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RE: Agency Information Collection Activities; Submission for OMB Review; Comment Request; Revision of Existing Data Collection; National Longitudinal Survey of Older Americans Act Participants (NSOAAP), OMB Control No. 201802-0985-002, FR Doc. 2018-03390

ATTN: OMB Desk Officer for ACL

Submitted via email to OIRA_submission@omb.eop.gov

The Fenway Institute at Fenway Health is writing to comment on the proposed gender and sexual orientation questions for the redesigned National Survey of Older Americans Act Participants (NSOAAP). Questions that can capture the experiences of lesbian, gay, bisexual, and transgender (LGBT) older adults are essential to adequately assess the extent to which programs funded under the Older Americans Act (OAA) serve all elders in the United States.

The Fenway Institute works to make life healthier for LGBT people, people living with HIV/AIDS, and the larger community. We do this through research and evaluation, education and training, and policy analysis. We are the research division of Fenway Health, a federally qualified health center that serves about 30,000 patients each year.

On September 26, 2017, the Administration for Community Living (ACL) proposed a new, longitudinal survey design for the NSOAAP that would continue to collect information on the sexual orientation of OAA-funded program participants, but would no longer collect information on program participants' gender identity. We believe that the proposed sexual orientation question on the NSOAAP (page 102) is acceptable, and should serve to collect important and useful data on LGB older adults.

As researchers who conducted research and policy analysis on the experiences and needs of LGBT elders, we strongly support the decision of ACL to continue to collect information about program participants' sexual orientation. This will enable ACL to fulfil its statutory obligation to ensure that funds allocated pursuant to the OAA are being targeted to older adults with "greatest social need," including lesbian, gay, and bisexual older adults, who are often underserved by these programs. The Massachusetts Executive Office of Elder Affairs designated LGBT elders as a population of greatest social need under the OAA in 2012.

At the same time, we are concerned that the proposed gender question on the survey—which currently only includes the response options male, female, don't know, or refuse—will not effectively capture data on transgender elders. Transgender people are people whose gender identity and assigned sex at birth do not correspond. We strongly encourage OMB to require ACL to fulfil its

commitment to conduct further testing to assess whether the proposed gender question on the survey will provide an adequate opportunity to assess the extent to which OAA-funded programs are serving transgender older adults. We further request that OMB not approve a final survey unless ACL can demonstrate that the survey will adequately assess the extent to which OAA-funded programs are serving this population.

In 2013 researchers at the Fenway Institute tested the understandability and acceptability of a two-part gender identity question among a diverse patient population at community health centers across the country. The sample was mostly heterosexual and majority Black and Latino. We published this analysis in *PLOS One* in 2014. The two-part gender identity question asks about current gender identity and sex at birth. The questions were widely understood and accepted. Among the respondents, 78% agreed that they understood all the choices in the gender identity question, 84% agreed that they would answer the sex at birth question, and 86% agreed that they would answer the current gender identity question.¹ The questions that we tested are:

What is your current gender identity?

(Check all that apply)

- Male*
- Female*
- Female-to-Male (FTM)/Transgender Male/Trans Man*
- Male-to-Female (MTF)/Transgender Female/Trans Woman*
- Genderqueer, neither exclusively male nor female*
- Additional Gender Category/(or Other), please specify _____*
- Decline to Answer, please explain why _____*

What sex were you assigned at birth on your original birth certificate?

(Check one)

- Male*
- Female*
- Decline to Answer, please explain why _____*

We encourage OMB and ACL to cognitively test these questions, rather than the proposed gender question currently on the survey, and ask the following probes to measure whether survey participants understand the questions, and whether the questions accurately reflect their gender identity:

In answering Question 1 (“What is your current gender identity?”), please let us know whether you agree or disagree:

(CHOOSE ONE ANSWER ON EACH LINE)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
1a. I understood what the	1	2	3	4	5

¹ Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, et al. (2014) Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers. *PLoS ONE* 9(9): e107104.

question was asking about me					
1b. I understood all of the answer choices	1	2	3	4	5
1c. The question was easy for me to answer	1	2	3	4	5
1d. I would answer this question on a survey.	1	2	3	4	5

2. In answering Question 2 (“what sex were you assigned at birth on your original birth certificate?”), please let us know whether you agree or disagree:

(CHOOSE ONE ANSWER ON EACH LINE)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
2a. I understood what the question was asking about me	1	2	3	4	5
2b. The question was easy for me to answer	1	2	3	4	5
2c. I would answer this question on a registration form at this health center.	1	2	3	4	5

3. In answering the gender identity questions (which includes questions 1 and 2), please let us know whether you agree or disagree:

3a. This set of questions allows me to accurately document my gender identity	1	2	3	4	5
3b. I think this information is important for elder service providers to know about me	1	2	3	4	5

4. Would you make any changes to this question?

- Yes
 No

4a. If yes, what changes would you make?

5. Please include any comments you have about the gender identity questions:

Research has shown that transgender older adults are likely to have the greatest social and economic need and may be less likely to receive the services and supports they need to live independently. Transgender people experience high rates of economic instability, disability, and mental health burden. The 2015 United States Transgender survey of nearly 28,000 transgender respondents found that nearly one third of participants (29%) were living in poverty, which is twice the rate of the general population. The survey also found that 39% of respondents had one or more disabilities as described by the American Community Survey, compared to 15% of the general population. Furthermore, 39% of respondents reported experiencing serious psychological distress in the month prior to completing the survey, compared to 5% of the general population. Some 40% of respondents had attempted suicide in their lifetime. Respondents also indicated that they commonly experienced discrimination in accessing healthcare services, with 33% of respondents reporting at least one negative experience, such as being verbally harassed or refused treatment.² Due to the high rates of disability and mental health burden, transgender older adults may be in greater need of elder services, but they may forego accessing these services due to past experiences of discrimination.

The NSOAAP provides critical data on whether federally funded aging programs like meals on wheels, family caregiver support, adult daycare, home care aides, and senior centers reach all older adults. A survey that does not capture gender identity information is not ensuring that programs funded under the OAA prioritize the neediest and most isolated segments of the population. If ACL does not collect data on the participation of transgender elders, ACL will not have the most basic data on whether the aging network is meeting the needs of this population.

ACL does not dispute the need to collect information about the extent to which OAA-funded programs meet the needs of transgender older adults. Rather, in response to the many comments requesting that ACL adopt or improve the collection of data regarding the extent to which OAA-funded programs are meeting the needs of transgender older adults, the agency said that, “[t]he first step in improving the methodology for measuring gender identity in the survey will be to conduct cognitive testing of the redesigned information collection tool.”

As part of the cognitive testing, ACL plans to assess whether the question in the revised survey that seeks information about respondents’ gender will provide an adequate means to assess whether OAA programs are serving transgender older adults. It is unlikely that the gender question included in the survey—which currently only has the response options male, female, refuse, or don’t know—will provide an adequate means to collect information about whether respondents are transgender. We therefore urge that OMB condition its approval of ACL’s request to conduct cognitive testing on a requirement that this testing meaningfully assess whether the revised survey collects information about

² James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *The Report of the 2015 U.S. Transgender Survey*. Washington, DC: National Center for Transgender Equality.

whether a respondent is transgender. To do so, ACL should ensure that the sample includes representatives from the LGBT community, and engage experts on the collection of sexual orientation and gender identity data.

Because ACL does not anticipate starting to administer the revised survey until June 2019, ACL should have ample time to make any modifications needed to assess the extent to which OAA-funded programs are meeting the needs of transgender older adults. Accordingly, OMB should not grant final approval to the revised survey until ACL demonstrates that it is collecting data about the participation of transgender older adults. ACL could do so by following the lead of other federal and state surveys that have successfully implemented procedures to identify transgender respondents, such as the National Crime Victimization Survey, the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Survey (YRBS), and the National Health Interview Survey (NHIS). Researchers at the Fenway Institute are ready and willing to assist ACL leaders in this important endeavor.

By collecting this data, and learning more about this population, ACL can ensure that more transgender older adults live independently, minimize the burden on the aging network, and ultimately save taxpayer resources by reaching those who are most vulnerable and helping them age successfully in place.

Sincerely,

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