The National Academies of
SCIENCES • ENGINEERING • MEDICINE

Board on Health Sciences Policy
Roundtable on Genomics and Precision Health

Understanding Disparities in Access to Genomic Medicine – A Workshop

June 27, 2018

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

Statement of Task:

Genomic medicine is advancing rapidly due to research breakthroughs and technology development. However, it is not clear if genetic/genomic services will reach all segments of the population both now and in the near future. To address potential gaps in access to these care services, an ad hoc committee will plan and conduct a one day public workshop to explore disparities in access to genetic/genomic services that exist across different segments of the population (e.g., in medically underserved areas and populations, across different racial/ethnic groups, and socioeconomic levels). The workshop may discuss model programs of care for diverse patient populations, with a focus on examining current challenges, approaches and best practices for alleviating disparities in access, which may include the geographic distribution of providers and services and the potential role of telemedicine. Workshop discussions may also focus on insurance coverage for genetic/genomic services, along with the financial costs for patients of genetic testing and downstream care. A broad array of stakeholders may take part in the workshop, including genomics experts, health economists, public health and health disparities researchers, clinicians, users of the health care system (e.g., consumers, patients), patient advocacy groups, payers, bioethicists, community members, and policy makers. The committee will develop the workshop agenda, select and invite speakers and discussants, and may moderate the discussions. Proceedings of the workshop will be prepared by a designated rapporteur in accordance with institutional policy and procedures.

AGENDA

8:30 a.m. **Opening Remarks**

GEOFFREY GINSBURG, *Roundtable Co-Chair*
Director, Duke Center for Applied Genomics & Precision Medicine
Professor, Medicine, Pathology, and Biomedical Engineering
Duke University Medical Center

MICHELLE PENNY, *Roundtable Co-Chair*
Director and Head of Computational Biology and Genomics
Biogen

8:35 a.m. **Charge to Workshop Speakers and Participants**

VENCE BONHAM, *Workshop Co-Chair*
Senior Advisor to the Director on Genomics and Health Disparities
National Human Genome Research Institute
National Institutes of Health

CATHY WICKLUND, *Workshop Co-Chair*
Director, Graduate Program in Genetic Counseling
Past President, National Society of Genetic Counselors
Feinberg School of Medicine, Center for Genetic Medicine
Northwestern University

8:50 a.m. **Opening Keynote Lecture**

OTIS BRAWLEY
Chief Medical and Scientific Officer
American Cancer Society

9:10 a.m. **Clarifying Questions from Workshop Participants**

SESSION I: VOICES OF THE COMMUNITY—EXPLORING THE BARRIERS TO ACCESSING GENOMICS/GENETICS SERVICES

Session Objective:

- To learn about ongoing challenges from those individuals who are having trouble accessing genetics/genomics services.

Session Moderator: Elda Railey, Co-Founder, Research Advocacy Network

9:20 a.m. CANDACE HENLEY
Executive Director and Founder
The Blue Hat Foundation

9:35 a.m. SUE FRIEDMAN
Executive Director and Founder
Facing Our Risk of Cancer Empowered (FORCE)

9:50 a.m. PAT JOLLEY
Director, Clinical Initiatives
Patient Advocate Foundation

10:05 a.m. JOHN MOESCHLER
Professor of Pediatrics, Geisel School of Medicine
Dartmouth College

10:20 a.m. **Panel Discussion with Speakers and Workshop Participants**

Discussant:
NATASHA BONHOMME
Chief Strategy Officer
Genetic Alliance

10:50 a.m. **Break**

SESSION II: THE ROLE OF HEALTH SYSTEMS IN DELIVERING EQUITABLE ACCESS

Session Objective:

- Explore the perspectives of health care delivery systems as they relate to delivering fair and equitable access to genetics and genomics services.

Session Moderator: Bruce Quinn, Founder, Bruce Quinn Associates LLC

11:05 a.m. LARRY MEYER
National Director, Genomic Medicine
Veterans Administration Medical Center

11:20 a.m. KATHERINE ANDERSON
Primary Care Specialist
Denver Health

11:35 a.m. KENT HOSKINS
Associate Professor of Medicine
Director, Familial Breast Cancer Program
University of Illinois at Chicago

11:50 a.m. **Panel Discussion with Speakers and Audience Members**

12:20 p.m. **Working Lunch**

SESSION III: HOW CAN PROVIDERS MAKE GENOMIC MEDICINE MORE ACCESSIBLE?

Session Objectives:

- Examine providers' perspectives with regard to the feasibility of ordering genetic tests and providing follow-up care, with a special focus on under-resourced settings.

Session Moderator: S. Malia Fullerton, Associate Professor, University of Washington

1:20 p.m. SEAN TUNIS
Founder and Chief Executive Officer
Center for Medical Technology Policy

1:35 p.m. BRIAN AHMEDANI
Director of Psychiatry Research
Research Scientist, Center for Health Policy & Health Services Research
Henry Ford Health System

1:50 p.m. KATRINA ARMSTRONG
Physician-in-Chief, Department of Medicine
Massachusetts General Hospital

2:05 p.m. PREETI MALANI
Chief Health Officer, University of Michigan
Professor of Medicine, University of Michigan Medical School

2:20 p.m. **Panel Discussion with Speakers and Workshop Participants**

2:50 p.m. **Break**

SESSION IV: EXPLORING INNOVATIVE SOLUTIONS AND MODELS OF SUCCESS

Session Objectives:

- Discuss new approaches that would ensure that genetics/genomics services are available to all, including medically underserved populations.
- Identify areas where there is a gap in the knowledge and consider research projects that would help answer open questions.

Session Moderator: W. Gregory Feero, Faculty, Maine Dartmouth Family Medicine Residency Program

3:05 p.m. MARC SCHWARTZ
Professor of Oncology
Co-Director of the Cancer Prevention and Control Program
Research Director, Fisher Center for Hereditary Cancer and Clinical Genomics Research
Georgetown University

3:20 p.m. RENA PASICK
Professor, Department of Medicine
Director, Office of Community Engagement
UCSF Helen Diller Family Comprehensive Cancer Center

3:35 p.m. JACQUELYN TAYLOR
Associate Professor and Vernice D. Ferguson Chair in Health Equity
NYU Rory Meyers College of Nursing

3:50 p.m. TODD SKAAR
Associate Professor of Medicine
Indiana University School of Medicine

4:05 p.m. **Panel Discussion with Speakers and Workshop Participants**

SESSION V: IDENTIFYING UNMET NEEDS TO ALLEVIATE HEALTH CARE DISPARITIES IN GENOMIC MEDICINE

Session Objectives:

- Identify potential solutions to overcoming barriers in access to genomic medicine and actionable next steps that can be taken in the near-term (1-3 years) and long-term (3-10 years) to reduce health care disparities in this area.
- Explore gaps in policy, knowledge, and/or institutional resources that could be addressed to ensure that genomic medicine is equitably distributed across populations.

Session Moderators: Vence Bonham, Senior Advisor to the Director on Genomics and Health Disparities, National Human Genome Research Institute, and Cathy Wicklund, Director, Graduate Program in Genetic Counseling, Northwestern University

4:35 p.m. **Concluding Keynote Lecture**

REED TUCKSON
Managing Director
Tuckson Health Connections, LLC

4:50 p.m. **Final Panel Discussion**

KATHERINE ANDERSON
OTIS BRAWLEY
SUE FRIEDMAN
JACQUELYN TAYLOR
REED TUCKSON

5:20 p.m. **Final Remarks from Workshop Co-chairs**

VENCE BONHAM, *Workshop Co-Chair*
Senior Advisor to the Director on Genomics and Health Disparities
National Human Genome Research Institute
National Institutes of Health

CATHY WICKLUND, *Workshop Co-Chair*
Director, Graduate Program in Genetic Counseling
Past President, National Society of Genetic Counselors
Feinberg School of Medicine, Center for Genetic Medicine
Northwestern University

5:30 p.m. **Adjourn**