November 28, 2023

U.S. Department of Health and Human Services Agency for Healthcare Research and Quality 5600 Fishers Lane Rockville, MD 20857 Submitted via email to doris.lefkowitz@AHRQ.hhs.gov

RE: Agency Information Collection Activities: Proposed Collection; Comment Request (88 Fed. Reg. 67291)

To Whom It May Concern:

We are grateful for the opportunity to provide comments to the Agency for Healthcare Research and Quality (AHRQ) of the U.S. Department of Health and Human Services (HHS) on proposed updates to the Medical Expenditures Panel Survey—Household and Medical Provider Components (MEPS). See 88 Fed. Reg. 67,291 (Sept. 29, 2023).

AHRQ has requested comments with regard to "whether the proposed collection of information is necessary for the proper performance of AHRQ's health care research and health care dissemination functions, including whether the information will have practical utility." The Medical Expenditure Panel Survey Household Component (MEPS-HC) seeks to "produce nationally representative estimates of health case use, ... respondent's health status, demographic and socio-economic characteristics, employment, access to care, and satisfaction with health care."

The undersigned are scholars of law and public policy affiliated with the Williams Institute at the University of California, Los Angeles School of Law. The Williams Institute is a research center dedicated to conducting rigorous and independent academic research on sexual orientation and gender identity, including on health disparities facing LGBT people and experiences of discrimination related to sexual orientation and gender identity ("SOGI"). We write to support AHRQ's proposal to add questions to the MEPS-HC Preventive Care Self-Administered Questionnaires (PSAQ) about sexual orientation and gender identity and to restructure the survey to allow for these additions. We present findings below that emphasize the need to collect this information and the relevance of data collected from the MEPS-HC for the LGBTQ+ community.

I. <u>LGBT People Are a Significant and Diverse Population in the US</u>

LGBT people comprise approximately 5.6% of the U.S. adult population.³ The Williams Institute estimates that approximately 14 million adults in the U.S. identify as LGBT,⁴ including

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¹ 88 Fed. Reg. 67,291.

² *Id.* at 67,291-2.

³ ANDREW R. FLORES & KERITH J. CONRON, WILLIAMS INST., ADULT LGBT POPULATION IN THE UNITED STATES 1 (forthcoming 2023).

⁴ *Id*.

approximately 1.3 million adults who are transgender.⁵ Younger Americans are more likely to identify as LGBT than older generations. At least 9.5% of the U.S. youth population (ages 13–17), or nearly 2 million youth, identify as LGBT.⁶ This estimate includes 300,000 youth in that age range who identify as transgender (1.4% of the youth population ages 13–17).⁷

LGBT adults in the U.S. are demographically diverse. Drawing from Gallup Daily Tracking data collected between 2015 and 2017, the Williams Institute estimated that 58% of LGBT adults are female.⁸ In terms of racial and ethnic diversity, 21% of LGBT adults identify as Latino/a or Hispanic, 12% as Black, 3% as Asian or Pacific Islander, 1% as American Indian or Alaska Native, and 5% as more than one race.⁹ And, a recent Institute study found that Latinx ¹⁰ people, American Indian or Alaska Native people, and biracial/multiracial groups are more likely than white people to identify as transgender.¹¹

Many LGBT people are living with same-sex partners and raising children. The Census Bureau recently estimated, based on 2019 data from the American Community Survey, that approximately 980,000 households were headed by a same-sex couple. ¹² The Census Bureau further determined that nearly 181,000 of those households were raising children under the age of 18. ¹³ Since this statistic excludes LGB people who are not in same-sex partnerships or are single and raising children, the number of LGB households with children under the age of 18 is likely much higher. For example, using the CDC's Behavioral Risk Factor Surveillance Survey, the Williams Institute recently reported that 27% of LBQ women, and 32% of LBQ women of color, had a child under 18 in their household. ¹⁴

⁵ JODY L. HERMAN, ANDREW R. FLORES & KATHRYN K. O'NEILL, WILLIAMS INST., HOW MANY ADULTS AND YOUTH IDENTIFY AS TRANSGENDER IN THE UNITED STATES? 4 (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Trans-Pop-Update-Jun-2022.pdf.

⁶ KERITH J. CONRON, WILLIAMS INST., LGBT YOUTH POPULATION IN THE UNITED STATES 2 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Youth-US-Pop-Sep-2020.pdf.

⁷ HERMAN ET AL., *supra* note 5, at 4.

⁸ *LGBT Demographic Data Interactive*, WILLIAMS INST. (2019), https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#demographic.

¹⁰ The term Latinx is a gender-neutral alternative to Latino or Latina and has been used by LGBTQ people, young people, and others as an inclusive term that embraces "a wide variety of racial, national, and even gender-based identifications." ED MORALES, LATINX: THE NEW FORCE IN AMERICAN POLITICS AND CULTURE (2018). "Latine" is also used for a similar purpose. *See*, *e.g.*, Alexis R. Miranda, Amaya Perez-Brumer & Brittany M. Charlton, *Latino? Latinx? Latine? A Call for Inclusive Categories in Epidemiologic Research*, AM. J. OF EPIDEMIOLOGY (2023), https://academic.oup.com/aje/advance-article/doi/10.1093/aje/kwad149/7214038?login=true.

¹¹ HERMAN ET AL., *supra* note 5, at 6.

¹² LAQUITTA WALKER & DANIELLE TAYLOR, U.S. CENSUS BUREAU, SAME-SEX COUPLE HOUSEHOLDS: 2019 (2021), https://www.census.gov/content/dam/Census/library/publications/2021/acs/acsbr-005.pdf. Using data from the Current Population Survey, the Census Bureau also estimated that as many as 191,000 children may be living with same-sex parents. Who is Living Together? Same-Sex Couples in the United States, CENSUS.GOV (Nov. 19, 2019), https://www.census.gov/library/visualizations/2019/comm/living-together-same-sex.html.

¹³ Id.

¹⁴ BIANCA D.M. WILSON ET AL., WILLIAMS INST., HEALTH AND SOCIOECONOMIC WELL-BEING OF LBQ WOMEN IN THE US 8 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LBQ-Women-Mar-2021.pdf.

II. Evidence of Disparities Between LGBTQ People and Non-LGBTQ People in Areas Addressed in The Medical Expenditure Panel Survey

The MEPS seeks to produce nationally representative estimates of respondents' health status, demographic and socio-economic characteristics, and experience with health care. 15 Research suggests that inclusion of SOGI measures in the MEPS-HC PSAQ will provide valuable insight into the health and economic needs of LGBTQ people. Research has demonstrated that LGBTQ people experience significantly worse physical and mental health conditions and face greater difficulties in accessing health care when compared to their cisgender and heterosexual counterparts. Disparities are especially pronounced among LBQ women, gender minority individuals, and LGBTQ people of color. The minority stress model, explained more fully below, suggests that health disparities are connected to and exacerbated by discrimination against LGBTQ people. Additionally, the MEPS interview will collect information concerning the economic barriers faced by respondents in accessing health care. 16 As is the case with health, research demonstrates that LGBTQ people experience greater economic insecurity when compared to non-LGBTQ people. Evidence of these experiences is presented below.

A. LGBTQ People Experience Worse Physical Health When Compared to Cisgender and Heterosexual People

Many LGBTO people report poor physical health. Data from the Williams Institute's Generations and TransPop studies show that one in five (20.8%) LGBTQ people report that their general health is fair or poor. 17 Subpopulations of LGBTO people who are likely to experience marginalization based on multiple characteristics, including women, transgender people, and people of color, are more likely than other populations to report fair or poor health. In the same studies, LBQ women (24.0%) and transgender people (25.9%) were more likely to report fair or poor general health than GBQ men (13.9%). 18 In addition, in a study of differences across LGBT people by race, more than a quarter (27%) of LGBT adults of color reported that their overall health was only fair or poor, compared to 22% of white LGBT adults. 19

Research also indicates that LGBT people are more likely to report that their health is fair or poor than non-LGBT people.²⁰ An analysis of data from the TransPop study found that

¹⁶ *Id.* at 67.292.

¹⁵ 88 Fed. Reg. 67,291-2.

¹⁷ ILAN H. MEYER, BIANCA D.M. WILSON & KATHRYN O'NEILL, WILLIAMS INST., LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES 30 (2021). https://williamsinstitute.law.ucla.edu/wp-content/uploads/Generations-TransPop-Toplines-Jun-2021.pdf. ¹⁸ *Id*.

¹⁹ BIANCA D.M. WILSON, LAUREN BOUTON & CHRISTY MALLORY, WILLIAMS INST., RACIAL DIFFERENCES AMONG LGBT ADULTS IN THE U.S.: LGBT ADULTS AT THE INTERSECTION OF RACE 1 (2022), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Race-Comparison-Jan-2022.pdf.

²⁰ Ethan C. Cicero et al., The Health Status of Transgender and Gender Nonbinary Adults in the United States, 15 PLoSONE e0228765 (2020); Gilbert Gonzales & Carrie Henning-Smith, Health Disparities by Sexual Orientation: Results and Implications from the Behavioral Risk Factor Surveillance System, 42 J. Community Health 1163 (2017), C.f. Ilan H. Meyer et al., Demographic Characteristics and Health Status of Transgender Adults in Select US Regions: Behavioral Risk Factor Surveillance System, 2014, 107 Am. J. Pub. HEALTH 582 (2017) (finding that

transgender adults were more likely to report that their health was fair or poor, and reported experiencing poor health days more frequently, than cisgender adults. Similarly, in a study of LBQ women, the Williams Institute found that nearly 29% of LBQ women described their health as only fair or poor, compared to 19% of straight women, with a higher proportion of LBQ women of color describing their health as only fair or poor compared with white LBQ women.

There is further evidence that a substantial percentage of LGBT people experience serious health conditions, including life-threatening conditions. The Generations and TransPop studies found that among LGBTQ people, 18.0% had asthma, 16.3% had high blood pressure, 10.2% had diabetes, 6.0% had heart disease, and 3.0% had cancer. An analysis of TransPop data also found that transgender people were more likely than cisgender people to report having emphysema and ulcers. Furthermore, series of reports by the Williams Institute focused on the well-being of LGBT people at the intersection of race found that LGBT people of every race reported similar or higher rates of serious health conditions compared to non-LGBT people, including asthma, cancer, heart attack, and diabetes. Serious health conditions compared to non-LGBT people, including asthma, cancer, heart attack, and diabetes.

These findings are consistent with those of other studies based on large government datasets. For example, an analysis of data from the Behavioral Risk Factor Surveillance System (BRFSS) collected between 2014 and 2020 found that LGB people are at higher odds than non-LGB people of having asthma, arthritis, diabetes, kidney disease, hypertension, cardiovascular disease, heart attack, stroke, and chronic obstructive pulmonary disease. Another analysis of BRFSS data collected in 2014 and 2015 found that lesbian and bisexual women were more likely to report worse physical outcomes such as activity limitations, arthritis, asthma, and chronic

transgender individuals are more likely to report fair or poor general health and higher prevalence of myocardial infarction, but similar rates of other health conditions as cisgender people).

²⁶ SOON KYU CHOI, BIANCA D.M. WILSON & CHRISTY MALLORY, WILLIAMS INST., BLACK LGBT ADULTS IN THE US 21 (2021), https://williamsinstitute.law.ucla.edu/publications/black-lgbt-adults-in-the-us/; BIANCA D.M. WILSON, LAUREN BOUTON & CHRISTY MALLORY, WHITE LGBT ADULTS IN THE US 20 (2022); https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-White-SES-Jan-2022.pdf; BIANCA D.M. WILSON, CHRISTY MALLORY, AMERICAN INDIAN AND ALASKAN NATIVE LGBT ADULTS IN THE US 24 (2021); https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Latinx-SES-Sep-2021.pdf; SOON KYU CHOI, BIANCA D.M. WILSON, LAUREN BOUTON & CHRISTY MALLORY, WILLIAMS INST., AAPI LGBT ADULTS IN THE US 230 (2021), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-AAPI-SES-May-2021.pdf [hereinafter, collectively: RACE & WELLBEING SERIES].

²¹ Jamie L. Feldman et al., *Health and Healthcare Access in the US Transgender Population Health (TransPop) Survey*, 9 ANDROLOGY 1707 (2021).

²² WILSON ET AL., LBQ WOMEN, *supra* note 14, at 8.

²³ KATHRYN O'NEILL, WILLIAMS INST., HEALTH VULNERABILITIES TO COVID-19 AMONG LGBT ADULTS IN CALIFORNIA 8 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-COVID-CA-Health-May-2020.pdf [hereinafter: O'NEILL, LGBT ADULTS & COVID-19]; ILAN H. MEYER & SOON KYU CHOI, WILLIAMS INST., VULNERABILITIES TO COVID-19 AMONG OLDER LGBT ADULTS IN CALIFORNIA 1–2 (2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Older-LGB-COVID-CA-Apr-2020.pdf [hereinafter: MEYER & CHOI, OLDER LGBT ADULTS & COVID-19].

²⁴ MEYER, WILSON & O'NEILL, LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES, *supra* note 17, at 29.

²⁵ Feldman et al.. *supra* note 21.

²⁷ Manasvi Pinnamaneni et al., *Disparities in Chronic Physical Health Conditions in Sexual Minority People Using the United States Behavioral Risk Factor Surveillance System*, 28 PREVENTATIVE MED. REP. 1 (2022).

obstructive pulmonary disease compared to heterosexual women.²⁸ Recent Williams Institute research on the impact of the COVID-19 pandemic on U.S. adults also suggests that LGBT people of color and gender minority people disproportionately experienced its impacts,²⁹ which could inform their ongoing health care needs. The proposed changes to the MEPS-HC, as a nationally representative survey, would further our understanding of the physical health disparities between LGBTQ and non-LGBTQ people.

B. <u>LGBTQ People Face Unique Challenges Concerning Their Mental Health And</u> Social Isolation

In addition to collecting data about respondents' physical health, the MEPS-HC asks respondents a variety of questions about their mental health, including factors that contribute to negative mental health outcomes like loneliness and social isolation. ³⁰ Research has demonstrated that LGBTQ people experience significant challenges with mental health. Additionally, measures related to assessing a respondent's mental health, such as those concerning substance use or isolation, have particular relevance in research concerning LGBTQ people's mental health.

Research shows a high prevalence of suicide attempts and ideation, as well as depression and anxiety, among LGBTQ people.³¹ For example, a Williams Institute analysis of data from the Generations and TransPop studies found that three-quarters (75.6%) of LGBTQ people reported suicidal ideation over the course of their lives, with nearly one-third (29.9%) having made a suicide attempt.³² In terms of mental health outcomes, three-quarters (75.6%) of LGBTQ people reported experiencing moderate psychological distress or serious mental illness over the 30 days prior to the survey, with 28.2% reporting serious mental illness.³³

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²⁸ Gonzales & Henning-Smith, *supra* note 20, at 1169.

²⁹ O'NEILL, LGBT ADULTS & COVID-19, *supra* note 23; MEYER & CHOI, OLDER LGBT ADULTS & COVID-19, *supra* note 23. *See also* Thom File & Joey Marshall, *Household Pulse Survey Shows LGBT Adults More Likely to Report Living in Households With Food and Economic Insecurity Than Non-LGBT Respondents*, U.S. CENSUS BUREAU (Aug. 11, 2021), https://www.census.gov/library/stories/2021/08/lgbt-community-harder-hit-by-economic-impact-of-pandemic.html (noting the U.S. Census Bureau's similar findings, based on data collected during the first waves of the Household Pulse Survey that included SOGI measures).

³⁰ AHRQ, MEDICAL EXPENDITURE PANEL SURVEY TOPICS: MENTAL HEALTH, https://meps.ahrq.gov/mepsweb/data stats/MEPS topics.jsp?topicid=11Z-1 (last revised Jan. 27, 2023).

³¹ See, e.g., Wendy B. Bostwick et al., Dimensions of Sexual Orientation and the Prevalence of Mood and Anxiety Disorders in the United States, 100 Am. J. Public Health 468 (2010); Michael King et al., A Systematic Review of Mental Disorder, Suicide, and Deliberate Self Harm in Lesbian, Gay and Bisexual People, 70 BMC PSYCHIATRY 1 (2008), https://bmcpsychiatry.biomedcentral.com/track/pdf/10.1186/1471-244X-8-70.pdf; Kimberly F. Balsam et al., Mental Health of Lesbian, Gay, Bisexual, and Heterosexual Siblings, 114 J. Abnormal Psych. 471 (2005); Susan D. Cochran & Vickie M. Mays, Relation between Psychiatric Syndromes and Behaviorally Defined Sexual Orientation in a Sample of the US Population, 151 J. EPIDEMIOLOGY 516 (2000). For comprehensive reviews of research on LGBT health, see Institute of Medicine, The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding (2011); The Health of Sexual Minorities: Public Health Perspectives on Lesbian, Gay, Bisexual and Transgender Populations (Ilan H. Meyer & Mary E. Northridge eds., 2007).

³² MEYER, WILSON & O'NEILL, LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES, *supra* note 17, at 32.

³³ *Id.*

Other research establishes that LGBT people are more likely to report negative mental health outcomes than non-LGBT people. Across Williams Institute reports examining LGBT wellbeing at the intersection of race, LGBT adults of every race were more likely to have been diagnosed with depression than non-LGBT adults. For example, 26% of Black LGBT adults have been diagnosed with depression, compared to 15% of Black non-LGBT adults. These findings are consistent with findings from other studies. An analysis of BRFSS data collected in 2014 and 2015 found that gay and bisexual men had higher odds of experiencing mental distress than heterosexual men, and lesbian and bisexual women had higher odds of experiencing mental distress and depression than heterosexual women.

Researchers have observed especially high rates of internalized stigma and suicidal ideation among transgender people, even when compared to their cisgender LGB peers.³⁷ For example, the Generations and TransPop studies found that 42.0% of transgender people had made a suicide attempt compared to 31.6% of LBQ cisgender women and 21.5% of GBQ cisgender men.³⁸ Among transgender respondents to the 2015 US Transgender Survey ("USTS"), 82% seriously thought about suicide at some point in their lives, with 48% reporting such thoughts in the previous year and 40% reporting actually having attempted suicide at some point in their lives.³⁹

The MEPS-HC also asks about respondents' experience with substance use. Existing research has documented higher rates of substance use among LGBTQ people. Substance use is often viewed as a stress-coping response and may be related to experiences of stigma and discrimination. As series of reports produced by the Williams Institute examined state-level disparities in substance use between LGBT and non-LGBT people using Behavioral Risk factor Surveillance System (BRFSS) data. Across these reports, focused on states that lack supportive policies for LGBT people, we found that LGBT people reported smoking, binge drinking, and heavy drinking at similar or higher rates than non-LGBT people. Research has further documented such disparities for LGBT youth. For example, one study found that transgender

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³⁴ RACE & WELLBEING SERIES, *supra* note 26.

³⁵ See, e.g., Choi, Wilson & Mallory, Black LGBT Adults in the US, supra note 26, at 18.

³⁶ Gonzales & Henning-Smith, *supra* note 20.

³⁷ See, e.g., Walter O. Bockting et al., Stigma, Mental Health, and Resilience in an Online Sample of the US Transgender Population, 103 Am. J. Public Health 943 (2013); Dejun Su et al., Mental Health Disparities within the LGBT Population: A Comparison between Transgender and Non-Transgender Individuals, 1 Transgender Health 12 (2016); Tyler G. Lefevor et al., Health Disparities between Genderqueer, Transgender, and Cisgender Individuals: An Extension of Minority Stress Theory, 66 J. Counseling Psych. 385 (2019).

³⁸ MEYER, WILSON & O'NEILL, LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES, *supra* note 17, at 32.

³⁹ Sandy E. James et al., Nat'l Ctr. for Transgender Equality, Report of the 2015 U.S. Transgender Survey 112, 114 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

⁴⁰ See, e.g., Richard T. Liu & Lauren B. Alloy, Stress Generation in Depression: A Systemic Review of the Empirical Literature and Recommendations for Future Study, 30 CLIN. PSYCH. REV. 582 (2010); Jon. D. Kassel, Laura R. Stroud & Carol A. Paronis, Smoking, Stress, and Negative Affect: Correlation, Causation, and Context Across States of Smoking, 129 PSYCHOL. BULLETIN 129 (2003); Kathleen T. Brady &

Susan C. Sonne, *The Role of Stress in Alcohol Use, Alcoholism Treatment, and Relapse*, 23 Alcohol Research & Health 263 (1999).

⁴¹ Williams Institute state reports are available at https://williamsinstitute.law.ucla.edu/publications/?issues=discrimination-violence.

youth were at increased odds of having consumed alcohol, cigarettes, marijuana, or non-marijuana illicit drugs over the past twelve months as compared to cisgender youth. 42

Additionally, the MEPS-HC asks respondents to assess their feelings of lack of companionship, being left out, and isolation. Research has demonstrated that LGBTQ people experience unique challenges in this area, especially as they age. LGBT older adults are less likely to be married and more likely to live alone and report social isolation compared to straight and cisgender adults. Transgender older people in particular face high rates of social isolation and loneliness and have limited social support. He USTS found that 37% of transgender people aged 45-64 had family members stop speaking to them or end the relationship while 18% of 18-24 year-olds had the same experience. The report additionally showed that for 20% of transgender people over the age of 65, a partner had ended the relationship due to their gender identity, two times the rate found among transgender people overall. The study reported that 45% of transgender people over the age of 65 were married compared with 56% of the general population. Williams Institute report which analyzed population-based data in California found that 43% of transgender adults aged 65 and older lived alone, whereas the Pew Research Center estimated that 27% of the U.S. population over the age of 60 lived alone.

C. Discrimination Negatively Impacts the Health and Wellbeing of LGBTQ People

The minority stress model, which the Institute of Medicine has recognized as a core perspective for understanding LGBT health, 50 describes how LGBT people experience chronic

⁴⁷ *Id.* at 59.

⁴² Sari L. Reisner et al., *Gender Minority Social Stress in Adolescence: Disparities in Adolescent Bullying and Substance Use by Gender Identity*, 52 J. SEX RES. 243, 249 (2015), https://www.tandfonline.com/doi/full/10.1080/00224499.2014.886321.

⁴³ Karen I. Fredriksen-Goldsen, Resilience and Disparities Among Lesbian, Gay, Bisexual, and Transgender Older Adults, 21 PUB. POL'Y & AGING RPT. 3, 4 (2011).

⁴⁴ Soon Kyu Choi & Ilan H. Meyer, Williams Inst., LGBT Aging: A Review of Research Findings, Needs, and Policy Implications 6 (2016), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf; Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, Charles A. Emlet, Anna Muraco, Elena A. Erosheva, Charles P. Hoy-Ellis, Jayn Goldsen, & Heidi Petry, Inst. for Multigenerational Health, The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults 26, 17 (2011), https://depts.washington.edu/agepride/wordpress/wp-content/uploads/2012/10/Full-report10-25-12.pdf; Karen I. Fredriksen-Goldsen, *Resilience and Disparities Among Lesbian, Gay, Bisexual, and Transgender Older Adults*, 21 Public Pol'y and Aging Report 3, 4 (2011) https://doi.org/10.1093/ppar/21.3.3.

⁴⁵ Sandy E. James, Jody L. Herman, Susan Rankin, Mara Keisling, Lisa Mottet, & Ma'ayan Anafi, Nat'l Ctr. for Transgender Equality, The Report of the 2015 U.S. Transgender Survey 34, 71 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

⁴⁶ *Id.* at 67.

⁴⁸ SOON K. CHOI, KRYSTAL KITTLE, & ILAN H. MEYER, WILLIAMS INST., AGING LGB ADULTS IN CALIFORNIA: FINDINGS FROM THE 2015–2016 CALIFORNIA HEALTH INTERVIEW SURVEY 36 (2018) https://williamsinstitute.law.ucla.edu/wp-content/uploads/Aging-LGB-CA-Aug-2018.pdf.

⁴⁹ Jacob Ausubel, Pew Research Center, Older People are More Likely to live Alone in the U.S. than Elsewhere in the World, (Mar. 10, 2020), https://www.pewresearch.org/short-reads/2020/03/10/older-people-are-more-likely-to-live-alone-in-the-u-s-than-elsewhere-in-the-world.

⁵⁰ Institute of Medicine, The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding 20 (2011), https://www.ncbi.nlm.nih.gov/books/NBK64806.

stress stemming from their stigmatization.⁵¹ While certain stressors—such as loss of a job—are ubiquitous in society, experienced by LGBT and non-LGBT people alike, LGBT people are uniquely exposed to stress arising from anti-LGBT stigma and prejudice. Prejudice leads LGBT people to experience *excess* exposure to stress compared with non-LGBT people who are not exposed to anti-LGBT prejudice (all other factors being equal).

Excess stress exposure confers an elevated risk for certain mental and physical health conditions.⁵² For example, one study found that LGB people who had experienced a prejudice-related stressful life event were about three times more likely than those who did not experience such an event to have suffered a serious physical health problem over a one-year period.⁵³

Stigma and stress related to sexual orientation and gender identity discrimination have also been shown to affect mental health and wellbeing. One study found that state policies that target stigmatized individuals for social exclusion had a deleterious effect on the mental health of LGB people. Another study found that living in stigmatizing communities may increase vulnerability to stigma-related stressors and risk for suicidality among transgender people. A third study focused on transgender veterans noted that "even after adjusting for key sociodemographic characteristics, transgender patients living in states with employment policies that include transgender status or gender identity had significantly lower odds of having a medical visit for mood disorders or self-directed violence than did their peers living in states without such legal protections." ⁵⁶

Additionally, LGBTQ people experience discrimination while seeking healthcare and these experiences, like other instances of discrimination and stigma, similarly contribute to adverse health outcomes. Research shows that LGBTQ people report various challenges in

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⁵¹ See, e.g., Ilan H. Meyer, Minority Stress and Mental Health in Gay Men, 36 J. HEALTH & SOC. BEHAV. 38, 38 (1995), https://www.jstor.org/stable/2137286; cf. Ilan H. Meyer, Sharon Schwartz & David M. Frost, Social Patterning of Stress and Coping: Does Disadvantaged Social Statuses Confer More Stress and Fewer Coping Resources? 67 Soc. Sci. & Med. 368, 371 (2008), https://pubmed.ncbi.nlm.nih.gov/18433961/ (examining "social stress theory").

⁵² See, e.g., Susan D. Cochran & Vickie M. Mays, Sexual Orientation and Mental Health, in Handbook of Psychology and Sexual Orientation 204, 208–09 (Charlotte J. Patterson & Anthony R. D'Augelli eds., 2013); Walter Bockting et al., Adult Development and Quality of Life of Transgender and Gender Nonconforming People, 23 Current Op. Endocrinology, Diabetes & Obesity 188 (2016), https://pubmed.ncbi.nlm.nih.gov/26835800/; Michael L. Hendricks & Rylan J. Testa, A Conceptual Framework for Clinical Work with Transgender and Gender Nonconforming Clients: An Adaptation of the Minority Stress Model, 43 Prof. Psych.: Res. & Prac. 460 (2012), https://psycnet.apa.org/record/2012-21304-001; Gregory M. Herek & Linda D. Garnets, Sexual Orientation and Mental Health, Ann. Rev. Clinical Psych. 353 (2007),

https://www.annualreviews.org/doi/abs/10.1146/annurev.clinpsy.3.022806.091510; Vickie M. Mays & Susan D. Cochran, *Mental Health Correlates of Perceived Discrimination Among Lesbian, Gay, and Bisexual Adults in the United States*, 91 Am. J. Pub. Health 1869 (2001), https://pubmed.ncbi.nlm.nih.gov/11684618/.

⁵³ David M. Frost, Keren Lehavot & Ilan H. Meyer, *Minority Stress and Physical Health Among Sexual Minority Individuals*, 38 J. BEHAV. MED. 1, 1 (2015), https://doi.org/10.1007/s10865-013-9523-8.

⁵⁴ Mark L. Hatzenbuehler, *Structural Stigma and the Health of Lesbian, Gay, and Bisexual Populations*, 23 CURRENT DIRECTIONS PSYCH. Sci. 127 (2014).

⁵⁵ Amaya Perez-Brumer et al., *Individual and Structural Level Risk Factors for Suicide Attempts among Transgender Adults*, 42 BEHAV. MED. 3, 164-171 (2015), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4707041/. <a href="https://www.ncbi.nlm.nih.gov/pmc

attempting to access healthcare across the course of their lives as compared to their non-LGBT peers, including direct experiences with discrimination by healthcare providers.⁵⁷ For example, a study of healthcare access in California based on data from the California Health Interview Survey found that "gay men, lesbian women, and bisexual women were more likely than straight men and women to report experiencing unfair treatment when getting healthcare."⁵⁸ Over 40% of lesbian women (44%) and bisexual women (45%) and about one-third of gay men (32%) reported being treated unfairly when receiving healthcare at some point in their lives.⁵⁹ These findings are consistent with results from national surveys. For example, one survey found that 56% of lesbian, gay, and bisexual respondents and 70% of transgender respondents reported experiencing at least one form of healthcare discrimination at some point in their lives.⁶⁰ A separate nationally representative survey by the Center for American Progress (the "CAP Study") found that 8% of lesbian, gay, and bisexual people and 29% of transgender people reported being refused care entirely in the preceding twelve months because of their sexual orientation or gender identity.⁶¹ Among transgender patients, 12% were specifically refused care related to gender transition in the prior year.⁶²

Similarly, several studies utilizing data collected through the National Health Interview Survey have shown higher incidence of other barriers to accessing healthcare among LGB people compared to non-LGB people including costs, trouble finding a provider, not having a regular provider, and other obstacles.⁶³

Past experiences of discrimination have been shown to result in hypervigilance and the expectation of negative regard from non-LGBT people, ⁶⁴ which may affect access to healthcare and the quality of care received. Among respondents to the Generations and TransPop studies, one-third of LGB people and almost two-thirds of transgender people reported worrying about being negatively judged in interactions with a healthcare provider. ⁶⁵ Another study based on national, probability-based survey data found that 18% of LGBTQ people reported avoiding

https://williamsinstitute.law.ucla.edu/publications/gaps-health-care-lgbt-ca/.

⁵⁷ See generally Soon Kyu Choi & Ilan H. Meyer, Williams Inst., LGBT Aging: A Review of Research Findings, Needs, and Policy Implications (2016), https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Aging-Aug-2016.pdf; Frost, Lehavot & Meyer, supra note 53; Ilan H. Meyer & David M. Frost, Williams Inst., Minority Stress and the Health of Sexual Minorities (2013), https://williamsinstitute.law.ucla.edu/publications/minority-stress-health-sm/; Susan H. Babey et al., Gaps in Health Care Access and Health Insurance among LGBT Populations in California (2022),

⁵⁸ BABEY ET AL., *supra* note 57.

⁵⁹ Id

⁶⁰ LAMBDA LEGAL, WHEN HEALTHCARE ISN'T CARING 5 (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.

⁶¹ Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Healthcare*, CTR. FOR AM. PROGRESS (Jan. 18, 2018), https://www.americanprogress.org/article/discrimination-prevents-lgbtq-people-accessing-health-care/.

⁶² *Id*.

⁶³ Williams Institute Scholars, Comment Letter on Review of the National Health Interview Survey (June 15, 2020), https://williamsinstitute.law.ucla.edu/wp-content/uploads/Comment-NHIS-Jun-2020.pdf (including citations to studies on LGB populations that have used data from the National Health Interview Survey).

⁶⁴ Ilan H. Meyer, *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations*, 129 PSYCH. BULL. 674, 681–682 (2003), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2072932/.

⁶⁵ MEYER, WILSON & O'NEILL, LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES, *supra* note 17, at 27.

healthcare due to perceived discrimination.⁶⁶ In addition, 8% of all LGBT respondents in the CAP Study avoided or postponed needed medical care because of disrespect or discrimination from healthcare staff; that figure rose to 14% among those who had experienced discrimination on the basis of their sexual orientation or in the past year.⁶⁷ The reports of discrimination were not distributed equally among LGBT respondents, with 22% of transgender people surveyed reporting avoiding care within the past year because of discrimination.⁶⁸ Additionally, 23% of respondents to the USTS reported that they did not seek needed care because they feared mistreatment.⁶⁹

While the MEPS does not include questions assessing experiences of discrimination in healthcare, it does include questions about the quality and type of care received and other burdens to receiving medical care. Thus, data collected from the MEPS will offer further insight into the overall experience of LGBTQ people in accessing and receiving medical care. This is especially important given our understanding of health disparities between LGBTQ and non-LGBTQ people and health challenges that may arise due to discrimination and stigma. Additionally, these data can be paired with research on discrimination in healthcare to provide a broad understanding of the extent to which experiences of healthcare discrimination or other barriers impact the lives of LGBTQ people when they seek medical care.

D. LGBTQ People Experience High Rates of Economic Instability

Questions that will be included on the MEPS-HC Core Interview will ask respondents about the impact of their economic situation on access to healthcare. AHRQ has proposed moving these questions from the PSAQ to the interview component of the MEPS-HC. These questions will provide important information about barriers to healthcare that many LGBTQ people likely face.

Research shows that LGBT people are more likely to experience economic instability than non-LGBT people. For example, a recent Williams Institute analysis of data collected through the Census Bureau's Household Pulse Survey found that LGBT people are more likely to live in poverty than non-LGBT people. In 2021, 17% of LGBT people were living below the federal poverty level compared to 12% non-LGBT people. Mirroring findings from earlier analyses, the study found that some subpopulations within the LGBT population were more likely to live in poverty than others. Approximately one-fifth of transgender and bisexual cisgender women were living in poverty, while gay and bisexual cisgender men had the lowest rates of poverty (approximately 10%). The LGBT parents were particularly likely to live in poverty,

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⁶⁶ Logan S. Casey et al., *Discrimination in the United States: Experiences of Lesbian, Gay, Bisexual, Transgender, and Queer Americans*, 54 HEALTH SERV. RES. 1454 (2019).

⁶⁷ *Id*.

⁶⁸ *Id*.

⁶⁹ JAMES ET AL., *supra* note 39 at 98.

⁷⁰ 88 Fed. Reg. 67,292.

⁷¹ *Id*

 $^{^{72}}$ Bianca D.M. Wilson, Lauren J.A. Bouton, M.V. Lee Badgett & Moriah Macklin, Williams Inst., LGBT Poverty in the United States: Trends at the Onset of COVID-19 1 (2023). 73 Id. at 7.

with one-quarter (26%) of LGBT people living in households with children (many of whom are parents) living in poverty compared to 16% of non-LGBT people living with children.⁷⁴

Poverty rates also varied by race and LGBT identity. LGBT people of color were significantly more likely to experience poverty than white LGBT people. Poverty rates were particularly high for LGBT American Indian/Alaska Native Adults (32%), Black LGBT adults (29%), and multiracial adults (28%). By comparison, 13% of white LGBT adults were living in poverty. In addition, across most racialized groups, LGBT people experienced higher rates of poverty than their non-LGBT counterparts. A separate analysis of data collected through the Williams Institute's Generations study similarly found that cisgender LBQ people were also more likely to live in low-income households (defined as less than 200% of the federal poverty level) compared to the general population. Assignment of the second content of the general population.

III. Recommendations

AHRQ has proposed multiple changes to the survey instrument to ensure the collection of high-quality, important, and useful information about LGBTQ respondents. These changes include the combination of the previously sex-segregated portions of the PSAQ, the moving of economic burdens from the PSAQ to the MEPS Interview, and adding one question assessing respondent's sexual orientation and a two-step gender identity question. As AHRQ states, these changes align with the objectives in President Biden's Executive Order 14075, "Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals," which emphasizes the importance of collecting SOGI data on federal surveys.

These proposed SOGI questions are mostly consistent with the recommendations of the National Academies of Science, Engineering, and Medicine's (NASEM) report on collecting sexual orientation and gender identity data.⁷⁹ However, the proposed questions make some notable deviations from the NASEM report recommendations.

First, the sex assigned at birth question comes after the current gender identity question. The NASEM report discussed the question order and determined that further research is needed to determine whether a change in the order of the two-step gender identity question would affect the performance of the measure. We recommend that the MEPS questionnaire reflect the ordering recommended in the NASEM report until adequate testing can be completed to assess the impact of ordering changes.

https://nap.nationalacademies.org/resource/26424/Issue Brief Research Recs.pdf.

⁷⁴ *Id*.

⁷⁵ *Id*. at 9.

⁷⁶ MEYER, WILSON & O'NEILL, LGBTQ PEOPLE IN THE US: SELECT FINDINGS FROM THE GENERATIONS AND TRANSPOP STUDIES, *supra* note 17, at 10–11.

⁷⁷ *Id*.

⁷⁸ 88 Fed. Reg. 67,292.

⁷⁹ NAT'L ACAD. OF SCIENCES, ENGINEERING & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION 117 (2022), https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation [hereinafter: NASEM REPORT].

⁸⁰ NAT'L ACAD. OF SCIENCES, ENGINEERING & MED., MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION: RESEARCH RECOMMENDATIONS 3 (Sept. 2022),

Second, AHRQ has proposed to include "nonbinary" as a response option for respondent's current gender identity but omits "transgender" as a response option. The other options are "female," "male," and "I use a different term," with a fill-in-the-blank. Although we do not oppose the inclusion of "nonbinary," we recommend that AHRQ include "transgender" as a response option, consistent with the NASEM report's recommendations. Furthermore, there has been limited published evidence of testing "nonbinary" as a response option in general population surveys of adults. Currently, the Census Bureau has proposed testing the inclusion of "nonbinary" as a response option to the American Community Survey. We would recommend that AHRQ wait for the results of the ACS testing before moving forward with the inclusion of "nonbinary" or the elimination of "transgender" as a response option.

IV. Conclusion

The MEPS seeks to assess a multitude of factors related to health and health care access. Existing research demonstrates that LGBTQ people experience physical and mental health disparities compared to non-LGBTQ people and are especially vulnerable to economic insecurity. Including SOGI measures in the MEPS-HC PSAQ would provide information about the health and health care access among LGBTQ people and the relationships between these outcomes and economic insecurity. Research from the Williams Institute and other scholars on health disparities and discrimination faced by LGBTQ people provide the evidentiary support for these changes to the survey instrument. Collecting this information would help the AHRQ to effectively administer the MEPS and provide utility for the AHRQ, researchers, and the public according to the objectives in President Biden's Executive Order 14075 to collect SOGI data. In particular, the data will serve a practical utility for the AHRQ as it will provide nationally representative information about LGBTQ people and increase HHS' ability to assess their healthcare needs.

In conclusion, the undersigned write to provide support for the AHRQ's proposal to add a question collecting sexual orientation data and a two-step question assessing gender identity amongst respondents to the MEPS, among additional proposed changes to accommodate these questions.

Thank you for your consideration. Please direct any correspondence, including questions, to tentindo@law.ucla.edu.

Respectfully Submitted,

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83 88 Fed. Reg. 64,404-7.

⁸¹ NASEM REPORT, *supra* note 79.

⁸² *Id.* at 124.

⁸⁴ 88 Fed. Reg. 67,292.

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