

**BEFORE THE UNITED STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES
CENTERS for DISEASE CONTROL and PREVENTION**

Agency Information Collection Activities;)
Proposed Data Collection Submitted;) **83 FR at 62865**
for Public Comment and Recommendations) **Docket ID CDC-2018-0102**

Submitted via www.regulations.gov

COMMENTS OF WHITMAN-WALKER HEALTH

Whitman-Walker Health (WWH or Whitman-Walker) submits these comments in response to the Centers for Disease Control and Prevention’s (CDC) request for information published on Dec. 6, 2018. While the agency’s notice is brief, we strongly support the goal of the research, which is aligned with the Department of Health and Human Services’ (HHS) broader efforts to stop the spread of HIV. The proposed research appears well-designed to measure the impact of multiple technology-assisted public health techniques.

EXPERTISE AND INTEREST OF WHITMAN-WALKER HEALTH

Whitman-Walker Health is a community-based, Federally Qualified Health Center offering primary medical care and HIV specialty care, community health services and legal services to residents of the greater Washington, DC metropolitan area. WWH has a special mission to the lesbian, gay, bisexual and transgender members of our community, as well as to all Washington-area residents of every gender and sexual orientation who are living with or otherwise affected by HIV. In calendar year 2018, more than 20,000 individuals received health services from Whitman-Walker.

Whitman-Walker has been a nationally recognized leader in HIV treatment and prevention for almost four decades. Our staff of almost 40 physicians, physician assistants, nurses and nurse practitioners, and medical assistants provided care to 3,505 people living with HIV in calendar year 2017. WWH has been at the forefront of the Nation’s response to the

epidemic since the very beginning. Through direct care and participation in extensive research funded by the Federal Government and by pharmaceutical companies, we have participated in the breakthroughs in HIV treatment and prevention which have transformed HIV from a largely untreatable, terminal disease to a manageable chronic condition, and which have made it possible to envision an end to the epidemic in our lifetimes. We also are a national leader in providing expert, affirming health services, including HIV treatment and prevention services, to gay, bisexual, and same-gender-loving men, including men of color. In calendar year 2017, 8,633 of WWH patients identified as gay, bisexual or otherwise non-heterosexual males. Of those patients, 2,663 identified as Black or African-American men, and 1,406 identified as Hispanic or Latino.

COMMENTS

Population of Interest: The CDC has identified an appropriate population for this research effort. The HIV epidemic is growing quickly in same-gender-loving men in African American, Black, Hispanic and Latino communities.

Privacy: Technology-assisted HIV prevention techniques have the opportunity to reduce health disparities by lowering barriers to accessing HIV testing, treatment, and prevention resources, but increase risks of accidental disclosure of private health information. HIV and LGBT status continues to carry immense stigma in many communities, particularly those across the rural South. Due to stigma, disclosing HIV status and sexual practices or identity has potential health risks. The CDC could put appropriate safeguards in place to protect participants from a potential data breach, including making study applications password secured, making low-profile application icons available to participants, and encrypting survey responses.

Study Design: The study design implicitly creates a participant bias toward men with smart phones and internet access. Using internet websites to recruit and communicate with respondents excludes low-income participants who cannot afford smart phones or internet access. CDC could ensure they are reaching the right communities by supporting, promoting, and conducting respondent recruitment and participation in public libraries and other free educational institutions in study states.

The study appears well designed to capture information about the efficacy of health promotion activities in linking people to appropriate HIV treatment or prevention services using web-based tools. We are pleased that each study arm receives an HIV test, the proven intervention, before they are divided into experimental groups. The CDC is using best practices by distributing the health intervention with established benefits to the widest population of their sample.

Limitations of the Study and Need for More Community Consultation: The study is likely to reach individuals with sufficient access to resources, education, and trust of the medical/public health establishment, and governmental agencies, to appreciate the CDC's intent and the importance of the project. However, many in the populations most heavily and disproportionately affected by HIV – Black or African American men, Hispanic or Latino men, and especially young men of color – are very distrustful of the medical establishment and the government – especially the federal government nowadays – and may not understand or trust the efforts to keep their highly sensitive information confidential. Many Latinex individuals may be particularly fearful of participation in a federal government initiative, given concerns about the actions of immigration officials and agencies. Other individuals may be fearful of HIV-themed mailings because their sexual orientation or practices are concealed from family members or neighbors. Therefore, this project is unlikely to reach many of the most at-risk individuals. We

recommend that the CDC engage in more focused community consultations – including focus groups and other measures – to learn more about community concerns and how they might be more effectively addressed.

Response Burden: While WWH cannot assess the quality, clarity or utility of the information collected without seeing the research questions; the estimated response burden seems to align with the medium and purpose of the study and the response burden appears reasonable for the length of the study and benefit provided to participants.

CONCLUSION

Whitman-Walker Health acknowledges that the study population is well chosen, the study design is thoughtful and innovative, and the study purpose is necessary and essential to the HHS’s mission to advance the public health and their goal of ending the spread of HIV. We note that the potential harms to respondents are reasonable and manageable in light of the potential benefits. WWH supports the CDCs continued efforts to create more effective HIV prevention and treatment linkages in African-American and Latino communities of MSM.

Respectfully submitted,



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