

BEFORE THE DEPARTMENT OF HEALTH AND HUMAN SERVICES  
CENTERS FOR DISEASE CONTROL AND PREVENTION

Proposed Data Collection Submitted for)  
Public Comment and Recommendations)

Docket No. CDC-2018-0039

COMMENTS OF WHITMAN-WALKER HEALTH IN SUPPORT OF PROPOSED HIV-  
RELATED STUDY OF TRANSGENDER WOMEN

Pursuant to the CDC's May 29, 2018 Notice, 83 Fed. Reg. 24478, Whitman-Walker Health (WWH or Whitman-Walker) submits these comments on the agency's proposed two-year information collection project, *National HIV Behavioral Surveillance Among Transgender Women* (NHBS-Trans).

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

Whitman-Walker is a Federally Qualified Health Center serving greater Washington, DC's diverse urban community, including individuals who face barriers to accessing care, and with a special expertise in HIV care and serving lesbian, gay, bisexual, transgender and questioning/queer (LGBTQ) populations. We empower all persons to live healthy, love openly, and achieve equality and inclusion. Our health center provides high quality, affirming health care to more than 20,000 individuals annually and is the medical home to more than 10,000 patients. The center has five sites and a team of more than 280 highly educated and practically experienced staff.

WWH services include primary medical care, HIV and LGBTQ specialty care, oral health, mental health care, addictions treatment services, psychosocial support, medical nutrition therapy, early intervention services, public benefits and insurance navigation, nurse-focused case management, HIV and STI screening, legal services, youth programs, and an onsite pharmacy. The health center has achieved Level 3 Patient Centered Medical Home accreditation with the National Committee for Quality Assurance.

Whitman-Walker's service area is the greater Washington, DC metropolitan area; we serve more than 25% of the District of Columbia's reported HIV-positive population, many of them low-income or members of otherwise underserved communities. Our patient populations include: African Americans; Hispanic individuals; gay and bisexual men; substance users; low-income and homeless individuals; and transgender persons. In 2017, our HIV testing program diagnosed 11% of the new cases of HIV reported in the District. We also diagnosed approximately 9% of the new HCV cases in DC; 27% of the new cases of primary and secondary syphilis; more than 18% of the new cases of gonorrhea; and more than 9% of the new cases of chlamydia.

Whitman-Walker has a robust portfolio of high-quality, holistic services to the transgender and gender-nonbinary community in the Washington, DC metropolitan area, and service a number of such individuals living at greater distances – much of the States of Maryland and Virginia, and some residents of Pennsylvania, West Virginia and Delaware. In calendar year 2017 we provided health care to more than 1,500 unique transgender and gender-nonbinary persons, and our Legal Services Department provided advice and representation to approximately 1,000 such individuals. Whitman-Walker also has a large and growing Research Department, which is participating in several studies that include or focus on transgender individuals, including the new LITE Study, Leading Innovation for Transgender Women's Health and Empowerment (NIH UG3-AI133669). In addition, WWH is participating with the O'Neill Institute of Georgetown University Law Center, and HIPS, a local community-based nonprofit, in a research study of the health and wellness of DC sex workers, many of whom are transgender women,

### **Comments on the Proposed Information Collection Project**

The May 29, 2018 Notice requests comments that

*[e]valuate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility (83 Fed. Reg. 24478, italics provided).*

We strongly agree that the proposed information collection project is important to the CDC's mission and performance, and that it is very likely to have practical utility in the attainment of national, state and local goals in the continuing fight against the HIV epidemic, as acknowledged in the May 29 Notice (*id.* at 24478-79). HIV infection rates among transgender women in the U.S. are staggeringly high, as the CDC has reported: approximately one-quarter of all transgender women, and one-half of Black transgender women. *HIV Among Transgender People*, <https://www.cdc.gov/hiv/group/gender/transgender/index.html>. Information on transgender women's risk factors, and effective strategies for HIV prevention in this hard-hit community, is woefully inadequate; much more data is needed. Gathering behavioral data is critical to better understanding the experiences of transgender women in relation to their HIV risk. This understanding can inform the development and implementation of culturally appropriate and sensitive interventions to prevent HIV transmission and to improve health outcomes of those living with HIV.

The May 29 Notice also requests comments on

*the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used (id. at 24478)*

Although we have not succeeded in obtaining the proposed data collection plan, despite several requests for this information, the estimates provided in the Notice appear to be consistent with our experience in studies that involve similar levels of screening, behavioral assessment, and

recruiter debriefing. We agree with the observation in the Notice (*id.* at 24479) that “respondent-driven sampling [is] a scientifically-proven recruitment strategy for reaching hidden, hard-to-reach, or stigmatized populations.” Whitman-Walker is successfully using this recruitment strategy for one of our current research projects, and in light of our experience we support this approach for this proposed data collection.

The Notice also requests comments on

*the quality, utility, and clarity of the information to be collected (id. at 24478)*

Since we have been unable to review the actual data collection instruments, we are unable to fully address this question. However, in addition to the assessment domains identified in the Notice (behavior related to the risk of HIV and other STIs, prior testing for HIV, and use of HIV prevention services), we propose considering the value of assessing needs related to social determinants of health (housing, food, legal services, employment assistance, stigma – including HIV stigma and its intersection with gender stigma). These social determinants are clearly related to elevated health risks, including HIV.

The Notice also requests comments on how the information collection project can

*[m]inimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses (id.)*

We suggest multiple formats of information collection including online or telephone survey, in addition to in-person surveying, as some participants may be less willing to provide answers in an in-person setting. The Notice does not indicate in which languages the survey may be completed. We recommend consideration of multiple languages, as a mean to increase the

ability to reach hard-to-reach populations. Spanish clearly will be vital in our experience; which other languages are advisable will depend on demographics of each of the MSAs selected.

Finally, the Notice requests feedback to assist in

*assess[ing] information collection costs (id.).*

The Notice does not provide an estimate of collection costs, and we have been unable to obtain any supporting documents that may include this information, so we are unable to comment.

However, one important point is that participating transgender individuals should be provided a reasonable financial incentive for participating. Many of these individuals are low-income, including many at the highest risk of HIV, and in our experience many in the transgender community are distrustful of researchers that ask for their time without providing anything in return.

### **Additional Comments**

We note that the proposed information collection project includes only transgender women, not transgender men or non-binary/genderqueer individuals. Although we agree that the available evidence indicates that transgender women have much higher HIV incidence and prevalence rates, transgender men have largely been ignored in studies of HIV incidence, prevalence and risk, and there is a great need for more and better data on this community. Moreover, to our knowledge there is virtually no data on persons who do not define themselves as male or female, many of whom are likely at elevated risk of HIV and other sexually-transmitted infections. We urge the CDC to devote more resources to these communities.

In addition, the Notice does not identify the specific MSAs being contemplated or targeted for this project. We submit that Washington, DC would be an ideal site, given the very high infection rates generally in this area, and particularly because the large size, and diversity,

of the transgender population here. Whitman-walker would be happy to work with the CDC on this project.

### **Conclusion**

Thank you for this opportunity to submit comments. We would be happy to provide any additional information that might be helpful.

Respectfully submitted,

A handwritten signature in cursive script that reads "Daniel Bruner".

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