

*The National Academies of*  
**SCIENCES • ENGINEERING • MEDICINE**

*Board on Health Sciences Policy*

***An Examination of Emerging Bioethical Issues in  
Biomedical Research: A Workshop***

**February 26, 2020**

Keck Building  
Room 100  
500 Fifth Street NW  
Washington DC 20001  
*(note location change as of 1/23/2020)*

**STATEMENT OF TASK:**

A planning committee of the National Academies of Sciences, Engineering, and Medicine will be appointed to conduct a one day workshop to bring together stakeholders to discuss potential ethical issues that may arise from new and emerging trends in biomedical research (including behavioral and social research) and society. The workshop will identify a range of current and emerging bioethical issues - both in basic and clinical research - and explore a broad-range of stakeholder perspectives. Input will be sought from a variety of perspectives which may include patients/participants/individuals, bioethicists, academic and industry researchers, clinicians, and government representatives. The workshop will describe the state of the emerging science and potential pressing, recurring, emerging, and/or anticipated future bioethical issues in biomedical research and society that fall within the scope of the research and policy activities of the NIH. Potential topics may include:

- Use of digital technologies, artificial intelligence, and machine learning in biomedical research and clinical care;
- Emerging ethical challenges for sharing data from human research participants and use of human biospecimens;
- Health equity and health disparities in research, including:
  - Recognizing and addressing barriers to participation in research and clinical care across diverse populations and groups
  - Understanding the impact of cultural and social context on health and disease
  - Equitable distribution of the benefits and burdens of research;
- Innovative study designs, including crowdsourcing of research and citizen science;
- Novel approaches for enhancing bioethics infrastructure and training;
- New means for assessing and enhancing scientific workforce diversity; and/or
- Innovative solutions for enhancing research oversight infrastructure.

Given the broad scope of bioethical issues in research and the difficulty in addressing all possible issues in a single workshop, the following topics fall outside the scope of this workshop as they are being addressed in multiple other venues: gene editing, gene drives, human-animal chimera research, human fetal tissue research, neuroethics, and animal care and welfare. The planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate or identify moderators for the discussions. A workshop proceedings will be prepared by a designated rapporteur based on the information gathered and discussions held during the workshop in accordance with National Academies institutional policies and procedures.

## **AGENDA**

### **8:30 a.m. Opening Remarks and Charge to Workshop Speakers and Participants**

JEFFREY KAHN

Andreas C. Dracopoulos Director, Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics and Public Policy, Berman Institute of Bioethics  
Professor, Health Policy and Management, Johns Hopkins Bloomberg School of Public Health  
Johns Hopkins University

## **SESSION I: DEVELOPING, TESTING, AND INTEGRATING NEW DIGITAL TECHNOLOGIES INTO RESEARCH AND CLINICAL CARE**

*Session Moderator: Bernard Lo, The Greenwall Foundation*

8:45 a.m. DEBORAH ESTRIN  
Associate Dean and Robert V. Tishman '37 Professor  
Cornell Tech

9:00 a.m. MICHELLE MELLO  
Professor of Law and Medicine  
Stanford University

## **SESSION II: USING ARTIFICIAL INTELLIGENCE AND MACHINE LEARNING IN RESEARCH AND CLINICAL CARE**

*Session Moderator: Bernard Lo, The Greenwall Foundation*

9:15 a.m. SUCHI SARIA  
John C. Malone Assistant Professor  
Departments of Computer Science and Health Policy & Management  
John Hopkins University

- 9:30 a.m. PILAR OSSORIO  
Professor of Law and Bioethics  
University of Wisconsin
- 9:45 a.m. **Panel Discussion with Speakers from Sessions I and II**
- 10:45 a.m. **Break**

### **SESSION III: ETHICAL QUESTIONS AROUND NON-TRADITIONAL APPROACHES FOR DATA COLLECTION AND USE**

*Session Moderator: Camille Nebeker, UCSD*

- 11:00 a.m. ERIC HEKLER  
Associate Professor  
Department of Family Medicine and Public Health  
University of California, San Diego
- 11:15 a.m. JOHN WILBANKS  
Chief Commons Officer  
Sage Bionetworks
- 11:30 a.m. **Panel Discussion with Speakers and Workshop Participants**
- ERIC HEKLER, University of California, San Diego  
JOHN WILBANKS, Sage Bionetworks
- CAMILLE NEBEKER  
Associate Professor  
School of Medicine  
University of California, San Diego
- 12:00 p.m. **Break for Lunch**

### **SESSION IV: UNDERSTANDING THE IMPACT OF INEQUALITY ON HEALTH, DISEASE, AND WHO PARTICIPATES IN RESEARCH**

*Moderator: Anita Allen, University of Pennsylvania*

- 1:15 p.m. DOROTHY ROBERTS  
George A. Weiss University Professor of Law and Sociology  
Raymond Pace and Sadie Tanner Mossell Alexander Professor of Civil Rights  
University of Pennsylvania
- 1:30 p.m. VANESSA HIRATSUKA  
Senior Researcher  
Southcentral Foundation

1:45 P.M.      **Panel Discussion with Speakers and Workshop Participants**

**SESSION V: CHALLENGES AND OPPORTUNITIES IN THE BIOETHICS RESEARCH  
WORKFORCE INFRASTRUCTURE AND FOR ENSURING DIVERSITY**

*Session Moderator: Maria Merritt, Johns Hopkins University*

- 2:15 p.m.      **BEN WILFOND**  
Director, Treuman Katz Center for Pediatric Bioethics  
Seattle Children's Hospital and Research Institute  
Professor and Chief  
Division of Bioethics and Palliative Care, Department of Pediatrics  
University of Washington School of Medicine
- 2:20 p.m.      **CARLA SAENZ**  
Regional Advisor on Bioethics  
Pan American Health Organization
- 2:25 p.m.      **MICHAEL SUMMERS**  
Professor of Chemistry and Investigator with Howard Hughes Medical Institute  
University of Maryland, Baltimore County
- 2:30 p.m.      **Moderated Discussion with Panelists**
- 3:00 p.m.      **Questions from Workshop Participants**
- 3:30 p.m.      Break**

**SESSION VI: LOOKING TO THE FUTURE AND ANTICIPATING ETHICAL ISSUES  
RELATED TO BIOMEDICAL RESEARCH**

Session Objectives:

- Discuss the action items covered during the day and what is needed to prepare for and address the challenges of emerging bioethical issues over the next 5-10 years.

*Session Moderator: Jeffrey Kahn, Johns Hopkins University*

- 3:45 p.m.      **Reactions from stakeholders**
- TANIA SIMONCELLI  
Director of Policy for Science  
The Chan Zuckerberg Initiative
- DAN O'CONNOR  
Head of Humanities and Social Science  
Wellcome

DAVID CASTLE  
Executive-in-residence, Genome Canada  
Adjunct Professor, University of Victoria, British Columbia

4:00 p.m.      **Discussion with Workshop Participants**

4:30 p.m.      **Insights from the Day's Discussions**

JEFFREY KAHN  
Andreas C. Dracopoulos Director, Robert Henry Levi and Ryda Hecht Levi Professor of  
Bioethics and Public Policy, Berman Institute of Bioethics  
Professor, Health Policy and Management, Johns Hopkins Bloomberg School of Public  
Health  
Johns Hopkins University

4:45 p.m.      **Concluding Remarks**

5:00 p.m.      **Adjourn**