

Leading Causes of Death and Disability in Sexual and Gender Minority Populations: Cancer

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March 1, 2023

Hello
my name is

Mandi

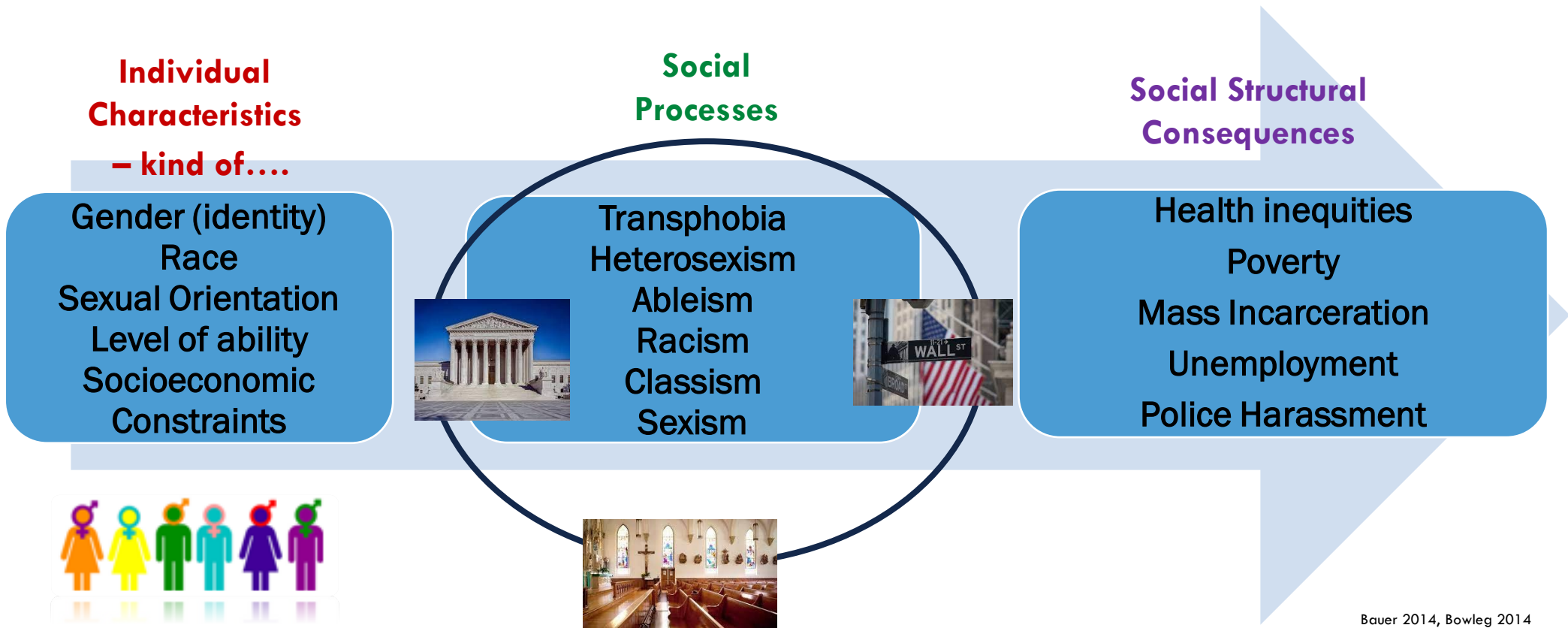
my pronouns are

She, Her

Objectives

- Describe a framework for understanding cancer health disparities for sexual and gender minority (SGM) populations
- Identify what is needed to address cancer disparities
- Access resources to advance health equity

What Causes Cancer Health Disparities?



Bauer 2014, Bowleg 2014

What Causes Cancer Health Disparities?



Social Processes

Transphobia
Heterosexism
Ableism
Racism
Classism
Sexism



Social Structural Consequences

Health inequities



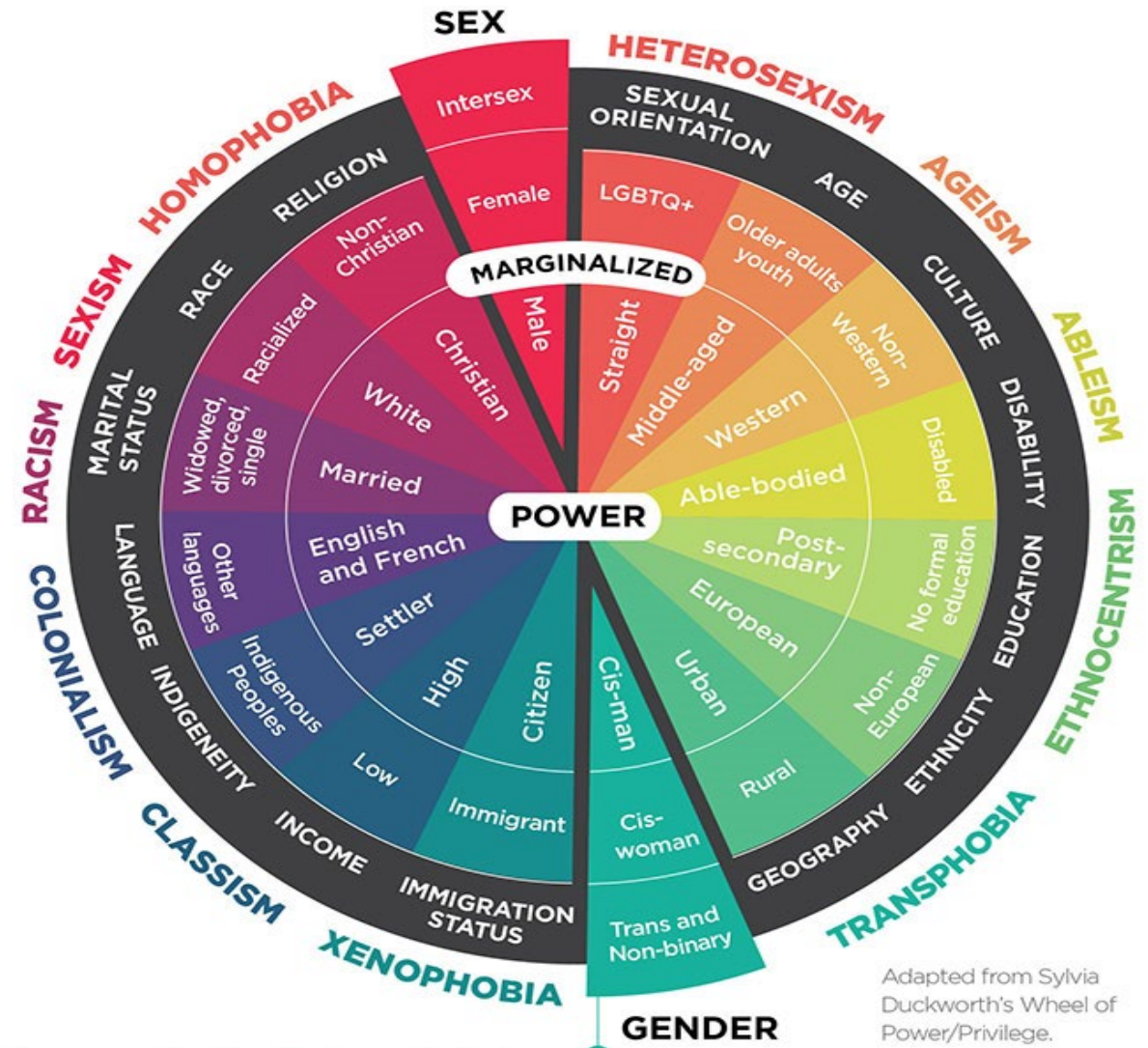
Intersectionality

We all experience power and disempowerment in different parts of our lives

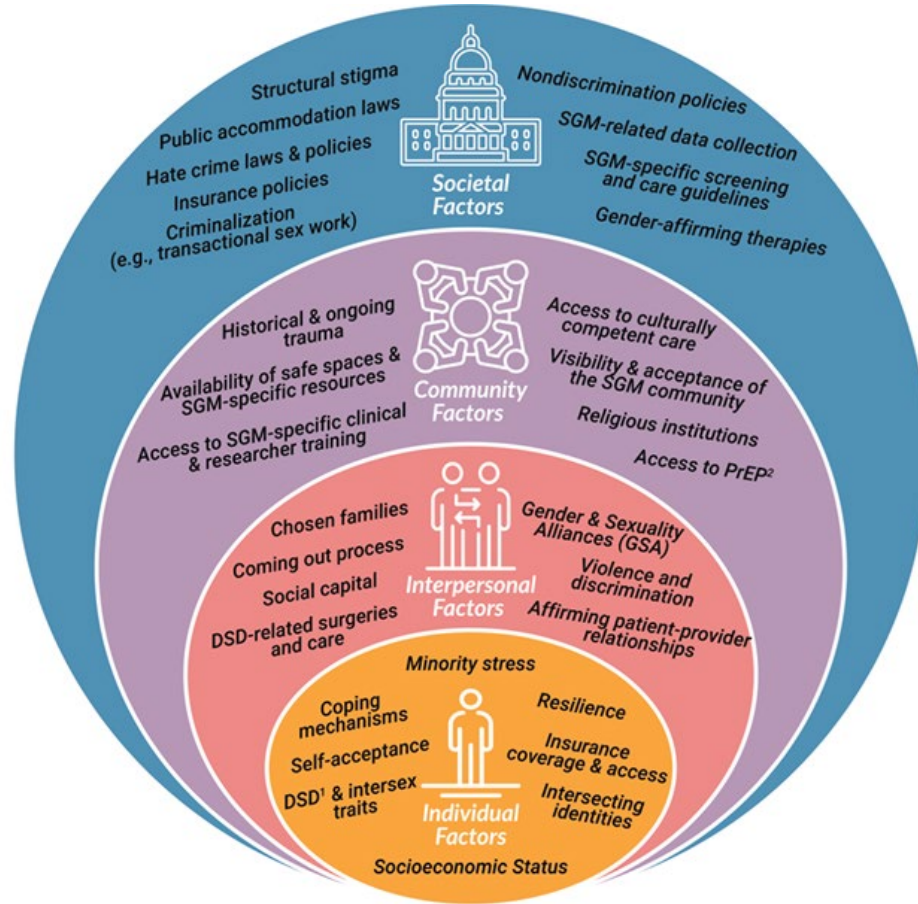
In what ways do you have power?

In what ways do you feel vulnerable to others?

How does your positionality affect your health?

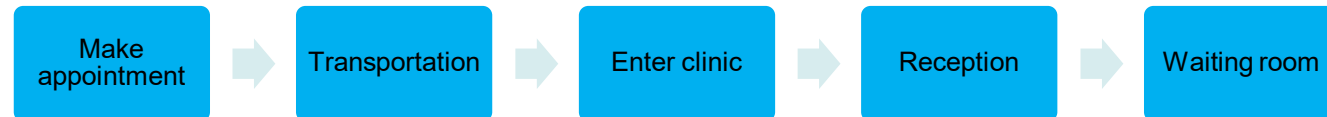


A Closer Look at SGM Stress and Trauma



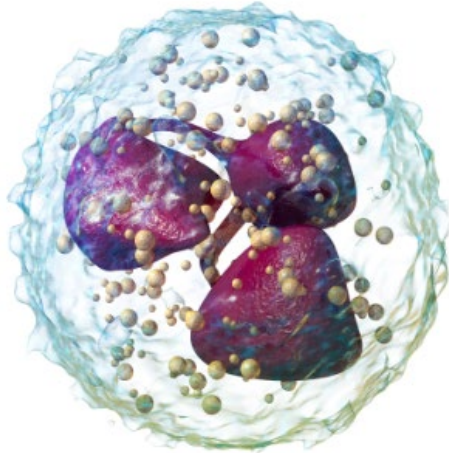
Common Assumptions

- Heterosexuality
- All patients use traditional labels
- Sexual orientation is based on appearance/behavior
- Sexual orientation is based on behavior
- Sexual behavior based on orientation
- Identity, attraction, and behavior don't change
- Gender identity = sexual orientation
- Gender identity is based on natal sex
- Gender identity depends on how far along a patient is in transitioning



NIH SGMRO, 2021

Stress is a Laboratory for Disease

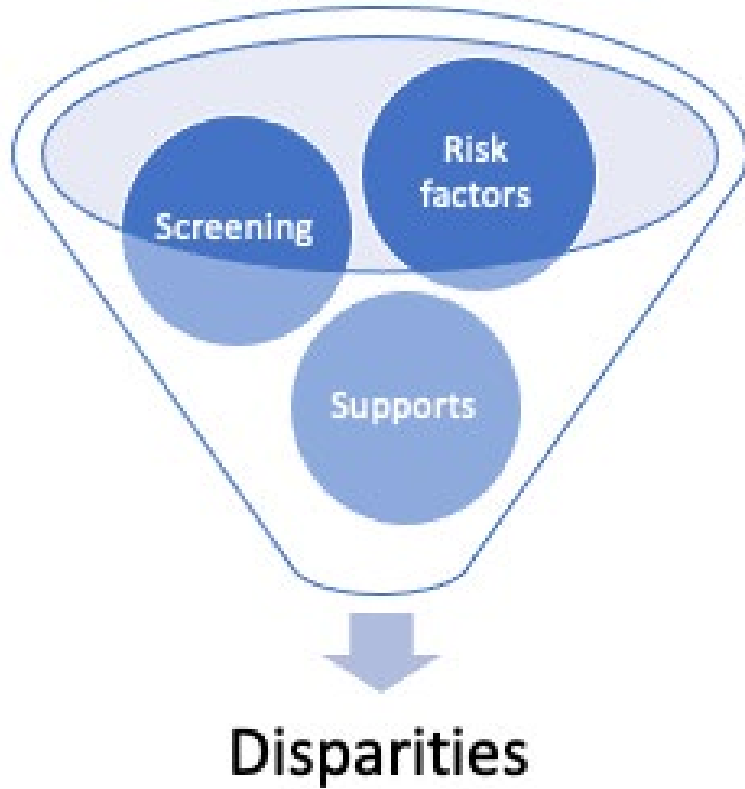


Stress hormones can alter the behavior of some neutrophils, potentially causing dormant cancer cells to reawaken, a study suggests.

Credit: Medical Gallery of Blausen 2014. WikiJournal of Medicine. doi:10.15347/wjm/2014.010. CC BY-SA 4.0



More concretely



truth initiative
HELPING LIVES
FREE FROM TOBACCO,
TAFFER & NICOTINE

LGBT

The **LGBT** community is disproportionately impacted by tobacco.

LGB FEMALE YOUTH
(Aged 14-17 years)

3x more than 3x as likely to use cigarettes and cigars as straight females in the past month.

2x more than 2x as likely to use e-cigarettes as straight females in the past month.

2x **LGBT ADULTS**
nearly 2x as likely to use e-cigarettes and little cigars.

20.5% LGB adults
34.9% transgender adults
15.3% straight adults

who smokes cigarettes?

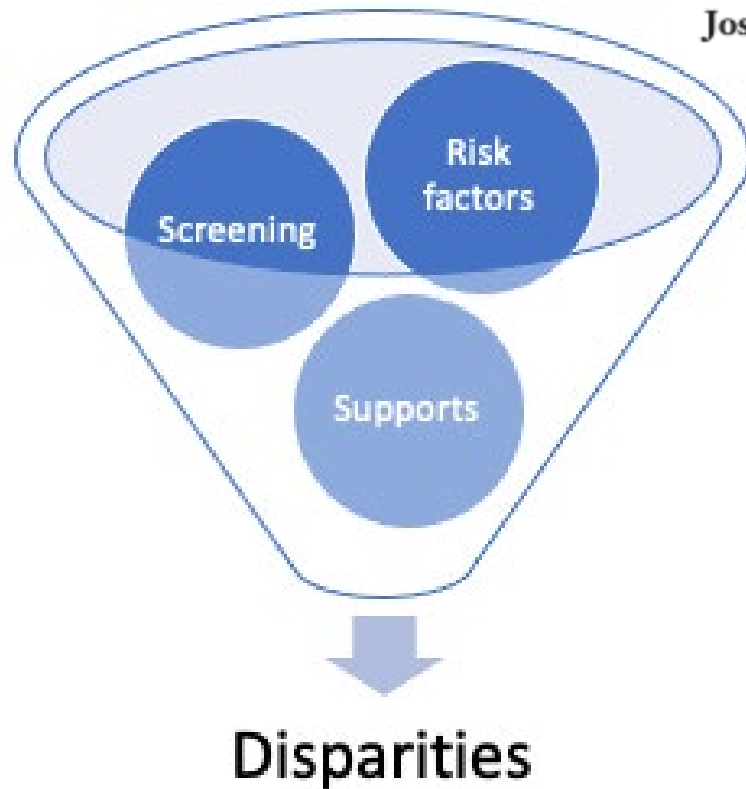
Project SCUM
One tobacco manufacturer's marketing strategy called Project SCUM targeted gay men and homeless individuals.

SCUM
"Sub-Culture Urban Marketing"

More concrete!

Cancer screening in the transgender population: a review of current guidelines, best practices, and a proposed care model

Joshua Sterling¹, Maurice M. Garcia^{2,3,4}



screening approaches for transgender patients. We performed a systematic search of PubMed, Google Scholar and Medline, using all iterations of the follow search terms: transgender, gender non-conforming, gender non-binary, cancer screening, breast cancer, ovarian cancer, uterine cancer, cervical cancer, prostate cancer, colorectal cancer, anal cancer, and all acceptable abbreviations. Given the limited amount of existing literature inclusion was broad. After eliminating duplicates and abstract, all queries yielded 85 unique publications. There are currently very few transgender specific cancer screening recommendations. All the guidelines discussed in this manuscript were designed for cis-gender patients and applied to the transgender community based on small case series. Currently, there is not sufficient to evidence to determine the long-term effects of gender-affirming hormone therapy on an individual's cancer risk. Established guidelines for cisgender individuals and can reasonably followed for transgender patients based on what organs remain *in situ*. In the future comprehensive cancer screening and prevention initiatives centered on relevant anatomy and high-risk behaviors specific for transgender men and women are needed.

Keywords: Cancer screening; trans male; trans female; transgender health; gender affirming hormone therapy

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More concrete!

Cancer screening in the transgender population: a review of current guidelines, best practices, and a proposed care model

Health outcomes of sexual and gender minorities after cancer: a systematic review

Mandi L. Pratt-Chapman^{1,2*}, Ash B. Alpert³ and Daniel A. Castillo⁴



g¹, Maurice M. Garcia^{2,3,4}

Abstract

Purpose: Cancer research on sexual and gender minority (SGM) populations is gaining momentum. The purpose of this systematic review was to examine what is currently known in the research literature regarding patient-reported health outcomes after cancer treatment among SGM populations.

Methods: In March 2021, a medical librarian conducted a systematic keyword search on PubMed, Embase, Scopus, Web of Science, PsycINFO, [ClinicalTrials.gov](https://www.clinicaltrials.gov/), and the Cochrane Central Register of Controlled Trials. The primary inclusion criterion was assessment of at least one physical, psychosocial, emotional, or functional patient-reported health outcome related to the impacts of cancer diagnosis and/or treatment. Articles that met inclusion criteria were reviewed in their entirety, charted in a Word Table, and assessed for quality. Quality considerations included study design, sampling approach, diversity of sample, measures used, and analytic procedures. Studies were synthesized based on type of cancer study participants experienced.

Results: Sixty-four studies were included in the final analysis: most were quantitative, secondary analyses or cross-sectional studies with convenience samples, and focused on people with a history of breast or prostate cancer. Differences between sexual minority men and women in terms of coping and resilience were noted. Few studies reported on experiences of transgender persons and none reported on experiences of intersex persons.

Conclusions: A growing literature describes the patient-reported health outcomes of SGM people with a history of cancer. This study summarizes important between-group differences among SGM and heterosexual, cisgender counterparts that are critical for clinicians to consider when providing care.

Implications for cancer survivors: Sexual orientation and gender identity are relevant to cancer survivors' health outcomes. Subgroups of SGM people have differential experiences and outcomes related to cancer and its impacts.

Keywords: Sexual and gender minorities, LGBTQI, Sexual orientation, Gender identity, Cancer survivorship, Patient-reported outcomes, QOL

"Surviving Discrimination by Pulling Together": LGBTQI Cancer Patient and Carer Experiences of Minority Stress and Social Support

Rosalie Power[†], Jane M. Ussher^{*†}, Janette Perz, Kimberley Allison and Alexandra J. Hawkey on

behalf of The Out with Cancer Study Team

Things we can probably agree on...

We need evidence to guide clinical care

Patients should be able to access the right care at the right time by the right provider

Clinicians and researchers need preparation to ensure patients have access to evidence-based care at the right place and time

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**Cancer Care is NOT
Equal & Outcomes
are not Equitable**

What is needed for evidence-based care?



| | |
|---------------------------------------|---|
| SOGI Data Collection and Use | <ul style="list-style-type: none">• Will to ask/ Belief in importance of SOGI• How to ask• Where to store• How to use |
| Cultural and Clinical Training | <ul style="list-style-type: none">• Communication• Clinical content• Mechanisms for training |
| Affirming care contexts | <ul style="list-style-type: none">• Intake forms, patient portals, notes• Posters, brochures, education• Billing specialist knowledge |

#1 We don't ask about SOGI

Annals of LGBTQ Public and Population Health, Volume 3, Number 1, 2022

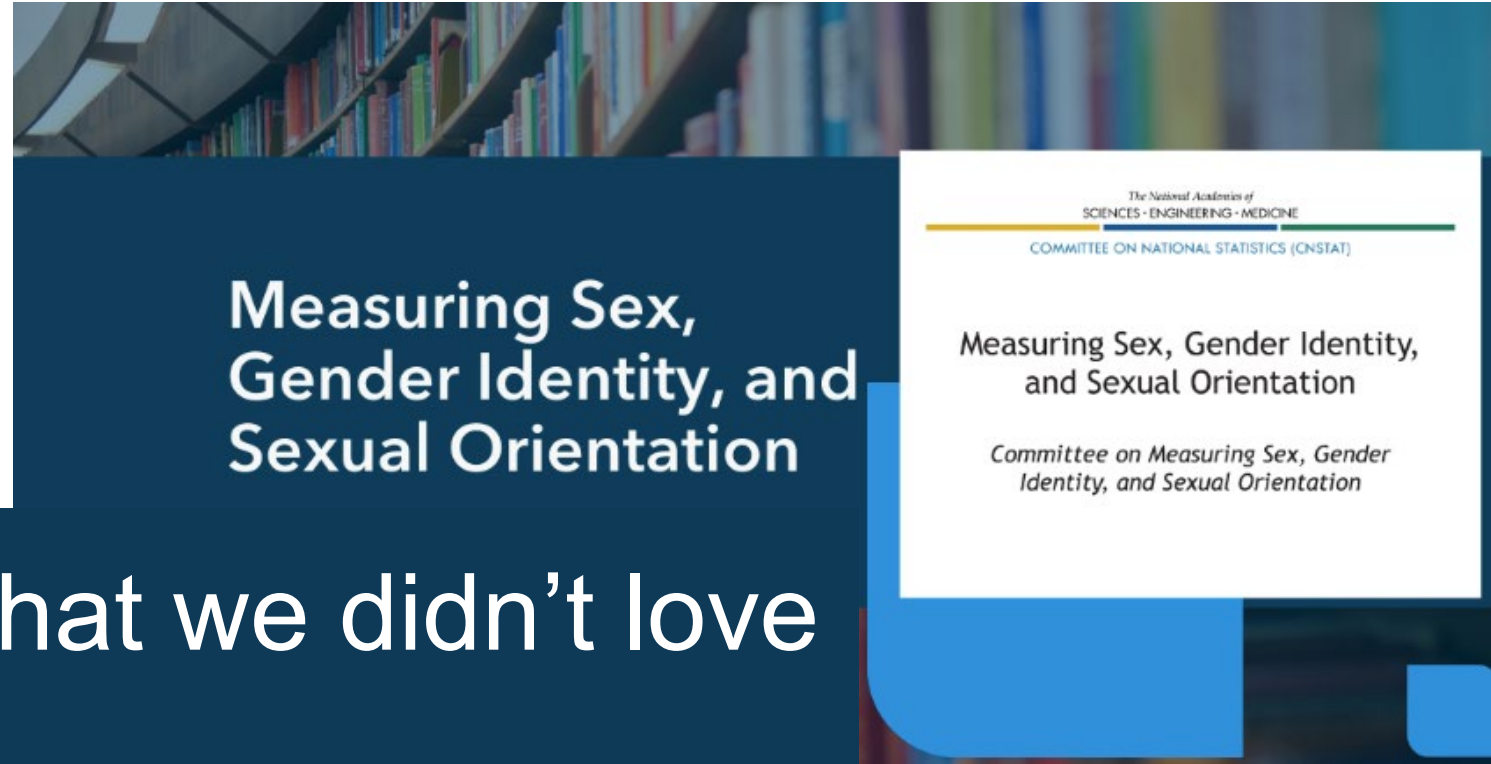
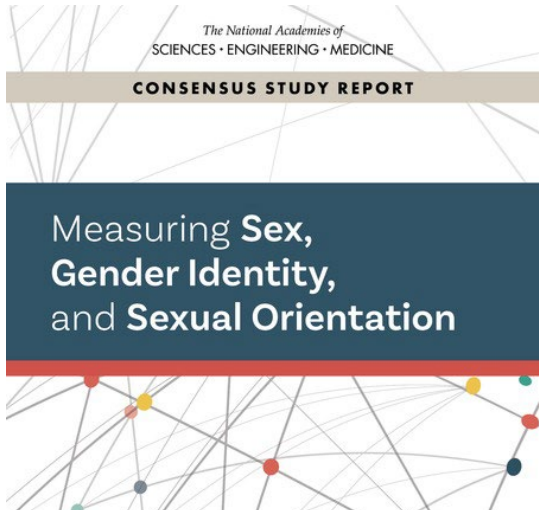
All Research Is LGBTQI Research: Recommendations for Improving Cancer Care Through Research Relevant to Sexual and Gender Minority Populations

*Mandi L. Pratt-Chapman^a, Jennifer Potter^{b,c,d}, Kristen Eckstrand^e, Matthew
B. Schabath^f, Gwendolyn P. Quinn^g, Don S. Dizon^h and Asa Radixⁱ*

Challenges to SOGI data collection

- Lack of standardized measures
- Lack of understanding of relevance to care and research
- Institutional inertia
- Lack of NIH requirements
- Gendered inclusion/ exclusion criteria
- Lack of clinician and staff training

#2 We don't know HOW to ask about SOGI



Recent Advice ...that we didn't love

NCI SOGI Data Standards Committee

1. Review of prior studies

2. Constructs to measure

- Sexual orientation
- Sex assigned at birth
- Gender/ gender identity
- Organ inventory
- Hormone status
- Intersex status

Current Status

- Approach: Two stage method of cognitive interviewing
- Online interviewing (mostly?)
- Refining sample composition and recruitment approach
- Resources: NCI fellows, national SMEs

#3 We don't know have a reliable way to document SOGI data in clinical care contexts

“It's not just the one program that is the master program for gender variables. **You have to do it on the program where they type your name when you come to hospital...that then has to talk to the program with the results. And my program. I am a radiologist and with the radiology reports and now they all need to have the same coding, so you can have male, female and non-binary, like this, that has to all be the same, so it'll come up as the same variable.** That's being changed at a department, a health department level, mainly because of one person in another health service who is non-binary and really really pushing, advocating for everybody. And so, they've been negotiating that that computer-based change and [name] as well as have all published LGBT inclusion strategies... So, state-based strategies, for like **5-year strategies** you know, we want to have a goal, like you know, I don't know, have a **better data collecting system** and so that's been driving that in [name] so something is changing and coming. But it's again something that it's hard to get it right. **It's never going to be right the first time and the first attempt trying, you know, gets destroyed or really made hard because it can't be perfect,** and people want to try and be as good as possible.” -Radiologist

Pratt-Chapman et al. 2023

#4 SGM Patients face challenges at each step of the healthcare delivery system

“ You know, with the way that the hospital administration - it starts off wrong, probably with the registration. When the patient come into register within the center, they have only two boxes: male or female...” -Radiation Oncologist

Scheduling & Registration



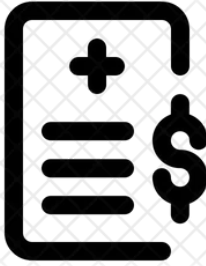
Environment



Consultation



Billing & Insurance



Supportive care



“ I don't even know the right term.”
-Radiation Oncologist



I think it's really difficult from the radiology point of view, because we gender things so much that, like in the breast clinic, it's all pink it has the word woman everywhere it's all very pink when we have men with breast cancer or anyone that doesn't identify as a woman, they have to come through this gauntlet of pink stuff. The word woman everywhere, sit in the waiting room with all these women. And that might be really uncomfortable for them. I'd like us to be able to have a separate part to the waiting room on another entrance, that they could use that's not that woman-centered bit because we need the pink woman-centered bit for 99% of our clients."

-Radiologist

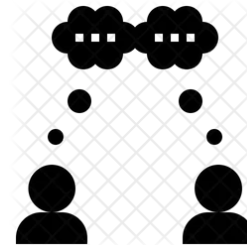
Supportive care



Billing



Consultation



Environment



Scheduling & Registration



“ I feel mildly uncomfortable because I’m not trans myself. It’s...paradoxical, because I’m a minority sexuality...I am...very out at work. I feel that the expectation would be that I’d be all over how to care appropriately for a trans person, use trans appropriate language.... And I know that I don’t, because it is different for everybody. I ... feel quite a bit of discomfort and apprehension, ‘cause ...I don't want to f*%! it up and do it wrong.” -Radiation Oncologist

“ I would say I did not know how to behave.”
-Radiation Oncologist

Scheduling & Registration



Environment



Consultation



Billing



Cultural Humility & Communication Training

Supportive care



“ If we're talking about anywhere on the pelvis, you know the anus, the vagina, obviously the penis and the penile base, there are a lot of long-term chronic changes that can happen after radiation: the ability to have long-term natural lubrication can be severely changed after radiation, and things like micro fissures of the mucosal surfaces with, for example, sexual activity can be much worse after radiation due to the friability of the tissues. It can really affect long term sexual function .”

-Radiation Oncologist

“ I guess in in those case we would advocate the use often of hyperbaric oxygen just to make sure that if there is any potential injury to the bowel or to the anastomosis of whatever they do afterwards, it would help them with the healing process, because it will be quite scar after radiation.” -Radiation Oncologist

Supportive care



Billing



Clinical Training

“ I don't think I did have one tutorial or one guideline on managing patients who are transgender.” -Radiation Oncologist

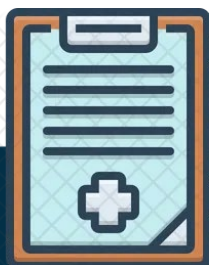
Consultation



Environment



Scheduling & Registration



“ I don't know if you have to be registered as a female to get a female ultrasound. I've reported on ovaries in trans men at the women's hospital, because they're on hormones. They have ovaries inside their pelvis that I need to report on the ultrasound, and I still think it's, the label of the study is still female, which is bad for them. If they get to see that record they're like, no, it's you know, it's their pelvis, and it's their male pelvis. But that's how we probably would code it on our radiology system.” -Radiologist

“ I don't know anything about that at all...This is the first time that I'm thinking about this, because that actually makes a lot of sense that some insurance companies might not cover things and people have to pay out a pocket for certain things.” -Radiation Oncologist

Scheduling & Registration



Environment



Consultation



Billing



“ I've heard of examples of patients being denied care because of how they identify as: A woman, and then maybe they have like a testicular ... So then, because there's some glitch in the insurance system, it like flags it as something .” -Radiation Oncologist

Supportive care



“[A] transgender patient going through [care], he or she may not be openly speaking about it. If they already have an established support network outside of the hospital, outside of the cancer care, they probably will continue with that rather than using our cancer care support for that particular reason.” -Radiation Oncologist

“If there's anything that we should be looking for specifically in this population that would really have an impact on positive patient care we don't know about it. And we'd really like to know about it things that are that we should be looking out for you know.” -Radiologist

Supportive care



Billing



“There are increasingly people who identify along the the gender spectrum within our field. And how how do we make those people feel most supported? And provide a community environment for them. –Radiation Oncologist

Consultation



Environment




Scheduling & Registration





Resources

Ways to Welcome SGM Patients



I WANT YOU TO KNOW...

My name is: _____ My pronouns are: _____ for example, he/him, she/her, they/theirs

I am most comfortable using this language or languages: _____

I believe in: _____ religion/faith

I identify as a person who is: _____, & _____
race/ethnicity sexual orientation gender identity

These are the people I want involved in my care (check all that apply):

| | |
|---|---------------------------------------|
| <input type="checkbox"/> Spouse/Partner | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Relative |
| <input type="checkbox"/> Child | <input type="checkbox"/> Anyone else? |
| <input type="checkbox"/> Brother/Sister | _____ |

I would like them to be able to (check all that apply):

| | |
|---|--|
| <input type="checkbox"/> Come to appointments | <input type="checkbox"/> Ask for information, materials, and resources |
| <input type="checkbox"/> Come into the exam room | <input type="checkbox"/> Discuss treatments |
| <input type="checkbox"/> Stay in the waiting room | <input type="checkbox"/> Help make financial decisions |
| <input type="checkbox"/> Help make decisions | <input type="checkbox"/> Anything else? |
| <input type="checkbox"/> Ask questions | _____ |

Over the last three (3) months, I have been worried about:

| | |
|---|---|
| <input type="checkbox"/> Transportation 🚗 | <input type="checkbox"/> School 🎓 |
| <input type="checkbox"/> Childcare 👶 | <input type="checkbox"/> Personal safety 🛡️ |
| <input type="checkbox"/> Housing 🏠 | <input type="checkbox"/> Insurance 📄 |
| <input type="checkbox"/> Money 💰 | <input type="checkbox"/> Spiritual concerns 🙏 |
| <input type="checkbox"/> Food 🍲 | <input type="checkbox"/> Anything else? |
| <input type="checkbox"/> Job or work 🏢 | _____ |

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FOR MORE INFORMATION, CONTACT: _____


bit.ly/TEAMPatientCards



bit.ly/YouAreWelcomePosters

PROVIDERS:

PRACTICE PATIENT-CENTERED CARE



Before you enter the exam room, remember to check your assumptions. What do you know about your patient?

Build trust - "Knowing your medical history helps me provide the best care to you."

- What is your chosen name?
- Ask about your patient's preferred pronoun by first sharing your own. For example, "Hi, I'm Dr. Smith, and I use the pronouns she and her. What about you?" then use that pronoun.
- What word(s) do you use to describe your sexual orientation? What do those words mean to you?
- What is your relationship or partnership status?
- Can you tell me what sex you were assigned on your original birth certificate and any body changes I should be aware of?
- What is your preferred language? (If not English, identify a medically licensed interpreter before continuing)
- Who would you like to be involved in your care and how would you like them to be involved?

Discuss what your patient values - "How can we work together to try and make sure you can do what is most important in your life?"

- What religion or faith do you practice, if any?
- Who do you turn to for support when you need it?
- What do you do for work?
- What do you like to do in your free time?
- What worries or concerns do you have today?

Work as a team and practice two-way communication

- Check for understanding - use teach back
- Make decisions together or arrange for follow-up
- Use a supportive/empathic tone
- Avoid medical jargon and use plain language

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bit.ly/TEAMProviderPosters

Screening Considerations

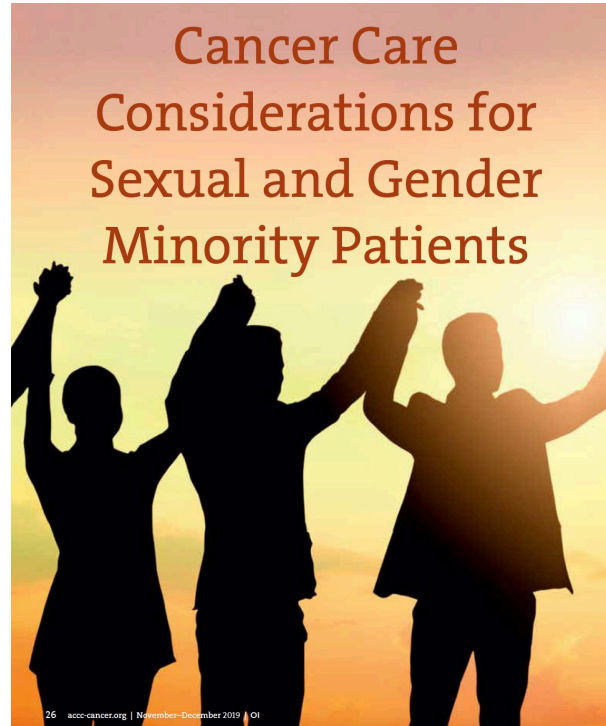


Table 3. Cancer Screening Considerations for Transgender and Intersex People

| Cancer Screening | Transfeminine | Transmasculine | Intersex |
|-------------------------|---|--|--|
| Breast | Screen per USPSTF guidelines for women if estrogen exposure is ≥ 5 years and age is 50+. | If top surgery has been performed, individualize screening based on amount of breast tissue and risk profile. If top surgery has not been performed, screen using USPSTF guidelines for women. | Individualize screening based on amount of breast tissue and risk profile. |
| Cervical | Not indicated | Screen per USPSTF guidelines for women if cervix is retained. Gender dysphoria is strong and gender-affirming precautions should be taken. Histological changes for people on testosterone may result in false positive screening. | Screen per USPSTF guidelines for women if cervix is present. |
| Endometrial and ovarian | Not indicated | If bottom surgery, not indicated. If no bottom surgery, inform of risks and symptoms; encourage patient to report unexpected bleeding. | Inform patients with a uterus of risks and symptoms. Encourage patient to report unexpected bleeding. |
| Prostate | Individualize based on risk factors, (e.g., ≥ 50 years old, African American) and benefits. Prostate-specific antigen 1 ng/mL is upper limit of normal if patient is on estrogen therapy. | Not indicated | Research is insufficient to provide recommendation. Individualize based on risk and benefits if patient has a prostate. |

Pratt-Chapman and Potter, 2019

Standards for Cultural Competency Training

LGBT Health
Volume 00, Number 00, 2022
Mary Ann Liebert, Inc.
DOI: 10.1089/lgbt.2021.0464

Open camera or QR reader and
scan code to access this article
and other resources online.



Developing Standards for Cultural Competency Training for Health Care Providers to Care for Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual Persons: Consensus Recommendations from a National Panel

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Asa Radix, MD, PhD,⁸ Markus P. Bidell, PhD,⁹ Daniel Bruner, JD, MPP,¹⁰ and Liz Margolies, LCSW¹¹

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Clinical Training: TEAM SGM (R01 Supp, R25 revision under review)

Journal of Cancer Education

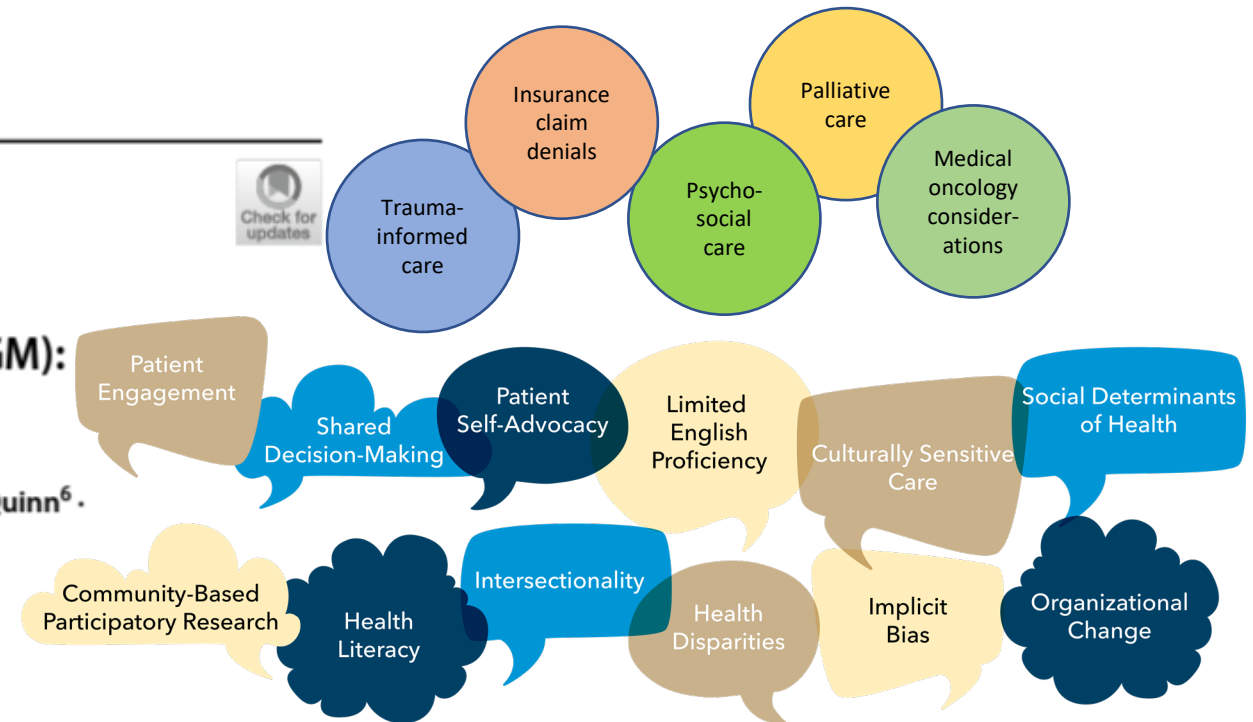
<https://doi.org/10.1007/s13187-022-02134-2>

Together-Equitable-Accessible-Meaningful (TEAM) Training to Improve Cancer Care for Sexual and Gender Minorities (SGM): Outcomes from a Pilot Study

Mandi L. Pratt-Chapman^{1,2} · Yan Wang³ · Kristen Eckstrand⁴ · Asa Radix⁵ · Gwendolyn P. Quinn⁶ · Matthew B. Schabath⁷ · Ana Maria Lopez⁸

Accepted: 2 January 2022

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Call to Action: Use Your Power to Change Systems

“I think that in my role as a doctor in the team that it would also be to **set the example for other staff** as to what was appropriate, because ... setting ground rules as being the one who's asked the patient what they like, disseminating that information to other members of the...almost **being an advocate for them, or a champion for this this type of practice in your setting.**

-Gynecologist

Collaborators

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