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MITRE's Response to the OSTP RFI to Help Inform Development of the Federal Evidence Agenda on LGBTQI+ Equity

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For additional information about this response, please contact:

Duane Blackburn
Center for Data-Driven Policy
The MITRE Corporation
7596 Colshire Drive
McLean, VA 22102-7539

policy@mitre.org
(434) 964-5023

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MITRE supports a variety of chief data officers throughout the federal government as they develop and implement their data strategies and governance programs. This includes analyzing the responsible and effective collection and use of data on sexual orientation, gender identity, and sex characteristics (SOGI data). For example, MITRE supported a federal agency by developing a report that focused on the need to collect and manage protected personal identifying information (PII), including protected health information and SOGI data. This assessment addresses key points of consideration through a comprehensive review of current policies and practices then consulting evidence-based best practices drawn from peer-reviewed consensus reports from the National Academies of Sciences, Engineering, and Medicine prepared for the National Institutes of Health and the Joint Commission for Accreditation of Healthcare Organizations.

Overarching Recommendations

Policy Conflicts. As often occurs in policy deliberations, multiple interests seem to be in conflict and in need of resolution. In the case of this RFI, longstanding aspirations to ensure the privacy of individuals is conflicting with the current desire to ensure LGBTQI+ equity, which in many cases requires the collection and analysis of SOGI data that can be very private information for many of these individuals. This conflict can create confusion within federal programs, limiting their potential effectiveness in protecting privacy and other rights and interests. Detailed research is thus required to understand areas of conflict (and alignment) for various data elements and how those differ across different use cases. This research can then be leveraged to create detailed guidance and examples for federal programs of when and how they should collect and use LGBTQI+ data while maximizing privacy protections.

Alignment to the Federal Data Strategy. To achieve full impact, OSTP's work on this topic should align with, and be incorporated into, the Federal Data Strategy. Since its inception in

2020, the Federal Data Strategy's aim has been to help the federal government embrace data to answer key questions. To that end, the 2021 Action Plan¹ includes actions such as:

- #4 – Use Data to Guide Decision-Making
- #8 – Monitor and Address Public Perceptions
- #26 – Share Data Between State, Local, and Tribal Governments and Federal Agencies

LGBTQI+ data is one type of data that has not been well represented within these efforts, limiting the government's ability to make informed decisions. A Data Ethics Framework² is also part of the Federal Data Strategy, and includes tenets such as:

- “Respect the public, individuals, and communities. ... Data initiatives should include considerations for unique community and local contexts.”
- “Respect privacy and confidentiality. Privacy and confidentiality should always be protected in a manner that respects the dignity, rights, and freedom of data subjects.”
- “Promote transparency. Individuals, organizations, and communities benefit when the ethical decision-making process is as transparent as possible.”

These tenets align with the above goals to share LGBTQI+ data, monitor and address public perceptions, and use data to guide decision making. Finally, the 2021 Federal Data Strategy Action Plan includes “Filling in gaps in government capacity and knowledge.” To attain this goal with LGBTQI+ data, the federal government should both harness more local data as well as consider strengthening data-gathering policies to ensure the LGBTQI+ community is fairly treated.

Questions Posed in the RFI

Describing Disparities: Section 11 of the Executive Order states that “Advancing equity and full inclusion for LGBTQI+ individuals requires that the Federal Government use evidence and data to measure and address the disparities that LGBTQI+ individuals, families, and households face.” With that charge in mind, OSTP seeks response to the following questions:

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?

Researchers and community advocates have highlighted disparities for LGBTQI+ Americans through intensive studies and surveys, in mental health, economic well-being, access to medical care, housing, employment, and public and private services. However, few of these disparities are easily monitorable via federal statistics, as only national data systems, such as the Behavioral Risk Factor Surveillance Survey, National Health and Nutrition and Examination Survey, National Survey of Family Growth, Youth Risk Behavior Survey, National Crime Victimization

¹ Federal Data Strategy 2021 Action Plan. 2021. The White House, <https://strategy.data.gov/assets/docs/2021-Federal-Data-Strategy-Action-Plan.pdf>.

² Federal Data Strategy Data Ethics Framework. 2020. The White House, <https://resources.data.gov/assets/documents/fds-data-ethics-framework.pdf>.

Survey, and in the last decade National Health Interview Survey and National Survey of Drug Use and Health, collect SOGI data. Many of these data gaps can be addressed by collecting SOGI data in primary federal census and financial statistics and allowing for disaggregation in a respectful, privacy-preserving manner.

Social capital disparities, however, may not be properly observed just by disaggregation of current federal data collections. Social capital refers to the goods of individuals' social connection—"social networks and the norms of reciprocity and trustworthiness that arise from them"—through both personal relationships and more formal associations.³ Social capital is a determinant and early predictor of physical and mental health; access to jobs and financial stability; and, on a communal level, resilience to crisis—whether natural disaster or the COVID-19 pandemic.⁴ Specific research studies indicate that LGBTQI+-identifying Americans experience less social capital than Americans who do not identify as LGBTQI+. Reasons provided include the effects of discrimination and stigma, resulting in conflict and estrangement with kin and communal institutions. Also, due to historical barriers to gay and lesbian families, older adults are less likely to have social and care support of younger family members.⁵

However, the disparity is likely not uniform across U.S. demographics: levels of acceptance vary by community and age, and in some contexts, LGBTQI+ Americans have compensated with strong networks of in-group support, socially and institutionally, and a phenomenon of "chosen family" (friends-as-family relationships).

In the context of incorporating social equity in climate resilience investments,⁶ MITRE surveyed the leading social capital indices across U.S. census blocks or counties based on federally furnished data, including the Joint Economic Committee Republicans Social Capital Project's Social Capital Index, Penn State University Northeast Regional Center for Rural Development's Social Capital Index, and research by Kyne, Aldrich, Fraser, and Page-Tan. MITRE found that these indices do not serve the purpose of measuring demographic-specific social capital. Even when the U.S. Census introduces sexual orientation and gender identity to the American Community Survey, this does not translate into the usability of these indices for LGBTQI social capital disparity assessment. The indices themselves are constructed based on neighborhood rate distal indicators, such as density of religious and social organizations in a region—which, depending on their relationship to LGBTQI+-identifying individuals, could contribute positively or negatively to their social capital. Researchers on LGBTQI+ health have called for the development of "better subgroup-specific indicators of social capital."⁷

An approach to solve the challenge of assessing social capital disparities across all marginalized and underserved populations would include measuring social capital nationally in the manner that sociologists do in smaller research studies: directly surveying residents, disaggregated by SOGI and other relevant demographic identities, about their social support, cohesion, and community trust.

³ R. Putnam. *Bowling Alone: The Collapse and Revival of American Community*. 2000. Simon and Schuster.

⁴ J. Stadlan. *Accounting for Social Capital*. 2022 (forthcoming). MITRE.

⁵ N. Hsieh and J. Wong. *Social Networks in Later Life: Similarities and Differences between Sexual-Minority and Heterosexual Older Adults*. 2020. *Socius*, vol. 6.

⁶ Stadlan, *Accounting for Social Capital*.

⁷ M. Zarwell et al. *A Psychometric Assessment of a Network Social Capital Scale among Sexual Minority Men and Gender Minority Individuals*. 2021. *BMC Public Health*, vol. 21, no. 1.

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?

As previously mentioned, a key area for research will be identifying how to collect SOGI data while also ensuring privacy protections. SOGI data can be quite beneficial in numerous contexts, such as a healthcare provider understanding the individual whose blood they are analyzing. But improper access to such data can potentially lead to embarrassment or more extensive harms of the individuals impacted. Protecting this information is also a privacy requirement, as all PII must be supported by specific legal foundations. Within federal government contexts, the collection of this information must be to advance the mission or purpose of a federal agency, as authorized in a statute or Executive Order, as indicated in the federal Privacy Act at 3 USC 552a(e)(3)(a). In the case of sensitive information such as LGBTQI+ status, this connection must be well analyzed and documented. Also, the subject individuals must be very clearly advised of their rights under the Privacy Act, per the remainder of that subsection (i.e., (e)(3)).

B. Informing Data Collections. Ultimately, individual agencies decide what data to collect and publish through their forms and surveys, taking into account considerations like informed consent, privacy risk, statistical rigor, intended use of the data, budget, burden to respondents, and more. With that in mind, OSTP seeks response to the following questions about where potentially useful data is lacking:

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?

One often overlooked factor to consider is two aspects of trust. First, in who administers the survey. Entities that are known and trusted by their subjects can receive better response rates and more accurate information. Second, if the collection is mandatory, that selection could result in skewed or biased results.

Privacy considerations also come into play as well, as its protection will vary widely based on the purpose of the data collected, the volume of the information collected, the demographics of the population, and other factors. This, in turn, impacts what data can be used within different surveys and analyses. A single set of criteria and controls cannot be established due to these variations; a flexible approach will be necessary.

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.

Data should be combined only when such variations have no impact on the analyses and should be clearly marked as such so that others do not misuse or inaccurately infer meanings or impacts within the combination. SOGI data collections for multiple purposes (or use cases) should not be combined.

3. Are there any Federal surveys or administrative data collections for which you would recommend the Federal Government should not explore collecting SOGI data due to privacy risk, the creation of barriers to participation in Federal programs, or other reasons? Which collections or type of collections are they, and why would you make this recommendation?

SOGI data must be collected and used only as is consistent with the Privacy Act, the HIPAA Privacy Rule, and other relevant laws and regulations. Protections provided by these authorities include a requirement for an authority to collect data; maintaining an accounting of disclosures for uses other than routine uses; and a provision of access rights as provided by the Privacy Act and HIPAA (where relevant and where not subject to exemptions or exceptions). For SOGI, in particular, agencies must not conduct data reuse—that is, uses that are not compatible with the purposes for which the data was collected originally.

Privacy, Security, and Civil Rights: The Executive Order calls on the interagency SOGI data body to identify privacy, confidentiality, and civil rights practices agencies should follow when collecting SOGI data. Though members have expertise in how privacy, confidentiality, and civil rights practices apply to other marginalized groups, OSTP seeks input on privacy, confidentiality, and civil rights considerations that are unique to the LGBTQI+ community and/or are experienced differently by LGBTQI+ people, including in intersection with other marginalized experiences. Accordingly, OSTP seeks response to the following questions:

1. While the confidentiality of data collected by the statistical system is protected by statute, OMB and other agency policies, and experience in protecting the confidentiality of respondents through data governance, privacy-preserving technology, and disclosure limitation practices, a wide range of privacy protections apply to data collected for programmatic purposes, such as applications for Federal programs or benefits, compliance forms, human resources data, and other data used to manage and operate Federal programs. What specific privacy and confidentiality 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, especially in the context of government forms and other collections of data for programmatic use?

Population Size. Given the relatively small population of SOGI individuals in the American population, it is critical to ensure deidentified SOGI data is used for programmatic efforts to reduce the risk of inadvertently identifying SOGI individuals in smaller communities.

Sensitivity of the Data. While SOGI data can be useful within many analyses, its access and use via improper or inadvertent disclosures can potentially lead to significant harms. This is especially true for those individuals who are hiding their status, with such disclosures resulting in reputational, financial, benefits access, or even personal safety ramifications.⁸ SOGI data can be thought of as an amalgamation of PII, sensitive medical information, and controlled unclassified information. It has aspects of each, but none of these existing data protection models fully supports the needs of SOGI data. Research is needed to enhance one of these models to fully manage and protect SOGI data, or to develop a new model for this category of data. These researchers should proactively consult with individuals and experts from within the LGBTQI+ community to ensure that they are fully aware of the concerns and risks faced by this data, and how the data itself can transition over time and the resulting issues that could create. Results of this research should drive the development of formal policy for handling and protecting SOGI data specifically, replacing the inconsistent patchwork that currently exists.

⁸ C. Wood et al. The Role of Data Protection in Safeguarding Sexual Orientation and Gender Identity Information. 2022. Future of Privacy Forum, <https://fpf.org/wp-content/uploads/2022/06/FPF-SOGI-Report-R2-singles-1.pdf>.

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.

In the privacy context, retention refers to how long something is retained in a record set, and the general practice is for it to be for the shortest retention period as needed to accomplish the stated purpose. An open question for further research is whether the sensitivity and utility of SOGI data means that it should be purged sooner or later than other data elements, and how that may vary based on the use case.

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?

As a general practice, SOGI data should not be transferred without the subject's concurrence, though special cases could exist, such as medical agreements.