations, scientific societies and to foreign governments. Also, she gave two TED talks, was featured on the Bill Nye show, Star Talk Radio and advised the National Institutes for Health, the Centers for Disease Control and Prevention, NASA, and the Department of Defense, among others.

Kim Erika Nichols, M.D.
St. Jude Children's Research Hospital

Dr. Nichols is Full Member in the Department of Oncology at St. Jude Children's Research Hospital, where she also serves as Director of the Division of Cancer Predisposition. Previously, she served as Director of the Cancer Predisposition Program at Children's Hospital of Philadelphia. Dr. Nichols's research interests focus on identifying novel hereditary causes for childhood cancer and how best to use germline genetic information to optimize the care of children and families at increased genetic risk.

Lauren Petrick, Ph.D.
Mount Sinai and Sheba Medical Center

Dr. Lauren Petrick is Associate Professor in the Department of Environmental Medicine and Public Health, and Head of Untargeted Metabolomics at the Senator Frank R. Lautenberg Environmental Health Sciences Laboratory at the Icahn School of Medicine at Mount Sinai. She holds an additional faculty appointment at Sheba Medical Center in Israel. Dr. Petrick is an analytical chemist with advanced training in metabolomics/exposomics and her research interests are in developing exposomics methodologies for environmental health research using high-resolution mass spectrometry (HRMS) and advanced biostatistics/bioinformatics techniques. In addition to performing urine, plasma, and serum analysis, her current work focuses on the development of untargeted methods for matrices such as archived neonatal dried blood spots that allow us to "go back in time" to directly measure early life exposures. Working with prospective samples, her work can establish whether metabolomic/ exposomic signatures exist around the time of birth that predict later life disease, including pediatric cancer. These assays capture both metabolites and exogenous chemicals that represent the human metabolome and internal exposome, thus allowing for "pre-diagnosis" of disease, targeted prevention measures, targeted health monitoring, and early interventions.

Sharon E. Plon, M.D., Ph.D., FACMG
Baylor College/Texas Children's Hospital

Dr. Sharon Plon is a board-certified medical geneticist and a longstanding cancer genetics researcher, including leading to the discovery of new cancer susceptibility genes and the implementation of genomic testing in medicine. Dr. Plon holds the Dan L. Duncan Comprehensive Cancer Center Professorship at Baylor College of Medicine in the Departments of Pediatrics/Hematology-Oncology, Molecular and Human Genetics and Human Genome Sequencing Center. She completed her genetics training at the University of Washington. Dr. Plon has been at Baylor College of Medicine for over 25 years and founded and continues to direct the Cancer Genetics Clinic at Texas Children's Hospital.

Dr. Plon served on the National Advisory Council for Human Genome Research of the National Institutes of Health (NIH) and served on the Board of Directors of the American Society of Human Genetics. Dr. Plon has also worked with the American Association of Cancer Research (AACR) to develop an online resource for physicians with up to date recommendations for cancer surveillance in those children at genetic risk of cancer. Drs. Plon and D. William Parsons were principal investigators of the NHGRI/NCI-funded BASIC3 clinical trial on the incorporation of exome sequencing into the care of newly diagnosed childhood cancer patients and this study is now being expanded into diverse patient populations across Texas (KidsCanSeq

trial). Since 2013, Dr. Plon has served as one of the Principal Investigators of the Clinical Genome (ClinGen) Resource and chairs the ClinGen hereditary cancer effort. She currently co-chairs the germline reporting effort of the national NCI/COG Pediatric MATCH Precision Oncology trial. Dr. Plon is also working closely with Dr. Philip Lupo on a population-based study to understand the association between birth defects and cancer risk in children.

Mark Purdue, Ph.D.
National Institutes of Health

Dr. Mark Purdue is a Senior Investigator in the Occupational and Environmental Epidemiology Branch of the National Cancer Institute's Division of Cancer Epidemiology and Genetics. Dr. Purdue's interests center on applying molecular and classical epidemiologic methods to identify environmental and occupational risk factors of cancer. His current projects include studies investigating cancer associations with exposure to chlorinated solvents, per- and polyfluoroalkyl substances (PFAS) and other chemicals.

Mónica Ramírez-Andreotta, M.P.A., Ph.D.
University of Arizona

Mónica Ramírez-Andreotta, M.P.A., Ph.D. is an Associate Professor of Environmental Science and Public Health at the University of Arizona. Using an environmental justice framework and participatory research methods, she investigates exposure pathways and communication strategies to translate environmental health research to action and achieve structural change.

Trevor Schaefer
Trevor's Trek Foundation

Trevor Schaefer was born on October 19, 1989, in San Diego, California. He moved to McCall, Idaho when he was six years old. Trevor lived with his parents on Payette Lake in McCall, Idaho until he was diagnosed with brain cancer in November of 2002. At that time, he and his mother moved to Boise, Idaho where he underwent an eight-hour surgery to remove a golf ball size tumor from the base of his brain. Post surgery Trevor endured 6 weeks of radiation treatment followed by 14 months of chemotherapy. With his mother Charlie by his side every
step of the way, in September 2007 Trevor helped organize the first childhood cancer awareness walk in Idaho. In 2009 Trevor co-founded Trevor's Trek Foundation to create childhood cancer

awareness and support research and investigative efforts into the causation and prevention of childhood cancer. Trevor was the inspiration behind Trevor's Law, cancer cluster legislation that was signed into law by President Barack Obama on June 22, 2016. Trevor has also co-authored a book entitled "The Boy on the Lake" which chronicles his life, battle with cancer and journey to the introduction of Trevor's Law. On May 4th, 2022, Trevor was a panelist on President Biden's Cancer Moonshot roundtable: Perspectives on Cancer and the Environment.

Michael E. Scheurer, PhD
Baylor College of Medicine

Michael E. Scheurer received his Master of Public Health degree (M.P.H.) in epidemiology from the University of Alabama, Birmingham in 1999 and a Ph.D. in Epidemiology from the University of Texas School of Public Health in 2004. He completed a postdoctoral fellowship in molecular epidemiology at MD Anderson Cancer Center and joined the faculty at Baylor College of Medicine, in Houston, TX, in 2007. Dr. Scheurer is a tenured Professor in the Department of Pediatrics at Baylor and holds the Sidney L. and Donald F. Faust Chair of Pediatric Cancer Epidemiology at Texas Children's Hospital. His research focuses on identifying risk factors for pediatric and adult brain tumors and adverse outcomes among patients with these conditions.

Recinda Sherman, M.P.H., Ph.D., CTR
North American Center for Cancer Registries

Recinda Sherman has a Bachelor's in Biology & Public Policy from Smith College, a Master's in Public Health in Epidemiology and Biostatistics from Oregon Health & Sciences University, and a Doctorate in Epidemiology from University of Miami. For over 20 years, she has been focused on population-based cancer research—collaborating with academic, clinical and community partners. She has worked for both the Oregon and the Florida state cancer registries and currently works for the North American Association of Central Cancer Registries, Inc (NAACCR), a not-for-profit focused on promoting collaboration, support, and standardization of cancer registry data collection and analysis. Dr. Sherman's main area of interest is to approach core public health questions about disparities using geospatial techniques to evaluate risk factors and disease.

Logan G. Spector, Ph.D.
University of Minnesota

Logan Spector, PhD, is a pediatric cancer epidemiologist specializing in the etiology of leukemia, bone, and liver tumors. He has been PI or co-PI of six National Cancer Institute funded studies of childhood cancer etiology or outcome, and is immediate past Chair for Epidemiology with the Children's Oncology Group. In his work he uses surveillance data, traditional case-control studies examining environmental and lifestyle risk factors, and genetic epidemiologic approaches. Regarding the latter, Dr. Spector uses both single nucleotide variant array and next-generation sequencing data to understand the germline basis of childhood cancer risk; his modes of analysis include genomewide association studies, transcriptome-wide association studies, gene burden analyses, de novo mutation analysis, and admixture mapping. The ultimate goal of Dr. Spector's research is to enable the prediction, early detection, and, eventually, prevention of childhood cancer.

E. Alejandro Sweet-Cordero, M.D.
University of California, San Franciso

Dr. Alejando Sweet-Cordero cares for children with cancer. He specializes in treating patients with sarcomas (a type of cancer that originates in bone or soft tissue) and in treating advanced cancers through precision medicine (the use of a patient's genetic data to optimize therapy).

In research, Sweet-Cordero has two areas of focus. First, he studies ways to use gene sequencing data from tumors to inform treatment decisions. Specifically, he directs the UCSF Molecular Oncology Initiative, which uses such data in determining the best treatments for relapsed, growing or other difficult-to-treat cases. Second, he runs a research lab dedicated to finding new therapies for sarcomas, particularly osteosarcoma and Ewing's sarcoma.

Sweet-Cordero earned his medical degree at UCSF, where he also completed a residency in pediatrics. He completed a fellowship in pediatric oncology at the Dana-Farber/Boston Children's Cancer and Blood Disorders Center. A native Spanish speaker, Sweet-Cordero enjoys working with Spanish-speaking patients and their families. He appreciates the diversity of UCSF's patient population and how it reflects the Bay Area's cultural diversity. In his free time, he enjoys spending time with family and friends, cooking, and reading.

Jack A. Taylor, M.D., Ph.D.
National Institutes of Health

Dr. Taylor's research on epigenetic modification addresses the hypothesis that different environmental exposures cause different patterns of DNA methylation in genes that are important in carcinogenesis. Much of this work has been on breast cancer investigating whether exposure and life course events lead to changes in the patten of DNA methylation across the genome and whether those patterns can be used to predict breast cancer and other diseases. Taylor's earlier work focused on the relationship between environmental exposure and acquired somatic mutations in critical target genes that drive cancer development, and on the interaction between between exposure and common inherited polymorphisms in cancer risk.

Dr. Taylor received a B.A. from Carleton College, an M.D. from the University of Wisconsin and a Ph.D. in epidemiology from the University of North Carolina at Chapel Hill. Taylor is licensed in North Carolina, and holds board certifications in Public Health and General Preventive Medicine. He has held Adjunct Professorships in the Department of Epidemiology, Department of Medicine and the Lineberger Comprehensive Cancer Center at the University of North Carolina at Chapel Hill, as well as in the Department of Medicine at Duke University. A listing of his more than 200 publications can be found at https://www.ncbi.nlm.nih.gov/myncbi/jack.taylor.1/bibliography/public/.

Joseph Wiemels, Ph.D.
University of Southern California

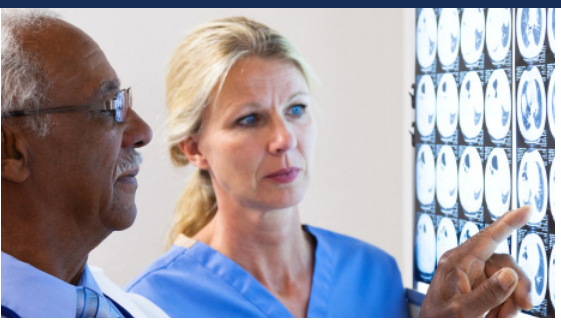
Dr. Wiemels is a professor in the Center for Genetic Epidemiology in the Department of Population and Public Health Sciences at USC studying the molecular epidemiology of childhood cancers, particularly childhood leukemia and brain cancer. Dr. Wiemels received his doctorate in Environmental Health Sciences at UC Berkeley, examining the metabolism and toxicity of benzene and butadiene, and he has worked throughout his career on establishing relationships between environmental agents and cancer risk. He has been a faculty member for over 22 years, concentrating on etiology and prevention, incorporating concepts of genetic susceptibility and interaction with environmental exposures and infections. His research group consists of both laboratory- and computational-based scientists who are focused on the interaction of inherited genetics and environmental factors to cause specific mutational and epigenetic changes, and the specific timing of these events during the development of the child. Dr. Wiemels was a Leukemia and Lymphoma Society Scholar and is currently an Associate Director of the Norris Comprehensive Cancer Center (NCCC) at USC, and manages the shared resources of the center.

Jinghui Zhang, Ph.D.
St. Jude Children's Research Hospital

Dr. Jinghui Zhang is the Chair of Department of Computational Biology and Endowed Chair of Bioinformatics at St. Jude Children's Research Hospital. Her research is to understand the effect of genetic alterations on cancer. Major accomplishments include mapping the landscapes of >20 pediatric cancers; development of novel algorithms leading to discoveries of targetable kinase fusion, novel oncogenic fusion, non-coding driver variants; defining germline cancer predisposition mutations in pediatric cancer; implementing an integrated clinical sequencing pipeline; and performing the first pan-pediatric cancer analysis unveiling striking difference in mutational signature and driver gene landscape of pediatric versus adult cancer. Her lab has discovered the therapy-related mutational signatures in relapsed acute lymphoblastic leukemia, osteosarcoma and most recently, survivors of pediatric cancer. An advocate for genomic data sharing, she has developed the St. Jude Cloud which now hosts multi-omics data generated from >10,000 pediatric cancer patients. Dr. Zhang is a recipient of the 2019 AACR Team Science Award and one of the most highly cited scientists in the last decade with a total of >150,000 citations.

NATIONAL CANCER POLICY FORUM

ABOUT THE FORUM



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

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

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

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NATIONAL ACADEMIES Sciences Engineering Medicine

Upcoming Workshops

Optimizing Public-Private Partnerships for Clinical Cancer Research

Collaborative workshop convened by:
National Cancer Policy Forum
Forum on Drug Discovery, Development, and Translation

October 17-18, 2023

Clinical cancer research has changed dramatically in recent years. Innovations in technology, improved understanding of disease biology, and an increasing number of potential therapeutics in the oncology pipeline has increased trial complexity. At the same time, there is continued pressure to conduct these trials in a timely and cost-effective manner. Public-private partnerships have the potential to more effectively leverage public funding and resources, increase the breadth and depth of research, and effect a more rapid translation from basic discoveries to public health applications. Industry, government, and nonprofit organizations could each make important and unique contributions to this endeavor. This workshop will examine opportunities to enhance and foster public-private partnerships for clinical cancer research and consider lessons learned from examples of public-private collaborations in oncology or other fields that have helped to advance clinical research and improve patient outcomes.

Workshop website in development

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

Collaborative workshop co-sponsored by:
National Cancer Policy Forum
American Society of Clinical Oncology

October 5-6, 2023

This year marks the 10-year anniversary of the Institute of Medicine (IOM) report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, and the ability of the cancer care delivery system to provide high-quality cancer care to all patients remains elusive. This workshop—co-sponsored by the National Cancer Policy Forum and the American Society of Clinical Oncology—is an opportunity for the cancer care community to discuss persistent barriers to achieving excellent and equitable cancer care for all, and additional actions that could be taken to implement the 2013 recommendations. Workshop presentations and discussions may also identify aspects of cancer care that have changed over the past decade and where new strategies are needed to improve the quality of care.

Workshop website in development

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

Collaborative workshop convened by:
National Cancer Policy Forum
Global Forum on Innovation in Health Professional Education

July 17-18, 2023

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

This workshop will examine opportunities to improve equitable access to multispecialty, multidisciplinary care for patients living with and beyond cancer. Workshop presentations and discussions will focus on strategies to expand and strengthen the multispecialty and multidisciplinary workforce, particularly in underserved areas; approaches for enhancing health professional education across the spectrum of non-oncology clinicians to include best practices for the care of patients with cancer; opportunities for collaboration and information-sharing among members of a patient's health care team across specialties and disciplines; payment and care delivery models to facilitate coordination and collaboration; and opportunities to strengthen the evidence base about the array of adverse effects of cancer and cancer treatment on patient outcomes, as well as interventions aimed at mitigating these effects.

Workshop website

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

Collaborative workshop convened by:
National Cancer Policy Forum
Roundtable on Genomics and Precision Health

April 13, 2023

This workshop will examine the state of the science regarding the identification of genomic and epigenomic biomarkers of environmental exposures associated with cancers, with emphasis on pediatric cancers. The workshop is sponsored by the Division of Environmental Health Science and Practice in the National Center for Environmental Health at the Centers for Disease Control and Prevention and will provide background information to assist the CDC in revising their Cancer Cluster Guidelines.

Workshop website

Recent Workshops

Incorporating Integrated Diagnostics into Precision Oncology Care

Collaborative workshop convened by:
National Cancer Policy Forum
Computer Science and Telecommunications Board
Board on Human-Systems Integration

March 6-7, 2023

Innovations in the diagnostic specialties have the potential to reshape cancer diagnosis and enable precision therapy. Spurred by advances in informatics, there are opportunities to combine information from imaging, pathology, and molecular testing. Multidisciplinary collaboration among pathologists, radiologists, and oncologists supplemented by machine-learning based tools could facilitate a more precise understanding of a patient's diagnosis, and what treatment strategies may be most effective to improve outcomes. Integrated diagnostics may also improve patient access to subspecialty expertise, particularly in community-based settings of cancer care. This workshop convened members of the cancer community better define the purpose, goals, and components of integrated diagnostics and provided an opportunity to discuss policy, research, technical, and workforce considerations to help realize the potential of integrated diagnostics.

Workshop videos and presentations

Addressing Resistance in the Development of Cancer Immune Modulator Therapeutics

Collaborative workshop convened by:
National Cancer Policy Forum
Forum on Drug Discovery, Development, and Translation

November 14-15, 2022

Many patients who initially respond to immunotherapy treatment may develop resistance to treatment over time. The reasons for the development of resistance are not fully understood, and resistance continues to pose a major threat to further advances in the field of immunotherapy for cancer treatment. This workshop gave participants in the cancer research and cancer care an opportunity to examine the current challenges related to resistance to immunotherapies and to discuss potential policy options that could help overcome these challenges.

Workshop videos and presentations

Advancing Progress in Cancer Prevention and Risk Reduction

June 27-28, 2022

This workshop considered the current state of knowledge on risk factors for cancer and best practices for cancer prevention and risk reduction. Workshop sessions focused on strategies to implement population-based and clinic-based prevention, with exemplar programs in both settings. Participants also examined opportunities to spur progress in cancer prevention and risk reduction.

Workshop videos and presentations

Family Caregiving for People With Cancer and Other Serious Illnesses

Collaborative workshop convened by:
National Cancer Policy Forum
Roundtable on Quality Care for People with Serious Illness
Forum on Aging, Disability, and Independence

May 16-17, 2022

This workshop used cancer as a lens to examine issues that affect family caregivers for people with serious illnesses. Presentations and discussions included: strategies to better capture, understand, and act on family caregiver input and experience to improve patient care and to support family caregivers; research and policy opportunities to better support family caregiving; and strategies to better embed a health equity focus in family caregiving research, policy and practice.

Workshop videos and presentations
Proceedings

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

Collaborative workshop convened by:
National Cancer Policy Forum
Computer Science and Telecommunications Board

February 28-March 1, 2022

Electronic Health Records (EHRs) are used across a wide variety of activities in cancer care and cancer research, including communication among health care team members and patients, clinical documentation and treatment planning, patient safety and quality improvement, scheduling and billing, as well as clinical research and disease surveillance activities. This workshop examined opportunities to improve patient care and outcomes through collaborations to enhance innovation in the development, implementation, and use of EHRs in oncology care, research, and surveillance.

Workshop videos and presentations

Proceedings

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
- Flatiron Health
- Merck
- National Comprehensive Cancer Network
- National Patient Advocate Foundation
- Novartis Oncology
- Oncology Nursing Society
- Partners in Health
- Pfizer Inc
- Sanofi
- Society for Immunotherapy of Cancer

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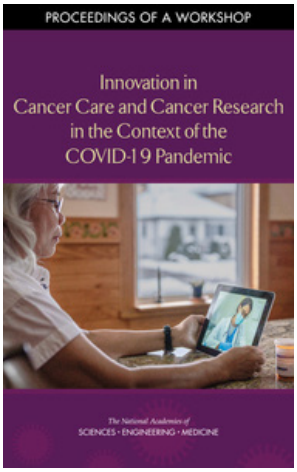
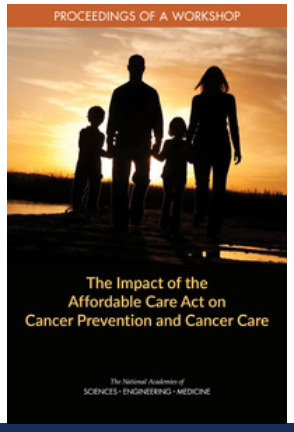
NATIONAL CANCER POLICY FORUM

WORKSHOP PROCEEDINGS AND RELATED PUBLICATIONS





WORKSHOP PROCEEDINGS

2023

Incorporating Integrated Diagnostics into Precision Oncology Care: Proceedings of a Workshop (In Process)

Addressing Resistance in the Development of Cancer Immune Modulator Therapeutics: Proceedings of a Workshop (In Process)

Advancing Progress in Cancer Prevention and Risk Reduction: Proceedings of a Wrokshop (In Process)

Realizing the Potential of Genomics across the Continuum of Precision Health Care: Proceedings of a Workshop

2022

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

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

Promoting Health Equity in Cancer Care: Proceedings of a Workshop

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

Innovation in Cancer Care and Cancer Research in the Context of the COVID-19 Pandemic: Proceedings of a Workshop

Impact of the Affordable Care Act on Cancer Prevention and Cancer Care: Proceedings of a Workshop

2021

Addressing the Adverse Consequences of Cancer Treatment: Proceedings of a Workshop

Opportunities and Challenges for Using Digital Health Applications in Oncology: Proceedings of a Workshop

Improving the Evidence Base for Treatment Decision Making for Older Adults with Cancer: Proceedings of a Workshop— in Brief

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

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

2020

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

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

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

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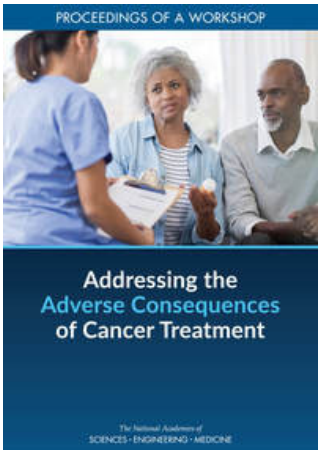
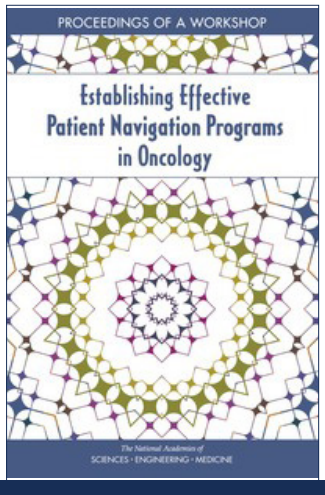




WORKSHOP PROCEEDINGS

2019

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

2018

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

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

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

2017

The Drug Development Paradigm in Oncology: Proceedings of a Workshop

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

Implementation of Lung Cancer Screening: Proceedings of a Workshop

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

2016

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

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

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

2015

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

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

Assessing and Improving the Interpretation of Breast Images: Workshop Summary

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

2014

Ensuring Patient Access to Affordable Cancer Drugs: Workshop Summary

Contemporary Issues for Protecting Patients in Cancer Research: Workshop Summary

2013

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

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

Sharing Clinical Research Data: Workshop Summary

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

Reducing Tobacco-Related Cancer Incidence and Mortality: Workshop Summary

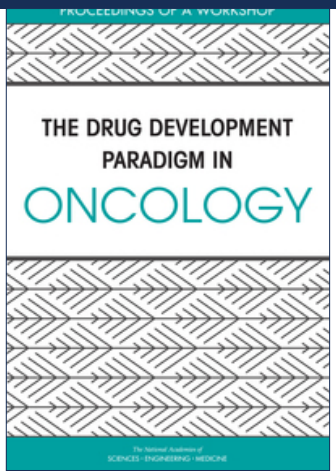
2012

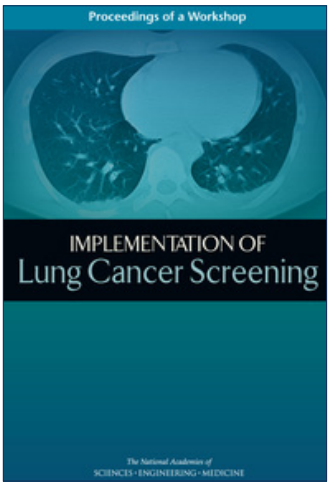
The Role of Obesity in Cancer Survival and Recurrence: Workshop Summary

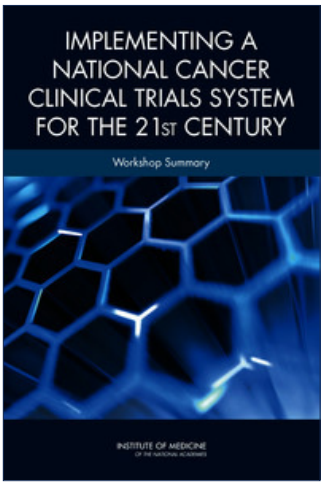
Informatics Needs and Challenges in Cancer Research: Workshop Summary

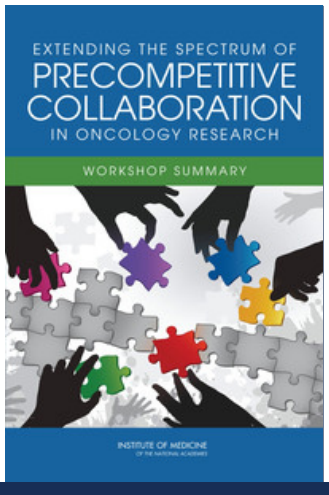
Facilitating Collaborations to Develop Combination Investigational Cancer Therapies: Workshop Summary

Nanotechnology and Oncology: Workshop Summary









WORKSHOP PROCEEDINGS

2011

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

2010

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

2009

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

2008

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

2007

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

2006

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

RELATED WORK

CONSENSUS STUDY REPORTS BUILDING ON NCPF WORK

Childhood Cancer and Functional Impacts Across the Care Continuum (2021)
Report: nap.edu/catalog/25944

Diagnosing and Treating Adult Cancers and Associated Impairments (2021)
Report: nap.edu/catalog/25956

Guiding Cancer Control: A Path to Transformation (2019)
Report: nap.edu/catalog/25438

Making Medicines Affordable: A National Imperative (2017)
Report: nap.edu/catalog/24946

Biomarker Tests for Molecularly Targeted Therapies: Key to Unlocking Precision Medicine (2016)
Report: nap.edu/catalog/21860

Ovarian Cancers: Evolving Paradigms in Research and Care (2016)
Report: nap.edu/catalog/21841

Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013)
Report: nap.edu/catalog/18359

Evolution of Translational Omics: Lessons Learned and the Path Forward (2012)
Report: nap.edu/catalog/13297

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

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

Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health Through Research (2009)
Report: nap.edu/catalog/12458

Cancer Biomarkers: The Promises and Challenges of Improving Detection and Treatment (2007)
Report: nap.edu/read/11892

INDIVIDUALLY AUTHORED PUBLICATIONS BUILDING ON NCPF WORK

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

2022

- Bono, K. and N. L. Keating. 2022. Addressing social determinants of health: Now is the time. *Journal of the National Cancer Institute.* https://academic.oup.com/jnci/advance-article/doi/10.1093/jnci/djac137/6705076?searchresult=1.
- Bradley, C. J., S. Kitchen, S., Bhatia , J. Bynum, G. Darien, J. L. Lichtenfeld, R. Oyer, L. N. Shulman, and L. Kennedy Sheldon. 2022. Policies and practices to address cancer's long-term adverse consequences. *Journal of the National Cancer Institute.* 114(8):1065-1071. https://academic.oup.com/jnci/article-abstract/114/8/1065/6570605?redirectedFrom=fulltext.
- Davidson, N. E., K. E. Knudsen, S. Fuld Nasso, R. Oyer, S. Pergam, L. Strawbridge, and L. Shulman. 2022. Cancer care at the beginning of the COVID-19 pandemic: Effects on patients and early interventions to mitigate stresses on care. *Cancer Journal* 28(2):107-110. https://journals.lww.com/journalppo/Abstract/2022/03000/Cancer_Care_at_the_Beginning_of_the_COVID_19.5.aspx.
- Fan, Q, D. Keene, M. Banegas, S. Gehlert, L. M. Gottlieb, K. R. Yabroff, C. E . Pollack. 2022. Housing insecurity among patients with cancer. *Journal of the National Cancer Institute..* https://academic.oup.com/jnci/advance-article/doi/10.1093/jnci/djac136/6705075?searchresult=1.
- Graboyes, E. M., K. H. Chaiyachati, J.S. Gall, W. Johnson, J. S. Krishnan, S. S. McManus, L. Thompson, L. N. Shulman, K. R. Yabroff. 2022. Addressing transportation insecurity among patients with cancer. *Journal of the National Cancer Institute.* https://academic.oup.com/jnci/advance-article/doi/10.1093/jnci/djac134/6705073?searchresult=1.
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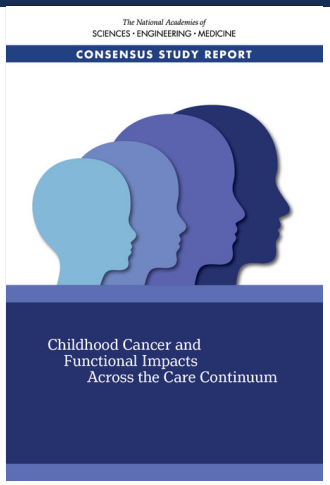
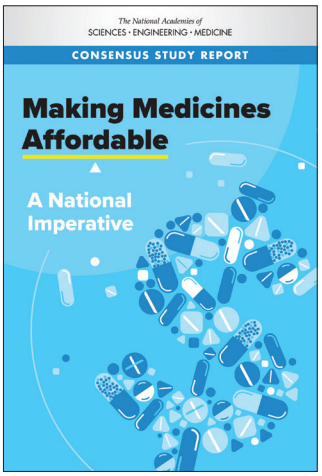
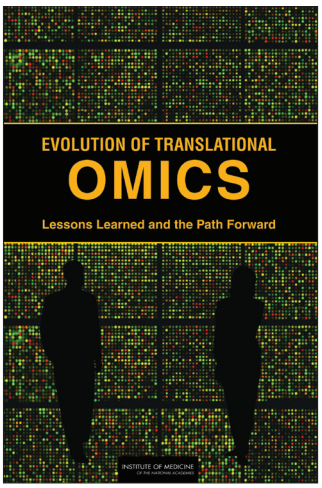
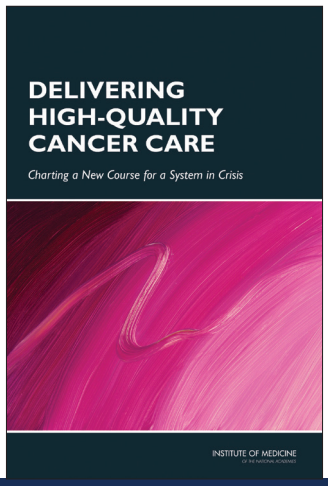
- Karzai, F., and W. L. Dahut. 2022. Lessons from the impact of the COVID-19 pandemic at the national cancer institute: Cancer research and care. *Cancer Journal* 28(2):118-120. https://journals.lww.com/journalppo/Abstract/2022/03000/Lessons_From_the_Impact_of_the_COVID_19_Pandemic.7.aspx.
- Nekhlyudov, L., L. A. Fleisher, and P. B. Jacobsen. 2022. Telemedicine across the cancer care continuum: Evidence and opportunities for clinical care, research, and policy. *Cancer Journal* 28(2):121-124. https://journals.lww.com/journalppo/Abstract/2022/03000/Telemedicine_Across_the_Cancer_Care_Continuum_.8.aspx.
- Nekhlyudov L., G. B. Campbell., K. H. Schmitz, G.A. Brooks, A.J. Kumar, P.A. Ganz, and D. Von Ah 2022. Cancer-related impairments and functional limitations among long-term cancer survivors: Gaps and opportunities for clinical practice. *Cancer* 128(2): 222-229. https://pubmed.ncbi.nlm.nih.gov/34529268/.









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NATIONAL ACADEMIES Sciences Engineering Medicine

Roundtable on GENOMICS and PRECISION HEALTH

The sequencing of the human genome is rapidly opening new doors to research and progress in biology, medicine, and health care. At the same time, these developments have produced a diversity of new issues to be addressed.

The National Academies of Sciences, Engineering, and Medicine has convened a Roundtable on Genomics and Precision Health (previously the Roundtable on Translating Genomic-Based Research for Health) that brings together leaders from academia, industry, government, foundations and associations, and representatives of patient and consumer interests who have a mutual concern and interest in addressing the issues surrounding the translation of genome-based research for use in maintaining and improving health. The mission of the Roundtable is to advance the field of genomics and improve the translation of research findings to health care, education, and policy. The Roundtable will discuss the translation process, identify challenges at various points in the process, and discuss approaches to address those challenges.

The field of genomics and its translation involves many disciplines, and takes place within different economic, social, and cultural contexts, necessitating a need for increased communication and understanding across these fields. As a convening mechanism for interested parties from diverse perspectives to meet and discuss complex issues of mutual concern in a neutral setting, the Roundtable: fosters dialogue across sectors and institutions; illuminates issues, but does not necessarily resolve them; and fosters collaboration among interested parties.

To achieve its objectives, the Roundtable conducts structured discussions, workshops, and symposia. Workshop summaries will be published and collaborative efforts among members are encouraged (e.g., journal articles). Specific issues and agenda topics are determined by the Roundtable membership, and span a broad range of issues relevant to the translation process.

Issues may include the integration and coordination of genomic information into health care and public health including encompassing standards for genetic screening and testing, improving information technology for use in clinical decision making, ensuring access while protecting privacy, and using genomic information to reduce health disparities. The patient and family perspective on the use of genomic information for translation includes social and behavioral issues for target populations. There are evolving requirements for the health professional community, and the need to be able to understand and responsibly apply genomics to medicine and public health.

Of increasing importance is the need to identify the economic implications of using genome-based research for health. Such issues include incentives, cost-effectiveness, and sustainability.

Issues related to the developing science base are also important in the translation process. Such issues could include studies of gene-environment interactions, as well as the implications of genomics for complex disorders such as addiction, mental illness, and chronic diseases.

Roundtable sponsors include federal agencies, pharmaceutical companies, medical and scientific associations, foundations, and patient/public representatives. For more information about the Roundtable on Genomics and Precision Health, please visit our website at nationalacademies.org/GenomicsRT or contact Sarah Beachy at 202-334-2217, or by e-mail at sbeachy@nas.edu.

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VISION	**Realizing the full potential of health for all through genomics and precision health.**
MISSION	**We bring together diverse voices to encourage innovation and actions that foster the wide adoption of and equitable access to the benefits of genomics and precision health.**

As a group of committed parties, we believe in…

- Creating an inclusive and optimistic environment for discussion
- Learning from successes and missteps in the field
- Demanding reproducible evidence-based science
- Sharing trustworthy information
- Embracing interdisciplinary strategies
- Optimizing data privacy and security
- Advancing health equity in all that we do

The Roundtable focuses its energy and resources on these priorities:

DRIVE **INNOVATION** IN GENOMICS AND PRECISION HEALTH	Identify the competing barriers and facilitators of innovation for genomics-based diagnostics, risk assessment tools, and therapies. Leverage opportunities to learn from and promote innovative approaches that can accelerate commercialization and integration to drive impact of genomics on precision health.
SPUR THE **ADOPTION** OF GENOMICS-BASED TOOLS AND PRECISION HEALTH APPROACHES	Cultivate evidence-based practices across the health care and public health systems for adopting genomics and precision health. Draw attention to gaps in adoption and their root causes and highlight potential solutions.
ACHIEVE **EQUITY** IN GENOMICS AND PRECISION HEALTH	Foster action related to underrepresentation and inequities in genomic research, workforce, and access to genomic services by people who need them. Look internally to improve the processes and practices the Roundtable employs to achieve its mission.
SHAPE THE **POLICY DIALOGUE** ABOUT GENOMICS AND PRECISION HEALTH	Accelerate the dissemination of actionable knowledge to shape practice and increase public awareness. Inform and influence how decisions are made.

DEFINITIONS

Precision Health | Inclusive of precision medicine, precision health is a broader, proactive and people-focused approach to health, relying on individual-focused care and everyday decision-making to better predict, prevent, and treat disease.

Genetics | Study of heredity, genes, and genetic variation.

Genomics | Study of the genome by using DNA sequencing and other technologies to understand gene structure, function, and regulation.

NATIONAL CANCER POLICY FORUM

Developing a Multidisciplinary and Multispecialty Workforce to Care for Patients with Cancer, from Diagnosis to Survivorship: A Workshop

July 17-18, 2023

Collaborators:
National Cancer Policy Forum
Global Forum on Innovation in Health Professional Education

Workshop Overview:
Patients living with and beyond cancer often require care from a wide range of clinicians as they navigate cancer diagnosis, treatment, and survivorship care. A multispecialty and multidisciplinary workforce is critical to ensuring that all patients with cancer receive high-quality care.

This National Academies workshop, convened by the National Cancer Policy Forum in collaboration with the Global Forum on Innovation in Health Professional Education, will examine opportunities to improve equitable access to multispecialty, multidisciplinary care for patients living with and beyond cancer. Workshop presentations and discussions will focus on strategies to expand and strengthen the multispecialty and multidisciplinary workforce, particularly in underserved areas; approaches for enhancing health professional education across the spectrum of non-oncology clinicians to include best practices for the care of patients with cancer; opportunities for collaboration and information-sharing among members of a patient's health care team across specialties and disciplines; payment and care delivery models to facilitate coordination and collaboration; and opportunities to strengthen the evidence base about the array of adverse effects of cancer and cancer treatment on patient outcomes, as well as interventions aimed at mitigating these effects.

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Project webpage here

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

October 5-6, 2023

Co-Hosts:
National Cancer Policy Forum
American Society of Clinical Oncology

Statement of Task:
An ad hoc planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and host a 1.5-day public workshop to discuss progress made to date and additional actions needed to implement the recommendations put forth in the Institute of Medicine (IOM) consensus report Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis (2013). It will also explore changes to cancer care that have occurred over the last decade since the report was released and consider potential new strategies to improve the quality of care. The workshop will feature invited presentations and panel discussions organized around the six components of the 2013 report's conceptual framework for a high-quality cancer care delivery system:

- Engaging patients to make informed medical decisions consistent with their needs, values, and preferences.
- Establishing an adequately staffed, trained, and coordinated workforce that works through interprofessional cancer care teams and is coordinated with family caregivers.
- Providing evidence-based care that is informed by clinical trials and other types of clinical research.
- Using information technology to advance the quality and delivery of cancer care, research, and quality measurement.
- Translating evidence into clinical practice guidelines, quality measurement, and performance improvement initiatives.
- Ensuring that high-quality cancer care is accessible and affordable to all patients with cancer.

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

Planning Committee Pending

Project Webpage Pending

Forum on DRUG DISCOVERY, DEVELOPMENT, and TRANSLATION

NATIONAL CANCER POLICY FORUM

Optimizing Public-Private Partnerships for Clinical Cancer Research: A Workshop

October 17-18, 2023

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

Statement of Task:
A National Academies of Sciences, Engineering, and Medicine planning committee will organize and host a 1.5-day public workshop that will examine opportunities to improve the care and outcomes for patients with cancer through public-private partnerships for clinical cancer research. The workshop will feature invited presentations and panel discussions on topics that may include:

- The potential for innovative public-private partnerships to expand and enhance clinical cancer research, including a greater emphasis on health equity.
- Strategies to further utilize the unique features of the National Cancer Clinical Trials Network (NCTN), the NCI Community Oncology Research Program (NCORP), the Experimental Therapeutics Clinical Trials Network (ETCTN), the Cancer Screening Research Network (CSRN), and other relevant networks in these partnerships.
- The unique roles of potential participants in these partnerships, including the NCTN, NCORP, ETCTN, CSRN, and the Advanced Research Projects Agency for Health (ARPA-H), FNIH and other foundations, health systems, health insurers, professional societies, disease-focused groups, and small biotech and biopharmaceutical companies.
- The patient-centered research questions or types of studies that would be most suited for public-private partnerships, such as prevention trials, adjuvant trials, comparative effectiveness trials, and pragmatic post-market trials to enable evidence generation across the lifecycle of a drug.
- Opportunities to leverage public-private collaborations to enhance the integration of cancer research within health care delivery and to utilize data that are collected during routine care to answer important questions in cancer research.
- Potential challenges to conducting efficient clinical cancer research through public-private partnerships, and potential policies and strategies to overcome those challenges.
- Characteristics and principles of effective public-private collaborations in clinical research.
- Examples of past and ongoing public-private collaborations in oncology or other biomedical fields.
- Appropriate metrics to assess the effectiveness of public-private partnerships.

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

Planning Committee Pending

Project Webpage in Development