NATIONAL ACADEMIES *Sciences Engineering Medicine*

Board on Health Sciences Policy
Board on Health Care Services

Examining Clinical Guidelines for the Adoption of Genomic Testing: A Workshop

Roundtable on Genomics and Precision Health
National Cancer Policy Forum

October 29, 2024

In-Person Location
Shared upon registering for in-person attendance

Remote Log on Information
https://www.nationalacademies.org/event/43378_10-2024_examining-clinical-guidelines-for-the-adoption-of-genomic-testing-a-workshop

Roundtable on GENOMICS and PRECISION HEALTH

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Table of Contents

AGENDA

Examining Clinical Guidelines for the Adoption of Genomic Testing: A Workshop

Tuesday, October 29, 2024

PURPOSE

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a public workshop to examine how clinical practice guidelines can impact adoption of genomics into routine medical care. The workshop will examine how guidelines for genomic testing are developed by various organizations and implemented within clinical practice, with a focus on exploring inconsistencies across guidelines.

The workshop's presentations and discussions may focus on:

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

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

SESSION I: Opening Remarks

8:30 AM ET

Welcoming Remarks

Catherine (Cathy) Wicklund (she/her/hers), *Roundtable Co-Chair*
Representing National Society of Genetic Counselors
Senior Manager and Medical Science Liaison, Clinical Strategy Lead
Myriad Genetics
Adjunct Professor of Obstetrics and Gynecology (Clinical Genetics)
Feinberg School of Medicine, Center for Genetic Medicine
Northwestern University

W. Gregory (Greg) Feero (he/him/his), *Roundtable Co-Chair*
Representing *Journal of the American Medical Association*
Professor, Department of Community and Family
Medicine, Geisel School of Medicine
Faculty, Maine Dartmouth Family Medicine Residency Program

8:40–8:50 AM

Introduction and Charge to the Workshop Speakers and Participants

Mylynda Massart (she/her/hers), *Workshop Planning Committee Co-Chair*

Associate Director, Clinical Services
UPMC Primary Care Precision Medicine Center
Associate Professor
University of Pittsburgh

Victoria (Vicky) Pratt, *Workshop Planning Committee Co-Chair*
Representing Association for Molecular Pathology
Director, Scientific Affairs for Pharmacogenetics
Agena Biosciences

SESSION II: Why Guidelines Matter for Genomic Testing

Moderator: W. Gregory Feero (he/him/his), Representing Journal of the American Medical Association

Objectives

- Understand how clinical practice guidelines for genomic testing impact patient care, clinical practice, and other relevant areas, specifically considering impacts on equity in each of these spaces.
- Discuss challenges patients, clinicians, and others face surrounding guidelines.
- Explore how genomic testing guidelines could be advanced to move the needle towards better, more equitable care.

8:50–9:05 AM

Robyn Temple-Smolkin (she/her/hers)
Senior Director, Clinical & Scientific Affairs
Director, Guideline Development
Association for Molecular Pathology

9:05–9:15 AM

Vimal Scott Kapoor
Public Health & Preventive, Occupational and Emergency Physician
University of Toronto
Markham Stouffville Hospital

9:15–9:35 AM

Panel of Reactants

Lindsay Zetzsche (she/her/hers)
Owner
Science Geek Games
Consultant
Integrity Genetics Consulting LLC

Brianne Phillips (she/her/hers)
Nurse Practitioner
University of Pittsburgh Medical Center

Aishwarya Arjunan (she/her/hers)
Senior Medical Science Liaison
GRAIL

9:35–10:05 AM

Panel Discussion

10:05–10:20 AM

Break

SESSION III: Guidelines for Genomic Testing Today

Co-Moderators: Wanda Nicholson, George Washington University Milken Institute School of Public Health & Rebecca Morgan (she/her/hers), Evidence Foundation

Objectives

- Discuss the benefits and challenges of the current clinical practice guideline development process for genomic testing.
- Explore patient-centric models of guidelines development and how equity is and can be incorporated.
- Consider options for circumstances in which guidelines are not compatible or available.

10:20–10:25 AM — **Introduction to the Session**

10:25–10:35 AM

Jennifer S. Lin (she/her/hers)
Director, Evidence-based Practice Center
Kaiser Permanente, Center for Health Research

10:35–10:45 AM

Kelly Caudle (she/her/hers)
Director
Clinical Pharmacogenetics Implementation Consortium (CPIC)
Associate Member
St. Jude Children's Research Hospital

10:45–10:55 AM

Funda Meric-Bernstam (she/her/hers)
Chair of the Department of Investigational Cancer Therapeutics
Medical Director of the Institute for Personalized Cancer Therapy
The Nellie B. Connally Chair in Breast Cancer
MD Anderson Cancer Center

10:55–11:05 AM

Heidi Rehm (she/her/hers)
Director, Genomic Medicine Unit
Center for Genomic Medicine
Massachusetts General Hospital
Institute Member and Clinical Laboratory Director
Broad Institute of MIT of Harvard
Professor of Pathology
Harvard Medical School

11:05–11:40 AM — **Panel Discussion**

11:40 AM–12:35 PM — **Lunch Break**

SESSION IV: How Genomic Testing Guidelines Impact Payer Decisions

Co-Moderators: Trish Brown (she/her/hers), CVS Health & Gabriel Lazarin, Myriad Genetics

Objectives

- Examine the role guidelines play in payer decisions (e.g., coverage, reimbursement).
- Discuss opportunities for advancing patient care and access related to these

decisions.
- Explore levers for aiding payer decisions such as establishment of or compatibility across guidelines and other possible facilitators.

12:35–12:40 PM	**Introduction to the Session**
12:40–12:55 PM	**Trent Haywood** (he/him/his) Founder Knowality, LLC
12:55–1:10 PM	**Gillian Hooker** (she/her/hers) Chief Scientific Officer Concert Genomics
1:10–1:25 PM	**Gautum Agarwal** (he/him/his) Director of Precision Medicine Mercy Health
1:25–1:55 PM	**Panel Discussion**

SESSION V: Clinical Care Implementation of Guidelines for Genomic Testing

Moderator: Pim Suwannarat (she/her/hers), Mid-Atlantic Permanente Medical Group, Kaiser Permanente

Objectives

- Understand how and when clinical practice guidelines for genomic testing are currently being implemented, or could be implemented, in the clinic.
- Explore the gaps in clinical implementation and what support may be needed to drive better, more equitable care.

1:55–2:00 PM	**Introduction to the Session**
2:00–2:15 PM	**David Chambers** (he/him/his) Deputy Director for Implementation Science Division of Cancer Control and Population Sciences National Cancer Institute National Institutes of Health
2:15–2:30 PM	**Charles Jonassaint** (he/him/his) Associate Professor University of Pittsburgh
2:30–2:45 PM	**Naveen L. Pereira** (he/him/his) Consultant for the Department of Cardiovascular Diseases Professor of Medicine Associate Professor of Pharmacology Mayo Clinic College of Medicine
2:45–3:15 PM	**Panel Discussion**

3:15–3:30 PM **Break**

SESSION VI: Guideline Development in a Rapidly Evolving Field – A Look Ahead

Moderator: Mary Nix (she/her/hers), Agency for Healthcare Research and Quality (AHRQ)

Objectives

- Consider the pace of advances in genomics and what opportunities there are for synergy between this field and guideline development.
- Discuss potential challenges ahead and what work could be started now to alleviate possible obstacles to care.

3:30–3:35 PM **Introduction to the Session**

3:35–3:50 PM

Kandamurugu Manickam (he/him/his)
Clinical Geneticist
Nationwide Children's Hospital
Associate Professor of Clinical Pediatrics
Ohio State College of Medicine

3:50–4:05 PM

Karli Kondo (she/her/hers)
Director, Evidence Synthesis
American Cancer Society

4:05–4:20 PM

Sandra Zelman Lewis (she/her/hers)
Past President, Founder
EBQ Consulting, LLC

4:20–4:50 PM **Panel Discussion**

SESSION VII: Final Reflections

4:50–5:05 PM **Wrap Up**

Mylynda Massart (she/her/hers), *Workshop Planning Committee Co-Chair*
Associate Director, Clinical Services
UPMC Primary Care Precision Medicine Center
Associate Professor
University of Pittsburgh

Victoria Pratt, *Workshop Planning Committee Co-Chair Representing Association for Molecular Pathology*
Director, Scientific Affairs for Pharmacogenetics
Agena Biosciences

WORKSHOP INFORMATION

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Planning Committee Member Roster

Co-Chairs

Mylynda Massart, M.D., Ph.D. (she/her/hers)
Associate Director, Clinical Services
UPMC Primary Care Precision Medicine Center
Associate Professor
University of Pittsburgh

Victoria (Vicky) Pratt, Ph.D., FACMG
Representing Association for Molecular Pathology
Director, Scientific Affairs for Pharmacogenetics
Agena Biosciences

Members

Trish Brown, M.S., CGC (she/her/hers)
Genomics and Precision Medicine Program
Executive Director
CVS Health

Pranil Chandra, D.O. (he/him/his)
Senior Vice President
Chief Genomics Officer
PathGroup

W. Gregory Feero, M.D., Ph.D. (he/him/his)
Representing Journal of the American Medical Association
Professor, Department of Community and Family Medicine, Geisel School of Medicine
Faculty, Maine Dartmouth Family Medicine Residency Program

Gabriel Lazarin, M.S., CGC
Vice President, Medical Affairs, Women's Health
Myriad Genetics

Funda Meric-Bernstam, M.D. (she/her/hers)
Chair of the Department of Investigational Cancer Therapeutics
Medical Director of the Institute for Personalized Cancer Therapy
The Nellie B. Connally Chair in Breast Cancer
MD Anderson Cancer Center

Rebecca Morgan, Ph.D., M.P.H. (she/her/hers)
Executive Director
Evidence Foundation
Assistant Professor
McMaster University
Adjunct Assistant Professor, Department of Population and Quantitative Health Sciences
School of Medicine
Case Western Reserve University

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Wanda Nicholson, M.D., M.P.H., M.B.A.
Professor and Senior Associate Dean, Diversity, Equity, and Inclusion
Director of the GWSPH Office of Inclusion Excellence
George Washington University Milken Institute School of Public Health

Mary Nix, M.S., PMP (she/her/hers)
Deputy Director, Division of Practice Improvement
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality (AHRQ)

Pim Suwannarat, M.D. (she/her/hers)
Geneticist and Regional Medical Director
Mid-Atlantic Permanente Medical Group
Kaiser Permanente

Planning Committee Member Biographies

Mylynda B. Massart, M.D., Ph.D. (she/her/hers), is a board-certified Family Medicine physician at UPMC, and associate professor at the University of Pittsburgh. She currently serves as the founder and Medical Director of the UPMC Primary Care Precision Medicine clinic and as the Associate Director of Clinical Services for the Institute for Precision Medicine. Dr. Massart is co-director of the HUB Core over Research Inclusivity and Community Partners Core at the Clinical and Translational Science Institute (CSTI). She has an interest in emerging technologies in multi-cancer early detection and frequently speaks on these topics through the speaker bureau at GRAIL. Her research interests are in developing education in genetics and precision medicine for primary care providers and trainees and being a research catalyst facilitating the inclusion of underrepresented populations in biomedical research. She teaches residents and medical students in her clinic and at the hospital and serves as medical director for Bethany Hospice. Dr. Massart is MPI of the Community Engagement Alliance Consultative Resource (CEACR), a partnership between the University of Pittsburgh CTSI and Community-Campus Partnerships for Health.

Dr. Victoria (Vicky) Pratt, Ph.D., FACMG, is Director of Scientific Affairs for Pharmacogenetics at Agena Bioscience and the Past President of Association for Molecular Pathology (AMP). Dr. Pratt continues to serve on the Centers for Disease Control and Prevention (CDC) GeT-RM program for reference materials for Molecular Genetics, the National Academy of Medicine's Roundtable on Genomics and Precision Health, and the American Medical Association's (AMA) Molecular Pathology Current Procedural Terminology (CPT) Advisory committee. She has developed guidelines with AMP related to genetic and pharmacogenetic testing including for CYP2C19, CYP2C9, Warfarin-related genes, CYP2D6, TPMT/NUDT15, CYP3A4/CYP3A5, and DPYD. Dr. Pratt graduated with a Ph.D. in Medical and Molecular Genetics from Indiana University School of Medicine. Her fellowship training was in Ph.D. Medical and Clinical Molecular Genetics at Henry Ford Hospital, Detroit MI.

Trish Brown, M.S., CGC (she/her/hers), is the current the Executive Director of Genomics and Precision Medicine for CVS Health. In this role she provides evidence based clinical consultation and guidance on precision medicine for companies and business units within the CVS Health enterprise. She currently serves on the Board of Directors for Midwives on Missions of Service (MOMS), a not-for profit organization that teaches evidence-based maternity care to Community Health Care Workers in Sierra Leone. Trish serves on the National Society of Genetic Counselors (NSGC) expert media panel to provide education about Medicare, Medicaid and Commercial insurance coverage policies. Prior to joining CVS Health, she has held executive leadership roles at distinguished corporations such as Illumina, LabCorp and Medco, and the entrepreneurial successes DNA Direct, Fabric Genomics, and BeaconLBS. Through her work she seeks to bridge business strategy with clinical care expertise and drive positive outcomes for healthcare consumers and the businesses that serve them. Trish attended the University of California, Davis and earned a master's degree in human genetics from Sarah Lawrence College. She is certified by the American Board of Genetic Counseling.

Pranil Chandra, D.O. (he/him/his), joined PathGroup in 2011 as Associate Medical Director of Molecular Pathology and now currently serves as Senior Vice President and Chief Genomics Officer at PathGroup. Dr. Chandra holds board certifications in anatomic and clinical pathology, hematopathology and molecular genetic pathology. He completed his AP/CP training and fellowships in hematopathology, oncologic pathology and molecular pathology at NYU Langone Medical Center and the University of Texas-MD Anderson Cancer Center, respectively. While at MD Anderson, he served as Chief Fellow and received numerous awards for his research in acute myeloid leukemia. He has presented numerous abstracts and platform presentations at various pathology meetings and has published peer-reviewed articles and book chapters. Dr. Chandra is a member of the American Society of Clinical Pathology, College of American Pathologists, and Association of Molecular Pathology where he also serves in a leadership capacity to the Economic Affairs Committee as Vice-Chair of Coverage. Dr. Chandra is a recognized medical consultant in molecular pathology and personalized medicine and is considered a national thought leader in Precision Medicine and Cancer Genomics.

W. Gregory Feero, M.D., Ph.D. (he/him/his), is a family medicine physician and human genetics specialist. Serving at Four Seasons Family Practice in Fairfield from 2001-06, Dr. Feero rejoined Maine General Medical Center's active staff at Four Seasons in July 2009 after working as chief of the Genomic Healthcare Branch of the National Human Genome Research Institute, National Institutes of Health in Bethesda, MD. Dr. Feero received a Doctorate in Human Genetics from the University of Pittsburgh Graduate School of Public Health and his medical degree from the University of Pittsburgh School of Medicine. He also serves as a faculty member in the Maine Dartmouth Family Medicine Residency program and is a Professor for the Department of Community and Family Medicine at the Geisel School of Medicine at Dartmouth in Hanover, NH. He is a co-chair for the Roundtable on Genomics and Precision Health of the National Academies of Sciences, Engineering and Medicine.

Gabriel Lazarin, M.S., CGC, is currently the Vice President, Medical Affairs for Myriad Women's Health, part of Myriad Genetics. Myriad is a genetic testing and precision medicine company that develops and offers genetic tests that help assess the risk of developing certain diseases or disease progression. In this position, Gabriel connects with clinicians to primarily discuss technology and practice around reproductive and hereditary cancer genetics. He has worked or advised several genomics, biotech, or healthcare tech startups toward integrating innovative technologies and workstreams into mainstream clinical care. In particular, he has been active in the introduction of new technologies in reproductive genetic testing, including expanded carrier screening and prenatal cell-free DNA screening. He has published on utility, usage, and delivery of these tests, building evidence toward widespread adoption. Gabriel is genetic counselor, certified by the American Board of Genetic Counseling, and has 15 years of experience in the molecular diagnostics industry.

Funda Meric-Bernstam, M.D. (she/her/hers), is the Chair of the Department of Investigational Cancer Therapeutics at The University of Texas MD Anderson Cancer Center, and Medical Director of the Institute of Personalized Cancer Therapy. In her capacities at MD Anderson, she has collaborated with many large pharmaceutical companies. She has extensive experience in novel therapeutics, with a focus on genomically-informed therapeutics and antibody-drug conjugates, as well as high throughput -omic technologies and correlative studies. She leads one of the premiere Phase I programs in the world, as well as several large-scale initiatives in precision oncology such as ComboMATCH. She has established a Precision Oncology Decision Support Team at MD Anderson that provides point of care input for actionability, builds a framework for rapid assessment of actionability of molecular alterations, launched a public website "www.personalizedcancer therapy.org" providing access to expert curation of information on therapeutic relevance of specific genes/variants created, created a knowledgebase and clinical trial alert systems that facilitate accrual to genotype-selected trials across the institution, and established efforts to monitor therapy after genomic testing to identify obstacles to trial enrollment. She also leads a basic and translational research program centered around cell signaling, biomarker discovery, and molecular therapeutics, with specific focus on antibody-drug conjugates, precision oncology, and patient-derived models.

Rebecca L. Morgan, Ph.D., M.P.H. (she/her/hers), a health research methodologist and epidemiologist, is a part-time Assistant Professor at McMaster University, Department of Health Research Methods, Evidence and Impact, in Hamilton, Ontario and adjunct Assistant Professor at Case Western Reserve University, School of Medicine, in Cleveland, OH, and Executive Director of Evidence Foundation. Much of Dr. Morgan's research on evidence synthesis and guideline development has focused on advancing methods for assessing environmental and occupational exposures, integration of non-randomized studies, guideline collaboration, and rapid or living reviews. Dr. Morgan serves as the Chair of the Guidelines Collaboration Working Group within the Guideline International Network, and Chair of the Environmental and Occupational Health Project Group within the GRADE Working Group. She joined the GRADE Working Group in 2009 and has extensive experience in teaching systematic review and guideline development methods to national and international audiences. Dr. Morgan serves as a methodologist for

global organizations such as the Advisory Committee on Immunization Practices, Infectious Diseases Society of America, Health Canada, the World Health Organization, among others. Dr. Morgan is a founding member of the U.S. GRADE Network and Evidence Foundation, a registered nonprofit whose mission is to support evidence-based health care through training, mentorship, education, and collaboration.

Wanda Nicholson, M.D., M.P.H., M.B.A., is dually trained in obstetrics and gynecology and epidemiology and is committed to evidence-based medicine and preventive care to improve patient outcomes. She is Chair of the United States Preventive Services Task Force and professor of prevention and community health at the Milken Institute School of Public Health at the George Washington University (GWU) in Washington, D.C and holds a joint appointment in the Department of Obstetrics and Gynecology at the GWU School of Medicine. She is the Director of the School of Public Health Patient-centered Outcomes in Women's Endocrine and Reproductive Health (POWER). Prior to joining GW, she was a co-I for "Comparing Options for Management: Patient-centered Results for Uterine Fibroids (COMPARE-UF), a 5-year PCORI-funded study. She is an MPI on an NICHD-funded study to conduct longitudinal follow-up of participants in the COMPARE study. She is immediate past vice president of the board of directors of the American Board of Obstetrics & Gynecology; past chair of the American College of Obstetricians and Gynecologists (ACOG) Diversity, Equity, and Inclusive Excellence Workgroup; and a past member of the executive board of ACOG and former chair of the Committee on Pregnancy and Postpartum Hemorrhage for the International Federation of Obstetrics and Gynecology (FIGO).

Mary Nix, M.S., PMP, (she/her/hers) is the Deputy Director of the Division of Practice Improvement at AHRQ. She is a health services research division leader, public servant, and certified project manager. Her master's degree is in clinical pathology, and she led laboratory testing operations in large academic medical centers assuring test accuracy and validity in support of high-quality patient care. In health services research, Mary has focused on data that informs clinical decisions and spent over 20 years on AHRQ's National Guideline Clearinghouse (NGC), reviewing thousands of clinical practice guidelines for scientific merit and trustworthiness. More recent work with researchers in the field moving evidence into practice reveals opportunities to improve guidelines' intrinsic and extrinsic factors toward swift and effective implementation.

Pim Suwannarat, M.D. (she/her/hers), is a clinical geneticist and biochemical geneticist. She is the Regional Medical Director of Genetics and Genomics at the Mid-Atlantic Permanente Medical Group. She leads a team of genetic counselors and geneticists in providing prenatal, cancer, and clinical genetic care across the lifespan to the Kaiser Permanente Mid-Atlantic States members. This includes implementation of various strategies to improve access to evidence based genetic testing and counseling. At the KP National level she chairs the Clinical Practice Workgroup that helps inform the Precision Medicine, Genetics and Genomics direction for the organization resulting in implementation of patient and provider education, care management guidelines, and processes to identify individuals at risk for genetic conditions including CDC3 tier

1 conditions. Dr. Suwannarat completed her medical education from Chiangmai University, Chiangmai, Thailand. She did her pediatric residency training at Inova Fairfax Hospital for Children and her clinical and clinical biochemical genetics training with the National Human Genome Research Institute, NIH.

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Speaker Biographies

Gautum Agarwal, M.D. (he/him/his), is a board certified Urologic Oncologist and Director of Precision Medicine at Mercy based in St Louis, Missouri. Dr. Agarwal received his M.D. from Saint Louis University, he completed residency at Loma Linda University and a fellowship at Moffitt Cancer Center before joining Mercy.

Aishwarya Arjunan, M.S., M.P.H., CGC, CPH (she/her/hers), is a board certified genetic counselor and a Senior Medical Science Liaison at GRAIL. She graduated with a Bachelor of Science degree in Biology from Case Western Reserve University and then received a MS in Genetic Counseling and MPH in Human Genetics from the University of Pittsburgh. She is also currently a Doctorate of Public Health in Leadership student at the University of Illinois School of Public Health. Prior to GRAIL she worked at Myriad Women's Health (formerly Counsyl), as the Senior Clinical Product Manager of the Foresight Carrier Screen and as a clinical genetic counselor at the Sarnoff Center for Jewish Genetics and Ann & Robert H Lurie Children's Hospital in Chicago. Aishwarya is actively involved with the genetic counseling community as a past Director at Large for the National Society of Genetic Counselors (NSGC) Board of Directors and past President of the Illinois Society of Genetic Professionals. She is also the immediate Past-President of the Case Western Reserve University Alumni Association Board of Directors. Aishwarya was the recipient of the 2018 NSGC New Leader Award and the 2020 NSGC Cultural Advocacy Award as well as the recipient of the 2020 Case Western Reserve University College of Arts and Sciences Young Alumni Award, 2022 North Allegheny Foundation Distinguished Young Alumni Award, 2022 GRAIL MSL MVP Award, and the 2023 University of Pittsburgh School of Public Health Early Career Excellence Award.

Kelly Caudle, Pharm.D., Ph.D., FCCP (she/her/hers), is an Associate Member in the Department of Pharmacy and Pharmaceutical Sciences at St. Jude Children's Research Hospital. She received her Pharm.D. and Ph.D. from the University of Tennessee Health Science Center and completed a pediatric residency at LeBonheur Children's Hospital. Dr. Caudle also serves as the MPI and Director of the NIH grant for the Clinical Pharmacogenetics Implementation Consortium (CPIC). CPIC provides guidelines that enable the translation of genetic laboratory test results into actionable prescribing decisions for specific drugs. To date, CPIC has published 28 gene-based clinical guidelines covering 29 genes and over 150 drugs. Dr. Caudle oversees all CPIC-related

projects and the CPIC guideline development process including the coordination of the guideline writing committees, the guideline evidence reviews, and the writing of the guideline manuscript and supplement. Over the past ten years, Dr. Caudle's research and practice interests have been in pharmacogenomics implementation, and she has written over 100 publications and abstracts and has numerous invited national and international presentations for this work. Furthermore, Dr. Caudle is involved in the clinical implementation of pharmacogenetics at St. Jude Children's Research Hospital.

David Chambers, M.Sc., D.Phil. (he/him/his), is Deputy Director for Implementation Science in the Office of the Director in the Division of Cancer Control and Population Sciences (DCCPS) at the National Cancer Institute (NCI). Dr. Chambers manages a team focusing on efforts to build and advance the field of Implementation Science through funding opportunities, training programs, research activities, dissemination platforms, and enhancement of partnerships and networks to integrate research, practice and policy. From 2008 through the fall of 2014, Dr. Chambers served as Chief of the Services Research and Clinical Epidemiology Branch (SRCEB) of the Division of Services and Intervention Research at the National Institute of Mental Health (NIMH). He arrived at NIMH in 2001, brought to the Institute to run the Dissemination and Implementation Research Program within SRCEB, developing a portfolio of grants to study the integration of scientific findings and effective clinical practices in mental health within real-world service settings. From 2006 to the fall of 2014, Dr. Chambers also served as Associate Director for Dissemination and Implementation Research, leading National Institutes of Health (NIH) initiatives around the coordination of dissemination and implementation research in health, including a set of research announcements across multiple NIH Institutes and Centers, annual scientific conferences, and a summer training institute. Prior to his arrival at NIH, Dr. Chambers worked as a member of a research team at Oxford University, where he studied national efforts to implement evidence-based practice within healthcare systems. He publishes on strategic directions in implementation science and serves as a plenary speaker at numerous scientific conferences. He received his A.B. degree (with Honors) in Economics from Brown University, and an MSc and DPhil degree in Management Studies (Organisational Behaviour) from Oxford University (UK).

Trent Haywood, M.D., J.D. (he/him/his), founded KNOWALITY LLC, a venture services firm dedicated to accelerating market adoption of innovative healthcare services and products that improve population health. Previously, Dr. Haywood served as Chief Medical Officer of the Blue Cross Blue Shield (BCBS) Association where he was responsible for guiding medical policy and clinical programs for the association's member health plans. In addition, he served as President of the Blue Cross Blue Shield Institute, a benefit corporation focused on addressing social determinants of health for BCBS plans. Prior, Dr. Haywood led national efforts to implement value-based healthcare as Chief Medical Officer at VHA, Inc. and Deputy Chief Medical Officer for the Centers for Medicare & Medicaid Services (CMS). He earned a medical degree from the University of Illinois at Chicago and a Juris Doctor degree from Northwestern University.

Gillian Hooker, Ph.D., Sc.M., CGC (she/her/hers), has focused her career on implementation and outcomes of genetic counseling and advanced diagnostics, first as an academic and now in her position as Chief Scientific Officer at Concert, a Nashville-based Health IT company. In her role, she leads the clinical content team developing content and tools for better management of diagnostic testing to support health insurance companies, hospitals and policymakers. She has advocated for access to care and to diagnostics via her previous role as the president of the National Society of Genetic Counselors and her current role as the chair of the Tennessee Rare Disease Advisory Council.

Charles Jonasaint, PH.D., M.H.S. (he/him/his), is a tenured associate professor of medicine and a practicing clinical health psychologist and an epidemiologist. He has clinical expertise in chronic disease self-management and cognitive behavioral therapy interventions and has had extensive experience working with health disparities populations, namely, adolescents and adults living with sickle cell disease. He completed his graduate training at Duke University and went on to do a masters in epidemiology and clinical research fellowship at Johns Hopkins University School of Medicine. Dr. Jonassaint is currently funded through the National Institutes of Health and the Patient-Centered Outcomes Research Institute to lead a program of research focused on designing and testing evidence-based digital health interventions for pain and mental health in health disparities populations.

Vimal Scott Kapoor, M.D., is the brother of the late Dr. Anil Kapoor, Full Professor of Surgery (Urology) at McMaster University, world-renowned Urologist, Renal Transplant Surgeon, and Uro-Oncologist. Dr. Anil Kapoor was one of the most published and distinguished Urologists in Canada, key opinion leader, and much sought after speaker and around the world, (including ASCO). Dr. Anil Kapoor was well- known among his peers to be a rare, naturally gifted surgeon, conducting a number of pioneering surgeries in Canada. Dr. Scott Kapoor is Residency-Trained and Board-Certified in the following four specialties: He is Board-certified and Residency-Trained in Emergency Medicine from the University of Western Ontario, in Family Medicine from McMaster University, in Public Health & Preventive Medicine from the University of Toronto, and in Occupational Medicine from the University of Toronto. As an H. Greville Smith Scholar, Dr. Kapoor completed his Bachelor of Science in Microbiology & Immunology at McGill University in Montreal. After completing Epidemiology and Biostatistics at the University of Western Ontario, he then served as a Rotary Ambassadorial Scholar to study at the world-renowned London School of Hygiene & Tropical Medicine in London, England. There, he was awarded his Master of Science and Diploma of the London School of Hygiene & Tropical Medicine. He was subsequently selected to intern at the World Health Organization in Geneva, Switzerland. Upon graduation from Dalhousie Medical School, Dr. Kapoor was selected to enter Canada's most prominent Royal College Public Health & Preventive Medicine Program at the University of Toronto. While in the program, he completed extra training in aviation medicine, toxicology, emergency preparedness and travel medicine. Upon completion, he was successful in obtaining the highest credential, FRCPC (Public Health & Preventive Medicine). He later subspecialized in Occupational Medicine from 2013-2015, again in the University of Toronto Royal College of Physicians and Surgeons program, to obtain the highest credential in

Occupational Medicine, FRCPC (Occupational Medicine). Dr. Kapoor was awarded the Fellowship of the Royal College of Physicians and Surgeons of Canada twice, in 2009 and 2015. Dr. Kapoor has completed one the largest and most detailed Cochrane Systematic Reviews for the Cochrane Eyes and Vision Group in London, UK, which involved a detailed meta-analysis using evidence-based evaluation using the GRADE criteria. He currently works as Chief Occupational Physician for Bruce Nuclear Power, Aviation Physician for the FAA and Transport Canada, Emergency Physician at Markham Stouffville Hospital, and Clinical Assistant Professor at the University of Toronto.

Karli Kondo, Ph.D., M.A. (she/her/hers), is the Director of Evidence Synthesis at the Center for Early Cancer Detection Science at the American Cancer Society (ACS). She leads the Cancer-related Evidence Synthesis Team (CrEST), which provides the evidence underpinning the ACS' cancer screening guidelines. As an experienced systematic reviewer, much of her research has focused on health equity, implementation, and mental health. Her methods work centers around the use of data to augment systematic reviews, living systematic reviews, and health equity. In addition to her role at the ACS, Dr. Kondo has served as Vice Chair of the Institutional Review Board (IRB) at Oregon Health & Science University since 2016.

Sandra Zelman Lewis, Ph.D. (she/her/hers), is Past President and Founder of EBQ Consulting. As a health services researcher and evidence-based guideline developer, Dr. Lewis previously served as President of EBQ Consulting, leading a 24-member team offering methodology, data analyses, library research, and additional services supporting systematic reviews and guidelines. She also served as the Chief Guidelines Officer and Executive Director of the nonprofit GROWTH division of Doctor Evidence and Assistant Vice President overseeing guideline development and quality improvement at the American College of Chest Physicians. Dr. Lewis (ORCID ID) has published more than 30 guideline and peer-reviewed publications on guideline methodology and EBM. She was invited to address 5 Institute of Medicine panels; served as faculty for EBM courses and webinars; and consulted for institutional review boards and methodology committees. She presented her work on developing the living guidelines model, trustworthy consensus-based statements, conflict-of-interest policies, anti-tobacco advocacy, technology platforms for evidence curation and analyses, and other topics at professional conferences across the globe. Dr. Lewis was the invited host of the Guidelines International Network's (GIN) first US conference (Chicago, 2010) and is a founding member and Past Chair of GIN/North America. She helped organize 3 E-GAPPS conferences; the Mexico International Forum; and Consumers United for Evidence-based healthcare (CUE) Summit.

Jennifer Lin, M.D., MCR, FACP (she/her/hers), is a board-certified practicing general internist in primary care with Northwest Permanente and the director of the Kaiser Permanente Evidence-based Practice Center (KP EPC). She is also a professor in Kaiser Permanente's School of Medicine, Department of Health Systems Science. Dr. Lin's career interests have focused on evidence-based medicine and health care policy in primary and preventive care. She serves as the EPC's principal investigator on U.S. Preventive Services Task Force (USPSTF) contracts for systematic reviews, methods work, and portfolio management to support the USPSTF

recommendation process. She is recognized by her peers as an expert in systematic review methodology, evidence-based medicine, and clinical prevention. Dr. Lin has significant experience conducting reviews on prevention in primary care, complex interventions, behavioral counseling, care of older adults, cancer screening, and prognosis and risk prediction, as well as genomic testing. She has led and consulted on methods work centered on health equity, evaluation of medical tests, and applied evidence reviews for health systems, guideline groups, and other decision-makers. She and her group have also conducted a number of rapid evidence products for Kaiser Permanente. Dr. Lin served on the American College of Physicians Clinical Guidelines Committee and its Methods Subgroup, and served as a non-voting member on Kaiser Permanente's National Guidelines Committee. Dr. Lin obtained her medical degree at New York University (NYU) School of Medicine. She subsequently completed both a residency and chief residency in internal medicine at NYU-Bellevue Hospital. She completed fellowships in evidence-based health care at Oxford University and in health services research at the Portland Veterans Administration Medical Center. She joined the Center for Health Research in 2007.

Kandamurugu Manickam, M.D., M.P.H., FACMG (he/him/his), is a clinical geneticist at Nationwide Children's Hospital as a Professor of Clinical Medicine with a joint appointment at the Nisonger Center at The Ohio State University Medical Center. He helped develop the 2021 ACMG Practice Guideline for exomes/genomes for anyone with congenital anomalies and intellectual disability. Additionally, he is a national expert on secondary findings from clinical testing and the use of genetic screening for adult onset conditions. Other areas of interest are the societal and ethical considerations of genetic testing and health disparities.

Funda Meric-Bernstam, M.D. (she/her/hers), is the Chair of the Department of Investigational Cancer Therapeutics at The University of Texas MD Anderson Cancer Center, and Medical Director of the Institute of Personalized Cancer Therapy. In her capacities at MD Anderson, she has collaborated with many large pharmaceutical companies. She has extensive experience in novel therapeutics, with a focus on genomically-informed therapeutics and antibody-drug conjugates, as well as high throughput -omic technologies and correlative studies. She leads one of the premiere Phase I programs in the world, as well as several large-scale initiatives in precision oncology such as ComboMATCH. She has established a Precision Oncology Decision Support Team at MD Anderson that provides point of care input for actionability, builds a framework for rapid assessment of actionability of molecular alterations, launched a public website "www.personalizedcancer therapy.org" providing access to expert curation of information on therapeutic relevance of specific genes/variants created, created a knowledgebase and clinical trial alert systems that facilitate accrual to genotype-selected trials across the institution, and established efforts to monitor therapy after genomic testing to identify obstacles to trial enrollment. She also leads a basic and translational research program centered around cell signaling, biomarker discovery, and molecular therapeutics, with specific focus on antibody-drug conjugates, precision oncology, and patient-derived models.

Naveen L. Pereira, M.D. (he/him/his), is a Professor of Medicine, Department of Cardiovascular Diseases; Associate Professor of Pharmacology, Department of Molecular Pharmacology and

Experimental Therapeutics; and Chair of Clinical Trials Operations and Medical Director of Clinical Trials Mayo Clinic. His research career has spanned the spectrum of basic science investigation in the laboratory describing common genetic variation by performing resequencing studies and determining the functional significance of this genetic variation by using basic molecular techniques to NIH funded population based studies by demonstrating the association of these and other genetic variants with biomarkers, adverse drug responses and disease states to performing NIH funded clinical trials to evaluate the utility and applicability of genetic variants that could modulate drug response in clinical practice by performing the largest genotype-based, international, multi-center randomized clinical trial in Cardiovascular Diseases. He has also adopted techniques in artificial intelligence to help develop heart failure risk prediction models using electronic health record data and screening for dilated cardiomyopathy using AI-ECG enabled tools. He has used disruptive NIH funded state of the art digital platforms to assess, follow, and transition patients enrolled in a clinical trial. Dr. Pereira has over 150 publications and was the Chair of the Professional/Public Education and Publications Committee of the Genomics and Precision Medicine Council of the American Heart Association. Dr. Pereira is the 2021 recipient of AHA's Councils on Genomic and Precision Medicine and Epidemiology Mid-Career Research Award. He has served on the Editorial board of Circulation: Genomics and Precision Medicine and currently serves on the Editorial board of Mayo Clinic Proceedings. He is currently a member of the NHLBI Clinical Trials Review Committee.

Brianne Phillips, B.S.N., D.N.P. (she/her/hers), completed both her BSN and Doctor of Nursing Practice degrees at Robert Morris University. Prior to obtaining her doctorate she worked as a nurse in Med-Surg, Oncology and Urgent Care settings. After completing her graduate degree, she briefly worked in interventional pain management and then went on join an internal medicine practice. She is currently working in the Primary Care Precision Medicine Clinic at UPMC where she works with an interdisciplinary team to provide genomic services from a primary care perspective.

Heidi Rehm, Ph.D., FACMG (she/her/hers), is an investigator in the Center for Genomic Medicine and Chief Genomics Officer at Massachusetts General Hospital, working to integrate genomics into medical practice. She is a board-certified laboratory geneticist and Chief Medical Officer of Broad Clinical Labs guiding genomic testing in medical practice. She is a principal investigator of ClinGen, providing free resources to support the interpretation of genes and variants. Rehm also co-leads the Broad Center for Mendelian Genomics focused on discovering novel rare disease genes. She is a strong advocate and pioneer of open science and data sharing, working to extend these approaches through her role as Chair of the Global Alliance for Genomics and Health. Rehm is also a principal investigator of the Broad All of Us Genome Center and gnomAD, the Genome Aggregation Database, generating genomic resources to fuel discovery.

Robyn Temple-Smolkin, Ph.D., M.B.A. (she/her/hers), is the Senior Director of Clinical and Scientific Affairs and Director of Guideline Development at the Association for Molecular Pathology (AMP). In this role, she oversees the development of AMP clinical practice guidelines,

programs, and collaborations to provide global expertise in molecular testing that drives patient care. As part of the senior leadership team, Dr. Temple directs initiatives for AMP's Clinical Practice and Publications Committees along with five scientific subdivisions: Informatics, Solid Tumors, Genetics, Infectious Disease, and Hematopathology. Dr. Temple holds a Ph.D. in Molecular & Cellular Biology from State University of New York Health Science Center at Brooklyn / Downstate Medical Center and an MBA from Regis University. Her diverse background spans molecular diagnostics, genomics, pathology, clinical laboratory compliance, project management, process improvement, and business development. She is board-certified as a Technical Supervisor and High Complexity Laboratory Director in Molecular Diagnostics by the American Board of Bioanalysis. Prior to AMP, Dr. Temple-Smolkin completed a fellowship in transplant immunogenetics at the University of Pittsburgh Medical Center and developed a clinical pharmacogenetic testing program at Shodair Children's Hospital. As co-founder of Big Sky Diagnostic Labs, she oversaw a CAP-accredited, CLIA-licensed molecular diagnostic laboratory. Also an AMP member, she served on the Infectious Disease Subdivision Nominating Committee and was one of the first members appointed to what became the organization's Membership Committee before joining the professional team. By directing and taking part in the collaborative efforts of AMP volunteer subject matter expert working groups, Dr. Temple has made considerable contributions to the development and implementation of multidisciplinary, evidence-based clinical practice guidelines in genomic medicine and informatics. She has co-authored and/or developed several AMP guidelines, including updated molecular testing recommendations for lung cancer, colorectal cancer biomarkers, and validation of next-generation sequencing assays and bioinformatics pipelines. Her expertise extends to facilitating organizational collaboration in guideline development. Dr. Temple contributed to research on using memorandums of understanding to enhance multi-group guideline development and participated in an international needs assessment survey of guideline developers. Dr. Temple's efforts are continuing to advance the field and improve patient care through development and implementation of scientifically rigorous and clinically relevant genomic medicine and informatics guidelines.

Lindsay Zetzsche, M.S., M.B.A. (she/her/hers), is a proud science geek and licensed genetic counselor with formal business education and experience in the clinical, laboratory, and insurance settings. Her most recent position was Director of Genetics Operations at UnitedHealthcare with experience in promoting the delivery of genetic medicine in ways that are high-quality, cost-efficient, patient-centered, and provider-friendly. Lindsay is the Owner & Founder of Science Geek Games, developing science-based games to ignite a spark of curiosity and joy of learning about the fascinating world of biological sciences through the power of play. She is also the owner of Integrity Genetics Consulting LLC with a special focus on coverage and appropriate billing/reimbursement of genetic testing.

Examining Clinical Guidelines for the Adoption of Genomic Testing: A Workshop

October 29, 2024

SPEAKER GUIDANCE: CONTEXT AND QUESTIONS

Following the Genomics Roundtable's strategic plan development in 2020, the Adoption working group has been interested in cultivating evidence-based practices across the health care and public health systems for adopting genomics and precision health as well as drawing attention to gaps in adoption and potential solutions. The goal of this workshop is to examine how guidelines for genomic testing are developed by various organizations and implemented within clinical practice, with a focus on exploring inconsistencies across guidelines. Thank you for joining us for this session!

SESSION II: Why Guidelines Matter for Genomic Testing

Session Objectives:

- Understand how clinical practice guidelines for genomic testing impact patient care, clinical practice, and other relevant areas, specifically considering impacts on equity in each of these spaces.
- Discuss challenges patients, clinicians, and others face surrounding guidelines.
- Explore how genomic testing guidelines could be advanced to move the needle towards better, more equitable care.

Questions to frame the keynote talk:

1. What are clinical practice guidelines? What is guidance? What are the standards of evidence used to develop guidelines vs guidance vs best practice? What are the differences in how these are used in practice?
2. How are guidelines generated? Why are these methods used?
3. Who is involved in guideline development and who is impacted by this process?
4. What are the challenges faced in guideline development for genomic testing? Where is there room for improvement? Explain why guidelines might be different when they come from different guideline developers.

Key Questions for panelists:

5. When do you refer to clinical guidelines in your work? How are genomic testing guidelines being used across medical specialties and by non-genomicists?
6. When there are multiple, possible conflicting, guidelines, how do you determine which to follow? What are the established tools you use to evaluate which guideline to follow?
7. What does lack of consistency across guidelines, or a lack of guidelines mean for patients, clinicians, guideline developers, payers, industry members?
8. What are the challenges faced surrounding genomic testing guidelines (e.g., conflicts between guidelines and clinical practice)?
9. From your perspective, how could the needle be moved forward in guideline development to create more equitable and efficient care in genomics? What part of the guideline development process is interfering with equity?

SESSION III: Guidelines for Genomic Testing Today

Session Objectives:

- Discuss the benefits and challenges of the current clinical practice guideline development process for genomic testing.
- Explore patient-centric models of guidelines development and how equity is and can be incorporated.
- Consider options for circumstances in which guidelines are not compatible or available.

Questions to frame speakers' talks:

1. What are some of the benefits and challenges to the current clinical guideline development process? Where are the gaps in genomic testing guidelines because of these processes?
2. How do professional societies and other guideline developers work, or not work, together to create consistent guidelines? What are some good examples where collaboration has occurred?
3. How can guidelines be successfully implemented and their impacts on equitable genomic testing be measured?
4. What tools can clinicians use to evaluate the quality of guidelines to help them determine which highest-quality guideline to follow?

Key Questions for Speakers:

5. What are the most time consuming and costly steps in the development of guidelines? Where could changes be made to speed up the process without compromising the rigor?
6. Are there specific challenges blocking patient care and equity in the development of guidelines for genomic testing?
7. Is there a way to work differently and synergistically across guideline developer groups? Are there best practices that can be shared across these groups?
8. What attributes of a guideline repository would be helpful?
9. From your perspective, how could the needle be moved forward in guideline development to create more equitable and efficient care in genomics?

SESSION IV: How Genomic Testing Guidelines Impact Payer Decisions

Session Objectives:

- Examine the role guidelines play in payer decisions (e.g., coverage, reimbursement).
- Discuss opportunities for advancing patient care and access related to these decisions.
- Explore levers for aiding payer decisions such as establishment of or compatibility across guidelines and other possible facilitators.

Questions to frame speakers' talks:

1. How are guidelines used in payer decisions? How does a lack of guidelines, inconsistency across guidelines, or lack of precision in language within guidelines affect coverage decisions?
2. Where are there evidence gaps? How do these affect coverage gaps?
3. What could the field do to ensure that genomic testing recommended in a guideline is equitably covered?

Key Questions for Speakers:

4. How can payors and clinicians work together to advance genomic guidelines and coverage determination? How can guidelines better meet the needs of payers to enable more equitable care?
5. How are coverage determinations, based on guidelines, creating barriers to equity in access to genomic testing and treatment?
6. How might prior authorization as it relates to guidelines play a role in coverage decisions?
7. How might the recent biomarker legislation as it relates to guidelines play a role in coverage decisions?
8. From your perspective, how could the needle be moved forward in guideline development to create more equitable and efficient care in genomics?

SESSION V: Clinical Care Implementation of Guidelines for Genomic Testing

Session Objectives:

- Understand how and when clinical practice guidelines for genomic testing are currently being implemented, or could be implemented, in the clinic.
- Explore the gaps in clinical implementation and what support may be needed to drive better, more equitable care.

Questions to frame speakers' talks:

1. How do you use clinical guidelines for genomic testing in your work? When there are multiple, possible conflicting, guidelines, how do you determine which to follow? What do you do when there are no guidelines?
2. What do implementation scientists and clinicians need from guidelines to best implement them into clinical care?
3. What are the challenges faced surrounding genomic testing guidelines (e.g., conflicts between guidelines and clinical practice, provider education)?
4. Where are there implementation gaps for genomic testing clinical guidelines? What can be done better during implementation to support and drive better care? What are the gaps in tracking implementation of genomic testing clinical guidelines?

Key Questions for Speakers:

5. What are some examples of where implementation has gone well for genomic testing clinical guidelines? Where has implementation not gone as well? And what could have been done to make the implementation better?
6. What does lack of consistency across guidelines or a lack of guidelines mean for adoption of genomic testing by clinicians and implementation scientists?
7. How do we reconcile evidence-based guidelines in genomics while simultaneously practicing precision or personalized medicine (n=1)?
8. From your perspective, how could the needle be moved forward in guideline development to create more equitable and efficient care in genomics?

SESSION VI: Guideline Development in a Rapidly Evolving Field – A Look Ahead

Session Objectives:

- Consider the pace of advances in genomics and what opportunities there are for synergy between this field and guideline development.
- Discuss potential challenges ahead and what work could be started now to alleviate possible obstacles to care.

Questions to frame speakers' talks:

1. What are the impacts of limitations, such as existing evidence, on guideline development for genomic testing? How do these affect adoption of rapidly advancing genomic test options? How does it impact the clinical relevance of guidelines?
2. How might the process of developing or revising clinical practice guidelines for genomic testing better fit this rapidly evolving field? Would this be possible, why or why not?

Key Questions for Speakers:

3. What are the possible impacts when guidelines contradict clinical practice, particularly for rare diseases?
4. What are the potential impacts for genomic testing of changing the guideline development process vs not changing?
5. What emerging tools can be used by all relevant parties to maintain rigor and expedite quality guidelines?
6. From your perspective, how could the needle be moved forward in guideline development to create more equitable and efficient care in genomics?

NATIONAL ACADEMIES *Sciences Engineering Medicine*

PREVENTING DISCRIMINATION, HARASSMENT, AND BULLYING:
POLICY FOR PARTICIPANTS IN NASEM ACTIVITIES

The National Academies of Sciences, Engineering, and Medicine (NASEM) are committed to the principles of diversity, inclusion, integrity, civility, and respect in all of our activities. We look to you to be a partner in this commitment by helping us to maintain a professional and cordial environment. **All forms of discrimination, harassment, and bullying are prohibited in any NASEM activity.** This policy applies to all participants in all settings and locations in which NASEM work and activities are conducted, including committee meetings, workshops, conferences, and other work and social functions where employees, volunteers, sponsors, vendors, or guests are present.

Discrimination is prejudicial treatment of individuals or groups of people based on their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws.

Sexual harassment is unwelcome sexual advances, requests for sexual favors, and other verbal or physical conduct of a sexual nature that creates an intimidating, hostile, or offensive environment.

Other types of harassment include any verbal or physical conduct directed at individuals or groups of people because of their race, ethnicity, color, national origin, sex, sexual orientation, gender identity, age, religion, disability, veteran status, or any other characteristic protected by applicable laws, that creates an intimidating, hostile, or offensive environment.

Bullying is unwelcome, aggressive behavior involving the use of influence, threat, intimidation, or coercion to dominate others in the professional environment.

REPORTING AND RESOLUTION

Any violation of this policy should be reported. If you experience or witness discrimination, harassment, or bullying, you are encouraged to make your unease or disapproval known to the individual at the time the incident occurs, if you are comfortable doing so. You are also urged to report any incident by:

- Filing a complaint with the Office of Human Resources at 202-334-3400 or hrservicecenter@nas.edu, or
- Reporting the incident to an employee involved in the activity in which the member or volunteer is participating, who will then file a complaint with the Office of Human Resources.

Complaints should be filed as soon as possible after an incident. To ensure the prompt and thorough investigation of the complaint, the complainant should provide as much information as is possible, such as names, dates, locations, and steps taken. The Office of Human Resources will investigate the alleged violation in consultation with the Office of the General Counsel.

If an investigation results in a finding that an individual has committed a violation, NASEM will take the actions necessary to protect those involved in its activities from any future discrimination, harassment, or bullying, including in appropriate circumstances **the removal of an individual from current NASEM activities and a ban on participation in future activities**.

CONFIDENTIALITY

Information contained in a complaint is kept confidential, and information is revealed only on a need-to-know basis. NASEM will not retaliate or tolerate retaliation against anyone who makes a good faith report of discrimination, harassment, or bullying.

Updated December 2, 2021

BACKGROUND MATERIALS

Links to Additional Resources

Session II: Why Guidelines Matter for Genomic Testing

- NASEM. 2011. Clinical Guidelines We Can Trust. *National Academies Press.* https://nap.nationalacademies.org/catalog/13058/clinical-practice-guidelines-we-can-trust
- Video. A Guide to Trustworthy Guidelines: What are They, and Why do We Need Them? https://www.youtube.com/watch?v=Ub6QlXsXNjk
- Schünemann, et al. 2014. Guidelines 2.0: systematic development of a comprehensive checklist for a successful guideline enterprise. *CMAJ.* https://pmc.ncbi.nlm.nih.gov/articles/PMC3928232/pdf/186e123.pdf
- Morgan, et al. 2018. Development of rapid guidelines: 3. GIN-McMaster Guideline Development Checklist extension for rapid recommendations. *Health Research Policy and Systems.* https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-018-0330-0
- Akl, et al. 2017. GRADE equity guidelines 2: considering health equity in GRADE guideline development: equity extension of the guideline development checklist. *JCE.* https://www.jclinepi.com/article/S0895-4356(17)30470-5/fulltext
- Munn, et al. 2020. Developing Guidelines Before, During, and After the COVID-19 Pandemic. *Annals of Internal Medicine*. https://pmc.ncbi.nlm.nih.gov/articles/PMC7505021/pdf/aim-olf-M204907.pdf
- Kolaski, et al. 2023. Guidance to best tools and practices for systematic reviews. *JBI Evidence Synthesis*. https://pmc.ncbi.nlm.nih.gov/articles/PMC10464882/pdf/srx-21-1699.pdf
- Sultan, et al. An International Needs Assessment Survey of Guideline Developers Demonstrates Variability in Resources and Challenges to Collaboration between Organizations. *Journal of General Internal Medicine.* https://link.springer.com/article/10.1007/s11606-021-07112-w
- Arjunan, et al. 2022. Addressing Reproductive Healthcare Disparities through Equitable Carrier Screening: Medical Racism and Genetic Discrimination in United States' History Highlights the Needs for Change in Obstetrical Genetics Care. *Societies*. https://www.mdpi.com/2075-4698/12/2/33
- Peters, et al. 2022. Trends in guideline implementation: an updated scoping review. *Implementation Science*. https://implementationscience.biomedcentral.com/articles/10.1186/s13012-022-01223-6
- Gan-Or. 2024. Clinical genetic testing in Parkinson's disease should become part of routine patient care. *BRAIN* https://doi.org/10.1093/brain/awae181
- Innocenti, et al. 2020. All You Need to Know About *DPYD* Genetic Testing for Patients Treated With Fluorouracil and Capecitabine: A Practitioner-Friendly Guide. *JCO Oncology Practice.* https://ascopubs.org/doi/10.1200/OP.20.00553

Session III: Guidelines for Genomic Testing Today

- Bauchner & Ioannidis. 2024. The Subjective Interpretation of the Medical Evidence. *JAMA Health Forum*. https://jamanetwork.com/journals/jama-health-forum/fullarticle/2816950
- Lin et al. 2012. Evaluating genomic tests from bench to bedside: A practical framework. *BMC Medical Informatics and Decision Making* https://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-12-117
    - Example application of the above framework: Doubeni et al. 2022. Development and evaluation of safety and effectiveness of novel cancer screening tests for routine clinical use with applications to multicancer detection technologies. *Cancer* https://acsjournals.onlinelibrary.wiley.com/doi/10.1002/cncr.33954
- Lin et al. 2024. Development of a Health Equity Framework for the US Preventative Services Task Force. *JAMA Network Open* https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2815866

Session IV: How Genomic Testing Guidelines Impact Payer Decisions

- Quinn. 2024. Journal Club: Horgan et al. on the gap between medical guidelines and payor policy utilization. Discoveries in Health Policy Blog. https://www.discoveriesinhealthpolicy.com/2024/08/journal-club-horgan-et-al-on-gap.html?lctg=145611892

Session V: Clinical Care Implementation of Guidelines for Genomic Testing

- NASEM. 2016. Applying an Implementation Science Approach to Genomic Medicine: A workshop Summary (Appendix E - Implementation Science: A Background) https://nap.nationalacademies.org/read/23403/chapter/13
- Chambers, et al. 2016. Convergence of Implementation Science, Precision Medicine, and the Learning Health Care System: A New Model for Biomedical Research. *JAMA* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5624312/

Session VI: Guideline Development in a Rapidly Evolving Field – A Look Ahead

- Lewis, SZ. Developing Trustworthy Consensus-Based Guidelines When Only Low-Quality Evidence Exists. Guidelines International Network Conference. Glasgow, Scotland. September 22, 2023. https://www.youtube.com/watch?v=0ebOxV81dpg
- Burke, et al. 2019. Improving recommendations for genomic medicine: Building an evolutionary process from clinical practice advisory documents to guidelines. *Genetics in Medicine*. https://doi.org/10.1038/s41436-019-0549-3
- Bunnell. 2023. Commentary: Modernizing Guidelines Development to Speed the Transfer of Science to Patient Care. *Am J Med Qual.* DOI: 10.1097/JMQ.0000000000000130.

- Michaels. 2023. Adapting Clinical Guidelines for the Digital Age: Summary of a Holistic and Multidisciplinary Approach. *Am J Med Qual.* DOI: 10.1097/JMQ.0000000000000138.
- Matson-Koffman, et al. 2023. An Integrated Process for Co-Developing and Implementing Written and Computable Clinical Practice Guidelines. *Am J Med Qual.* DOI: 10.1097/JMQ.0000000000000137.
- Tailor, et al. 2023. An Evaluation Framework for a Novel Process to Codevelop Written and Computable Guidelines. *Am J Med Qual.* DOI: 10.1097/JMQ.0000000000000140.
- Michaels, et al. 2023. Adapted Kaizen: Multi-Organizational Complex Process Redesign for Adapting Clinical Guidelines for the Digital Age. *Am J Med Qual.* DOI: 10.1097/JMQ.0000000000000133.
- Alper BS. 2024. Making guidelines computable. *Clin Pub Health Guidelines*. https://doi.org/10.1002/gin2.12014
- Tendala, et. al. 2021. Weekly updates of national living evidence-based guidelines: methods for the Australian living guidelines for care of people with COVID-19. *Journal of Clinical Epidemiology*. https://pubmed.ncbi.nlm.nih.gov/33188858/
- Vogel, et.al. 2019. Developing and applying a 'living guidelines' approach to WHO recommendations on maternal and perinatal health. *BMJ Global Health*. https://pmc.ncbi.nlm.nih.gov/articles/PMC6703290/
- Cheyne, et al. 2023. Methods for living guidelines: Early guidance based on practical experience: Paper 1: Introduction. *Journal of Clinical Epidemiology*. https://www.jclinepi.com/action/showPdf?pii=S0895-4356%2822%2900344-4

ANNOUNCEMENTS

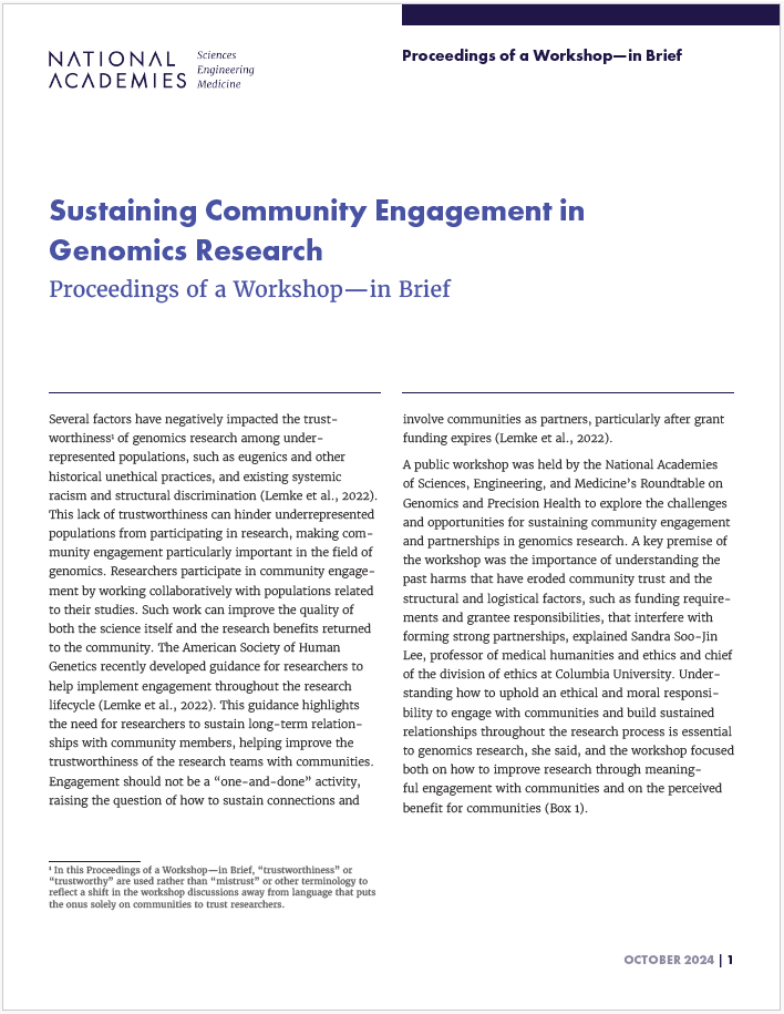
NATIONAL ACADEMIES Sciences Engineering Medicine

Roundtable on Genomics and Precision Health

New Proceedings in Brief of a Workshop!

Sustaining Community Engagement in Genomics Research

Link: https://nap.edu/28044



NATIONAL ACADEMIES Sciences Engineering Medicine

Proceedings of a Workshop—in Brief

Sustaining Community Engagement in Genomics Research

Proceedings of a Workshop—in Brief

Several factors have negatively impacted the trustworthiness[1] of genomics research among underrepresented populations, such as eugenics and other historical unethical practices, and existing systemic racism and structural discrimination (Lemke et al., 2022). This lack of trustworthiness can hinder underrepresented populations from participating in research, making community engagement particularly important in the field of genomics. Researchers participate in community engagement by working collaboratively with populations related to their studies. Such work can improve the quality of both the science itself and the research benefits returned to the community. The American Society of Human Genetics recently developed guidance for researchers to help implement engagement throughout the research lifecycle (Lemke et al., 2022). This guidance highlights the need for researchers to sustain long-term relationships with community members, helping improve the trustworthiness of the research teams with communities. Engagement should not be a "one-and-done" activity, raising the question of how to sustain connections and involve communities as partners, particularly after grant funding expires (Lemke et al., 2022).

A public workshop was held by the National Academies of Sciences, Engineering, and Medicine's Roundtable on Genomics and Precision Health to explore the challenges and opportunities for sustaining community engagement and partnerships in genomics research. A key premise of the workshop was the importance of understanding the past harms that have eroded community trust and the structural and logistical factors, such as funding requirements and grantee responsibilities, that interfere with forming strong partnerships, explained Sandra Soo-Jin Lee, professor of medical humanities and ethics and chief of the division of ethics at Columbia University. Understanding how to uphold an ethical and moral responsibility to engage with communities and build sustained relationships throughout the research process is essential to genomics research, she said, and the workshop focused both on how to improve research through meaningful engagement with communities and on the perceived benefit for communities (Box 1).

[1] In this Proceedings of a Workshop—in Brief, "trustworthiness" or "trustworthy" are used rather than "mistrust" or other terminology to reflect a shift in the workshop discussions away from language that puts the onus solely on communities to trust researchers.

OCTOBER 2024 | 1

NATIONAL ACADEMIES Sciences Engineering Medicine

Upcoming Consensus Study Report Release!

The Use of Race & Ethnicity in Biomedical Research

Register for the October 31, 2024 Report Release Webinar:
https://www.nationalacademies.org/event/43893_10-2024_the-use-of-race-and-ethnicity-in-biomedical-research-report-release-webinar

Statement of Task

An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine will assess the current use of the social constructs of race and ethnicity in biomedical research and provide recommendations to guide the scientific community in the future use of race and ethnicity in biomedical research.

More specifically, the committee will:

- Document and evaluate how racialized group and ethnic categories are currently being used in biomedical research (e.g., as a descriptor, to stratify data, to apply race norming, to infer differences between groups due to environmental and social impacts), including describing consequences and contributions to health inequities in current clinical practices;
- Identify the circumstances in which it is appropriate to use the social constructs of race and ethnicity in biomedical research, for example in studying the health effects of racism, and the circumstances in which race and ethnicity should not be used to inform inferences;
- Review existing guidance for researchers on the use of race as a variable in biomedical research.

Based on its review of the literature and other expert input, the committee will develop a report with its findings, conclusions, and recommendations for entities such as researchers, funders, publishers, scientific and medical societies, health systems, and industry regarding:

- The use of race and ethnicity in biomedical research, including identifying current practices that should be continued, stopped, or modified.
- Policy changes to reform the use of race and ethnicity in biomedical research, with specific attention to the practice of race norming or race correction.
- Implementation strategies to help enhance the adoption of best practices across the biomedical research community.

The committee's work will focus on the use of racialized group and ethnic categories across the spectrum of biomedical research, including the development of clinical prediction models and other clinical decision tools. Related topics in the provision of clinical care, such as inequitable access to health care and racism in care delivery, are beyond the scope of this study.

NATIONAL ACADEMIES *Sciences Engineering Medicine*

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Funded by the Doris Duke Foundation and the Burroughs Welcome Fund

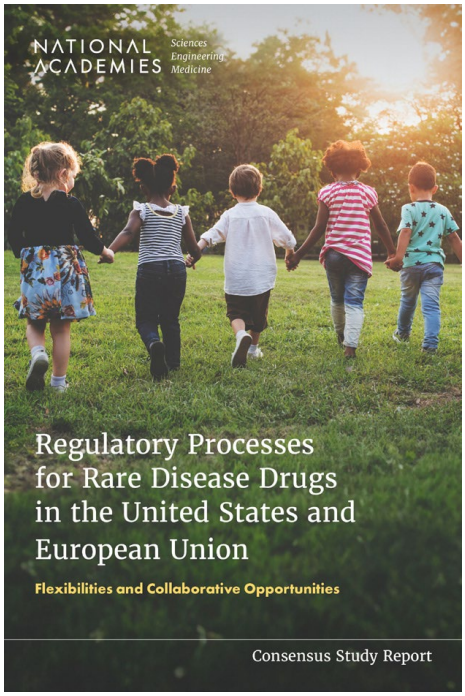
Find more information on the project page: https://www.nationalacademies.org/our-work/the-use-of-race-and-ethnicity-in-biomedical-research

NATIONAL ACADEMIES Sciences Engineering Medicine

New NASEM Consensus Study Report!

Regulatory Processes for Rare Disease Drugs in the United States and European Union: Flexibilities and Collaborative Opportunities

Link: https://nap.nationalacademies.org/catalog/27968/



There are more than 7,000 life-threatening and chronically debilitating rare diseases. While each disease affects a small number of people, together rare diseases affect up to 30 million individuals in the United States and at least 300 million across the globe.

Congress called on the U.S. Food and Drug Administration (FDA) to sponsor a study of the National Academies of Sciences, Engineering, and Medicine on processes for evaluating the safety and efficacy of drugs for rare diseases or conditions in the United States and European Union (EU). The consensus study committee was tasked with examining the regulatory flexibilities available to FDA and the European Medicines Agency (EMA), the current use of supplemental data in regulatory decisions (the committee elected to use the term "alternative and confirmatory data [ACD]"), and the ongoing collaboration between FDA and EMA.

The resulting report provides recommendations for enhancing and promoting rare disease drug development by improving engagement with people affected by a rare disease, advancing regulatory science, and fostering collaboration between FDA and EMA. These regulatory agencies play critical roles in ensuring rare disease drugs are safe and effective. Regulatory flexibilities help the agencies protect and advance public health, but opportunities exist for improvements in engagement, collaboration, and regulatory science.

More resources are available through the project page

A recording of the report release webinar can be found here

ROUNDTABLE AND FORUM INFORMATION

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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The National Academy of Sciences, National Academy of Engineering, and National Academy of Medicine work together as the National Academies of Sciences, Engineering, and Medicine ("the Academies") to provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions. The Academies also encourage education and research, recognize outstanding contributions to knowledge, and increase public understanding in matters of science, engineering, and medicine.

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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.

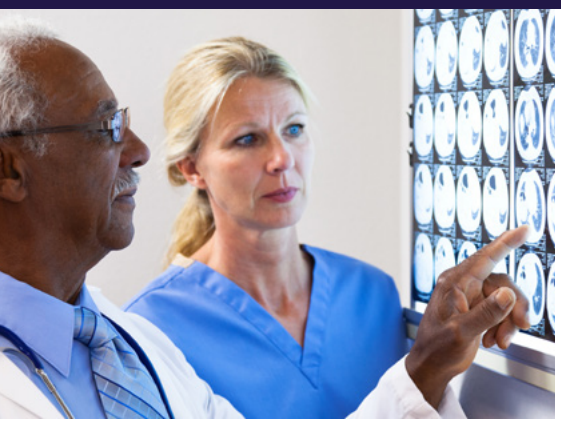
DEFINITIONS

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 ACADEMIES Sciences Engineering Medicine



National Cancer Policy Forum

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

The forum has addressed a wide array of topics, including

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

NATIONAL CANCER POLICY FORUM

Upcoming and Recent Workshops

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

Collaborative workshop convened by:
National Cancer Policy Forum
Board on Mathematical Sciences and Analytics
Board on Life Sciences

May 20–21, 2025

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

Learn more and register here

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

Collaborative workshop convened by:
National Cancer Policy Forum
Forum on Mental Health and Substance Use Disorders

March 17-18, 2025

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

Learn more and register here

Examining Clinical Guidelines for the Adoption of Genomic Testing

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

October 29, 2024

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

Learn more and register here

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

October 28-29, 2024

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

Learn more and register here

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

July 29–30, 2024

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

Workshop videos and presentations

Toward a Framework to Improve Diversity and Inclusion in Clinical Trials

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

May 20, 2024

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

Workshop videos and presentations

Recent Workshops

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

March 20–21, 2024

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

Workshop videos and presentations

Optimizing Public–Private Partnerships for Clinical Cancer Research

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

October 17–18, 2023

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

Workshop videos and presentations

Proceedings

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

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

October 5–6, 2023

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

Workshop videos and presentations

Proceedings

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

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

July 17–18, 2023

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

Workshop videos and presentations

Proceedings

The Impact of the Dobbs Decision on Cancer Care Webinar Series

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

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

Webinar series website

Interactive webpage

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

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

April 13, 2023

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

Workshop videos and presentations

Proceedings

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 Cancer Care Centers

Cancer Center at Illinois

Flatiron Health

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National Comprehensive Cancer Network

National Patient Advocate Foundation

Novartis Oncology

Oncology Nursing Society

Partners In Health

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