

COMMEMORATING THE 50TH ANNIVERSARY OF THE NATIONAL RESEARCH ACT

2024 OHRP VIRTUAL EVENT

Friday, July 12, 2024, 12:00 p.m. to 2:30 p.m. EDT

July 12, 2024, marks the 50th anniversary of the enactment of the National Research Act. The National Research Act was a response to public outcry that the federal government let hundreds of Black men in rural Alabama go untreated for syphilis for 40 years to study the impact of the disease on the human body. The Act included the creation of federal rules to protect human research participants. It also led to the establishment of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to identify ethical standards to guide human research. This OHRP commemorative event will reflect on what happened following the passage of the National Research Act, showcase the diverse role research participants play in contemporary research, and consider what future scientific advances may mean for research participants and public trust in research.

AGENDA

Time	Sessions
Session Title	Opening
12:00 p.m. – 12:15 p.m.	<ul style="list-style-type: none">• OHRP's Welcome• ASH's Address
Session Title	What Followed the National Research Act
12:15 p.m. – 12:50 p.m.	<ol style="list-style-type: none">1. Reflections on the Work of the National Commission<p>The former Commissioner of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research will talk about her experience serving on the Commission, her reflections on the Commission's work, and its impact on research.</p><p>Speaker: Patricia A. King, J.D.; <i>Professor Emerita, Georgetown Law</i></p>2. The Evolution of the Regulations for Human Research Protections and the Establishment of OHRP<p>The OHRP speaker will provide a brief overview of the National Research Act, describe how the initial regulations came about, and how the Office for Human Research Protections was established.</p><p>Speaker: Ivor A. Pritchard, Ph.D.; <i>Senior Advisor to the Director of the HHS Office for Human Research Protections</i></p>3. A Brief History of Public Responsibility in Medicine and Research (PRIM&R) – A Response from the Research Community<p>The Executive Director of PRIM&R will provide a historical overview of the nonprofit founded 50 years ago as a response to the new law requiring the development of guidelines and laws to oversee and regulate human research, and offer an account of how the organization came about, what role it hoped to play, and how it would achieve its objective.</p><p>Speaker: Ivy Tillman, Ed.D.; <i>Executive Director of PRIM&R</i></p>

Event website: <https://www.hhs.gov/ohrp/education-and-outreach/national-research-act-50th-anniversary/index.html>

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Session Title	From Research Subject to Research Partner
12:50 p.m. – 1:45 p.m.	<p><i>Fifty years after the passage of the National Research Act, people are no longer seen as merely “subjects” in research but are now regarded as integral partners. This session will showcase the different ways the public may be engaged in the research process to advance science and further their interests as individuals and members of a community.</i></p> <p>1. Why I Participated in Research - A Participant’s Voice A former participant will reflect on their experience in research and address how participating led them to a career in research recruitment and coordination involving teenagers and young adults. Speaker: Rey Calabrese; <i>Former Research Participant and Current Research and Community Coordinator at Fenway Health</i></p> <p>2. Participants as Investigators: Participatory Action Research and Community-Led Studies Community research coordinators have an increasing role in research, especially in social, behavioral, and education studies. A community research coordinator will discuss how, as a member of the local community, he became involved in community participatory-action research and the role he and participants have played in facilitating meaningful research for their communities. Speaker: Basaime Spate; <i>Community Research Coordinator, Center for Justice Innovation</i></p> <p>3. Respecting Cultural Values: Doing Research with Indigenous Populations An enrolled member of the Choctaw Nation of Oklahoma with a deep commitment to engaging tribal leadership in community-based participatory health research will discuss efforts taken to build research partnerships with tribal nations while ensuring respect for cultural values and interests. Speaker: Karina L. Walters, Ph.D., M.S.W.; <i>Director, NIH’s Tribal Health Research Office (THRO)</i></p> <p>4. Listening to the People: Community Ethics Review Boards Community Ethics Boards are one way in which the community can give feedback and improve research proposals. A member of a Community Ethics Board will discuss how they advise researchers on the community’s needs, perspectives, and values, and ultimately shape local research. Speaker: Ella Greene-Moton; <i>Member of a Community Ethics Board in Flint, MI, and President of the American Public Health Association</i></p>

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12:50 p.m. – 1:45 p.m.	<p>5. Engaging the Community in Research: The Insight of an Investigator</p> <p>Community engagement has become an important part of a successful research program. Dr. Aguilar-Gaxiola will share his insights on why this is important, the benefits it brings to research, what he's learned from the communities he's worked with, and how this has enriched him as a researcher.</p> <p>Speaker: Sergio Aguilar-Gaxiola, M.D., Ph.D.; <i>Professor of Clinical Internal Medicine; Director, Center for Reducing Health Disparities (CRHD); Director, Community Engagement Program of the Clinical Translational Science Center (CTSC), University of California, Davis, School of Medicine</i></p>
Session Title	Contemplating the Future
1:45 p.m. – 2:30 p.m.	<p><i>Speakers in this panel discussion will explore the potential impact of scientific advances in the coming decades, the challenges they may present to the notion of "human research protection," the stress they may put on public trust, and what the scientific community can do and prepare for it.</i></p> <p>Moderator: Laura Ruse Brosch, R.N., Ph.D., COL., AN, USA (ret); <i>Assistant Vice President for Research Initiatives and Compliance, Office of the Vice President for Research, Uniformed Services University of the Health Sciences</i></p> <p>Panelists: Jodi Halpern, M.D., Ph.D.; <i>Chancellor's Chair and Professor of Bioethics, UC Berkeley</i></p> <p>Misha Angrist, Ph.D., M.F.A.; <i>Associate Professor of the Practice, Social Science Research Institute, Senior Fellow Duke Initiative for Science & Society, Visiting Associate Professor of the Practice, Sanford School of Public Policy</i></p> <p>Lee McIntyre, Ph.D.; <i>Research Fellow, Center for Philosophy and History of Science, Boston University</i></p> <p>Aaron F. Mertz, Ph.D.; <i>Director, Science and Society, Aspen Institute</i></p>