

**BEFORE THE UNITED STATES DEPARTMENT OF  
HEALTH AND HUMAN SERVICES  
ADMINISTRATION for CHILDREN and FAMILIES**

<b>Proposed Information Collection Activity;</b>	)	
<b>Youth Empowerment Information, Data;</b>	)	<b>84 FR at 2874</b>
<b>Collection, and Exploration on Avoidance</b>	)	<b>Docket ID FR-2019-01566</b>
<b>of Sex (IDEAS)</b>	)	

*Submitted via email to [OPREinfocollection@acf.hhs.org](mailto:OPREinfocollection@acf.hhs.org)  
Attn: OPRE Reports Clearance Officer*

**COMMENTS OF WHITMAN-WALKER HEALTH**

Thank you for the opportunity to comment on the Administration for Children and Families' (ACF) Office of Planning, Research and Evaluation's (OPRE) proposed information collection activity regarding the Youth Empowerment Information, Data Collection, and Exploration on Avoidance of Sex, 84 Fed. Reg. 2874 (02/08/2019). We are concerned that the survey instruments are stigmatizing and potentially harmful to sexual and gender minorities. Specific concerns and recommendations for this data collection to achieve ACF's goals of fostering health and well-being are outlined below.

**EXPERTISE AND INTEREST OF WHITMAN-WALKER HEALTH**

Whitman-Walker Health (Whitman-Walker or WWH) is a community-based Federally Qualified Health Center, whose mission is to provide high-quality, culturally competent health services to Washington, DC's diverse urban community. We have a special focus on HIV treatment and prevention and on the health and wellness of the LGBTQ (Lesbian, Gay, Bisexual, Transgender and Questioning) community and others who face barriers accessing care. We offer primary medical and specialty HIV and transgender care; dental care; mental health and addictions counseling and treatment; HIV education, prevention, and testing services; other community health services; legal services; and medical adherence care management. Of the

more than 20,000 persons to whom we provide health services every year, approximately one-half identify as homosexual, bisexual, or otherwise non-heterosexual. In 2018, approximately 9% of our over 20,000 medical patients identify as transgender or gender-nonconforming, 17% were youth or young adults aged 15-24, and of the youths and young adults, 14% identified as transgender or gender non-conforming.

Whitman-Walker has been a nationally recognized leader in HIV treatment and prevention for almost four decades. In calendar year 2018, we provided health care to 3,505 people living with HIV. 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. Eighty three percent of our patients living with HIV are virally suppressed – a success rate much higher than the national and DC averages for people living with HIV, and comparable to the success rate for Ryan White-funded programs.

Whitman-Walker's Medical, Behavioral Health and Community Health Departments have been at the forefront of HIV education and prevention since the earliest days of the epidemic. In 2018, we provided HIV tests to 7,787 individuals, and our walk-in Sexual Health and Wellness clinics, which offer STI and HIV testing, served 1,719 individuals. In 2017, our STI testing program diagnosed approximately 9% of the new HCV cases, 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 in the District of Columbia. Whitman-Walker also has more than 1,000 patients on Pre-exposure Prophylaxis for HIV, or PrEP, and has instituted a low-barrier "PrEP clinic" to make it easier for individuals who would benefit to start and remain adherent to the therapy.

WWH has been conducting clinical research since 1987, when the first HIV treatments were being tested. Our studies investigate new ways to prevent or treat diseases in our community, particularly HIV and other sexually transmitted diseases. Our research priorities also include new treatments for opioid addiction and the health and wellness priorities of LGBTQ youth. WWH's current research studies include clinical trials that test the long term effects of HCV treatments, how well new medications work, and the safety and efficacy of treatments for HIV and HCV co-infected adults; as well as behavioral intervention studies that investigate ways to improve adherence to HIV treatments and engagement with PrEP and other HIV prevention strategies among young men, transgender women, and gender-expansive youth of color who have sex with men.

Whitman-Walker's Youth Services Program offers a wide range of education, prevention, testing and care management services to young people and their families, with an emphasis on sexual and reproductive health and wellness. The WWH Youth Services Prevention team provides sex education programming to youth throughout the community and is an essential source of connection and building of knowledge and skills for many young people across the city. We also provide mental health services to LGBTQ youth who have been victims of crimes, as well as long-term care navigation for LGBTQ HIV-positive youth. Between 2004 and 2015, WWH Youth Services worked with District of Columbia Public Schools (DCPS) on evidence-based health curricula and out-of-school time sexual health programming for students in grades 5-12. WWH also trained all DCPS middle and high school health teachers on issues relating to bullying, LGBTQ sensitivity and how to be creative while teaching sexual health education. Finally, WWH implemented a co-teaching model with approximately 25 DCPS health educators to assist them in delivering sexual health education.

Making Proud Choices (MPC) is our CDC-approved, evidence-based curriculum geared toward middle school students. MPC provides a series of fun and interactive learning experiences regarding making healthy decisions around HIV/AIDS, teen pregnancy and drug prevention. Becoming A Responsible Teen (BART) is our high school curriculum that provides students an opportunity to explore HIV/AIDS, STIs, drugs and teen pregnancy in an engaging manner. BART allows teens to speak about personal situations in a safe, fun environment. Visionary Youth Becoming Empowered (VYBE), our afterschool program, is our flagship program that blends material from MPC/BART with life skills and fun, interactive discussions and field trips.

Our interest in ensuring that the new health standards are inclusive of the needs of all students, including sexual and gender minority youth, is grounded in this extensive experience working with LGBTQ youth daily in many capacities. It is clear that LGBTQ people suffer from a wide range of health challenges and disparities – as highlighted, for instance, in the U.S. Department of Health and Human Service’s *Healthy People 2020*<sup>1</sup> and the Institute of Medicine’s *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* (2011).<sup>2</sup> Inclusive health education programming in the schools is an essential component in reducing health disparities among LGBT individuals and communities, while also addressing the problem that many LGBTQ youth do not see themselves reflected in their health education classes, many clinical settings, and public health initiatives.

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<sup>1</sup>Office of Disease Prevention and Health Promotion, *Lesbian, Gay, Bisexual, and Transgender Health, Healthy People 2020*, <http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>.

<sup>2</sup> Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender People*, National Academies Press; 2011, available at <http://nationalacademies.org/hmd/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>.

## **Insights from Focus Groups with LGBTQ Youth and Young Adults**

As a component of a two-year research project into LGBTQ Youth Health and Wellness funded by the Washington AIDS Partnership, WWH conducted five focus groups with a total of 43 LGBTQ youth and young adults, ages 16-24 between September and November 2015. The purpose of these focus groups was to learn about the experiences and viewpoints of a diverse range of DC-area LGBTQ youth and young adults on what “wellness” means to them; and their needs for health-related services and education, and the barriers and opportunities they perceive to living healthy lives.

An overarching theme that arose within the focus groups was the experience of participants being left to their own devices to learn about the sexual behavior in which they were engaged – or would someday engage. Participants overwhelmingly shared that the health education received in school was not inclusive of or relevant to their experiences as LGBTQ youth. They indicated a desire and need for comprehensive sex education that provides concrete and useful information about the full range of sexual behavior, including that among same sex partners, and about gender identity. They expressed a need for educators who are not afraid to explain “how things work” when teaching about sex and were comfortable and knowledgeable talking about gender identity.

If young people do not seem themselves represented in the survey data collection efforts, it risks disengaging them from data collection efforts and further leaves their needs out of efforts to develop effective and responsive sexual health education – putting them at further risk. In turn, failure to include information that is relevant to sexual and gender minority youth within sexual health education efforts pushes them to other sources of potentially incorrect information. Youth are likely to learn about sexual practices online from venues that do not prioritize sexual

health and development and often create or exacerbate risks. For example, one participant described how young people who engage in anal sex without adequate information about lubricant are at risk of internal tearing and bleeding, which can diminish their sexual experience and increase their risk of contracting HIV and other sexually transmitted infections. Focus group participants also shared that in the absence of relevant sexual health education, youth often learn about queer sex from pornography – and they recognized that pornography as the educator was problematic for many reasons.

Our findings make clear that health education that incorporates the full range of sexual behavior and sexual and gender identities is essential to fostering the physical and mental health of LGBTQ students – and to promoting an understanding of and respect for diversity in all students.

Failing to teach LGBTQ young people about the full range of sexual behavior and gender identities contributes to the social bias toward sexual and gender minorities as “less than” and “other”, and sends the message to LGBTQ youth that they are not worthy of being fully acknowledged. In thinking beyond a risk-based strategy, youth expressed a need for a more expansive approach to teaching about sex, which addresses consent, communication, and healthy relationships. This is a clear call for health education that presents a positive and healthy perspective on sex, while providing the knowledge and skills to identify risks, make sound decisions, and navigate relationships in a healthy way. The effects of taking a survey too heavily focused on risks can be stigmatizing and fear inducing, which reduces the effectiveness of public health efforts to encourage open and honest dialogue around sexual behaviors, risks, and healthy relationships.

## **General Recommendations for the Youth and Parents Survey Instruments**

**Youth Survey Section B.** The questions implicitly present lots of reasons for not having sex and discuss pressures to engage in sexual activity. The items are focused on abstinence, sexual pressures, and sexual risks. Adding questions about sources of pleasure and of risk would provide important information to build sexual health programming that supports young people in having open communication that reduces risk and harm that may come from sexual activity. We also recommend asking about masturbation. Masturbation and other solo sexual practices, of course, are quite common among young people; failing to name them or ask questions about them contributes to ignorance and may render surveys less credible. Moreover, they often are a healthy alternative to sex with a partner and are important for sexual development.

Our research indicates that LGBTQ youth are interested in learning more about sexual orientation and gender identity. The ACF misses an opportunity to gain insight on the sources of information and education on gender and sexuality by failing to ask participants about them. We strongly recommend that the questions on preferred and actual sources of education on gender identity and sexual orientation be included in the instrument.

**Youth Survey Questions C21-25.** These questions address intentions and attitudes toward marriage that raise concerns about the survey's internal validity. We recognize the focus on marriage in the survey reflects the government's pro-marriage policies. Under the Supreme Court's ruling in *Obergefell v. Hodges*, the 14<sup>th</sup> Amendment of the Constitution guarantees the right to marry as a fundamental liberty.<sup>3</sup> *Obergefell* expansively extends the right to marry to two consenting, unmarried adults, regardless of sex, gender identity or sexual orientation. The marriage questions are currently written in a sufficiently inclusive way, but because the

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<sup>3</sup> *Obergefell v. Hodges* 135 S. Ct. 2584 at 22 (2015) (“The Court now holds that same-sex couples may exercise the fundamental right to marry.”).

instrument seeks to obtain information on people’s attitudes on marriage, the entire instrument needs to be inclusive of LGBTQ people or the survey fails to maintain consistency and will likely miss and mischaracterize sexual and gender minorities. Our specific recommendations include ways to improve the instrument’s internal validity and align with the Constitutional right to marriage that is enjoyed by people of all genders and sexual orientations.

### **Specific Recommendations related to the Youth and Parents Survey Instruments**

**Youth Survey Question A6.** The current question does not appropriately address transgender and gender non-conforming youth. We recommend removing the “Something else” option and replacing it with four more accurate and respectful options. We suggest the options: “Transgender man,” “Transgender woman,” “Genderqueer or gender non-conforming,” and “Another gender identity.” Participants may feel that the “Something else” option fails to respectfully and meaningfully engage with youth gender identities. Due to the higher potentials for drug and alcohol use and self-harm in transgender communities, it is especially important to obtain accurate information on transgender and gender non-conforming youths.

**Youth Survey Questions B1-B3, B5-B7, F5, F9; Parent Survey Questions C1, C2, C4.** Based on the reasons outlined in the above general recommendations, we recommend including three additional items for each of these questions:

- Benefits of masturbation and solo sexual pleasure;
- Diverse gender identities and sexual orientations;
- Experiences of guilt and shame from masturbation or sex.

**Youth Survey Questions C16- 21.** The phrasing of these questions presupposes a binary view of gender (either “male” or “female”) that does not reflect the lived experience of many youth and young adults. We recommend that the questions adopt more expansive, inclusive



language. Specifically, we recommend using the phrase “romantic partner” in place of “boyfriend or girlfriend.” The phrasing is often acceptable and understandable and has the benefit of being inclusive of gender non-conforming and transgender youths. Our recommendation will align with language already used in the youth survey instrument in question C24.

**Youth Survey Questions F5 and F9.** The survey question says “Female and male reproductive systems” in an item. We reflect that the current language assumes a common form of female and male reproductive systems that is not inclusive of transgender and intersex youth. We suggest that the item should use more expansive and descriptive language. We recommend using “Reproductive biology and anatomy (including information about sex organs and the menstrual cycle or period).” This phrasing eliminates the implicit assumptions about genitalia present in the question and is more inclusive of transgender, intersex, and other people with reproductive anatomy that diverge from the norm.

**Youth Survey Section G – Sexual Risk Behavior.** The definition of “sex” in this section is very narrow - limited to vaginal, oral, and anal sex. The definition might not match up with youth expectations or definitions of sex and could send a stigmatizing message that other forms of sexual behaviors are unnatural or invalid. We appreciate that oral, anal, and vaginal sex pose heightened risks of exposure to infections and (for vaginal sex) pregnancy compared to other kinds of sexual behaviors. As such, we recognize the benefit of limiting the scope of these questions to only asking about these specific types of sexual behavior. However, to avoid confusion, it is important to distinguish between these specific sexual behaviors and “sex” more generally. Therefore, we recommend changing the introductory language at the beginning of Section G. We recommend that the introduction read:

The following questions are about three common sexual behaviors. We ask questions about oral, anal, and vaginal sex. Oral sex is when someone stimulates another's genitals with the mouth. Vaginal sex is when someone puts a penis into another's vagina. Anal sex is when someone puts a penis into another's anus, butt, or rectum.

This phrasing removes the limiting language and implicitly informs the participant that there are a diversity of sexual behaviors, reducing the potential for confusion and alienation. The updated phrasing is also inclusive of transgender and gender non-conforming participants whose identity as male or female is not connected to their genitalia (e.g. a young transgender woman with a penis).

### **CONCLUSION**

Whitman-Walker Health's expertise and experience delivering behavioral health and healthcare services to youths and young adults, and our work in health prevention and education efforts and healthcare delivery research indicates that inclusive, comprehensive health education programming is an essential component in reducing LGBTQ health disparities. Inclusive education and healthcare delivery messaging can address the invisibility that many LGBTQ youth experience in their health education classes, many clinical settings, and public health initiatives. Our experience with patients and research findings make clear that health education

that incorporates the full range of sexual behavior and sexual and gender identities is essential to fostering the physical and mental health of LGBTQ students – and to promoting an understanding of and respect for diversity in all students.

Respectfully submitted,



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