THE GERONTOLOGICAL SOCIETY OF AMERICA®

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October 3, 2022

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

via email: equitabledata@ostp.eop.gov

RE: Federal Evidence Agenda on LGBTQI+ Equity RFI

Dear Colleagues:

On behalf of The Gerontological Society of America (GSA), thank you for the opportunity to provide input to the request for information for the **Federal Evidence Agenda on LGBTQI+ Equity.**

Our mission at GSA is to cultivate excellence in interdisciplinary aging research to advance innovations in practice and policy. GSA's 5,400 members include gerontologists, health professionals, behavioral & social scientists, biologists, demographers, economists, and many other disciplines. These experts study all facets of aging with a life-course orientation. The multidisciplinary nature of the GSA membership is a valued strength, enabling the Society to provide a 360-degree perspective on the issues facing our population as we age. GSA is advancing major initiatives related to improving adult immunization rates, earlier detection of cognitive impairment, improving oral, hearing, and vision health, framing our language to improve the public's understanding of aging, and understanding the impact of the longevity economy.

GSA policy is to embed diversity and inclusion as fundamental principles and practices as we pursue greater equity across the Society. The Board-of Directors approved the GSA Policy on Diversity, Equity, and Inclusion in 2021. GSA convenes the Rainbow Research Group to facilitate connections between researchers interested in LGBTQI+ aging as well as researchers who identify as LGBTQI+ and leaders of the interest group provided input for these comments. Leaders in the field regularly disseminate their research at the GSA Annual Scientific Meeting and publish in our highly respected series of journals including *The Gerontologist* and *Journals of Gerontology Series B*.

As a professional membership organization that values the importance of evidence-informed practice and policy GSA **commends the Administration for establishing The Interagency Working Group on Equitable Data** and tasking it with the development and release of a Federal Evidence Agenda on LGBTQI+ Equity, to improve the Federal government's ability to make data-informed policy decisions that advance equity for the LGBTQI+ community.

GSA is pleased to offer the following responses to selected questions on how requirements in the Federal Evidence Agenda on LGBTQI+ Equity should be addressed by the Subcommittee on SOGI Data.

Describing Disparities

1. What disparities faced by LGBTQI+ people are not well-understood through existing Federal statistics and data collection? Are there disparities faced by LGBTQI+ people that Federal statistics and other data collections are currently not well-positioned to help the Government understand?

The current state of federal statistics and data collection on LGBTQI+ identities are not well-positioned to identify and track disparities within this heterogeneous community, as there is currently no federal standard to collect these data. Most federal surveys do not collect consistent and accurate data on sexual orientation and gender identity (SOGI) and very often rely on proxy measures to estimate the size of the LGBTQI+ population and their needs.

Future research should disaggregate the heterogeneous LGBTQI+ population by focusing on subgroups differences within the broader community. For example, research on intersex populations is nearly nonexistent and there is a need for more research on transgender/nonbinary and bisexual populations along with non-white LGBTQI+ populations. The current state of knowledge on institutionalized LGBTQI+ populations and older LGBTQI+ populations should also be prioritized and expanded in federal initiatives.

The majority of data regarding disparities faced by LGBTQI+ people stem from research on lesbian and gay individuals. For example, we know that lesbian and bisexual women are less likely to seek regular pap smears due to prior experiences of discrimination in health care settings and this may lead to their higher rates of cervical cancer compared to their heterosexual peers (Burkhalter et al., 2016). However, the same type of data is not currently being collected from intersex or transgender individuals. There is very little information on cancer among transgender populations—the data that exists is primarily in the form of case studies and not epidemiologic data. Besides disparities in cancer incidence, treatment, and mortality, we do not have enough information about disparities impacting LGBTQI+ people routinely, such as discrimination in the workplace, unequal pay, unfair dismissal of employees, everyday microaggressions, etc.

2. Are there community-based or non-Federal statistics or data collection that could help inform the creation of the Federal Evidence Agenda on LGBTQI+ Equity? Are there disparities that are better understood through community-based research than through Federal statistics and/or other data collection?

The National Health, Aging, Sexuality/Gender Study (NHAS): Aging with Pride is a community-based non-federal longitudinal study that documents and tracks health disparities among LGBTQI+ populations. Karen Fredriksen Goldsen, this landmark study is the first federally funded longitudinal national project designed to better understand the aging, health, and well-being of LGBTQ+ midlife and older adults and their families. The project is in collaboration with 17 community agencies serving LGPTQ+ older adults in every census division throughout the United States.

Given the marginalization and history of misconduct by medical and governmental authorities, the transgender population may be a subgroup of LGBTQI+ individuals who may be more reticent to engage in federal reporting of data. This subgroup may be better attended to through community-based research in which a transgender researcher builds trust with the community and can maintain long-term connections with the community.

3. Community-based research has indicated that LGBTQI+ people experience disparities in a broad range of areas. What factors or criteria should the Subcommittee on SOGI Data consider when reflecting on policy research priorities?

GSA respectfully requests the Subcommittee consider the current state of NIH funding for research with LGBTQI+ populations. In the 2019 Annual Report from the Sexual & Gender Minority (SGM) Research Office, NIH pursued the advancement of SGM health and research through a variety of activities. We appreciate NIH continuing to support funding opportunity announcements, administrative supplements, and notices of special interest to support SGM research. However, until the SGM Research Office was established U.S. federally supported funding for LGBTQI+ specific health research outside the context of human immunodeficiency virus (HIV) disease and other sexually transmitted diseases had been limited. (Burkhalter, et.al. 2016). We appreciate comment opportunities such as these which allow for the LGBTQI+ community to provide input on policy research priorities.

To stimulate more inclusive research, GSA recommends applying **the Health Equity Promotion Model (HEPM**) as a framework to guide future LGBTQI+ research and policy priorities (Fredriksen-Goldsen et al., 2014). The HEPM is a framework oriented toward LGBTQI+ people reaching their full mental and physical health potential that considers both positive and adverse health-related circumstances. The model highlights (a) heterogeneity and intersectionality within LGBTQI+ communities; (b) the influence of structural and environmental context; and (c) both health-promoting and adverse pathways that encompass behavioral, social, psychological, and biological processes. It also expands upon earlier conceptualizations of sexual minority health by integrating a life course development perspective within the health-promotion model. By explicating the important role of agency and resilience as well as the deleterious effect of social structures on health outcomes, it supports policy and social justice to advance health and well-being in these communities. Important directions for future research as well as implications for health-promotion interventions and policies are offered.

Informing Data Collections

1. In some instances, there are multiple surveys or data collections that could be used to generate evidence about a particular disparity faced by the LGBTQI+ community. In addition to factors like sample size, timeliness of the data, and geographic specificity of related data publications, what other factors should be considered when determining which survey would best generate the relevant evidence? Are there data collections that would be uniquely valuable in improving the Federal Government's ability to make data-informed decisions that advance equity for the LGBTQI+ community?

It is critically important to use community-specific terminology when crafting questions and response options to create more inclusive data collection measures. This should allow for better measures that more accurately reflect the array of identities within this heterogeneous community. The National Academies of Science, Engineering, and Medicine recently published a consensus report outlining the best methods for collecting SOGI. The recommendations are guided by research and ensure that questions of sexual orientation and gender identity are asked in the most inclusive manner. For example, same gender loving is commonly used African American/Black and two spirit is a term used by Indigenous peoples.

2. To protect privacy and maintain statistical rigor, sometimes publicly-released data must combine sexual and gender minority respondents into a single category. While this approach can provide valuable evidence, it can also obscure important details and differences. Please tell us about the usefulness of combined data, and under what circumstances more detailed data may be necessary.

Combining data on sexuality and gender into a single category is problematic as sexuality and gender are two distinct constructs representing radically different realities. It is both impractical and ineffective to combine these data into a single category. It could be useful to combine data on sexuality (i.e., gay, lesbian, bisexual) or gender (i.e., transgender, nonbinary, gender nonconforming) when sample sizes are small and do not have the power to complete advanced statistical analyses. For example, many transgender individuals are heterosexual and by grouping transgender and sexually diverse communities together, we are assuming their experiences are similar when really, they face diverse and unique disparities.

4. How can Federal agencies best communicate with the public about methodological constraints to collecting or publishing SOGI data? Additionally, how can agencies encourage public response to questions about sexual orientation and gender identity in order to improve sample sizes and population coverage?

Fredriksen Goldsen and Kim (2015) found that the nonresponse rate for sexual orientation is notably lower than income and slightly higher than education and race/ethnicity. This is an important finding that counters common misconceptions that questions about sexuality are too sensitive to ask research participants. As the sociopolitical context becomes increasingly accepting of sexual and gender diversity so too should response rates for these questions.

Strategies to encourage responsiveness include asking open-ended question about sexual orientation and gender identity, using language and terminology that is community specific, asking respondents to separately identify their sex, sexuality, and gender, not using binary measures, only asking questions that are necessary and appropriate for the research being conducted. Research findings should be shared with respondents and community members to ensure they benefit from the data they have shared.

One of the main tenets of community-based participatory research is the transparency between the scientists conducting the research and the community with which the research is conducted (Nguyen et al., 2021). To this end, best practices involve disseminating the study findings back to the study participants. Dissemination is defined by PCORI as “the intentional, active process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of evidence and motivate its use in policy, practice, and individual choices” (Esposito et al., 2015). Prior research has demonstrated that 75% of past research participants believe they should receive study results and both past research participants and researchers believe that sharing findings with participants could improve community support and trust in research (Melvin et al., 2020).

Disseminating findings to study participants also ensures that the knowledge gained from the research reaches the individuals and communities who could benefit the most (Cunningham-Evres et al., 2021). Despite recommendations for sharing study findings with participants, it is not a common practice (Long et al., 2019). In fact, only one-third of prior participants from health research report receiving results, and half report not being able to request study results (Long et al., 2019). Researchers often report barriers to sharing their findings with study participants such as a lack of knowledge regarding the best way to do so (Melvin et al., 2020). Recommendations include tailoring content for different learning styles and needs, as study participants may have different preferences for receiving information regarding findings from studies in which they participated (Cook et al., 2019).

The publication of study findings in traditional academic journals may not be accessible to past study participants (Reilly et al., 2018) or may contain unnecessary jargon that makes the findings difficult to apply to real-world settings. The ability to use study findings in actively improving population health is especially important for the most underserved and vulnerable groups. In order to do so, “researchers must be equipped to engage in dissemination practices beyond those traditionally accepted and encouraged in academia” (Cunningham-Evres et al., 2021, p.1418).

5. Data collection on vulnerable populations is often incomplete, creating challenges for creating data-informed decisions to advance equity for those populations. How can statistical techniques help identify missing SOGI data, and make statistically rigorous estimates for that missing data? How should qualitative information help agencies analyze what SOGI data might be missing?

Asking SOGI questions in a few different ways may increase the possibility to obtain SOGI data and reduce challenges associated with missing data. For example, in addition to asking how participants self-identify in terms of sexual orientation and gender identity, questions regarding sexual attraction and behavior, romantic relationship, and gender expression and ideation can be asked in various terms including frequency and extent. These variables may be utilized to statistically estimate and impute missing information.

Qualitative information can be used to help identify additional areas where data is needed. While qualitative data is often seen as less rigorous than quantitative data, it can be crucial in gaining a deeper understanding of the lived experience of LGBTQI+ populations. To that end, federal agencies need to consider funding qualitative research studies in addition to the more traditional quantitative/population-based studies. Qualitative studies may serve as the best first method of identifying disparities that need further attention. Creative methodologies have been used with historically marginalized populations as a way to center the experiences of these individuals and may provide a unique manner of engaging this resilient and creative community (Jen & Paceley, 2021).

Privacy, Security, and Civil Rights

2. Unique risks may exist when collecting SOGI data in the context of both surveys and administrative forms. Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.

Surveys that collect SOGI data may put sexual and gender minority people at increased risk of discrimination and victimization as these data are vulnerable to misuse and must be used, maintained, and shared under rigorous privacy and confidentiality standards. There is a potential for these data to be misinterpreted and used to inform harmful policies and practices. Thus, it is important to weigh the benefits of collecting these data with the risks of harm. Respondents should always be given the opportunity to opt out of providing this information.

3. Once SOGI data have been collected for administrative or statistical purposes, are there considerations that Federal agencies should be aware of concerning retention of these data? Please tell us how privacy or confidentiality protections could mitigate or change these concerns.

The same protocols to protect privacy of respondents and confidentiality of data as applied to other human subjects health research data should be ensured to be strictly followed including complete deidentification, i.e., separation of identifiable information and other data, restricted access to identifiable data, access granted only to authorized persons following security protocols, and destruction of data after defined period of data-retention time. Commercial privacy and confidentiality platforms may have useful tools that provide secure protections.

4. Where programmatic data is used to enforce civil rights protections, such as in employment, credit applications, or education settings, what considerations should the Subcommittee on SOGI Data keep in mind when determining promising practices for the collection of this data and restrictions on its use or transfer?

Disadvantages experienced by SOGI individuals that require civil rights protections may occur in complex ways as they have multiple identities and the centrality and/or importance of an identity dimension among others differ between individuals. In addition, people may perceive an infringement on their civil rights attributable to another identity such as race/ethnicity (than SOGI) or multiple intersecting identities of theirs. Therefore, collection of data in light of their SOGI should ensure placing SOGI in context of other diverse identities, particularly those known to disadvantage people with such identities. In other words, data on other identities and characteristics should also be collected, and questions pertaining to civil rights protections should carefully consider diverse contexts and identities so as to effectively utilize data toward improving civil rights of SOGI individuals.

GSA is pleased to submit these responses for consideration. If you have any questions or need additional information, please do not hesitate to contact Patricia M. D'Antonio, Vice President, Policy and Professional Affairs at 202-587-5880 or pdantonio@geron.org

Sincerely,

James C. Appleby

James C. Appleby, BSPharm, MPH, ScD (Hon)
Chief Executive Officer

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