

Jeffrey M. Zirger
Information Collection Review Office
Centers for Disease Control and Prevention
1600 Clifton Road NE, MS H21–8
Atlanta, Georgia 30329

Re: (Docket No. CDC-2023-0070) Proposed Data Collection Submitted for Public Comment and Recommendations

Dear Jeffrey Zirger,

On behalf of the undersigned six organizations dedicated to improving the health and wellbeing of LGBTQI+ and other underserved communities, we write regarding the Centers for Disease Control and Prevention (CDC) notice inviting comment on a proposed information collection for the 2024 National Health Interview Survey (88 FR 56823).¹ Specifically, we write to convey our support for the CDC’s proposal to include questions about sexual orientation and gender identity on the National Health Interview Survey (NHIS) and to urge the CDC to engage in research and testing to add measures that allow for the identification of people with intersex traits.

The CDC has demonstrated a commitment to advancing the rights of LGBTQI+ communities and to adopting a data-driven approach to policymaking.² We appreciate the CDC’s recognition of the critical role that data collection plays in conducting rigorous research, designing programs, crafting evidence-based policies, and developing strategies to improve health equity for LGBTQI+ people.³ As the U.S. Department of Health and Human Services and its operating divisions implement the recommendations of the Federal Evidence Agenda on LGBTQI+ Equity (“Equity Agenda”) and adopt comprehensive sexual orientation, gender identity, and sex characteristics (SOGISC) Data Action Plans (DAP) required under Executive Order 14075,⁴ we urge the CDC and its National Center for Health Statistics (NCHS) to make voluntary sexual orientation and gender identity measures on NHIS permanent and to invest in research and testing to add a measure that allows for the identification of people with intersex traits.

We Strongly Support NCHS Collecting Voluntary Demographic Sexual Orientation and Gender Identity Data on NHIS

NHIS is the principal source of information on the health of the U.S. population, providing accurate and current statistical information on the amount, distribution, and effectiveness of illness and disability, as well as the services and treatments that people receive for such conditions.⁵ NHIS generates nationally representative household data that are used to monitor trends in health status, identify barriers to accessing care, and assess progress to achieving national health objectives.⁶ It

provides valuable information that allows researchers inside and outside of government to examine health status, analyze health behaviors, and track health insurance coverages, areas where LGBTQI+ communities continue to face substantial disparities.⁷ We support NCHS' proposal to add content to the 2024 NHIS, including items on health-related behaviors, including smoking history and cessation, lung cancer screening, alcohol use, psychological distress, doctor's advice to exercise, and sleep, among other topics.⁸

Notably, NHIS already collects voluntary demographic data on sexual orientation and gender identity on the adult questionnaire. In 2011, HHS announced its plan to begin collecting health data on LGB populations through the 2013 NHIS adult questionnaire in order to fill the gaps that exist in the state of knowledge about the general health behaviors, health status, and health care utilization of LGB persons, and to monitor changes over time.⁹ These data have subsequently been used to generate research about the chronic health conditions, disability status, health insurance, health care access and use, and health-related behaviors of LGB populations.¹⁰

Recognizing the need to improve data collection on transgender populations in order to further efforts to advance equity and combat discrimination, in 2023 NCHS added gender identity measures to the NHIS adult questionnaire.¹¹ We support the inclusion of the gender identity measures in the 2024 NHIS and urge the CDC to make their use permanent. Doing so is critical to provide valuable information about the health status, health care utilization, and health behaviors of transgender population now and over time. This is especially important during a period when access to medically necessary care and insurance coverage for gender-affirming care is under attack in states across the country.

Improving SOGISC data collection on NHIS is critical to improve data collection, reporting, and analysis on the diverse health needs and experiences of the LGBTQI+ population. By disaggregating NHIS data by SOGISC in combination with other demographic variables – including race, ethnicity, age, language, and disability – researchers can better understand the health conditions and experiences of those living at the intersection of multiple marginalized identities, such as LGBTQI+ people of color, LGBTQI+ aging adults, low-income LGBTQI+ people and LGBTQI+ people with disabilities.¹² Such research is critical to shaping evidence-based policymaking and equipping organizations with quality, accurate information to advocate for the needs and rights of the communities they champion.

We Urge NCHS to Collect Data on People with Intersex Traits on NHIS

In addition to making the sexual orientation and gender identity measures permanent fixtures of the annual core adult questionnaire, we urge NCHS to invest in research and testing of NHIS measures that allow for the identification of people with intersex traits. Although data collection on people with intersex traits is limited, existing evidence reveals that people with intersex traits face discrimination, stigma, and non-consensual, medically unnecessary medical interventions that

detrimentally impact their health and well-being.¹³ Lack of accurate data on people with intersex traits poses significant barriers to engaging in rigorous research on intersex populations and advancing evidence-based policymaking to improve health equity of intersex communities.

As NCHS works to implement the recommendations of the Equity Agenda and adopt comprehensive SOGISC DAPs required under Executive Order 14075,¹⁴ we urge NCHS to test, validate, and implement a standalone NHIS measure that allows for the identification of people with intersex traits. Doing so is critical to answer questions posed by the Equity Agenda, for example, by providing information to help better understand the extent to which intersex people may experience disparate rates of access to health insurance coverage, to what extent to health outcomes vary by intersex status, and the degree of progress to achieve national health objectives to improve the health of intersex communities.¹⁵ In identifying and evaluating an appropriate measure for NHIS (and potentially other surveys), NCHS should consult with other agencies and researchers about existing methodological research and best practices.

Conclusion

Our organizations are dedicated to supporting NCHS' implementation of a comprehensive SOGISC DAP in order to fulfill the goals of the Federal Evidence Agenda on LGBTQI+ Equity and to better identify and address the health care and health insurance needs of LGBTQI+ populations. To advance these goals, we encourage NCHS to make the sexual orientation and gender identity measures on NHIS permanent and to invest in research and testing to add measures that allow for the identification of people with intersex traits.

Thank you for your consideration of this comment. Please do not hesitate to contact Caroline Medina at CMedina@whitman-walker.org if you need any additional information.

Sincerely,

Whitman-Walker Institute
Movement Advancement Project
National Health Law Program
National LGBT Cancer Network
The Fenway Institute
interACT: Advocates for Intersex Youth

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- ¹ *Federal Register* 88 (160) 2023: 56823-56825, available at <https://www.federalregister.gov/documents/2023/08/21/2023-17923/proposed-data-collection-submitted-for-public-comment-and-recommendations>
- ² See Centers for Disease Control and Prevention, “Collecting Sexual Orientation and Gender Identity Information”, available at <https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-providers/collecting-sexual-orientation.html> (last accessed October 2023)
- ³ See Centers for Disease Control and Prevention, “Data Modernization and Policies”, available at <https://www.cdc.gov/surveillance/policy-standards/data-modernization-policies.html> (last accessed October 2023) and Centers for Disease Control and Prevention, “CDC’s Policy Analytical Framework”, available at <https://www.cdc.gov/policy/paeo/process/analysis.html> (last accessed October 2023)
- ⁴ National Science & Technology Council, “Federal Evidence Agenda on LGBTQI+ Equity”, available at <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>
- ⁵ Centers for Disease Control and Prevention, “NHIS - About the National Health Interview Survey”, available at https://www.cdc.gov/nchs/nhis/about_nhis.htm
- ⁶ Centers for Disease Control and Prevention, “National Health Interview Survey,” available at <https://www.cdc.gov/nchs/nhis/index.htm> (last accessed October 2023)
- ⁷ National Academies of Sciences, Engineering, and Medicine, “Understanding the Well-Being of LGBTQI+ Populations” (Washington: 2020), available at <https://www.nap.edu/read/25877/chapter/1>.
- ⁸ *Federal Register* 88 (160) 2023: 56823-56825, available at <https://www.federalregister.gov/documents/2023/08/21/2023-17923/proposed-data-collection-submitted-for-public-comment-and-recommendations>
- ⁹ Centers for Disease Control and Prevention, “NHIS - Sexual Orientation Information Background”, available at https://www.cdc.gov/nchs/nhis/sexual_orientation/background.htm (last accessed October 2023)
- ¹⁰ Centers for Disease Control and Prevention, “National Health Interview Survey Sexual Orientation Statistics”, available at https://www.cdc.gov/nchs/nhis/sexual_orientation/statistics.htm (last accessed October 2023)
- ¹¹ See Office of Information and Regulatory Affairs, Office of Management and Budget, “ICR Documents”, available at https://www.reginfo.gov/public/do/PRAViewDocument?ref_nbr=202210-0920-008 (last accessed October 2023)
- ¹² NHIS does not currently collect demographic information on the written and spoken language of participants. This is a critical intersection to understand health access and equity for Limited English Proficient individuals. See, for example, Jessica Himmelstein and others, “Health Care Spending And Use Among Hispanic Adults With And Without Limited English Proficiency, 1999–2018,” *Health Affairs*, July 2021, available at <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.02510>, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7201401/>; Al Shamsi H, Almutairi AG, Al Mashrafi S, Al Kalbani T. Implications of Language Barriers for Healthcare: A Systematic Review. *Oman Med J*. 2020 Apr 30; 35(2):e122. doi: 10.5001/omj.2020.40. PMID: 32411417; PMCID: PMC7201401; Diamond L, Izquierdo K, Canfield D, Matsoukas K, Gany F. A Systematic Review of the Impact of Patient-Physician Non-English Language Concordance on Quality of Care and Outcomes. *J Gen Intern Med*. 2019 Aug; 34(8):1591-1606. doi: 10.1007/s11606-019-04847-5. Epub 2019 May 30. PMID: 31147980; PMCID: PMC6667611.
- ¹³ Caroline Medina and Lindsay Mahowald, “Key Issues Facing People With Intersex Traits,” Center for American Progress, October 26, 2021, available at <https://www.americanprogress.org/article/key-issues-facing-people-intersex-traits/>
- ¹⁴ National Science & Technology Council, “Federal Evidence Agenda on LGBTQI+ Equity”, available at <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>
- ¹⁵ Ibid.