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## **COMMENTS OF WHITMAN-WALKER HEALTH ON THE NIH FY 2016-2020 STRATEGIC PLAN TO ADVANCE RESEARCH ON THE HEALTH AND WELL-BEING OF SEXUAL AND GENDER MINORITIES**

Pursuant to the National Institutes of Health's October 1, 2015 notice in the Federal Register, 80 Fed. Reg. 59169, Whitman-Walker Health (WWH or Whitman-Walker) offers these comments on the proposed strategic research plan to address the health and well-being of sexual and gender minorities (SGM) – or lesbian, gay, bisexual and transgender (LGBT) people. We applaud the Institute's initiatives to advance "basic, clinical, and behavioral and social sciences research" to better understand and promote health and well-being of SGM (Strategic Plan, p.1). It is clear that sexual and gender minorities suffer from a wide range of health challenges and disparities, and a concerted and coordinated effort to better understand the bases of these disparities and hence identify appropriate responses and interventions is essential. Moreover, as the document acknowledges, there are significant gaps in our knowledge about the health and well-being of SGM communities, and the Strategic Plan provides a necessary road map for prioritizing research topics and practices. A robust and thriving research community focused on SGM health will contribute significantly to ensuring that these individuals and their needs are more visible to health care providers.

### **Interest and Expertise of Whitman-Walker Health**

WWH 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 LGBT 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; LGBT 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 LGBT 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 LGBT health and wellness. In calendar year 2014, we provided health services to more than 14,700 individuals. Approximately one-half of those individuals identified as gay, lesbian or bisexual. Transgender and gender nonconforming individuals comprise a substantial and growing part of our patient and client base: approximately 6% of all those receiving health services; 13% of medical patients; 20% of persons receiving mental health services; and 8% of those receiving substance abuse treatment services. We also have a longstanding, robust Clinical Research Department, that has worked with the Institutes, the Centers for Disease Control and Prevention, major pharmaceutical companies, and others. Our interest in commenting on this Strategic Plan is grounded in our experience as a direct health care provider to the LGBT community, as a researcher, and as an advocate for sound public health policies.

### **NIH Should Establish a Community-Based SGM Research Network**

To take full advantage of existing expertise, we recommend that the Strategic Plan include the establishment of a “Community-Based SGM Research Network” comprising a core of community-based health care centers with a proven history of intentionally serving SGM populations. The inclusion of additional community-based social support service agencies as partners in the network would help to ensure that a full range of research questions are considered when designing projects, while also enhancing access to SGM communities. This network would be modeled after previous successful NIH-supported collaborative groups such as the AIDS Clinical

Trials Group (ACTG), Mycoses Study Group (MSG), multiple collaborative cancer research groups currently supported by Cancer Treatment Evaluation Program (CTEP), and multiple special interest research collaborative groups supported by the Centers for AIDS Research (CFAR) as well as those programs supported by the Office on Research on Women's Health (ORWH). This network would be charged with developing a shared research agenda and conducting joint projects in response to the Strategic Plan. This network could be designed also to have an advisory role in the trans-NIH activities of the proposed Sexual and Gender Minority Research Office (Goal 2, Objective 1 of the Strategic Plan) – leveraging the extensive knowledge base of SGM communities that the members of the network already possess. Similarly, this network could play a key role in the 2018 convening of SGM health research experts for a mid-course review of the Strategic Plan (Goal 4, Objective 2).

Establishing a Community-Based SGM Research Network would provide the infrastructure for the clinical care and research organizations that already serve many SGM patients to formally collaborate in key ways to advance the Strategic Plan, such as:

- identifying priority research questions that could be answered with their existing data bases, either as individual organizations or jointly;
- identifying opportunities for joint research programs based on shared interests and combined capacity (addresses Goal 1, Objective 1);
- disseminating findings to support future research and inform programmatic and health policy development and capacity-building;
- ensuring that NIH's evolving SGM research strategy includes community-initiated and – driven questions that inform practice “on-the-ground” and already “in-the-clinic”;
- developing an academic fellowship program to expand the workforce of researchers skilled in conducting research in SGM communities and successfully competing for NIH grants (Goal 2, Objective 2); and

- creating opportunities for community-based, clinical health researchers with proven track records in conducting productive NIH-funded research programs to directly access NIH funding for collaborative research programs. Consultation with academic centers via existing or new collaborations for technical assistance would be welcomed.

We also support the Plan’s inclusion of research to explore methodological challenges that contribute to the relative lack of well-designed research studies among SGM populations. Specific issues identified in the plan include small sample sizes, challenges in identifying members of SGM communities, and reluctance among SGM individuals to self-identify to clinicians or researchers. The small SGM population size also further complicates studying subpopulations based on “sexual orientation, gender identity, race and ethnicity, age and other factors” (p.7). The “Community-based SGM Research Network” would be in an ideal position to conduct research related to these methodological challenges, given their extensive experience in successfully working with hard-to-reach populations. As a collective, the Network would provide a forum to develop methods for joint research, including operationalizing key social and behavioral concepts and SGM terminology and creating common data elements to facilitate pooling of data – and thereby increasing sample sizes. Addressing and resolving methodological issues will provide essential tools for other researchers interested in this topic but concerned about barriers to conducting sound research among SGM populations.

Organizations such as Whitman-Walker with significant expertise in caring for and conducting NIH-funded research studies with SGM communities have always incorporated the varying perspectives identified in the Strategic Plan – minority stress, life course, intersectionality, and social ecology – into our work with patients. Our experience with SGM populations constantly informs our understanding of the complexities of gender and sexuality and of the forces that continue to marginalize many, despite current cultural shifts and legislative progress. Similarly,

consideration of family and interpersonal relationships, health services, and mental health and physical health – as also identified in the Strategic Plan -- has always been central to providing integrated and comprehensive care for SGM patients. This experience positions us to be an active member of our proposed “Community-based SGM Research Network,” along with other organizations with a demonstrated, long-standing commitment to improving SGM health and well-being.

**The Strategic Plan Should Include a Specific Focus on Research Into Effective Ways to Increase Clinical and Cultural Competency of Health Care Providers Regarding CGM**

We appreciate NIH’s recognition in the plan of the importance of cultural competency for both researchers and those working directly with SGM communities. However, the lack of information about the effectiveness of various training programs, strategies, and content creates challenges for those advocating for or implementing cultural-competency efforts. We simply do not know what works, and we support NIH efforts to fund research necessary to designing effective programs for a range of settings and audiences. This comment echoes the sentiments shared in the Strategic Plan (Appendix B, p. 71):

The stark reality that we do not know what components constitute a successful cultural competency training program is an ongoing challenge. Adding to the difficulty, we do not know the effective individual or institutional dose, what outside supports are needed for institutional change, or what factors make some trainers more and less successful. All of these questions can be answered with research.

Cultural competence is repeatedly suggested as a valid way to change healthcare providers’ attitudes and treatment of LGBT patients, but there is no data to suggest that this method is successful in achieving changes in provider-patient interactions. We need research on best practices. In the meantime, trainings are offered all over the country with simple pretest/posttest measures and these may be accomplishing nothing of value.

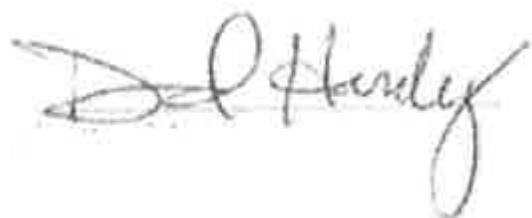
Our experience providing a range of services to SGM communities clearly demonstrates that cultural competency must resonate with clinicians as essential to doing their work as health care providers and doing it well, if training programs are to be effective. Provider understanding of why cultural competency is important in clinical work is a critical first step, and we also support research into

how to effectively infuse this message throughout training in order to receive provider buy-in and support. Becoming culturally competent can no longer be viewed as a training requirement to be “checked-off” in publically-funded health care and other facilities, but as a basic level of knowledge for providing the best healthcare or other service to persons in need of the service.

### **Conclusion**

Thank you for the opportunity to submit these comments. Whitman-Walker stands ready to provide any additional assistance that might prove helpful.

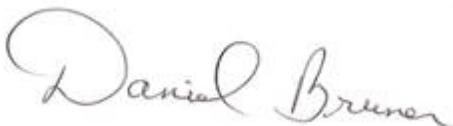
Respectfully submitted,



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