WE COUNT! The Importance of and Barriers to SOGI Data Collection

Trey Jenkins & Jason Vail Cruz
Let’s Get Better Together June 08, 2018
Part I: Background
THE LGBTQ+ COMMUNITY: IDENTITIES FACING OPPRESSION
THE HISTORY
Sexual Orientation is a term used to describe our patterns of emotional, romantic, and sexual attraction—and our sense of personal and social identity based on those attractions. A person's sexual orientation is not a black or white matter; sexual orientation exists along a continuum, with exclusive attraction to the opposite sex on one end of the continuum and exclusive attraction to the same sex on the other.

--Psychology Today
There are binary sexual orientations within the GSM community which include:

- Lesbian
- Gay
- Bisexual
- Straight/heterosexual

There are also non-binary sexual orientations in the GSM community including:

- Pansexual
- Queer
- Asexual
- Demisexual
THE TRANSGENDER COMMUNITY
Venn Diagram

- Gender Identity
- Sexual Orientation
- Biological Sex
FOR EXAMPLE…

• An individual who was **ASSIGNED** male at birth (Biological Sex) currently **IDENTIFIES** as a transgender woman (Gender Identity). Additionally, this woman is **ATTRACTED** to men and identifies as a straight woman (sexual orientation).
THE FIRST MISCONCEPTION: WHAT DETERMINES GENDER?
When children are born, a doctor diagnoses the gender of the child. The child is obviously too young to give input on this and as a result may be misdiagnosed. The medical profession largely uses social constructs about the body to make this diagnosis. The reaction by the child later in life determines how they are identified by themselves or others in the dominant society. If the diagnosis of gender is inaccurate, the person may describe themselves or be described as Transgender. This is someone who identifies as a gender other than what they were assigned at birth. For those whose gender diagnosis is accurate at birth, they are described as Cisgender. Most are unaware of this term as it is erroneously thought to be the norm.
COMING OUT AS TRANSGENDER

Many Paths!
WHAT DOES IT MEAN “TO TRANSITION”? 

Transitioning is the personal process of affirming one’s gender and identity.
TRANSGENDER COMMUNITY
<table>
<thead>
<tr>
<th>Non-Binary Genders</th>
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<tbody>
<tr>
<td>Genderqueer</td>
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<tr>
<td>Agender</td>
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<td>Bigender</td>
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<td>Ambigender</td>
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<td>Amaregender</td>
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<td>Androgyne</td>
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<td>Demigender</td>
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<tr>
<th>Non-Binary Genders</th>
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<tr>
<td>Neutrois</td>
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<td>Pangender</td>
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<td>Gender Fluid</td>
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<td>Gender creative</td>
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<td>Gender Variant</td>
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<tr>
<td>Two-spirit</td>
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<td>Polygender</td>
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TWO-SPRIT
# Gender Pronouns

Please note that these are not the only pronouns. There are an infinite number of pronouns as new ones emerge in our language. Always ask someone for their pronouns.

<table>
<thead>
<tr>
<th>Subjective</th>
<th>Objective</th>
<th>Possessive</th>
<th>Reflexive</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>She</td>
<td>Her</td>
<td>Hers</td>
<td>Herself</td>
<td>She is speaking. I listened to her. The backpack is hers.</td>
</tr>
<tr>
<td>He</td>
<td>Him</td>
<td>His</td>
<td>Himself</td>
<td>He is speaking. I listened to him. The backpack is his.</td>
</tr>
<tr>
<td>They</td>
<td>Them</td>
<td>Theirs</td>
<td>Themself</td>
<td>They are speaking. I listened to them. The backpack is theirs.</td>
</tr>
<tr>
<td>Ze</td>
<td>Hir/Zir</td>
<td>Hirs/Zirs</td>
<td>Hirself/Zirself</td>
<td>Ze is speaking. I listened to hir. The backpack is zirs.</td>
</tr>
</tbody>
</table>

Trans Student Educational Resources

design by Landyn Pan

For more information, go to transstudent.org/graphics
IMPORTANT POINTS FOR TRANSGENDER PEOPLE

Not all Transgender individuals follow the same path in fully embracing their identity:

- If people say that they are transgender we should believe them
- No one has to conform to any specific standard of beauty or look to deserve respect
Transgender individuals often face complex trauma throughout their lives and this may enhance the intensity of their reaction to sexual assault and associated service providers. The National Task Force to End Sexual and Domestic Violence Against Women has taken a firm stance against the commonly reported fears of transgender people perpetrating sexual violence against strangers. It is important that we all challenge this misconception, especially when it is being placed on a survivor seeking shelter or other services.
APPROPRIATE LANGUAGE & MIRRORING
Respect
INTERSECTIONALITY
PRIVILEGE

Advantages, rewards, and/or benefits given to those in the dominant group without members of the dominant group asking for them
Dominant groups are groups of people in power. They are often considered the default group or "normal."
Disparities

“A health outcome that is seen to a greater or lesser extent between populations. Can include race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location.”

~Healthy People 2020

Source: https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities
For LGBTQ+ Folks…
THE DIFFERENCE IS VULNERABILITY
Part II: Key Surveys
U.S. Decennial Census

Source: https://www.census.gov/about/what/census-at-a-glance.html
“Powerful tool for targeting and building health promotion activities”

~ CDC
Sexual orientation and gender identity data collection on the 2015 BRFSS

No SOGi data collection
Used the SOGi module to collect SOGi data
Did not use the module to collect SOGi data
Used the SOGi module in 2014 but discontinued it in 2015

Note: Micronesia and Samoa do not currently field BRFSS. Palau did not respond to inquiries and is excluded from this analysis.

ACL: CENTERS FOR INDEPENDENT LIVING PROGRAM PERFORMANCE REPORT

The Centers for Independent Living Program Report is an annual program evaluation to assess the
“effectiveness of and equity of programs designed to serve people with disabilities”

Source: https://www.acl.gov/programs
According to a spokeswoman for ACL, in March 2017 SOGI questions were removed from the NSOAAP survey and the Performance Report due to “insufficient sample size.”

ACL: National Survey of Older Americans Act Participants (NSOAAP)

- National survey of programs on aging funded by Title III of the Older Americans Act (OAA).

- Objective of the survey is to provide program evaluation on the effectiveness of the Title III programs.

- Title III helps state and local agencies develop in-home and community based long-term services like congregate and home-delivered meals, transportation, and case management for adults age 60 and older.

<table>
<thead>
<tr>
<th>Table 1: SOGI related questions from National Population Surveys¹</th>
<th>Sexual Identity</th>
<th>Sexual Attraction</th>
<th>Sexual Behavior</th>
<th>Gender Identity</th>
<th>Household Relationships</th>
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<tr>
<td>National Survey of Older Americans Act Participants (NSOAAP) ACL</td>
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<td>ACL Annual Program Performance Report</td>
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<td>National Health and Nutrition Examination Survey (NHANES) CDC</td>
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<td>Youth Risk Behavior Surveillance System (YRBSS) CDC</td>
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<td>National Inmate Survey (NIS) BJS</td>
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</tbody>
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² also asks SOGI to determine if event was a hate crime.
³ does not explicitly include same-sex couples
⁴ binary sex only
Part III: In the News!
CDC gets list of forbidden words: Fetus, transgender, diversity - The ...  
https://www.washingtonpost.com/.../f503837a-e1cf-11e7-89e8-ede1c1...  
Dec 15, 2017  
... and evidence data in program evaluations and budget decisions.* ... HHS has also removed information ...

Trump Administration Removes LGBTQ From 2020 Census - YouTube  
https://www.youtube.com/watch?v=OyQLpkn3WA  
Mar 30, 2017 - Uploaded by BLACKNESS.TV | TWIBnation  
U.S. Census Bureau removes 'LGBT' question from 2020 census ... Trump Erases Job Protections for LGBT ...

Trump administration rolls back protections for transgender students ...  
https://www.washingtonpost.com/.../550a83b4-f913-11e6-bf01-d4...  
Feb 22, 2017  
“The president’s made it clear throughout the campaign that he’s a firm believer ... speak out as election ...

Trump administration will stop collecting data on LGBTQ health issues  
LGBTQ Nation - May 19, 2018  
“The BRFSS is one of the few federally-supported data collection activities that make the needs of LGBT people known to governmental ...
Will let respondents indicate their relationship to members living in their household (e.g. same-sex husband/wife/spouse)

“By capturing distinct data only on same-sex couples living together...the 2020 census will tell us nothing about the entire LGBT population, including LGBT people who are single or bisexuals in different-sex relationships. Nor will it capture specific data on transgender youth and adults” ~Associated Press

Trump administration will stop collecting data on LGBTQ health issues / LGBTQ Nation

BRFSS will stop collecting SOGI data beginning in 2019.

Arizona added the module this year (2018).

Source: https://www.fitkonek.com/trump-administration-will-stop-collecting-data-on-lgbtq-health-issues-lgbtq-nation/
The Good News!

Hey there, and welcome to Arizona’s Statewide LGBTQ+ Health Survey!

The goal of this survey is to learn about the health needs of Arizona’s LGBTQ+ population so that the state can plan and implement initiatives to help members of our LGBTQ+ community lead healthy lives.

The survey should take you about 15-20 minutes to complete. All of your responses will be kept anonymous. No personal information will be shared. For more information, check out the privacy policy here.

Your participation is voluntary. If you’d like, you can skip any question. But, to get an accurate picture of the state of LGBTQ+ health in Arizona, it’s helpful if you answer each question.

You will receive a $15 Target gift card for completing the survey as a way to thank you for participating. Every voice counts in documenting and better understanding the lives,
Why is this important?

- Understand the need
- Erasure
- Bad polices create vulnerability and increases costs.

Part IV: Policies & Action
Policies that hurt

- Lack of Workplace/Housing discrimination protections
- CMS guidance on work and community engagement for Medicaid beneficiaries

“Workplace discrimination data should be collected through the inclusion of sexual orientation and gender identity questions in population-based surveys of the workforce such as the Census, American Community Survey, and surveys fielded by the Bureau of Labor Statistics and other agencies.” ~U.S. Commission on Civil Rights

Source: https://williamsinstitute.law.ucla.edu/research/lgbt-adults-medicaid-insurance/
THE COMMUNITY CAN HELP!

WE WANT YOU!
Check to see if your assessment tools include culturally competent data collection for LGBTQ+ individuals. If not, inquire how you can help change that.

Source: http://healthinnovators.info/the-case-for-sogi-data/
WHERE DO WE START?

- Access to care
- Quality care
- Research and recommendations
WHERE DO WE START?

- Learn
- Understand LGBT concerns with the system
FIGURE 2-1 New opportunities for gathering LGBT data during the process of care.
NOTE: EHR = electronic health record.
SOURCE: Makadon presentation.
FEDERAL GUIDANCE

• Currently there is no federal guidance on how to collect the data.

• CMS is working with the Office of the National Coordinator for Health Information Technology to define and standardize the questions.
  – Issue: Meaningful Use
GUIDANCE

• The issues collecting the data are not technical,
• Agencies can collect the data using EHRs.
• Local agencies can provide guidance and ongoing Technical assistance.
• Do your research:
  – Article of interest: Collecting Sexual Orientation and Gender Identity in Electronic Health Records
RECEIVE TECHNICAL SUPPORT ONGOING

- Having an advisory board or other group to help with supporting a welcoming environment can be very useful
  - Advisory groups are low cost and should be made up from community members
  - These groups bring honesty and positive growth in the desire to be more welcoming

Other TA support can be obtained from local LGBTQ organizations.
References


References


Additional Articles and Resources


Questions?

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Jason@acesdv.org