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SUBJECT LINE: Federal Evidence Agenda on LGBTQI+ Equity RFI
DUE DATE: October 3

NSTC Subcommittee on Equitable Data
Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Avenue, NW
Washington, DC 20504

Dear Subcommittee Members:

Thank you for the opportunity to share with you why LGBTQI+ data inclusion is important to us. AIDS Foundation Chicago is a 501(c)3 nonprofit organization that is dedicated to mobilizing communities to create equity and justice for people living with and vulnerable to HIV or chronic conditions. AFC was founded in 1985 during the height of the HIV epidemic by advocates and physicians who saw institutional failing around them to support individuals living with and dying of AIDS. We have served our community for more than 35 years and have continued to expand beyond our initial scope to address other systemic barriers that make people vulnerable to HIV, including housing insecurity and substance use. While HIV can affect anyone, it has disproportionately impacted the LGBTQI+ community. As such, we appreciate that LGBTQI+ data inclusion is critical to advancing LGBTQI+ equity and are excited about the work you're doing as a subcommittee.

While AFC has served and advocated for the LGBTQI+ community since its inception, it took the pivotal step of welcoming Pride Action Tank (PAT) in October of 2015, seven years to the day. PAT, an initiative of AIDS Foundation Chicago, is a project incubator and think tank that is focused on action that leads to improved outcomes and opportunities for LGBTQI+ communities in the Chicago region through a collaborative process of inquiry, advocacy and action. PAT's mission is to improve the health, safety and progress of individuals and groups within the LGBTQI+ community by inspiring, supporting and leading collaborative action that improves policy, service, access and community dynamics in the core areas of housing, health, safety, financial security, youth and aging.

Through summits, panels, policy writing, research and storytelling, PAT has given voice to the most marginalized within LGBTQI+ communities, and in particular Black, Indigenous and other People of Color (BIPOC). Recognizing that gathering demographic data on sexual orientation, gender identity, and sex characteristic is critical to obtain an accurate and comprehensive understanding of LGBTQI+ people and their experiences across key areas of life, PAT has worked to collect SOGI data from those who engage in our programming. However, our data collection efforts are limited in scope by our organizational size and geographic reach. We value what we measure and measure what we value. Therefore it is paramount that federal agencies collect comprehensive, accurate data on LGBTQI+ individuals and their families to better understand and address disparities, to evaluate policy impact, and improve the wellbeing of LGBTQI+ communities.

Currently, surveys such as the American Community Survey, Current Population Survey, and decennial census only allow for respondents to self-identify as same-sex spouses and unmarried partners in a household. Lack of specific questions about sexual orientation, gender

identity, and variations in sex characteristics, mean that these surveys do not account for single LGB people or LGB people who are in a relationship but not cohabitating with their partner(s), and overlook transgender people and intersex people entirely. To mitigate this in Illinois, and thanks to the leadership of AFC and PAT, the Illinois state legislature passed the Inclusive Data Collection bill for SOGI data collection in 2021, Public Act 102-0543. This new state law requires ten state agencies to collect critical demographic data based on age, sex, sexual orientation, gender identity, disability status, and primary or preferred language of individuals who utilize major services administered by state government. While this improves our ability to serve LGBTQI+ people in our state, we need the federal government to demonstrate its commitment to inclusion for this community. Multiple federal agencies use data from federally-supported surveys to enforce nondiscrimination laws, which is crucial to combat discrimination that LGBTQI+ people face in the workplace, health care settings and elsewhere. Without more detailed questions on large-scale surveys, researchers and advocates are also often unable to disaggregate data so they can analyze the diversity of experiences among different parts of the LGBTQI+ community.

Within the field of HIV, the experiences of transgender women are continually erased when they are grouped together with cis-gender males under the label of “Men who have Sex with Men,” or MSM. The lived experiences of transgender women are vastly different from that of cis-gender gay men¹—they face different degrees of discrimination in accessing jobs, housing, and health care, among others—and greatly influence how transgender women are impacted by HIV. When transgender women are lumped together with cis-gender males, it is impossible for us to have a full understanding of the impact of HIV on the transgender community, let alone other gender-diverse people who don’t subscribe to the gender binary of male and female. While, as a field, we have tried to collect our own SOGI data to improve linkage to care, prevention services and to better advocate for this community, we are unable to utilize data collected by the federal government to its full potential, and in the end, it’s LGBTQI+ people who suffer.

Without more robust data collection, LGBTQI+ people are excluded from federal datasets that inform policymaking and the allocation of billions of dollars in funding that impact our everyday lives with respect to health care, housing, employment, education, and government services and benefits use. Despite the desire of multiple Presidential administrations in the last several years to eradicate HIV in the U.S. in our lifetime, we will not be able to achieve this if we don’t have an accurate understanding of the LGBTQI+ community, which continues to be disproportionately impacted by HIV.

Enhancing LGBTQI+-inclusive data collection will allow us to²:

- Capture a more comprehensive, accurate, and data-driven understanding of the experiences of LGBTQI+ communities;
- Develop evidence-based policy solutions to improve outcomes and address disparities;
- Ensure that funding and services are distributed equitably; and
- Assess how the government is progressing in its mission to meaningfully advance LGBTQI+ equity.

¹ Tonia C Poteat and others, “Inclusion as Illusion: Erasing Transgender Women in Research with MSM”, *Journal of the International AIDS Society* 24(1) (January 2021): e25661, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7836207/>

² National Institutes of Health. See National Academies of Sciences, Engineering, and Medicine, “Understanding the Well-Being of LGBTQI+ Populations” (Washington: The National Academies Press, 2020), p. 2 available at <https://nap.nationalacademies.org/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>

The Biden-Harris Administration has demonstrated a commitment to advancing LGBTQI+ rights and to investing in equitable data collection. Our communities stand ready to see ourselves counted in the nation's various surveys.

Thank you for the opportunity to share our interest in LGBTQI+ data inclusion.

[SIGNATURE/AFFILIATION]