

Integrating Health Equity into Serious Illness Care Research for the LGBTQ Community

Carey Candrian, PhD (she/her)

Roundtable on Quality Care for People with Serious Illness

Washington, D.C.

November 2-3, 2023



Division of General Internal Medicine
SCHOOL OF MEDICINE
UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**

(Nothing to disclose.)



Division of General Internal Medicine
SCHOOL OF MEDICINE
UNIVERSITY OF COLORADO **ANSCHUTZ MEDICAL CAMPUS**



Health disadvantages

- Financial
- Social Support
- Stigma and discrimination

Stigma: effects on health

-12 years

Source: *Harvard Medical Magazine*, 2020

Stigma: The health burden

- Anxiety, depression
- Substance abuse
- Cardiovascular disease
- Cancer burden (lung, breast)
- Suicide

Sources: National LGBT Cancer Network & Healthy People 2020

Do not come out to medical provider:

48%

Source: AARP, 2018

Discrimination in healthcare

- **56%** report experiencing discrimination.
- **70%** of trans or gender diverse experience discrimination.

Source: American Heart Association, 2021



Breaking the script

- Who's the biggest support in your life?
- Do you live with anyone?
- Who needs to be in the room when we talk about your care?
- Who's going to need support, so they can support you?
- Who are your people?

Data: Sexual Orientation and Gender Identity (SOGI)

For Gender Identity:

- **What sex were you assigned at birth?**
- **What is your current gender?**
- Response categories:
 - Male
 - Female
 - Transgender
 - Nonbinary
 - This person uses a different term (w/ space to write in a response)

Source: Federal Register/ Vol. 99, No. 180 September 19, 2023

These questions are in alignment with current recommendations from NASEM and OMB

For Sexual Orientation:

- **Which of the following BEST represents how you think of yourself?**
- Response categories:
 - Gay or lesbian
 - Straight – that is, NOT gay or lesbian
 - Bisexual
 - This person uses a different term (w/ space to write in a response)

Source: Federal Register/ Vol. 99, No. 180 September 19, 2023

These questions are in alignment with current recommendations from NASEM and OMB

Summary of Research Recommendations

- **Break the script: “Are you married?”**
 - Who’s the biggest support in your life?
 - Do you live with anyone?
- **Break the script: “Family meeting”**
 - Who needs to be in the room when we talk about your care?
 - Who’s gonna need support, so they can support YOU?
 - Who are your people?
- **Consistently ask questions about Sexual Orientation & Gender Identity (SOGI) & include SOGI data in research.**





















