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Concerns about Safety of Minorities in the Collection of SOGI Data

A position paper prepared for the Oregon Health Authority

Purpose and Position Statement

This is a position paper concerning the ethics of routine collection of SOGI demographic data, with particular attention paid to erasure and the closet. We hope that the Health Authority will use the perspective presented here to respond to concerns around the safety of individuals who disclose minority sex, minority sexual orientation, or minority gender status. We are epidemiologists with history working on issues of queer demography and social policy. We have both collaborated with OHA's Office for Equity and Inclusion on the development of the SOGI demographic instrument. We both occupy queer social locations and approach this work through the lens of queer experience.

Introduction

Concerns about mandated data collection related to sexual orientation and gender identity, or SOGI¹ have been voiced from within and outside of the Oregon Health Authority.² Many worry that asking individuals who hold **sex minority, sexual minority, or gender minority (SSGM)** identities to disclose information about these identities in health and social services contexts will threaten the safety of these individuals. This concern is well-founded: SSGM populations experience widespread societal stigma as well as interpersonal and institutional forms of discrimination emerging from our politically contested social position, and both stigma and discrimination are often present in health and social services contexts where these data will be collected. In particular, the collection and maintenance of these data risks revealing individuals' SSGM status without their informed consent—in effect potentially “outing” people to hostile actors during data collection or dissemination. Such risks are both immediate—such as disclosure in the presence of a bigoted medical provider, or a homophobic family member who could impact the individual immediately and directly—and ongoing—such as when the dissemination of de-identified data that includes small SSGM-identified populations (e.g., county- or facility-specific data) allows re-identification of respondents.[†]

Caution is justified in considering the potential immediate and ongoing ramifications of collecting SOGI data, and it is necessary to consider risk management when constructing the process for the collection, management, dissemination, and storage of this information. This caution is

^{*} This terminology is adopted by Oregon Health Authority and align with the UN-backed Yogyakarta principles, which aim toward unifying global language surrounding human rights efforts targeting sex minority, sexual minority, and gender minority populations. The acronyms SOGIE or SOGIESC may also appear, in accordance with the updated [Yogyakarta Principles plus 10](#) that include gender expression and sex characteristics.¹

[†] Because SSGM are frequent targets of political attacks, the routine collection and storage of these data may have far-term implications for the safety of SSGM communities. In a theorized future where hostile government actors become the custodians of these data (akin to recent state-level anti-queer actions in Texas and Florida), individuals who disclose SSGM identities could be targeted directly. This concern may seem remote in Oregon, where strong statewide protections for SSGM exist to guard against government-supported attacks, but the rapid radicalization of the national political landscape should motivate us to take this possibility seriously. We cannot guard against all future possibilities and are ultimately better served by imagining and building toward a future where SSGM are an uncontested part of Oregon's diversity.

familiar territory in routine state epidemiology, as data safety must be managed for all potentially identifiable demographic data that is collected by the state. Specific questions should be foregrounded:

How can the Health Authority mitigate the risk associated with SSGM status disclosure that opens individuals to hostility in their home, service provider, or community environment?

How will the Health Authority protect individuals whose data may be identifiable due to small sample sizes?

How will the Health Authority guard against the risk that a government entity that is hostile to the wellbeing of SSGM populations may weaponize these data?

Collecting accurate data about the experiences of minority populations including SSGM is fundamentally necessary to promote health equity in Oregon, and the fact that disclosure of these experiences comes with risk is evidence of the need for accurate data to understand and address possible health related injustice experienced by queer, trans and other minority individuals.

Key takeaway: There are valid and well-intentioned concerns about the safety of individuals who disclose sex minority, sexual minority, or gender minority status during SOGI data collection. However, collection of these data is necessary to advance health equity between SSGM and non-SSGM populations, and SSGM population health. Appropriate caution can be used to minimize safety concerns, but these safety concerns should not prohibit or impede the collection of these data.

Autonomy, Privacy, and The Closet

The concerns considered here appear to reflect anxiety voiced by SSGM individuals and their advocates who are wary of the implications of being ‘counted’. Within this community, the institution of the closet (i.e., concealment of SSGM status in any or all contexts, over the short or long term) serves as a protective strategy in the face of forms of anti-queer violence, including homophobic, biphobic, transphobic, and other queer-phobic stigmas. Closeting strategies are used by individuals, small groups (e.g., supportive and protective families of origin who maintain silence), and by organizations and governments (e.g., ‘Don’t Ask, Don’t Tell’). However, closeting strategies are also *always* a form of anti-queer violence which perpetuates anti-queer stigmas, and for individuals serve as a form of self-violence which perpetuates queer minority stress and vulnerability.³ So ubiquitous is our cultural emphasis on the function of the closet as *protective* that it is easy to overlook the violence inherent in choosing to conceal the truth of one’s identity for the purpose of conformity to dominant cultural expectations. The institution of the closet does not exist because SSGM desire privacy *per se*, but because without the closet SSGM live under threat of violence. And while the closet is, in this sense, protective, the cost associated with this protection is high: SSGM are rendered invisible, put at greater risk of mental illness, and are made ‘safe’ only because they have been denied both the ability to live authentically and recognition within social and institutional structures. In failing to provide opportunities for individuals to more accurately identify their experiences, demographic data collection efforts regenerate institutionalized closeting. The consequence of institutional closeting is the perpetuation of a legacy of erasure and suppression.

In truth, the protective value of the closet lies in its connection to **individual autonomy**.⁴ The widespread norm of withholding disclosure of another person's SSGM status unless given consent to disclose by the individual in question promotes that individual's autonomy—we see this small measure of freedom as a bulwark against social and cultural forces that have often stripped SSGM individuals of their autonomy. SSGM people who are fully—or even mostly—closeted may have little freedom to choose how they present themselves, who they love, and what name they are called. In such cases it may be deeply meaningful to respect the autonomy of the individual regarding disclosure of their SSGM status.

While it is the right of individuals facing persecution to elect not to provide information that may put them at risk, we argue that it is the responsibility of those tasked with implementing SOGI demographic data collection to provide opportunities for those individuals to decide whether and how to represent themselves, and thereby contribute to our collective understanding of the health of their communities. Failing to provide these opportunities by declining to ask questions strips autonomy by mandating, in effect, that all SSGM individuals and populations remain closeted. This ultimately and leads to erasure that perpetuates violence and discrimination, by way of the analytical assumption that SSGM people do not exist (or at minimum, do not need to be considered).

Key takeaway: Those making demographic data collection policies must provide opportunities for SSGM individuals to decide whether and how to represent themselves in order to not inflict the violence of the closet on SSGM populations.

Equal Protection and Erasure of SSGM

In the absence of an opportunity to for individuals to routinely identify their sexual orientation and gender identity, there is no analytical capacity to consider either SSGM population health, or population health inequities faced between SSGM and non-SSGM populations. In effect, SSGM populations become invisible and closeted. The erasure is insidious: populations are *de facto* analyzed as if they are cisgender, heterosexual, and binary gender, and it is assumed that there are no patterns in population-level variation by experiences of minority sex, minority sexual orientation, or minority gender that warrant consideration or intervention. This effectively reinforces structural cisheteronormativity and gender binarism. In order to advance effective SSGM population health and health equity between SSGM and non-SSGM populations, it is necessary to base policy on appropriate population-specific research.⁵

Both non-SSGM individuals and non-SSGM populations reap benefits from effective demographic data collection. These data are used to ensure populations are more validly represented, and that those with group-specific needs receive group-specific services. By insisting that SSGM individuals and populations remain invisible during data collection, policies advanced by states and organizations deny SSGM constituencies these benefits.

COVID-19 furnished a valuable example of the utility of accurate demographic data collection. During the contact tracing process, individuals who tested positive for COVID-19 were presented with the Health Authority's REALD questionnaire and these data were used to identify COVID-related disparities associated with race, ethnicity, language, and disability. This data was collected in part to aid policymakers in targeting interventions to specific populations at higher risk for adverse outcomes related to COVID-19.⁶

Because widespread collection of SOGI data has not been routinized, we know relatively little about the impact of COVID specific to SSGM populations.⁷ We can infer that disparities exist particularly between transgender groups and cisgender groups and between minority gender identity groups versus gender binary groups given widespread employment discrimination and lack of access to affirming health services,⁸ however, in the absence of demographic and epidemiological data we have little hope of either accurately measuring these disparities or effectively targeting interventions to address them.

Key takeaway: By insisting that SSGM individuals and populations remain invisible during data collection, policies advanced by states and organizations deny SSGM the benefits conferred by appropriate population-specific research. Consequently, it is not possible to accurately identify or create policy that adequately addresses disparities experienced by SSGM.

Creating Safety

The Health Authority collects and protects demographic data regarding many minority experiences—race, ethnicity, disability status, and more—that are similarly associated with possible disclosure risk for individuals, but only in the case of SSGM persons are we inclined to question whether the risk associated with collecting and reporting the data may outweigh the value of collecting and reporting the data. Ultimately, it is impossible to create a safer world for SSGM while refusing to create opportunities for SSGM individuals to authentically identify themselves; therefore, it is incumbent upon those engaged with this process to focus not on whether these questions should be asked, but rather on how to minimize the risk associated with asking while honoring the autonomy of those who are being asked. Data confidentiality and reporting methods are best handled by experts familiar with the Health Authority data collection system, but we offer the following as guiding principles that may aid in this endeavor.

To promote safety around SOGI data collection:

Safety protocols must be responsive to the needs expressed within SSGM communities, which is only possible through direct involvement of community members in the process of establishing safety practices. This is in step with OHA's Office for Equity and Inclusion's standard practice of community-involved SOGI instrument development. Community involvement in this process will identify safety concerns not covered in this brief—e.g., violations of culturally specific taboos related to discussing sex and sexuality that may arise from community norms that are unrelated to queerphobic discrimination (for example, in some cultures it is taboo to ask questions about the sexuality of another family member).

Guarantees and limitations to data confidentiality must be communicated transparently and accessibly when the data is collected to allow individuals to make informed decisions about disclosure. Some examples of potentially necessary information to be communicated to respondents include: what capacity they will have to change their responses in the future, who will be able to access respondents' data and how it will be used, and whether minors' responses may be disclosed to parents or guardians.

The SOGI instrument itself should reflect community involvement by allowing for nuanced, accurate responses and creating options that allow for autonomy in disclosure,

including different kinds of refusal (e.g., ‘questioning/exploring, ‘prefer not to answer’, ‘I don’t know’, and ‘not listed, please specify’).

Key takeaway: It is impossible to create a safer world for SSGM while refusing to create opportunities for SSGM individuals to authentically identify themselves. Demographic policy makers must focus not on whether these questions should be asked, but on how to minimize the risk associated with asking while honoring the autonomy of those who are being asked.

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