



Vivian Pinn Symposium 2025 Meeting Summary

ORWH Director's Remarks and NIH Data Resources and Repositories Flash Talks

Janine Clayton, M.D., FARVO, NIH Associate Director for Research on Women's Health and Director of the NIH Office of Research on Women's Health (ORWH), opened the 2025 Vivian W. Pinn Symposium by acknowledging the legacy of Vivian W. Pinn, M.D., the first full-time Director of ORWH. Dr. Clayton reaffirmed the enduring mission of ORWH, namely to advance research that improves the health of women across the life course, and she highlighted ORWH's signature programs, including the Building Interdisciplinary Research Careers in Women's Health ([BIRCWH](#)) and the Specialized Centers of Research Excellence ([SCORE](#)) on Sex Differences. BIRCWH is a mentored career-development program designed to connect junior and senior faculty with a shared interest in women's health and sex differences research. Since its inception in 2000, BIRCWH has supported more than 800 scholars. In addition, for more than 20 years, SCORE has been the only NIH center-level program supporting disease-agnostic research on sex differences and major medical conditions affecting women in the United States. As ORWH celebrates its 35th anniversary in 2025, Dr. Clayton emphasized the importance of considering biological, social, and structural determinants of health and celebrated the symposium as a flagship event during National Women's Health Week. She encouraged continued engagement with ORWH as it pursues a future where all women may receive evidence-based, individualized care and may thrive in scientific careers.

Following Dr. Clayton's remarks, program staff from across NIH presented flash talks on selected NIH [data resources and repositories](#) that can be used to support data science, sharing, and innovation across the women's health research ecosystem. Flash talks highlighted the *All of Us* Researcher Workbench; the NIH Common Data Element (CDE) Repository, hosted and maintained by the National Library of Medicine; DiscoverWHR; the National Addiction & HIV Data Archive Program; the PhenX (consensus measures for Phenotypes and eXposures) Toolkit and the PhenX Social Determinants of Health Collections; and the Science Collaborative for Health disparities and Artificial intelligence Reduction of Errors (SCHARE).

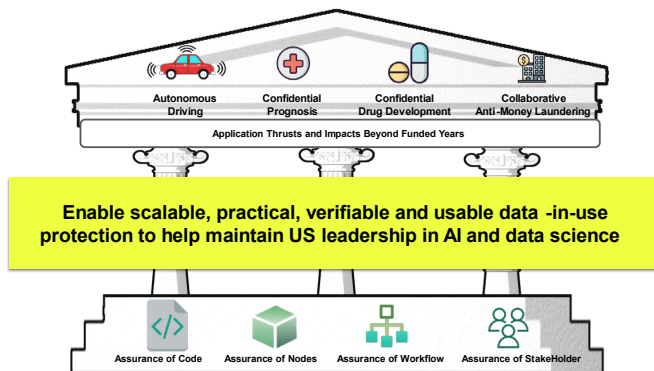
Raquel Hill, Ph.D.: Advancing Data Innovations for Health Improvements: Possibilities and Pitfalls

Dr. Hill, Chair of Computer and Information Sciences and Professor at Spelman College, delivered the capstone address, which centered on the interaction between data privacy, health disparities, and technological innovation in health care. Drawing from her early work with the Kinsey Institute and real-world experiences, Dr. Hill illustrated how one's ZIP code, as a social determinant of health, can predict one's life expectancy and health outcomes with startling accuracy. Tracking her personal trajectory living in multiple ZIP codes, Dr. Hill demonstrated how barriers to access to care tied to geography—such as poverty rates and education levels—underscore the urgent need to integrate environmental and socioeconomic data into biomedical research and electronic health records. She



emphasized that addressing health disparities requires more than genetic or clinical data; it required policy reforms and analytical models that account for the full and complex impact of lived environments on health.

Vision of Center for Distributed Confidential Computing (CDCC)



Dr. Hill then discussed challenges to collecting and analyzing health data for underrepresented and small populations, noting that existing datasets are often homogeneous in ways that limit robust, disaggregated analyses. Dr. Hill highlighted the risks of participant re-identification and the limitations of traditional privacy protections, arguing that new mechanisms must enable secure, privacy-preserving data sharing and computation across institutions. To that end,

she introduced the work of the Center for Distributed Confidential Computing, which is developing infrastructure to support trusted execution environments—technologies that allow sensitive data to be shared and analyzed without being exposed and thereby enable collaborative research across institutions without compromising privacy or violating data ownership.

Concluding her talk, Dr. Hill discussed practical applications of trusted execution environment infrastructure in confidential disease prognosis, artificial intelligence (AI) model training, and clinical decision support. Dr. Hill emphasized the importance of enforceable data-use policies, program certification, and policy-driven computing environments that align with institutional standards and patient trust. Dr. Hill noted that her vision for data innovation is both technical and ethical, because advancing health outcomes for all requires building systems that honor privacy, ensure accountability, and make all populations visible in data-driven health care. Dr. Hill closed by inviting further collaboration across the medical and technological communities to realize this transformative potential.

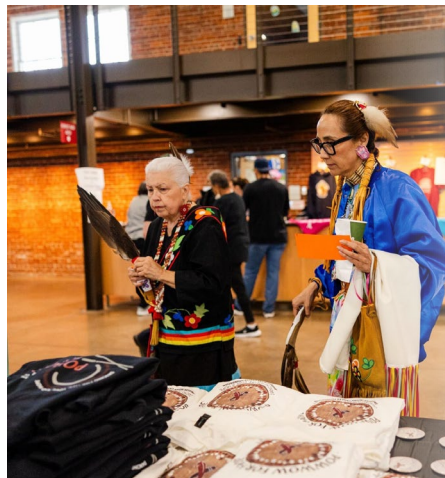
Panel Discussion: Innovations in Data-Driven Women's Health Research

Following the capstone presentation, a panel discussion highlighted innovations in data-driven women's health research.

Melissa Buffalo, M.S.: From Story to Data, From Data to Healing: Data Sovereignty for Native Women



Ms. Buffalo, CEO of the American Indian Cancer Foundation, delivered a powerful presentation on the role of culturally grounded data practices in addressing cancer disparities among American Indian and Alaska Native (AI/AN) women. Ms. Buffalo emphasized the lasting impact of historical trauma and systemic neglect on health outcomes and research mistrust, highlighting how small AI/AN sample sizes often result in statistical exclusion—a phenomenon some AI/AN communities describe as transforming them into an “asterisk nation.” Ms. Buffalo advocated for Indigenous data sovereignty, underscoring the need for Native-led data collection and interpretation to ensure visibility, accountability, and healing. Through community-based prevention programs, culturally tailored education, and provider training, the American Indian Cancer Foundation aims to empower Native communities to design responsive interventions that honor lived experience and promote health for AI/AN populations.



Unique Cancer Burdens Among Native Women

- Native women experience higher rates of certain cancers compared to other populations, highlighting an urgent health concern.
- Access to quality healthcare is limited for many Native women, hindering early detection and treatment of cancer.
- Recognizing the unique challenges faced by Native women is crucial for developing effective healthcare interventions and support.

Rochelle Prosser, RN, CLNC:

Fostering Data-Driven Decisions for Patients and Caregivers

Ms. Prosser, Founder of Orchid Healthcare Solutions, offered a data-driven analysis of survivorship in pediatric and adolescent brain tumor populations. Ms. Prosser emphasized the need to address the long-term physiological and psychosocial effects of cancer treatment, such as cardiovascular

and reproductive health complications, particularly for pediatric and adolescent populations. Highlighting the pivotal role that nurses play in collecting and applying patient-reported outcomes, Ms. Prosser advocated for early, multidisciplinary interventions that prioritize quality of life. Ms. Prosser also highlighted barriers to access to care posed by geography, insurance status, and fragmented transitions from pediatric to adult health care delivery systems. She noted that these challenges demonstrate the need to advance integrated, patient-centered models supported by digital tools such as virtual nursing and AI. Ms. Prosser concluded with a call to democratize data access and empower patients as informed collaborators in their care.





Alex Carlisle, Ph.D.: Advancing Precision on Women's Health: Empowering Impacted Populations to Transform Women's Health Through AI and Data Innovation

Dr. Carlisle, Founder, Chairman, and CEO of the National Accelerator for Discovery in Precision Health (NADPH), discussed the importance of data innovation in addressing persistent disparities in women's health outcomes, emphasizing a multidimensional and community-centered approach to innovation. At NADPH, this approach includes integrating research, real-world evidence, and technology within a co-design model that involves impacted populations throughout the research lifecycle. Dr. Carlisle's presentation highlighted barriers to women's participation in research—including economic, social, and structural factors—and underscored the need for intentional study design, improved data disaggregation by sex, and more inclusive data governance policies. Dr. Carlisle described the value of enhanced data science practices, such as incorporating real-world evidence and applying AI to train robust, representative models capable of informing risk calculations, treatment response, and care delivery. Finally, he showcased community-based initiatives, including efforts in maternal health and postpartum depression, as examples of how participatory data ecosystems can be leveraged to produce actionable insights in women's health.

Liat Shenhav, Ph.D.: Computational Biology for Women's Health

Dr. Shenhav, Assistant Professor at the New York University Grossman School of Medicine, presented her translational work at the intersection of microbiology, computer science, and women's and children's

health, guided by the slogan

"From Code to Care." Dr.

Shenhav's lab focuses on

developing scalable,

clinically relevant AI models

grounded in comprehensive,

multimodal longitudinal

data—spanning -omics,

imaging, and clinical

variables—to drive

discovery and precision

health care. In particular,

she highlighted recent work

on human milk and the infant microbiome, presenting breast milk as a dynamic, biologically

complex system that adapts to both maternal physiology and the developmental needs of an infant.

By integrating rich time-series data from the Child Cohort Study, her team investigates how the

evolving composition of milk and its interactions with the infant microbiome influence early-life

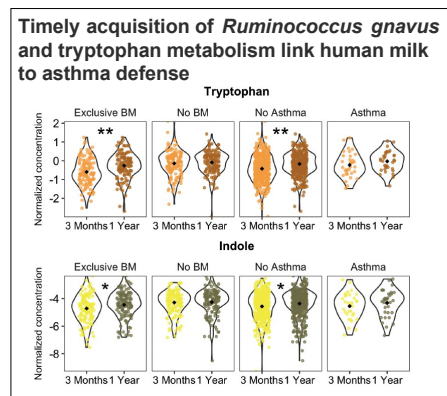
Timing is everything



Healthy microbiome development is not only about having the 'right microbes'.

They need to arrive in the right order at the right time.

Exclusive breastfeeding and the dynamic nature of human milk regulate this intricately structured microbiome development.



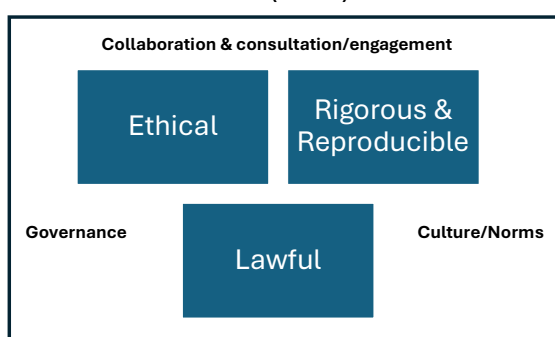


health outcomes, such as asthma, demonstrating the potential of computational biology to uncover the mechanisms underlying the protective effects of breastfeeding.

Pilar Ossorio, Ph.D., J.D.: Ethical Biomedical Research in the Era of Data-driven Science

Dr. Ossorio, Professor of Law and Bioethics at the University of Wisconsin-Madison, discussed the ethical imperatives that guide the use and sharing of biomedical research data. Dr. Ossorio highlighted the dual responsibilities of both data producers and secondary users to respect and

Responsible use of data (RUD)



protect the communities represented in datasets, even when those datasets are de-identified. Her presentation underscored that privacy, while critical, is one of many values that influence biomedical research; others include fostering public trust, advancing scientific knowledge, and minimizing social risk. Dr. Ossorio described responsible use of data practices, including robust governance frameworks, data use certifications, privacy-preserving

techniques, a culture of respect, and legal tools. Certificates of Confidentiality and Data Use Certifications were presented as two key legal mechanisms to safeguard sensitive data while enabling beneficial research, reinforcing that ethical data stewardship is essential to maintaining trust and promoting biomedical innovation for all people.

Vivian Ota Wang, Ph.D., FACMG, CGC, Moderator: Panel Discussion

In a moderated discussion, Dr. Vivian Ota Wang, Acting Director of the NIH Office of Strategic Coordination, invited the panelists to reflect on strategies for balancing data accessibility, data generation, and data privacy, and to consider challenges for researchers, patients, and communities as well as how individuals and institutions can work to overcome those challenges.

In response, Dr. Ossorio spoke about the challenge of meaningfully integrating patient and participant voices into data governance structures. Dr. Shenhav highlighted the importance of developing an integrated process to incorporate machine learning models into experimental settings for validation to drive clinical implementation and translation. Dr. Carlisle discussed the imperative to standardize and structure data, particularly qualitative and real-world data. Ms. Prosser closed the panel discussion by commenting on the value of data sharing for patients.

Vivian W. Pinn, M.D.: Closing Remarks

To close the symposium, Dr. Pinn spoke about the essential role of data in driving scientific advances for women. She reiterated the importance not only of including women as trial participants but also



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of considering women's health in trial design. She concluded by emphasizing the ethical imperative to share information derived from research with the communities involved in scientific studies.

For more information, please contact ORWHInnovation@od.nih.gov.