# Response to NSTC Subcommittee on Equitable Data Submitted by Elizabeth A. Jensen, PhD, PE, CSP October 1, 2022

## **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?
- 1) Detransitioners, Desisters, and now Eunuchs are not included in the LGBTQI+ in statistics and data collection.
- 2) As I discussed in the following article, no objective measure exists for TQI+. How do you measure disparities for a subjective identification? Religious affiliation is a subjective identification. How does TQI+ vary from a religion?
- 3) Assuming this information is important to address suicide, the suicide data is not being collected to support these major policy changes.

Jensen, E.A. (2022) "Medical Safety: Risk Study of Gender Medicine, Part 2", 4W.pub. https://4w.pub/medical-safety-risk-study-of-gender-medicine-part-2/

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?

Same information as in #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 I stated in Jensen (2022):

Significant policy changes have been enacted to protect transgender people based on the largely unmeasured phenomena discussed above. For example, a professor at the UC Berkeley School of Law testified at the Senate Judiciary Committee, "I want to recognize that your line of questioning is transphobic and it opens up trans people to violence by not recognizing them...[asked to clarify]...I want to note that one out of five transgender persons have attempted suicide" (C-span, 2022). There is no evidence to support this assertion, and there is no intention among USA Gender Medicine community leadership to study this scientifically. So accommodations in the form of limits on free speech are being implemented because of this small, virtually unstudied risk (e.g. Meriwether, 2021). How do other policy accommodations impact safety?

First of all, there are fundamental biological differences between females and males that are critical to acknowledge in the health care setting (search "female" in American Medical Association, 2021). While the nursing home court case, Taking Offense (2021), was not concerned with patient safety insofar as receiving the correct care, this is a developing issue as sex-specific definitions fall under

scrutiny (e.g. American Medical Association, 2021). Also, recall that the definition of transgender does not require any form of medicalization; it is a subjective identity. Impact sports become unnecessarily hazardous if females play against males (e.g. World Rugby, 2022). Imprisoning females with males is particularly dangerous (e.g. Chandler v CDCR, 2022). Then there are various activities, such as bathing, in which the presence of a naked male is inherently threatening (e.g. Hoyt, 2021; note it is concerning that the wider media did not follow-up on the safety issues in this incident after the suspect's criminal history became known). These are a small sampling of the incidents, injuries, and close-calls that are being experienced by the policies intended to protect transgender people from suicide. For comparison, the USDA (2017) regulation change was based on a measured issue, worker safety for chicken farmers. It is concerning that in comparison to this USDA regulation that was not modified, Gender Identity based regulation changes are occurring across the breadth of the federal government in the absence of an objective measure of harm and to whom (e.g. Title IX, 2022).

Just as measuring the full suicide rate has not been conducted here in the USA, documentation of these safety incidents in health care, sports, prison, and facilities for partial or full-nudity are similarly under sampled. The safety risks to females is significantly greater under these policies, but they also impact all Gender Medicine patients when it comes to health care. My educated guess is that the size of the population put at risk by these changes far exceeds the population at risk without these protections. Also note that due to the complexity of suicide, social contagion and pharmaceutical secondary side effects in particular, there is no data suggesting that these policy changes will have any impact regardless.

Finally, current research on detransitioners, Gender Medicine's patients who regret medicalization, found that they experience negative interactions with the LGBT community (Vandenbussche, 2022). Safety concerns that transgender people raise also apply to those who medicalized yet no longer identify as transgender; however, no policies are being developed to support this growing population.

## **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?

In addition to the information above, more issues are present relative to studying the TQI+ (subjectively identified) population and the LGB (objectively identified) population.

## Jensen (2022) states:

- 1) It is not unusual to make policy changes to address small populations which are at risk (e.g. USDA, 2017); however, these changes are debated in terms of the expected impacts on other people (see the comments on the proposed change). In the absence of data (Jensen, 2022), my educated guess is that
- the number of transgender people who commit suicide is smaller than most populations on which major policy changes are directed. This is important for the upcoming safety discussion.
- 2) Gender Medicine does not change the suicide rate/ratio. In other words, it is not "life-saving". The WPATH (2022) document claims the reverse and then fails to discuss the studies in Table 1 that contradict that assertion.
- 3) Where suicide has patterns relative to the individual, as a social contagion, and as a side effect of certain pharmaceuticals, it is impossible to isolate one versus another with the available research.

Levine et al. (2022) warns practioners,

"Providers of gender-affirmative care should be careful not to unwittingly propagate misinformation regarding suicide to parents and youths. They should also be reminded that any conversations about suicide should be handled with great care, due to its socially contagious nature."

The necessity of this warning suggests to me that practitioners, particularly in promulgating the transition-or-die misinformation, could themselves be socially spreading suicide.

Also, Gender Medicine involves lifetime consumption of off-label use pharmaceuticals (American Medical Association, 2016). Dresser and Frader (2009) warn about the weak evidence base for these sorts of prescriptions,

"More than half the respondents in a survey of academic medical centers reported that innovative off-label prescribing raised concerns in their institutions, such as lack of data, costs, and unfavorable risk-benefit ratios. When substantial uncertainty exists about off-label applications, patients are at risk of receiving harmful or ineffective treatments."

The side effects from Gender Medicine pharmaceuticals is not discussed here, but their off-label status and uncertainty in effectiveness in suicide cannot be dismissed.

- 4) The suicide completion data on these Gender Medicine patients is not being collected here in the USA (Jensen, 2022). Green (2022) makes an estimate on effectiveness by comparing pediatric suicide data against pediatric access to Gender Medicine pharmaceuticals, for example.
- 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.

See response to #1 above.

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?

Any policy change must weigh the safety risks of the change and objectively identify who is harmed/protected and the nature of the harm. If this information is not obtained for whatever reason, then no policy changes should be enacted.

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?

Surveys are only useful to show where research should be conducted. As I mention the statement by Becerra, Xavier in Jensen (2022) terms such as "life-saving" are unsubstantiated and indicate that communications are politically motivated. I have an email from NIH Bioethics showing that ethics concerns on human experimentation are not taken seriously (25 Mar 2022 13:11:13 -0500 Berkman, Benjamin (NIH/NHGRI) [E] <br/>
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| Serkmanbe@mail.nih.gov> wrote). I discuss this issue in more detail here: Jensen, Elizabeth A. (2022b) "Medical Safety: Risk Study of Gender Medicine, Part 1", 4W.pub. https://4w.pub/medical-safety-risk-study-of-gender-medicine-part-1/

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?

See answers above.

# 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?

See answer #3 above in the "Informing Data Collections" section and answer #1 in "Describing Disparities" section.

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.

As I discuss in Jensen (2022), there is no objective measurement of risk. The only risk that is clearly shown is discussed in Jensen (2022b): the LGB and TQI+ communities are being experimented on without any safety controls. Furthermore, "experimentation" is not the correct term to use as results are not being collected scientifically to modify the hypotheses.

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.

Among the references in Jensen (2022) and Jensen (2022b), particularly Levine et al. (2022), the time frame in which the full adverse impact of experimentation on the LGB and TQI+ communities is reached varies from 5 to 30 years or longer. If you watch the following video, it shows that the experimentation is also generational, pregnancy and child development health are included in the adverse results. Isaac Uncooked (2002), "TroonTube #3 - September Medical Studies",

YouTube video. <a href="https://www.youtube.com/watch?v=BiSDqkZRxa8">https://www.youtube.com/watch?v=BiSDqkZRxa8</a>

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?

Assuming a separation of church and state, civil rights should be based on objective measures of harm to an objective measure of who. The LGB and Detransition communities obviously fall under this. There is no objective measure of TQI+. Without it, no civil rights protection, besides those to freely practice one's religion within reason should be accorded.