

COMMENTS OF THE WHITMAN-WALKER INSTITUTE AND WHITMAN-WALKER HEALTH ON THE TRANS-NIH FY 2021-2025 STRATEGIC PLAN TO ADVANCE RESEARCH ON THE HEALTH AND WELL-BEING OF SEXUAL AND GENDER MINORITIES

Pursuant to the December 13, 2019 notice in the Federal Register, 84 Fed. Reg. 68179, the Whitman-Walker Institute (WWI or WW Institute) and Whitman-Walker Health (WWH) – collectively referred to in this document as Whitman-Walker – offer these comments on the Request for Information issued by NIH’s Sexual & Gender Minority Research Office. We appreciate the Office’s solicitation of information from a wide range of stakeholders to inform the development of the Trans-NIH Strategic Plan for the next five years for research on the health and well-being of sexual and gender minorities (SGM) – or lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) people.

Interest and Expertise of the Whitman-Walker Institute and Whitman-Walker Health

Our interest in commenting on this Strategic Plan is grounded in Whitman-Walker’s extensive experience as a direct health care provider to the LGBTQ community, as a research institution, and as an advocate for sound public health policies.

Whitman-Walker Health is a Federally Qualified Health Center located in Washington, DC. Our mission is to be the highest quality, culturally competent community health center serving greater Washington’s diverse urban community, with a special focus on LGBTQ individuals and families, persons living with HIV, and other individuals and families who face barriers to accessing care. We offer primary medical for all individuals and HIV; LGBTQ primary and specialty care; dental care; mental health care and addictions counseling and

treatment; HIV education, prevention, and testing services; other community health services; legal services; and nurse care management.

We have been committed to advancing LGBTQ health and wellness since our founding in November 1973 as the Gay Men's VD Clinic, then part of the Washington Free Clinic. For more than three decades, WWH has been a nationally recognized leader in HIV treatment and prevention and LGBTQ health and wellness. In calendar year 2018, we provided health services to more than 20,700 unique individuals. Almost 60% of those individuals who provided their sexual orientation identified as gay, lesbian, bisexual, or otherwise non-heterosexual.

Transgender and gender nonconforming individuals comprise a substantial and growing part of our patient and client base: approximately 9% of all those receiving any health services; 15% of medical patients; 23% of persons receiving mental health services; and 6% of those receiving substance abuse treatment services.

Whitman-Walker's robust Clinical Research Department, operated for many years as part of Whitman-Walker Health and now part of our Institute, has been conducting research on HIV treatment and prevention, hepatitis treatment, the treatment of Sexually Transmitted Infections, and LGBTQ health for more than 30 years. Our Research Department has worked with multiple institutes of NIH, the Centers for Disease Control and Prevention, major pharmaceutical companies, and others. We currently average 20-30 drug trials. In addition, we currently have 18 active NIH-funded clinical and behavioral studies. All 18 of these studies are open to members of the LGBTQ community. Fourteen of the studies have an HIV focus, three are specifically focused on PrEP use and adherence; three are specifically for transgender women; two are focused on SGM youth; and one study, "Strength and Stressors," is solely focused on the health of Black men.

Whitman-Walker Institute was founded in 2019 to centralize and expand the research, education, and public policy work conducted by Whitman-Walker Health. Through the strategic integration of these fields, WWI leverages our deep expertise in clinical care and the health of LGBTQ populations to advance knowledge, accelerate and improve the scientific study of SGM populations, build inclusive communities, and secure legal and social climates that promote equity and justice for all people.

Comments on the Next Five Years of NIH-Funded SGM Research

Whitman-Walker supports the Office’s commitment to further expand the scope of SGM/LGBTQ research beyond HIV, in order to encompass more of the many other health challenges faced by our communities. We also fully support the commitment to research to benefit “all individuals and populations who do not self-identify with binary constructs of sexual orientation, gender, and/or sex,” including “a focus on specific populations on which the lack of research remains significant” (84 Fed. Reg. at 68180). In particular, much more research is needed on the health and wellness of transgender and gender nonbinary populations; bisexual persons; LGBTQ elders and youth; and the health challenges faced by LGBTQ persons in racial and ethnic minority and other marginalized communities – as well as their sources of strength and resilience.

In addition, we applaud the specific mention in the RFI of research into the health and wellness needs of persons with intersex traits and other differences in sex development. These populations are too often overlooked and their health needs poorly understood. In particular, we urge NIH to fund research into long-term physical and mental health consequences of “gender-confirming” surgeries on infants with intersex traits; on the appropriate counseling of families of

such infants; on the appropriate medical treatment and behavioral health assistance for individuals who present with intersex traits during puberty.¹

We note that, in listing “specific populations on which the lack of research remains significant,” the RFI includes “persons who have detransitioned/desisted people” (84 Fed. Reg. at 68180). Whitman-Walker fully supports expanded research into the multi-faceted relationships between gender identity and health and wellness, including health outcomes for persons with minority gender identities who engage in gender-affirming hormonal and/or surgical care; for such persons who desire hormonal or surgical interventions but are unable to access such care; and for individuals who decline such procedures. Given the significant lack of research on gender minority populations, and given significant contemporary challenges to ensuring the civil rights of gender minority persons, we would encourage caution in dedicating already limited resources to the study of persons who have “detransitioned” or “desisted” from gender transition. We would urge that if conducted, such study be undertaken as part of much larger studies of the health and well-being of gender minorities generally, with clear plans for community consultation, ethical assessment and analysis, and dissemination of findings in ways that do no harm.

We support the Office’s acknowledgement of the importance of “community and culturally grounded research” (84 Fed. Reg. at 68180). We urge the Office, and NIH in general, to emphasize the importance of engaging community health centers (CHCs) as full partners in LGBTQ health research. Along with WWH, a number of CHCs have considerable experience

¹ E.g., Ernst MM, Liao L-M, Baratz AB, et al. Disorders of sex development/intersex: Gaps in psychosocial care for children. *Pediatrics* 2018; 142(2): e20174045; Lee PA, Nordenström A, Houk CP, et al. Global disorders of sex development update since 2006: Perceptions, approach and care. *Horm Res Paediatr* 2016; DOI 10.1159/000442975.

working with LGBTQ-identified patients and deep connections to LGBTQ communities – more experience and deeper community connections than exist in most academic institutions.

Research in which CHC providers and community health workers are full partners is likely to produce more community-relevant insights, and generate more community trust, than purely academic endeavors. To this end, we encourage efforts to promote and enhance partnerships between CHCs and university-based researchers.

In addition to funding more research with a specific SGM focus, and identifying strategies and resources to support research partnerships across a greater variety of institutions, we believe it is imperative for researchers in all health areas to collect accurate data on the sexual orientation, sex assigned at birth, and gender identity of all of their research subjects. Collection of accurate information on these questions, that is consistent across studies, would greatly advance our knowledge of health disparities and our understanding of possible interventions. We urge the Institute generally to require such data collection whenever possible and appropriate, and urge the Office to provide technical assistance to researchers on best practices for SOGI data collection.

Conclusion

We appreciate this opportunity to offer our suggestions, and would be happy to provide additional information on request, or to assist the Office's important work in any other way.

Respectfully submitted,

A handwritten signature in black ink that reads "Daniel Bruner". The signature is written in a cursive style with a large, looping initial "D".

Daniel Bruner, JD, MPP, Senior Director of Policy
dbruner@whitman-walker.org, (202) 939-7628
Benjamin Brooks, JD, MPH, Assistant Director of Policy

WHITMAN-WALKER INSTITUTE
WHITMAN-WALKER HEALTH
1377 R Street, NW
Washington, DC 20009

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