Society for
Women's Health
Research

February 28, 2022

Submitted electronically via: connectedhealth@ostp.eop.gov

Jacqueline R. Ward, PhD
Assistant Director
White House Office of Science and Technology Policy

Re: 87 FR 492, Request for Information on Strengthening Community Health Through Technology

Dear Dr. Ward:

The Society for Women's Health Research (SWHR)—a national nonprofit dedicated to promoting research on biological differences in disease and improving women's health through science, policy, and education—is pleased to offer comments in response to the White House Office of Science and Technology Policy (OSTP) Request for Information (RFI) on Strengthening Community Health Through Technology.

SWHR appreciates OSTP's commitment to exploring how digital technologies could be used in the future to transform community health, individual wellness, and health equity and, notably, how science and technology innovation could remove barriers for Americans to access quality health care and lead healthier lives. Technology, despite its endless potential, also has the ability to make health care disparities worse. By engaging in conversations with partners and hearing from key stakeholders, as is being done through this RFI, OSTP is helping to ensure that the innovation in health care delivery stemming from science and technology serve, rather than harm, the American people.

For the purposes of this RFI, SWHR will focus its comments on *Topic 7: Health Equity*.

Women's health is inherently an equity issue. Not only are women more prone than men to some risk factors that can cause medical issues, such as heart disease, dementia, and stroke, but our understanding of and ability to care for women is operating at a deficit due to historic underrepresentation in research or societal factors that can affect lifestyle and access to care. While strides have been made in women's health research over the past 30 years, women as a population are often underrepresented in studies across conditions[1]; do not receive optimal treatment, whether from a lack of access and/or knowledge; and are significantly

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[1] Feldman S, Ammar W, Lo K, Trepman E, van Zuylen M, Etzioni O. Quantifying Sex Bias in Clinical Studies at Scale With Automated Data Extraction. *JAMA Netw Open.* 2019;2(7):e196700. doi:10.1001/jamanetworkopen.2019.6700

underrepresented in science, technology, education, engineering and math (STEM) workforce, making up only 28% of it.[2] These deficiencies in representation create challenges for identifying the root causes of disparities as well as the optimal ways to address them, resulting in the potential exacerbation of already existing disparities amongst subpopulations of women.

Healthy People 2030 defines health equity as "the attainment of the highest level of health for all people."[3] SWHR's vision is to make women's health mainstream. Below, we outline areas for OSTP to consider as part of explores how to reduce health disparities and achieve health equity through health technology:

- **System cross-communication and interoperability**. As we increasingly look to digital technologies, whether mobile applications, telehealth services, or artificial intelligence, and build out innovative digital technology platforms within the U.S. health care system, their maximum potential will hinge on these systems and technologies being interoperable.

  The Healthcare Information and Management Systems Society (HIMSS) defines health information interoperability as "the ability of different information systems, devices, and applications to access, exchange, integrate, and cooperatively use data in a coordinated manner, within and across organizational, regional, and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals…"[4] This type of system provides clinicians with an individual's complete health story, including their preferences and other determinates of health that can inform their care. As HIMSS states, through this system, "Clinicians can better inform care and decision making, patients can become active participants in their care plans, and health IT developers and implementers can leverage evidence to create and adopt systems that support clinical processes and improve care delivery." Taken together, these elements are foundational to our greater shift of providing value-based care, driving down cost and improving patient care and outcomes, and are essential for maximizing the potential of health technology.

- **Records across the lifespan**. SWHR would encourage OSTP to consider how new platforms and technologies, when integrated into the health care system, could be utilized to capture health data across the individual's lifespan.

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[2] The STEM Gap: Women and Girls in Science, Technology, Engineering and Mathematics, AAUW. https://www.aauw.org/resources/research/the-stem-gap/. Accessed 23 Feb 2022.

[3] Healthy People 2030 Questions & Answers, U.S. Department of Health and Human Services. https://health.gov/our-work/national-health-initiatives/healthy-people/healthy-people-2030/questions-answers#:~:text=Healthy%20People%20defines%20health%20equity,of%20health%20for%20all%20people. Accessed 23 Feb 2022.

[4] Interoperability in Healthcare, HIMSS. https://www.himss.org/resources/interoperability-healthcare. Accessed 24 Feb 2022.

Discussions about women's health are often focused on reproductive years; yet, women live over half of their lives in the pre- or post-reproductive life stages (the reproductive stage of a woman's life lasts, on average, about 36 years,[5] whereas the average life expectancy for women in the United States is closer to 80 years[6]). The reproductive years in a woman's life are critical, but too often, a woman's health at that point in time is viewed predominately through that lens. Prenatal records and information should not be only accessible during that period of time in a woman's life—just as her records from before pregnancy should be accessible to better inform her prenatal, postpartum, and later life care.

All health care records are critical to providing quality health care; the ability to share and access this information is necessary for having a complete and accurate picture of an individual's health. Harmonizing these longitudinal records across platforms could be transformative for coordinating care, improving patient care safety, and providing greater insight into a woman's health.

- **Standardized data points**. In order to access data and evidence that can inform decision-making in health and health care, providers, policymakers, and researchers need access to high-quality databases—and, notably, databases that seamlessly integrate with one another. Achieving that level of data collection will require standardized methods for collection, including format, as well as standardized and comprehensive data points that will allow for intersectional analysis between variables so that distinctive health and social issues and their intersectional impacts can be identified and addressed appropriately. From sex and gender identity to race, ethnicity, geographic location, and other key measures, having access to reliable data that is high-quality, timely, and able to be disaggregated for tracking and analysis is essential for improving health outcomes.

- **Incorporating key perspectives and considerations to optimize technology.** SWHR believes that a ground-up approach that incorporates real-world, lived experiences of patients and their caregivers, will be important to consider in our nation's digital transformation.

  Inclusion of lived experiences and patient and caregiver perspectives for digital health development. In order to maximize their potential, health technologies need to be developed in a way that ensures their data will be collected reliably, appropriately, and

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[5] Ley S, Li Y, Tobias D, Manson J, Rosner B, Hu F, and Rexrode K. Duration of Reproductive Life Span, Age at Menarche, and Age at Menopause are Associated with Risk of Cardiovascular Disease in Women. *Jour of the Amer Heart Assoc*. 2017;6:e006713. https://doi.org/10.1161/JAHA.117.006713.

[6] Arias E, Tejada-Vera B, Ahmad F. Provisional Life Expectancy Estimates for January through June, 2020. Vital Statistics Rapid Release, National Vital Statistics System. February 2021. https://www.cdc.gov/nchs/data/vsrr/VSRR10-508.pdf. Accessed 24 Feb 2022.

efficiently and that the technologies themselves can be seamlessly integrated into current practices and systems. This can all be informed by involving the perspectives of those who will use and benefit most from them, including individual patients, specifically those who experience the worst health outcomes as a result of structural inequities, as well as their caregivers.

Beyond the patients and caregivers themselves, there are several stakeholders whose voices would be beneficial throughout the development and implementation process. These include health care delivery, coverage, and patient advocacy organizations, as well as representatives from the research and regulatory sectors. Their insights will be valuable for improving the integrity of the data in addition to enhancing the interoperability and connection between systems across the U.S. health care landscape.

Meeting people where they are. As referenced above, utilizing new technologies to the best of our ability will rely on the involvement of those who will use and benefit from the platform. As part of that effort, it will be important to understand how individual patients and their caregivers are currently getting access to their health information and sharing it with their health care providers. Better understanding how a diversity of patients manage and navigate their care could provide critical insight into which digital technologies to pursue and which aspects of those technologies could succeed or fail, depending on an individual's unique circumstances.

- **Policy alignment**. Federal policies and regulations related to digital health continue to evolve to reflect the digitization and modernization of health care delivery. Yet, there are still barriers—spanning technical, motivational, economic, political, legal, and ethical barriers[7]—that are potentially hindering data sharing and interoperability. In addition, for most types of data, there are not universal frameworks or guidelines for data sharing or for the application of universal data standards.

  In a health care system that is bound to become increasingly reliant on data sharing and interoperability, it will be important for policymakers to understand the current barriers that are in place and change laws, regulations, and policies, where necessary, to stimulate and incentivize interoperable and interconnected systems while still protecting the privacy and autonomy of patients.

- **State and federal investment in digital technologies**. Finally, our pivot into digital technologies in health care will require greater investment in these technologies by
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[7] van Panhuis, W.G., Paul, P., Emerson, C. *et al.* A systematic review of barriers to data sharing in public health. *BMC Public Health* 14**,** 1144 (2014). https://doi.org/10.1186/1471-2458-14-1144

both the state and federal government as well as the private sector. SWHR is encouraged by initiatives like last year's $80 million Public Informatics & Technology Workforce Development Program from the Office of the National Coordinator for Health Information Technology and this RFI from OSTP, that show the government's continued commitment to digital and technological excellence in health care. Strengthening our public health informatics and eliminating health care inequities will require ambitious investments and public-private partnerships to achieve sustainable digital transformation.

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SWHR is pleased to see OSTP's concerted effort to determine how to maximize the benefits of science and technology across the United States. The COVID-19 pandemic, though exposing severe limitations in U.S. public health surveillance, also revealed its potential to revolutionize how care is delivered. SWHR fully believes that placing the right data in the right hands through the right platforms has the potential to not only empower women but also to transform the quality and outcome of their care.

Thank you for the opportunity to provide feedback to the OSTP on this important effort. We look forward to continued opportunities to engage with the agency on this issue. If you have questions, please contact me at kathryn@swhr.org or SWHR's Chief Advocacy Officer Lindsey Horan at lindsey@swhr.org.

Sincerely,

Kathryn G. Schubert

Kathryn G. Schubert, MPP
President and Chief Executive Officer