

## Research Section Spotlight

# Diversity and inclusion: Potential trends for data in research

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### Introduction

From the pre-meeting emails by MLA leadership soliciting feedback on the proposed community models to the closing plenary speakers, the theme of the annual meeting, “Adapting, Transforming, and Leading,” was thoroughly integrated with all aspects of the 118<sup>th</sup> Medical Library Association Annual Meeting in Atlanta, GA. Amid the standard conference program, and the historical naming of Beverly Murphy as the first African-American MLA president, the meeting fostered an environment of engagement and inclusiveness.

The MLA’s Diversity and Inclusion Task Force and the Communities Strategic Goal Task Force promoted safe spaces for all MLA attendees to ask questions and voice their opinions on issues relevant to governance of MLA and their perceptions of diversity within the health and medical information profession. For example, attendees were afforded numerous venues and opportunities to collectively or individually speak with representatives from MLA’s Communities Strategic Goal Task Force with questions, comments, or concerns to the proposed restructuring of the MLA Section and Special Interest Groups (SIGs). The dialogues extended beyond formal spaces to informal spaces providing MLA attendees the opportunity for meaningful exchanges with health and medical information professionals from diverse perspectives and experiences.

However, my main takeaway from the annual meeting was the overview by [Dr. Dara Richardson-Heron](#) of the *All of Us* Research Program (AoU). The presentation directly aligned with the annual meeting’s theme of “adapting, transforming, and leading,” and connected to my future research interest.

### Transformative Research in Practice

Dr. Richardson-Heron is the Chief Engagement Officer of the [National Institute of Health All of Us Research Program](#) (AoU) and a health advocate. The main objective of AoU is to advance the [Precision Medicine Initiative](#) through the collection of data from more than a million participants over the span of a decade. The Precision Medicine Initiative is a transformative approach for treatment and disease prevention that focuses on the uniqueness of individuals and accounts for distinct factors, such as lifestyle, genetics, and habits to deliver “the right treatment for the right person at the right time” [1].

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Committed to implementing innovative policies and practices to increase the success of the program, AoU has established a set of core values as a framework to achieve widespread participation from diverse people, geography, health status, and data types. Dr. Richardson-Heron states these core values are very important to her. In response to unethical historic research practices (for example, Henrietta Lacks and the Tuskegee Syphilis study) that caused harm or excluded vulnerable populations, AoU has initiated policies and practices to re-establish participant trust and increase participation with, and transparency of, the research process and data collection through education, awareness, and immediate notifications of data breaches. AoU's implementation of a transparent approach to research has the potential to benefit participants in meaningful ways. Some of the key benefits for participants include knowledge of health conditions and personal risk factors that may affect long-range health. In addition, participants will have access to their data to share with health care teams.

Similarly, researchers will also benefit from the data collected in the ten-year longitudinal study at no cost in what Dr. Richardson-Heron describes as a democratized research model. The democratized model will afford researchers (1) a rich resource of data, (2) a longitudinal dataset, (3) a diverse cohort of research participants, (4) de-identified and anonymized raw data and data, (5) an existing secure data infrastructure, and (6) a collaborative working environment.

Finally, expressing her appreciation for libraries and librarians, Dr. Richardson-Heron shared the plans of a three-year partnership with the National Network of Libraries of Medicine to design, develop, and implement activities for public libraries to make available to their local communities. The libraries role would be to educate and increase awareness of the *All of Us* research initiative, in addition to providing technology resources for individuals without access to the internet.

### Research and Advocacy

The *All of Us* Research Program provides a framework for research considerations for all disciplines. In my future research, I will focus on the health information and decision-making of veteran women. As a veteran woman and researcher, it is important to me to advocate in the interest of veteran women. My research objective is to examine the history of women veterans in the United States and propose a possible conceptual framework for describing and understanding how the information needs, access, and use of health information reflects and contributes to the marginalization of women in the Veterans Health Administration (VHA).

Despite the historically strong opposition of women in the military and in combat roles, women have demonstrated valor in combat since the Revolutionary War [2], preceding policy and withstanding resistant societal and cultural norms with rigid standards and perceptions of women. Today, there are approximately 1.84 million living female veterans

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of more than 23 million surviving veterans in the United States [3], and by the year 2020 the number of woman veterans is projected to reach 2 million [4].

The priorities for women at the VA have ranked relatively low level in the past due to their small numbers, and military law and policy that limited their military involvement [5]. Thus, the medical needs and long-range effects of combat on the health of women have historically been poorly understood in medicine and research [5][6].

Women are a numerically small population within a largely male-oriented VHA healthcare system [6]. Historically, due to insufficient data collection on female veterans, there remains a gap in understanding how veteran women utilize VA healthcare services and benefits [7]. Another challenge for researchers has involved the representation of health issues related to vulnerable and marginalized groups, such as African-American and other minorities, the homeless, rural communities, and lesbian, gay, bisexual, transgender, and queer (LGBTQ) veterans who have not been traditionally represented in research. Addressing intersectionality in research can potentially improve health outcomes and inform stakeholders in the development of health information resources and technology to address the specific needs of veteran women.

Whatley and Worcester propose that when women have access to health information, not only do they have a better understanding of their body; they also are more likely to make better health-related decisions [8]. A copious amount of research focused on various aspects of women in general, and health information behavior, has provided a potential foundation for comparing and identifying key behaviors that may be salient to understanding the health information behavior and decision-making of veteran women. As the VHA implements quality initiative to improve care for female veterans, understanding their health information needs will help to tailor health care delivery to veteran women and address health disparities.

### Conclusion

The success of the *All of Us* Research Program will have a widespread impact on health, research, and the value of libraries. The availability of a rich source of data will allow comparison between veterans and non-veterans, in particular female veterans, to identify gaps in research to improve the immediate and long-range health of the veteran population. Gaps in research will be more identifiable, eliminating duplicate research efforts. Furthermore, partnerships with initiatives like *All of Us* will continue to enhance the value of librarians and health information professionals, and help connect people from diverse backgrounds to health-related resources and information.

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### Works Cited

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