

COMMEMORATING THE 50TH ANNIVERSARY OF THE NATIONAL RESEARCH ACT

By Yvonne Lau



On Friday, July 12, 2024, the Office for Human Research Protections (OHRP) at the Department of Health and Human Services (HHS) commemorated the 50th anniversary of the National Research Act with a [live virtual event](#) that reflected on the past, present, and future of research with human subjects. The HHS Assistant Secretary for Health, Admiral Rachel Levine, delivered the welcome address

iterating the department's promise to the American people for ensuring safe, equitable, and inclusive access to research participation.

The National Research Act was enacted as a direct response to the public outrage to revelations about the untreated syphilis study at Tuskegee. Between 1932 and 1972, researchers at the U.S. Public Health Service conducted research without informed consent on hundreds of African American men infected with syphilis and withheld effective treatment in order to study the disease's natural progression. The egregious disregard for the research subjects was shocking and caused irreparable harm to public trust in research.

The National Research Act acknowledged past failures and committed the federal government to a future where ethical principles are paramount to the conduct of research involving humans. It established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research which, in 1979, published the seminal [Belmont Report](#) describing the key ethical principles of respect for persons, beneficence, and justice for research involving human subjects.

OHRP's commemorative anniversary event took place against a backdrop of significant advancements in research and bioethics over the past half-century. It featured a diverse array of interested parties, including policymakers, investigators, and ethicists, and showcased the diverse role research participants play in contemporary research.

In reflections on the past, Patricia King, a former Commissioner of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, described what the Commission was able to achieve while lamenting the missed opportunity to delve more thoroughly in the concept of justice. Ivor Pritchard, who recently retired as Senior Advisor to the Director of OHRP, gave an overview of the National Research Act, the charges to the National Commission, and provided a brief description of how the Common Rule came about. Finally, Ivy Tillman, the 3rd Executive Director of Public Responsibility in Medicine and Research, described how the organization was founded in 1974 to support research professionals in navigating the ethics of human research and the then-new regulations.

Today, people are seen as partners in research and not subjects. The second session featured an array of speakers including Rey Calabrese, Basaima Spate, Karina Walters, Ella Greene-Moton, and Sergio Aguilar-Gaxiola. They


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each provided a personal account of their work in research as participant, research coordinator, community ethics reviewer, advocate for special community groups, and investigator dedicated to community-engagement. In their remarks, they communicated the powerful message of “do not research us without us” and partner with the community to further ethical research.

In the final session, Laura Brosch, Assistant Vice President for Research Initiatives and Compliance at the Uniformed Services University, moderated a distinguished panel to explore the potential impact of scientific advances and the challenges they might present to public trust. Jodi Halpern, Misha Angrist, Lee McIntyre, and Aaron Mertz offered their respective perspectives. These can be summarized to include: 1) the need to remind scientists of their ethical obligations and accountability to the public when pursuing science; 2) the importance of having the public “meet” everyday scientists, “see” what they do, and understand how science constantly evolves and how the fruits of science contribute to everyday lives; and 3) the value of clear and consistent messaging regarding scientific progress and discovery.

The 50th anniversary commemorative workshop underscored meaningful engagement and effective communication with the public as being critical to the success of scientific endeavors. To encourage greater participation in research, empathy, honesty, and respect from the scientific community is essential.

The speakers' biographies, event recording, and summary report are available on the [OHRP's website](#). Over 900 people have viewed the event as of the end of July!

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