

Understanding the Invisibility and Misrepresentation of Transgender People in Official Statistics



María Celeste Sánchez Linares

Background and Introduction

Data invisibility refers to the absence or underrepresentation of certain groups or experiences in data collection. Transgender historically individuals exclusion and faced have underrepresentation in data collection efforts (Whittington, C., 2018) which resulted in LGBTQI+ data being "missing in action" from systematic power-integrated forms of governance (Arantes, J. & Vicars, M., 2023). This translates invisibility and marginalization which has led to distorted policy outcomes. Moreover, the lack of understanding regarding the experiences of the LGBTQI+ community and their intersections demographic factors has exacerbated inequalities within society (Mahowald, L., 2021). In this context, we have observed multiple data justice efforts taking form in recent years. In 2021, Canada became the first country to collect and publish data on gender diversity from a national census. (Easton, R., (2022). Similarly, in 2022 Congress passed the LGBTQI+ Data Inclusion Act (US Congress, 2022).

Objective

The goals of this project are to:

- Identify the key challenges and considerations involved in accurately representing transgender individuals within official datasets.
- Assess the extent of current data representation efforts regarding the transgender population, including the driving forces behind these initiatives.
- Analyze the methods and strategies employed in accurately representing transgender individuals within official datasets, focusing on their effectiveness and limitations.
- Highlight the impact of data representation and suggest appropriate data collection practices.

Methods

References

In order to identify the challenges involved in transgender data collection and current data justice efforts, this project was developed based on extensive qualitative research with two components. First, a comprehensive literature review that analyzed scholarly papers and gray literature, such as reports, news articles and public commentaries. Second, for the purpose of illustrating the current state of official data collection on SOGI characteristics, RStudio was used to curate a list of all federally supported surveys and plot bar charts displaying the proportion of surveys collecting in specific information across different SOGI areas.

Results and Discussion

Self-identification limitations: The standard practice of using pre-established categories for survey data collection ignores the fluidity of gender identity and expression, posing a barrier to accurate self-identification. In trying to balance community responsiveness and reducing measurement error there is a need to standardize questions on SOGI in general population surveys. Write-in data responses allows researchers to monitor and analyze the use of terminology over time, informing decisions about adding new response categories in the future (CAP, 2022), helps individuals exercise autonomy.

Privacy concerns and trust-building: We must ensure that visibility in datasets of transgender individuals is not risky or threatening to their physical and emotional integrity. Thus, there is a need for regulations on: data collection, usage, maintenance, and sharing, which adhere to robust standards of privacy, anti-deanonymization, confidentiality, and ethics to reduce the possibility of data exposure and misuse (Gebhart, 2019). Similarly, the development of mechanism that allow people to exercise their right to be forgotten is essential (Correia et al, 2021). In order to mitigate the lack of trust in governmental entities and encourage public response to the data justice efforts, it is important to collaborate with community-based organizations and scholars that have being advocating for SOGI data collection for years. In addition, to avoid backlash and mitigate bias, the collection and use of data in gender minorities should be LGBTQI+ informed and carried out by people who are adequately capacitated (CAP, 2022).

Who is currently leading data justice efforts? Given the lack of official statistics, civil-society, communitybased organizations, and scholars have pioneered and led responsible data collection efforts on gender minorities (Reia, 2022). These initiates have developed extensive research on ethical data collection practices, digital rights, data-informed policy agendas, and the ongoing threats to human rights. Examples include; the ACLU, the CAP, the U.S. Transgender Survey; conducted by the NCTE in partnership with BTAC, TransLatin@ Coalition, and NQAPIA, and the TransPop Study; conducted by researchers across 4 different academic institutions.

Of those who sought coverage

for transition-related surgery in the past year were denied Of those who saw a health care provider

this past year had at least one negative experience related to being transgender Did not see a doctor when they

needed to because of fear of being mistreated as a transgender person

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

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Why is data visibility important?

To Advance research agendas

Identify community-based needs

Track and address discrimination

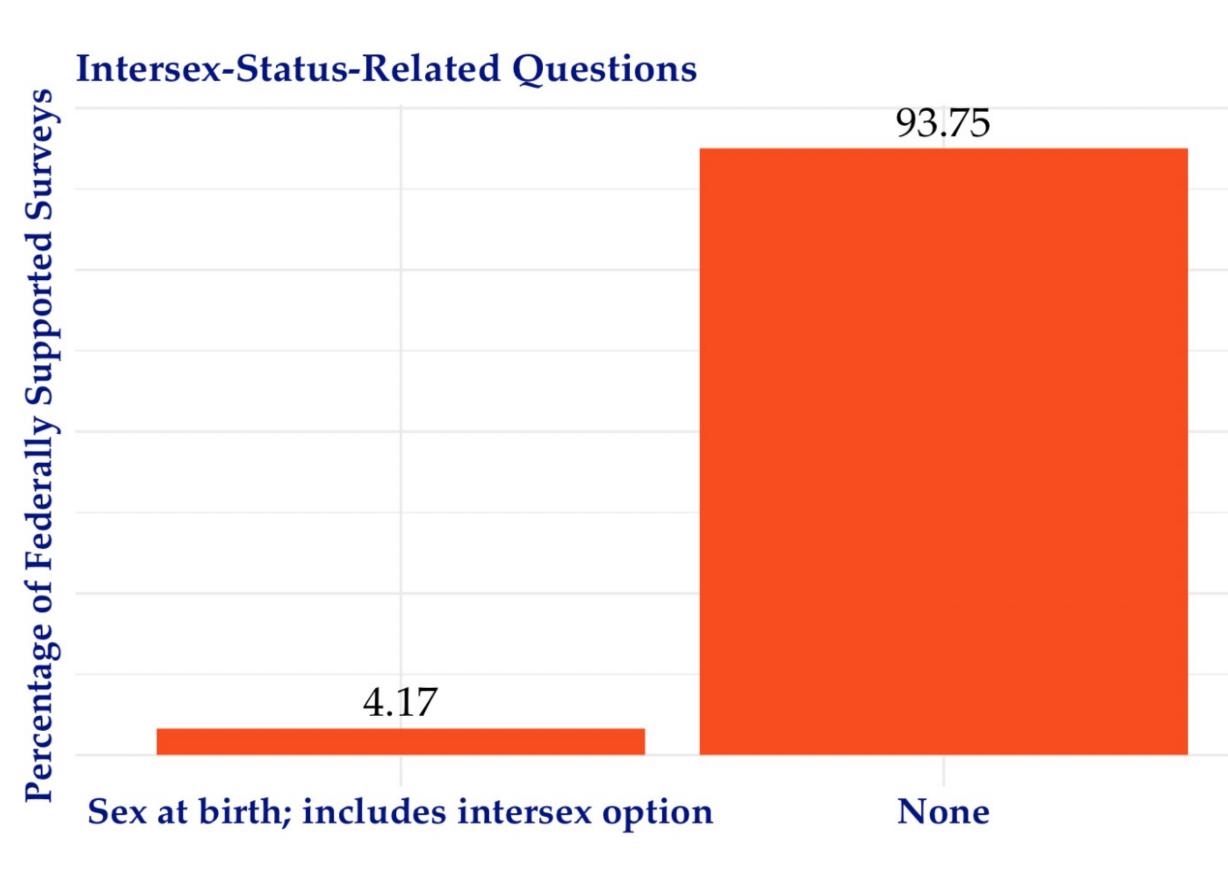
Shape evidence-based policy solutions

Equitably distribute funding and other resources

Evaluate population trends

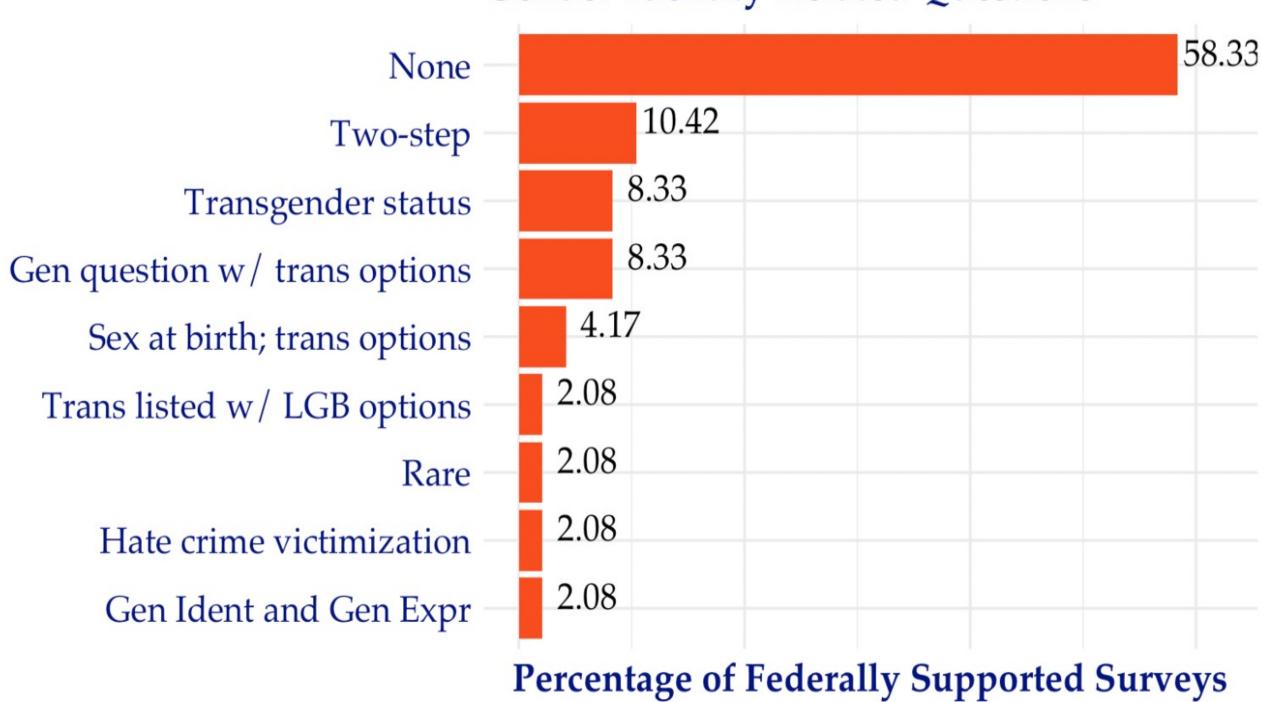
Provide high-quality services

Current State of Data Collection



National Academies of Sciences, Engineering, and Medicine. 2020. Understanding the Well-Being of LGBTQI+ Populations. Washington, DC: The National Academies Press

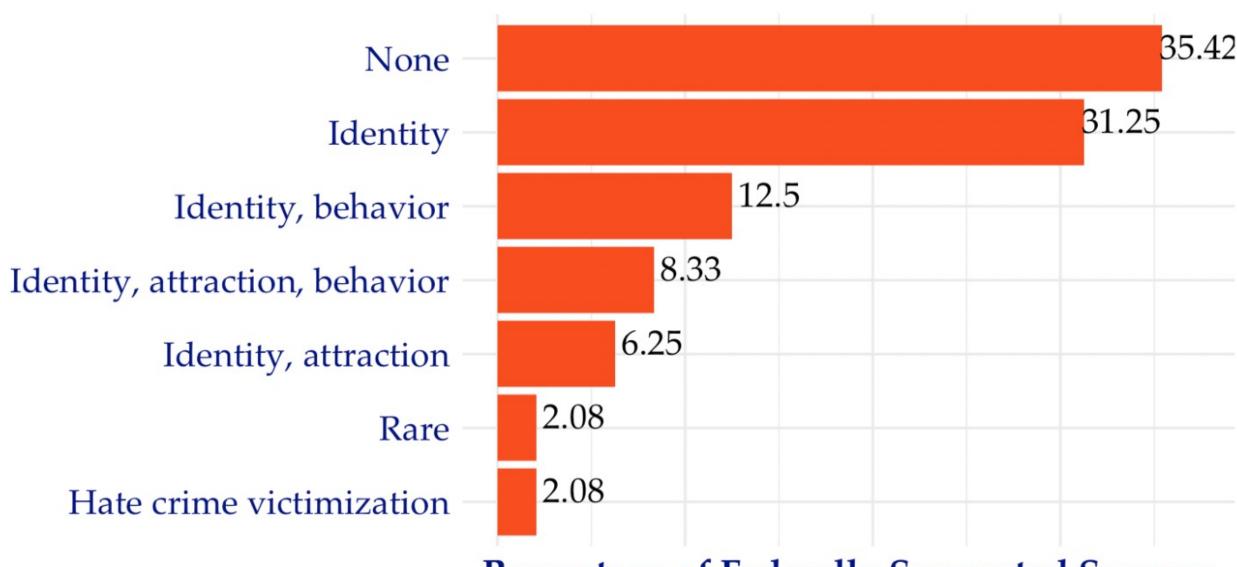
Gender-Identity-Related Questions



National Academies of Sciences, Engineering, and Medicine. 2020. *Understanding the Well-Being of LGBTQI+ Populations.* Washington, DC: The National Academies Press

Next steps include incorporating the findings from this study into the report being developed for the Center for Global Health Equity at the University of Virginia. Additionally, accessing and exploring wider data sources is key to expanding the findings of this study, hoping that it will contribute global conversation about SOGI data collection and responsible data science.

Sexual-Orientation-Related Questions



Percentage of Federally Supported Surveys

National Academies of Sciences, Engineering, and Medicine. 2020 Understanding the Well-Being of LGBTQI+ Populations. Washington, DC: The National Academies Press

Future Steps

Whittington, C, (2018) Invisible in data: The lack of LGBTQ data collection. Georgetown Policy Review. Mahowald, L. (2021). Hispanic LGBTQ Individuals Encounter Heightened Discrimination, Williams Institute.

Easton, R. (2022). 'Historic' census data sheds light on number of trans and non-binary people for first time. CBC News. Congress.gov. (2022). H.R.4176 - LGBTQI+ Data Inclusion Act.

National Academies of Sciences, Engineering, and Medicine. 2020. Understanding the Well-Being of LGBTQI+ Populations. Washington, DC: The National Academies Press. Medina, C. & Mahowald, L. (2022). Collecting Data About LGBTQI+ and Other Sexual and Gender Diverse Communities, Center for American Progress.

Luis A. Vasquez (2022). Recommendations for Inclusion of Sexual Orientation and Gender Identity (SOGI) Measures in the American Community Survey (ACS) and Puerto Rico Community Survey (PRCS), Williams Institute.

& Nunes, R. (2021). Gender Transition: Is There a Right to Be Forgotten?. Health Care Analysis, 29, 283–300. Correia, M., Rêgo, G. Reia, J. (2022) Responding to the Federal Evidence Agenda on LGBTQI+ Equity Request for Information. School of Data Science, University of Virginia.

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.

Arantes, J. A. & Vicars, M. (2023) Missing in action: queer(y)ing the educational implications of data justice in an age of automation, Learning, Media and Technology, 48:2, 213-225