September 29, 2022

Comments in response to the Request for Information: Inviting comments on the National Institutes of Health Office of Research on Women's Health NIH-Wide Strategic Plan for Research on the Health of Women (NOT-OD-22-186)

Submitted via NIHWideSPWH@nih.gov

The American Psychological Association (APA) is pleased to provide comments on the Request for Information (RFI) on the NIH-Wide Strategic Plan for Research on the Health of Women (NOT-OD-22-186).

APA is the leading scientific and professional organization representing psychology in the United States (U.S.), comprised of more than 133,000 researchers, educators, clinicians, consultants, and students. Its mission is to promote the advancement, communication, and application of psychological science and knowledge to benefit society and improve lives.

APA appreciates the opportunity to comment on the National Institutes of Health (NIH) Office of Research on Women's Health's (ORWH) NIH-Wide Strategic Plan for Research on the Health of Women.

Over the last couple of decades, scientific and public attention to issues related to women's health has intensified. ORWH's leadership and the subsequent NIH-funded research have led to this continued progress. Accordingly, APA applauds the current NIH-Wide Strategic Plan for Research on Women Health's focus on maternal mental health, cervical cancer, chronic and debilitating diseases, and sex and gender through a life course lens. However, while we have witnessed the Plan's success in bringing attention to these research areas, APA believes continued attention to these and other women/gender-related health issues is warranted in the updated Plan.

APA would like to share the following comments and recommendations from psychological scientists with the National Institutes of Health (NIH) and the NIH Office of Research on Women's Health (ORWH).

APA urges the agency to use the term "biomedical and behavioral" as it did in its NIH-Wide Strategic Plan, Fiscal Years 2021-2025. The association understands that the agency uses the term "biomedical" as shorthand when discussing its broad portfolio. However, APA believes the use of "biomedical and behavioral" research in the updated Strategic Plan so that the scientific community interested in participating in NIH-funded research recognizes the agency's efforts to reach the broadest scientific community to conduct women's health research. Including "behavior" in descriptions of NIH-supported research signals the embrace of a more integrated vision of health. We know stress, psychological and behavioral factors impact health outcomes at multiple levels (e.g., genetic changes, immune function, adherence to treatment factors, beliefs surrounding vaccines, maternal outcomes, etc.).

The current Strategic Plan places too little emphasis on prevention and promotion of quality of life or well-being across the life span. The updated Strategic Plan is an opportunity for the NIH to highlight the importance of research in these areas across the NIH. In addition, there is the opportunity for the updated Plan to highlight the need for more research on biopsychosocial factors that reduce risk, disease burden, and improve response to treatment and quality of life. For example, the work of psychologist Elissa Epel, PhD, and Elizabeth Blackburn,
PhD, on stress and telomere length, genetic changes, and risk of illness in poor women. Another example is Janice Keicolt-Glaser's, PhD, work on caregiver and other stressors on immune markers and illness.

Research opportunities in the NIH Strategic Plan for Women’s Health Research F.Y. 2019-2023 that should be modified to account for recent scientific advances

Advancing rigorous research that is relevant to the health of women

Objective 1.3: Identify the immediate, mid-, and long-term effects of exposures on health and disease outcomes
APA appreciates the inclusion of social and psychological exposures in the Plan and recommends the addition of “dementia,” given that the incidence rates of any dementia and Alzheimer's Disease are greater in women than men.

Objective 1.5: Expand research on female-specific conditions and diseases, including reproductive stages, and maternal and gynecologic health
APA suggests using more inclusive language, for instance, when referring to gynecological care and pregnancy, since not all these conditions identify women only.

APA appreciates the distinction between sex and gender referenced in the Strategic Plan. However, there is a concern about perpetuating the assumption that sex and gender are binary (male/female; man/woman). For example, in at least one area, men and women are referenced in relation to sex rather than gender. Therefore, it would be more consistent to talk about males and females with regard to sex.

Given the recent scientific advancements regarding sex and gender, APA would like to suggest updating the language in Strategic Goal 1.5. The focus on female-specific conditions in this goal is greatly appreciated as it is sorely needed. However, the cisgender-specific language does not reflect current

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4 Gender and Health, World Health Organization, https://www.who.int/health-topics/gender#tab=tab_1
5 Smith-Bynum, Mia A., Aparicio, Elizabeth M., Shin, Richard Q., Lare, Sean, Vigorito, Michael, Fish, Jessica N., Williams, Natasha D., Boekeloo, Bradley O., Community-Expert Authors: UMD-PRC Community Advisory Board,* Competencies for Mental Health Clinicians working with LGBTQ+ People in Mental Health Care, Competencies for Mental Health Clinicians working with LGBTQ+ People in Mental Health Care
scientific knowledge and omits recognition of the diversity of folks who may be encountering gynecological concerns and pregnancy. Not all with female anatomy or who are pregnant identify as women.\textsuperscript{7,8,9,10} Reportedly, nonbinary individuals have indicated the avoidance of gynecological healthcare because of the language surrounding the names of clinics (e.g., Women’s Health Clinic). Updating the plan with gender-inclusive language could make a significant difference in shaping population health.

APA also recommends NIH include such conditions as polycystic ovary syndrome (PCOS) and other specific understudied conditions in females. PCOS involves not only the reproductive system but multiple body systems. It has been severely understudied since it was first identified in 1935. PCOS is an all-encompassing condition impacting metabolic, endocrine, reproductive, cardiovascular, and mental health in women and individuals of diverse gender with ovaries. Estimates of healthcare costs in the U.S. alone are $8 billion related to diagnosis and $6 billion more for mental health impacts. It is the leading cause of infertility in women. It is linked with heart disease, diabetes, fatty liver, depression, anxiety, and eating disorders. It is estimated to impact as much as 20 percent of the female population.\textsuperscript{11}

The NIH must redouble its efforts to enhance gender representation on NIH Study Sections.\textsuperscript{12} Therefore, the association believes it is important that funding opportunities require applicants to explain how the proposed research will account for unconscious biases in the study’s design. Additionally, APA believes NIH should direct investigators to prepare a plan for accountability to the populations studied. For

\textsuperscript{7} Smith-Bynum, Mia A., Aparicio, Elizabeth M., Shin, Richard Q., Lare, Sean, Vigorito, Michael, Fish, Jessica N., Williams, Natasha D., Boekeloo, Bradley O., Community-Expert Authors: UMD-PRC Community Advisory Board,* Competencies for Mental Health Clinicians working with LGBTQ+ People in Mental Health Care, Competencies for Mental Health Clinicians working with LGBTQ+ People in Mental Health Care
example, it should address whether anyone involved in the study design is a member of the population studied. Was there a consultation process to uncover any biases in the research questions?

To this end, APA supports efforts, like those being implemented by the Chief Officer for Scientific Workforce Diversity (COSWD), to diversify the national scientific workforce and expand recruitment and retention. APA encourages similar efforts directed at expanding female-specific research. In the updated Plan, APA encourages NIH, via the Center for Scientific Review, to provide support, education, and countermeasures for grant reviewers so that more researchers doing the work of understanding health inequities for women and people of color are being funded. Materials developed to educate the scientific community on how the agency accomplished this goal can subsequently be offered to other research institutions as a model for correcting the biases that have led to unequal research. 13

The association recognizes this may require NIH to produce or fund materials development that is researcher- and institution-facing about unconscious biases in research and support more education about designing research questions and studies through an anti-oppressive lens. In addition, implementation of this recommendation may require the creation of consultation or mentorship resources for interdisciplinary fields intended to support in improving their processes or how to navigate if their institution is not supportive.

Developing methods and leveraging data sources to consider sex and gender influences that enhance research for the health of women

Objective 2.4: Expand and refine methodologies to improve the recruitment and retention of women underrepresented in clinical research

To expand and refine methodologies to improve the recruitment and retention of women underrepresented in clinical research, it is crucial NIH continues to make efforts to ensure that the reviews, processes, and infrastructure that support them are perceived as fair and unbiased by all applicants regardless of race or research topic (i.e., UNITE, COSWD). The NIH must continue to redouble its efforts to enhance gender representation on NIH Study Sections. APA supports and encourages NIH to continue the agency's efforts to explicitly understand the challenges associated with recruiting and retaining specific populations. Implementation of policies and infrastructure that discourage one-size-fits-all approaches to recruitment and retention of women from different racial-ethnic, economic

backgrounds as well as sexual orientation and ability. Funding research that fails to consider the challenges of recruiting women from underrepresented backgrounds will perpetuate the problem. It is essential to know why current methods do not capture or fully explain the barriers to participating. This effort includes supporting research designed to answer the question of "what are the barriers" and treat this question as much of a priority as the health-related question researchers seek to answer.

Enhancing dissemination and implementation of evidence to improve the health of women

3.2 Identify collaborative opportunities and leverage partnerships to disseminate research that improves the health of women.

APA supports the inclusion of and supports implementation science as a strategic goal for NIH in its updated Strategic Plan. Implementation research would help to address the gaps in care and to speed up the process by which treatment models are adopted in routine care. To ensure maximum collaborative opportunities and partnership, APA recommends that the Strategic Plan’s language makes it clear that it is necessary to disseminate the research to inform clinicians across all disciplines, not just physicians.

The updated Plan's objectives should include the development and accessibility of anti-oppressive teaching tools for all those involved, thereby increasing the dissemination and implementation of NIH-funded research, including tools for:

- Educators to present information without bias and encourage critical thinking
- Administrators to enhance 'buy-in' of medical staff to change their perspective to incorporate new findings and reduce unconscious biases in medical practice
- Interagency collaboration that reduces proprietary attitudes is also needed
- Support public health officials in understanding the psychology of change and where mistrust of public health information stems.

It will be necessary to provide these tools in multiple languages, with cultural consultation from members of these communities and in language for the layperson. For example, the Navajo vaccination campaign, https://navajohopisolidarity.org/vaccination-campaign, focused on community values of being a good ancestor and interdependence. It is an example of a community knowing best what works for them.

The updated Strategic Plan should prioritize health literacy and ensure the knowledge gained through NIH research is accessible to folks of all education levels, ages, and stages of life. It should be readable, easier to understand, and include information about how to apply it in daily life. It should also prioritize how to utilize media better to disseminate information for the layperson or non-researcher, including a goal to commit to contributing to a more educated and informed population by giving the data back to the people who it impacts in whatever form accessible to them.

Promoting training and careers to develop a well-trained, diverse, and robust workforce to advance science for the health of women

APA applauds the Strategic Plan’s efforts to promote training and careers to develop a well-trained, diverse, and robust workforce. APA recognizes that ORWH has been a leader in this area. The association appreciates the Strategic Plan’s focus on promoting training and careers and recommends that NIH continue its focus on making the current research spaces safer for women and diverse people to flourish. The agency must commit to funding projects, institutions, or researchers that commit to anti-oppressive environments, including transparent hiring practices and flexible work schedules to accommodate parents, pregnant people, and disabled people.

The updated Plan should reflect NIH’s intent to fund and prioritize research about what disabled people, LGBTQ+, and people of color need to be successful in biomedical work. This reflection should emphasize factors like alternate work schedules, childcare resources, flexible timelines to complete research; develop resources and guidelines for institutions to use when changing internal practices that have oppressed women, LGBTQ, and employees of color. It is also vital to establish feedback processes for the stakeholders to identify if these processes are effective.
Improving evaluation of research that is relevant to the health of women

APA agrees with the Strategic Plan. NIH must fund research projects that look at how to reduce the cost of innovative technological procedures. It requires working with public health, advocacy leaders, insurance companies, hospital administrators, and state and national legislators to make innovative and advanced biomedical resources available regardless of insurance, income, or other socioeconomic factors that currently exist to maintain inequity in who reaps medical research’s benefits.

Emerging research needs and opportunities

Research on vaccination uptake in pregnant and postpartum people and their children. Widespread misinformation and poor public-health messaging regarding the safety of vaccines during pregnancy and postpartum have resulted in high rates of hesitancy and under-vaccination in these groups and the under-vaccination of their offspring.

Research on substance use in pregnancy/postpartum. Substance use in pregnancy/postpartum is a persistent, intractable problem (e.g., evidence that rates of perinatal opioid use and other substances have not decreased, and rates of perinatal marijuana use are increasing). In addition, opioid use disorder (OUD) rates among pregnant women are rising precipitously. Increased attention is being devoted to the biomedical mechanisms underlying harmful maternal and child outcomes of opioid-exposed pregnancies. Yet, despite the documented vulnerability of these women and the treatment barriers they face, little research and clinical attention are being directed toward the life-context factors that affect their health.24 Current NIH funding for research on these topics is fractionated across the National Institute on Drug Abuse (NIDA), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute of Mental Health (NIMH). The research should be integrated into a single set of programs focused on perinatal substance use.

Women and COVID. The COVID-19 pandemic and ensuing public health measures have dramatically altered the lives of millions of people worldwide, creating a public mental health crisis with high rates of depression, anxiety disorders, and suicidality.25 Although the pandemic highlighted several issues related to women’s health, many of the problems are relevant to many other aspects of women's health, which remain with us. Consequently, the pandemic created an urgent need to examine the extent to which pandemic-related stress predicts heightened anxiety in pregnant people who were pregnant during this crisis. The long-term impacts of perinatal COVID exposure and infection on childbearing individuals and their infants/children are yet unknown: the NIH must commit to funding research on these topics.26

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Research on mental health, pregnancy, and childbirth in the context of COVID. High stress among individuals pregnant and giving birth during the pandemic resulted in higher rates of depression, anxiety, and obsessive-compulsive disorder (OCD) symptoms in these individuals. However, the long-term impacts of high perinatal stress and poor mental health for childbearing individuals and their infants/children are not sufficiently understood. As the COVID-19 public health crisis evolves, additional research is crucial "to evaluate mental health difficulties in pregnant and postpartum women and examine the resilience and risk factors associated with favorable outcomes vs. persistent psychopathology and their effects on perinatal and long-term health."

Reproductive health issues for trans and non-binary people in the context of COVID. The supplemental materials in the current Plan state: "Pregnancy is associated with alterations in the immune system, and pregnant women are susceptible to respiratory pathogens and to the development of severe pneumonia, which may make them more susceptible to COVID-19 infection or its consequences than the general population, especially if they have chronic diseases or pregnancy-related complications."

Trans and nonbinary (TNB) gestational parents face minority stress, prejudice, microaggressions, and uninformed medical providers. In addition, as TNB people often face employment and housing discrimination, additional psychosocial issues may impact stability during pregnancy (unstable employment or housing, changes to health insurance, lack of access to health insurance, and long wait times for healthcare). All these stressors burden the immune system and developing more resources and meeting the unique needs of trans and non-binary people during pregnancy is necessary for competent care within a COVID context.

Long COVID, healthcare access, and equity. Research needs should include sex and gender differences in the impact and expression of long-COVID. Also needed is the development of a more inclusive and trauma-informed assessment of long-COVID systems and clinical practice needs for medical settings. This need includes fact sheets and culturally representative information about long-COVID to mitigate unconscious bias in medical providers who minimize self-report.

Women, people of color, LGBTQ+ people, people with disability, those who do not speak English as a first language, those with mental health conditions and substance use disorders, and those affected by systemic marginalization already deal with unconscious bias of medical providers that affect whether they are believed when describing pain, areas of dysfunction, and symptoms. Given that little research has been conducted about long-COVID, it is probable that without deliberate research into how long-COVID

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affects these communities, long COVID will be missed, minimized, and dismissed within medical settings when reported by minoritized people.

**Understanding the impact of COVID on the health of the workforce.** Given the limited protections in place for the workforce during the last few years, several of which are/have expired (COVID leave, COVID testing, etc.), understanding the impact of long-COVID and the development of recommendations for policymakers about caring for the workforce long-term is vital. Particularly in sections of the workforce where women are a greater percentage of those employed (healthcare, education, childcare settings), research and science to understand better the functional impact of long-COVID are needed. In addition, asking the questions if mobility, cognitive, or endurance issues resulting from long-COVID need to be accommodated and cared for within the workforce are also needed. Likewise, understanding that women are often the primary caregivers for spouses, children, relatives, elder-parents and that even if not directly impacted by long-COVID symptoms themselves, what is the additional impact of caregiving on those with long-COVID on the workforce.

**Cross-cutting scientific themes**

**Basic/Pre-Clinical Research.** APA wants to underscore the continued importance of basic and preclinical research to elucidate issues in women's health better. Fundamental studies of exercise and aging, brain health and learning, addiction, and stress must undergird tomorrow's applications. Some years ago, women's health experts ensured that animal studies include female and male subjects. Improving basic research is critically important but calls to end research with non-human animals are, at best premature.

**Gender Identity and health research.** APA appreciates that a guiding principle refers to diverse experiences and a mission to enhance research on diseases/disorders affecting women. Likewise, there is an appreciation for the distinction between sex and gender. The association, however, recommends that the NIH further highlight the importance of gender identity in research. The association believes gender identity is as important as sex, if not more critical, in behavioral research.29 30

While we agree with including a distinction between sex and gender, consistency could be enhanced. For example, the terms men and women were used to refer to sex rather than gender. Additionally, in Figure 4, sex is treated as internal, whereas gender is treated as external.

Accordingly, revision of enrollment tables is needed to reflect the increased attention to gender identity. Unfortunately, behavioral health researchers have been advocating for table revisions for years without success. Consequently, the inaccuracy with which researchers are required to report their participants


and summarize their findings using these categories continues to be problematic. Accurate reporting is needed to measure health outcomes leading to improved health in all populations.

**Intersectionality Framework and health research.** Given the growing body of research on the importance of infusing an intersectionality framework in research. Such a framework considers the multiple levels of analysis, from the individual identification and behavior to the social structure that accounts for health and, therefore, interventions to improve it. Intersectionality is a framework that can address the complexity of lived experiences of diverse populations of women.

APA recognizes that the NIH has made many of these commitments before. However, sustained, increased attention is needed to make significant progress in reaching these goals, especially as they relate to including the under-recognized and under-served, gender-diverse individuals and diversifying and equalizing the workforce which is severely lagging.

The association also believes increased attention is needed to address the following questions: What metrics could be used by the NIH to know that they are meeting these goals? How do we enhance infusion of behavioral research questions with biomedical approaches such that scientists view them as part of an integrated approach to women’s health? How does policy affect women’s health and support professional women working in this field? How will the NIH diversify the interdisciplinary teams they choose to fund and put more of a focus on translational pragmatic science aimed at helping the under-recognized and under-served? Finally, how can the NIH start equitably funding diverse researchers associated with institutions that prioritize equitable pay, support, and leadership?

Again, APA is grateful for the opportunity to respond to this request for information. The association believes that the updated NIH-Wide Strategic Plan on Women’s Research Plan will continue to enhance our understanding of women's health and make a difference in women's day-to-day professional and personal lives. If APA can be of further assistance, do not hesitate to contact Angela Sharpe, Senior Director, Congressional & Federal Relations, asharpe@apa.org.

Sincerely,

Mitch Prinstein, PhD, ABPP
Chief Scientific Officer

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