Improving cancer care for sexual and gender minority populations

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NIH NATIONAL CANCER INSTITUTE

Outline

1. **Who** are SGM populations?
2. **Why** are SGM populations vulnerable to poorer cancer outcomes?
3. **What** are cancer centers doing to provide equitable care for SGM patients?

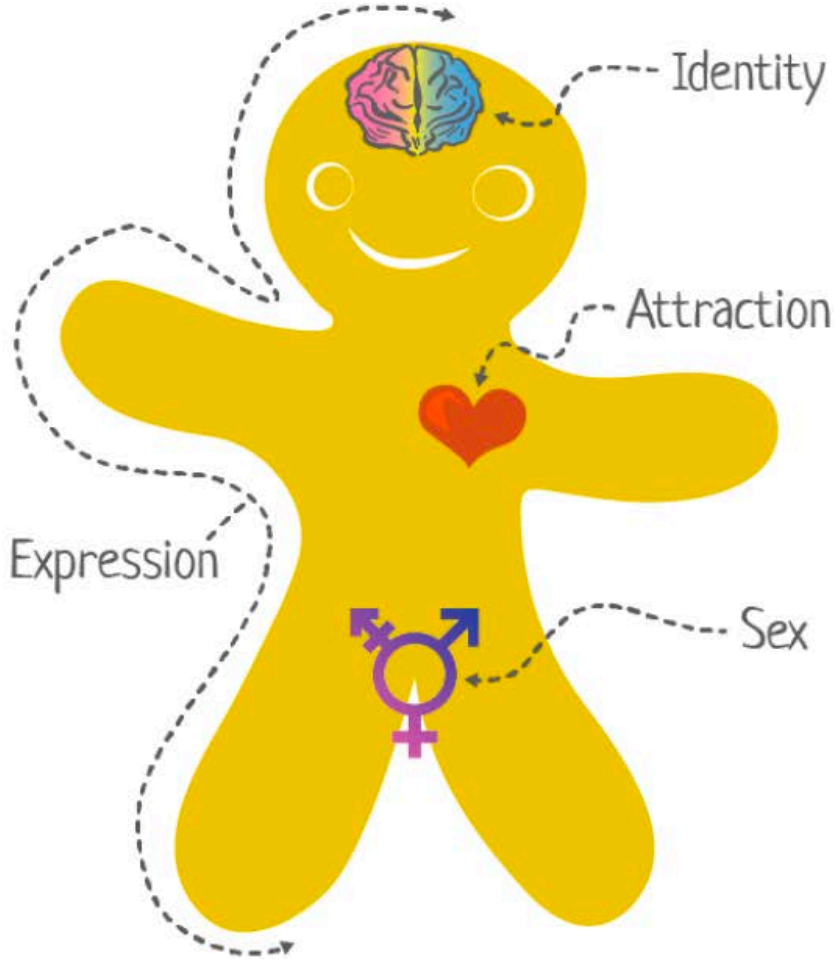
Sexual and Gender Minorities in the U.S.

“Sexual and gender minority (SGM) populations include, but are not limited to, individuals who **identify** as lesbian, gay, bisexual, asexual, transgender, two-spirit, queer, and/or intersex. Individuals with same-sex or -gender **attractions** or **behaviors** and those with a difference in sex **development** are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or **expression**, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.”

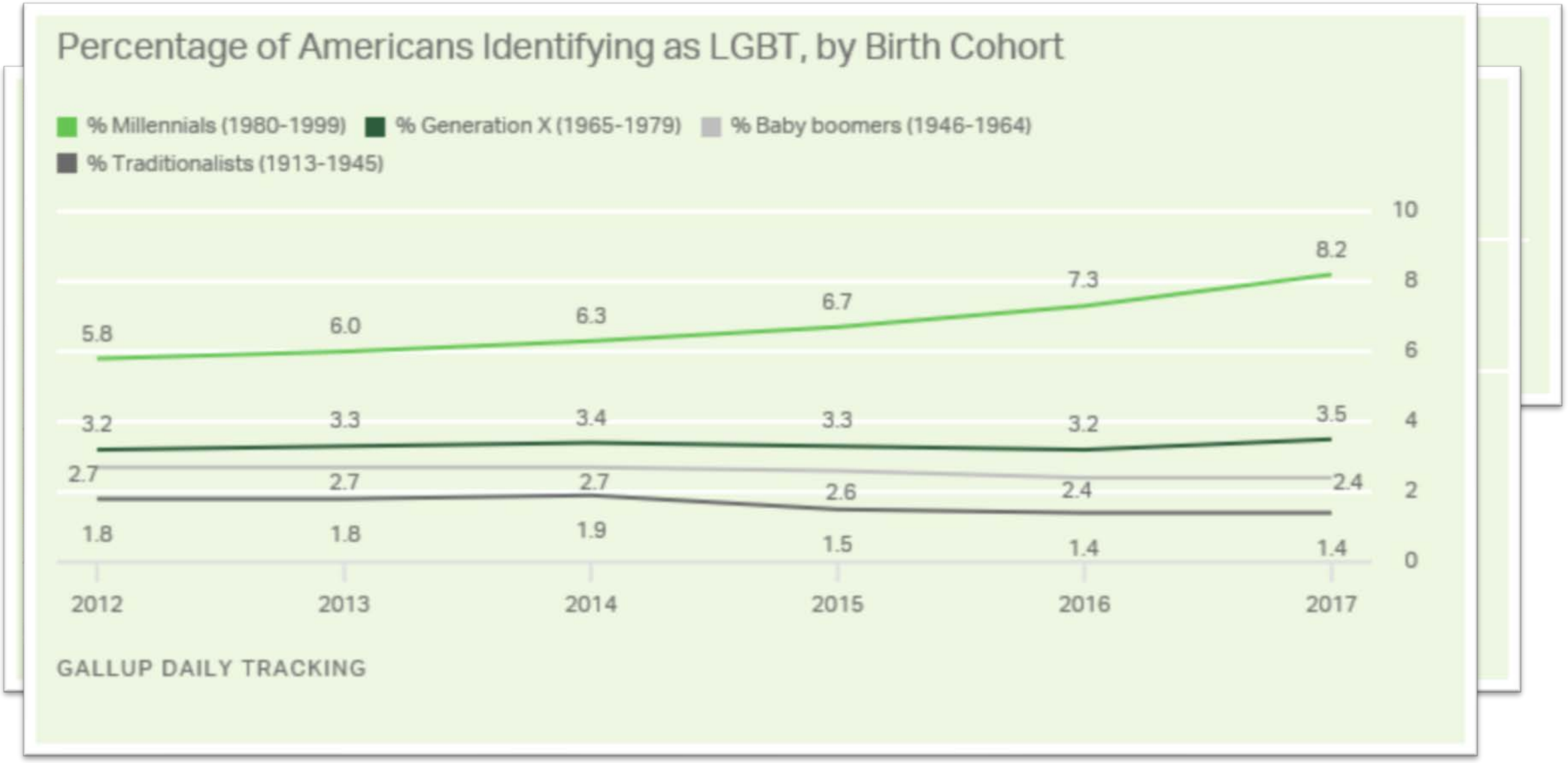
-NIH Sexual and Gender Minority Research Office

The Genderbread Person v4

by it's pronounced METROsexual .com



More than 11 million self-identified LGBT persons in US



Director's Message

October 6, 2016

Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes

On behalf of many colleagues who have worked together to make today possible, I am proud to announce the formal designation of sexual and gender minorities (SGMs) as a health disparity population for NIH research. The term SGM encompasses lesbian, gay, bisexual, and transgender populations, as well as those whose sexual orientation, gender identity and expressions, or reproductive development varies from traditional societal, cultural, or physiological norms.

Mounting evidence indicates that SGM populations have less access to health care and higher burdens of certain diseases, such as depression, cancer, and HIV/AIDS. But the extent and causes of health disparities are not fully understood, and research on how to close these gaps is lacking.

In addition, SGM populations have unique health challenges. More research is needed to understand these challenges, such as transgender people taking exogenous hormones.

Progress has been made in recent years, with gains in legal rights and changing social attitudes. However, stigmatization, hate-violence, and discrimination are still major barriers to the health and well-being of SGM populations. **Research** shows that sexual and gender minorities who live in communities with high levels of anti-SGM prejudice die sooner—12 years on average—than those living in more accepting communities.

The Minority Health and Health Disparities Research and Education Act of 2000 authorizes the Director of the National Institute on Minority Health and Health Disparities (NIMHD), in consultation with the director of the Agency for Healthcare Research and Quality (AHRQ) at the U.S. Department of Health and Human Services, to define health disparity populations. This month, with strong support from AHRQ Director Andrew Bindman, M.D., I formally designate sexual and gender minorities as a disparity

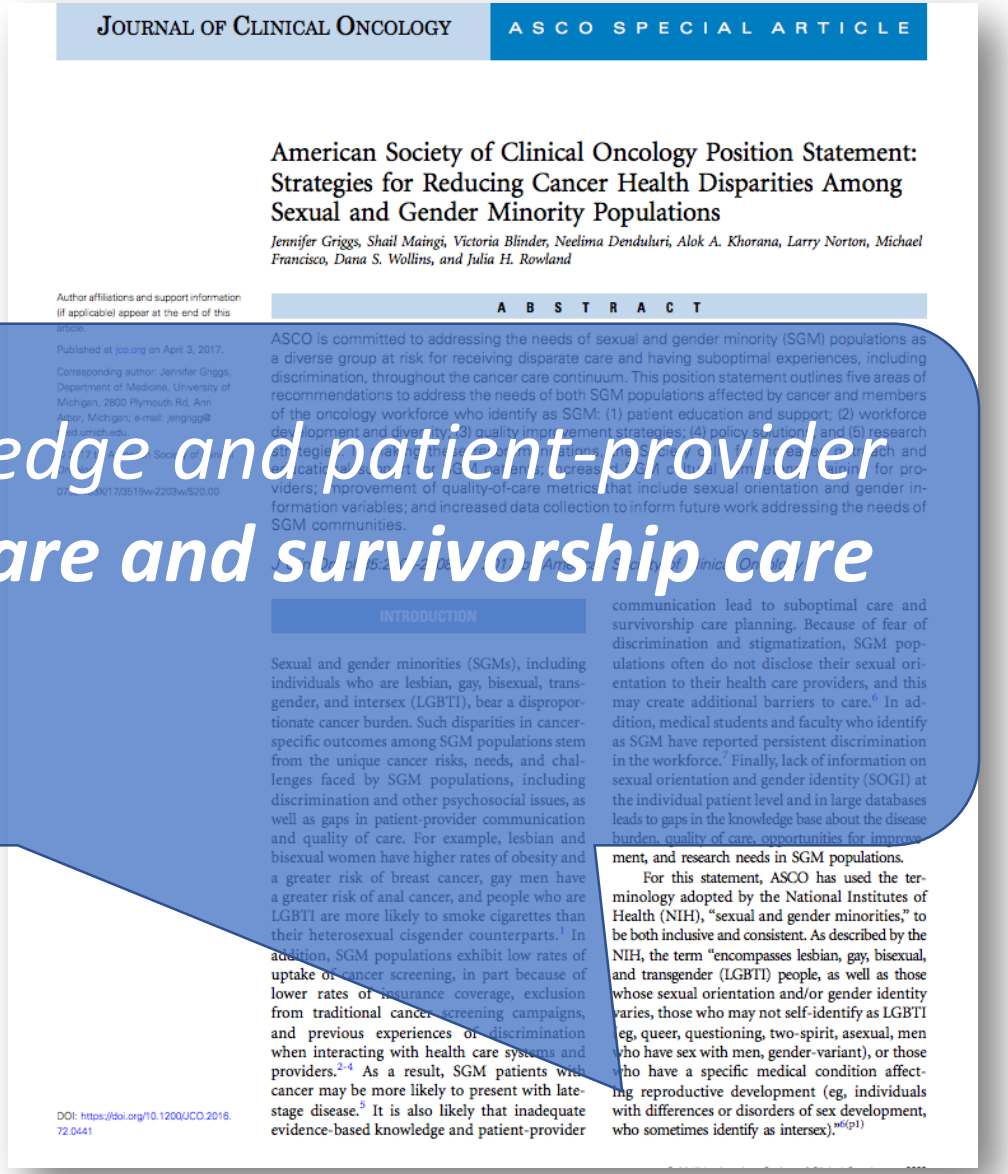
National Institute on Minority Health and Health Disparities

*"…**stigmatization**, hate-violence, and **discrimination** are still major **barriers to the health** and well-being of SGM populations"*

Eliseo J. Pérez-Stable, MD
Director, NIMHD 2016

SGM populations experience a disproportionate cancer burden

*"…inadequate evidence-based knowledge and patient-provider communication lead to **suboptimal care and survivorship care** planning." - ASCO*



JOURNAL OF CLINICAL ONCOLOGY | ASCO SPECIAL ARTICLE

American Society of Clinical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations

Jennifer Griggs, Shail Maingi, Victoria Blinder, Neelima Denduluri, Alok A. Khorana, Larry Norton, Michael Francisco, Dana S. Wollins, and Julia H. Rowland

Author affiliations and support information (if applicable) appear at the end of this article.

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ABSTRACT

ASCO is committed to addressing the needs of sexual and gender minority (SGM) populations as a diverse group at risk for receiving disparate care and having suboptimal experiences, including discrimination, throughout the cancer care continuum. This position statement outlines five areas of recommendations to address the needs of both SGM populations affected by cancer and members of the oncology workforce who identify as SGM: (1) patient education and support; (2) workforce development and diversity; (3) quality improvement strategies; (4) policy solutions; and (5) research strategies, including increased data collection to inform future work addressing the needs of SGM communities.

INTRODUCTION

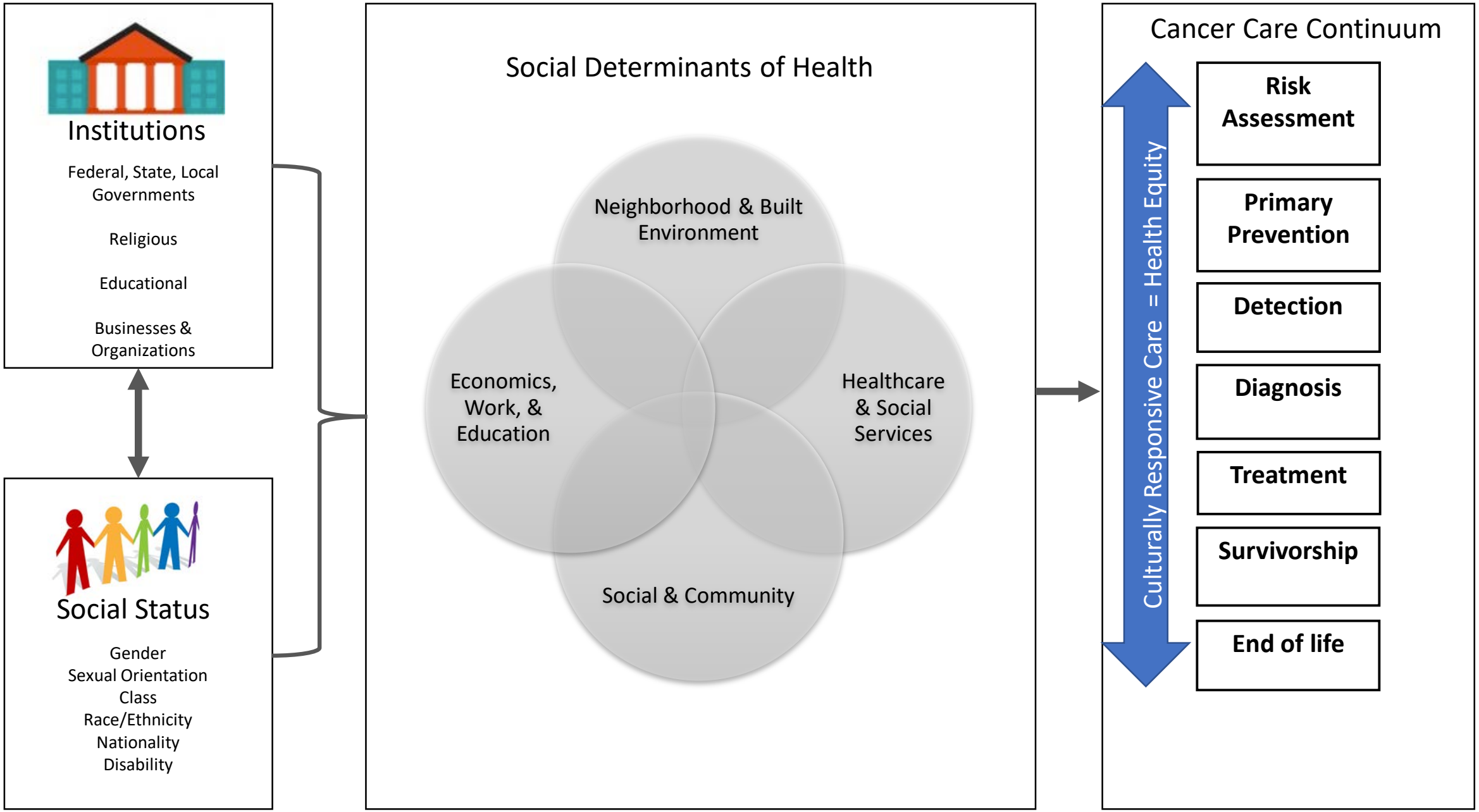
Sexual and gender minorities (SGMs), including individuals who are lesbian, gay, bisexual, transgender, and intersex (LGBTI), bear a disproportionate cancer burden. Such disparities in cancer-specific outcomes among SGM populations stem from the unique cancer risks, needs, and challenges faced by SGM populations, including discrimination and other psychosocial issues, as well as gaps in patient-provider communication and quality of care. For example, lesbian and bisexual women have higher rates of obesity and a greater risk of breast cancer, gay men have a greater risk of anal cancer, and people who are LGBTI are more likely to smoke cigarettes than their heterosexual cisgender counterparts.[1] In addition, SGM populations exhibit low rates of uptake of cancer screening, in part because of lower rates of insurance coverage, exclusion from traditional cancer screening campaigns, and previous experiences of discrimination when interacting with health care systems and providers.[2-4] As a result, SGM patients with cancer may be more likely to present with late-stage disease.[5] It is also likely that inadequate evidence-based knowledge and patient-provider communication lead to suboptimal care and survivorship care planning. Because of fear of discrimination and stigmatization, SGM populations often do not disclose their sexual orientation to their health care providers, and this may create additional barriers to care.[6] In addition, medical students and faculty who identify as SGM have reported persistent discrimination in the workforce.[7] Finally, lack of information on sexual orientation and gender identity (SOGI) at the individual patient level and in large databases leads to gaps in the knowledge base about the disease burden, quality of care, opportunities for improvement, and research needs in SGM populations.

For this statement, ASCO has used the terminology adopted by the National Institutes of Health (NIH), "sexual and gender minorities," to be both inclusive and consistent. As described by the NIH, the term "encompasses lesbian, gay, bisexual, and transgender (LGBTI) people, as well as those whose sexual orientation and/or gender identity varies, those who may not self-identify as LGBTI (eg, queer, questioning, two-spirit, asexual, men who have sex with men, gender-variant), or those who have a specific medical condition affecting reproductive development (eg, individuals with differences or disorders of sex development, who sometimes identify as intersex)."[6(p1)]

DOI: https://doi.org/10.1200/JCO.2016.72.0441

Vulnerabilities in SGM populations

1. Social Determinants of Health
2. Risk factors and unique care needs

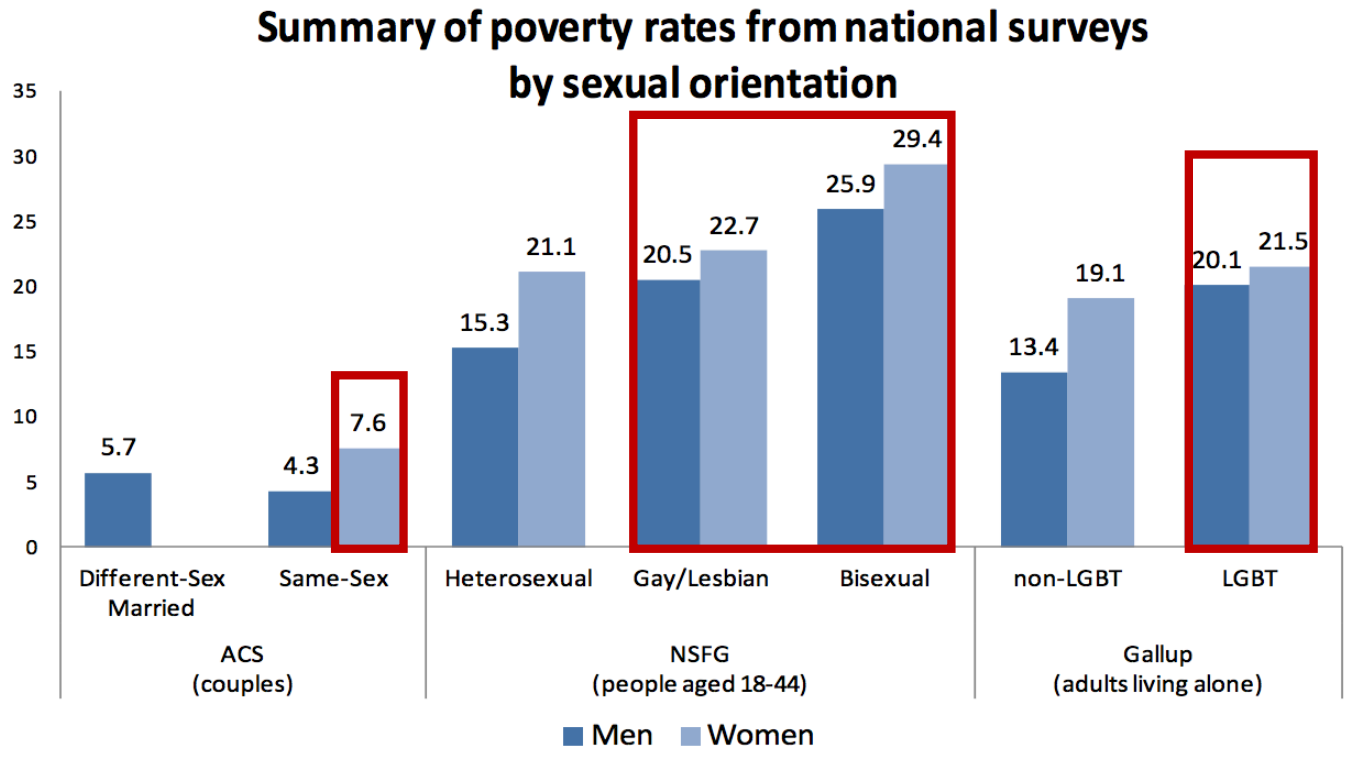

Institutions
Federal, State, Local Governments
Religious
Educational
Businesses & Organizations
Social Status
Gender
Sexual Orientation
Class
Race/Ethnicity
Nationality
Disability
Social Determinants of Health
Neighborhood & Built Environment
Economics, Work, & Education
Healthcare & Social Services
Social & Community
Cancer Care Continuum
Culturally Responsive Care = Health Equity
Risk Assessment
Primary Prevention
Detection
Diagnosis
Treatment
Survivorship
End of life

Social Determinants of Health

Economic, Work, & Education

Poverty

- 1 in 5 lesbian women living in poverty
- Bisexual men & women are more vulnerable
- 2 times poverty rate among African American same-sex couples compared to heterosexual African American couples



(Badgett et al 2013; Gonzalez et al JAMA Int Med, 2016)

Social Determinants of Health

Economic, Work, & Education

Workplace discrimination

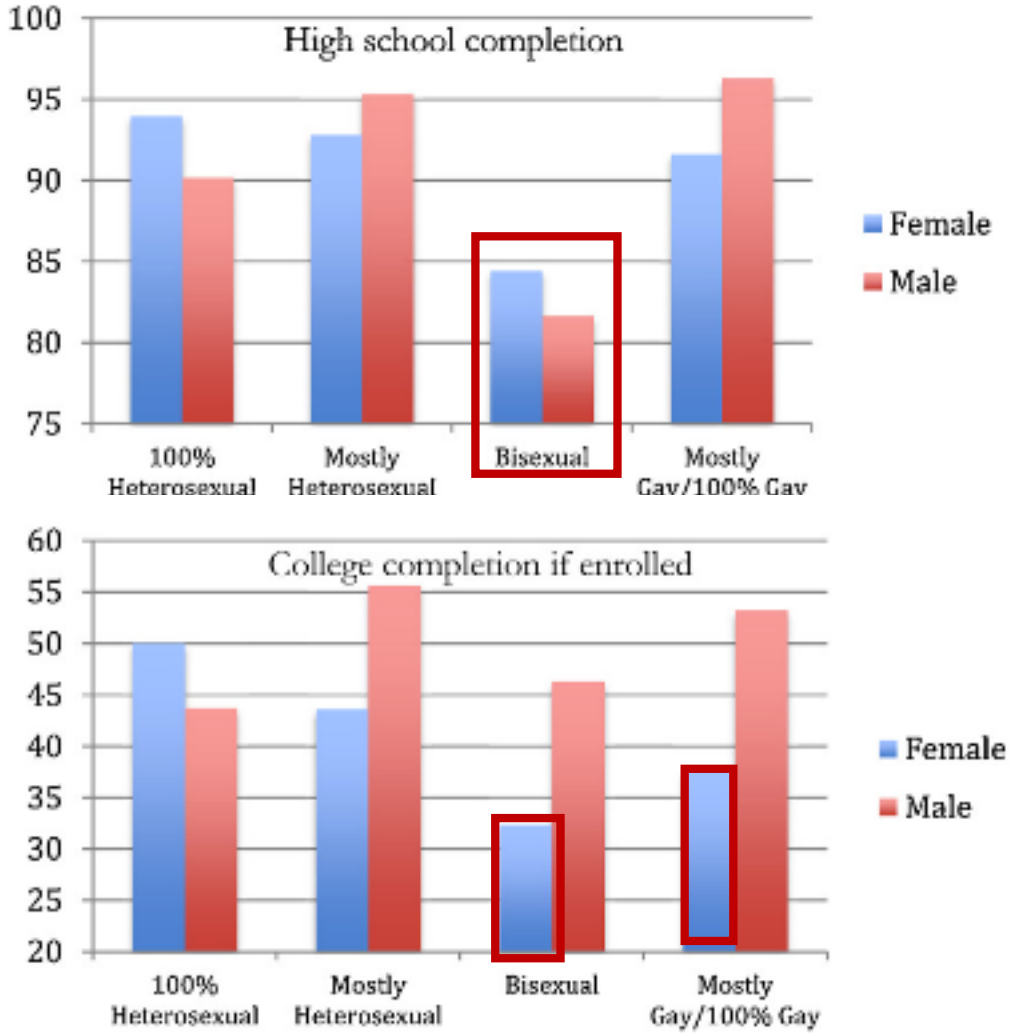
(National LGBT Workers Center)

Social Determinants of Health

Economic, Work, & Education

Education

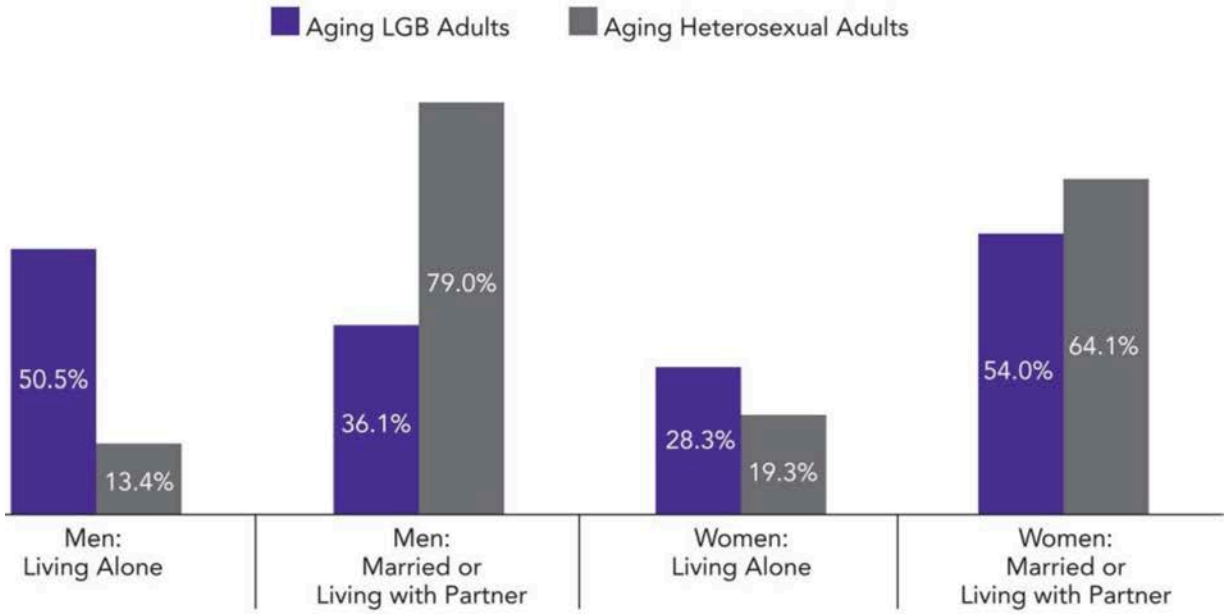
- Sexual minority women (particularly bisexual) have lower educational attainment (opposite for men)
- Transgender adults 66% less likely to finish high school than cisgender adults



(Mollborn et al, 2015; Wheldon et al, 2019)

Social Determinants of Health

Social & Community: Support and isolation



Who do you consider to be part of your personal support network?

	Lesbians	Gay Men
Gay/Lesbian or bisexual friends	80%	70%
Straight friends	81%	68%
Spouse or partner	67%	50%
Neighbors	42%	32%

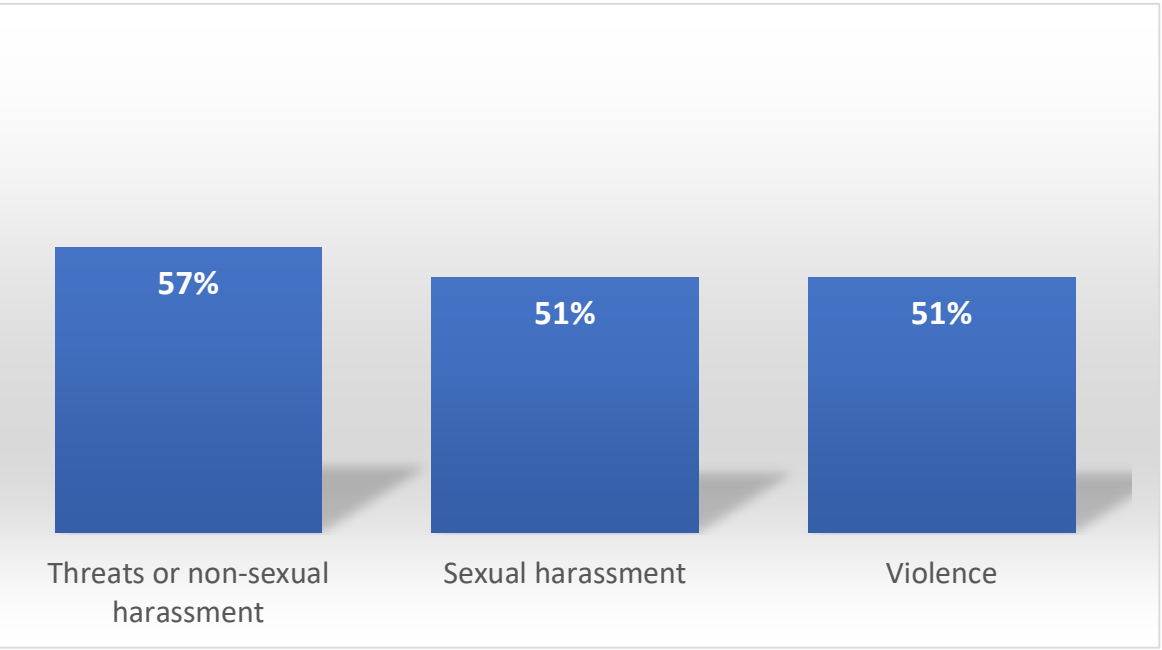
76%

Concerned about having adequate family and/or social supports to rely on as they age

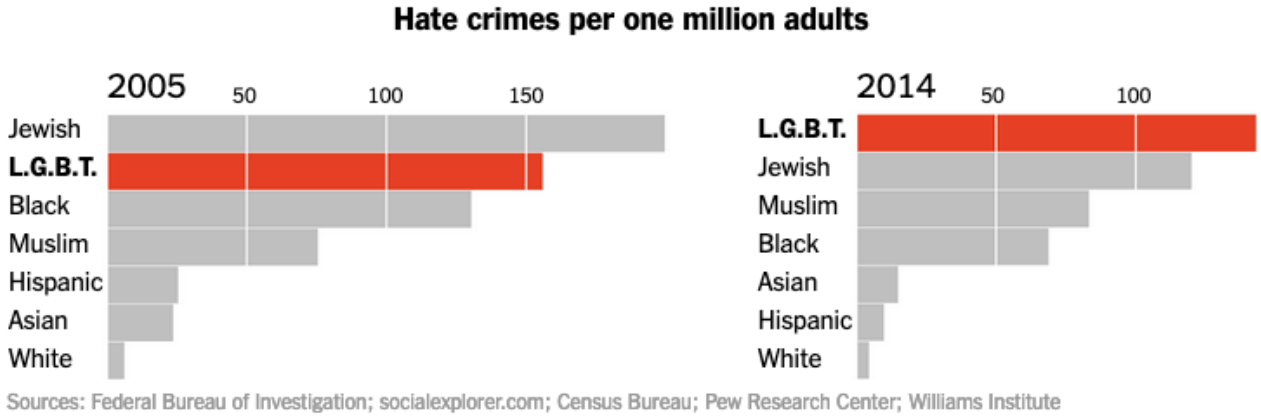
(Sources: AARP, 2018; Yang et al 2018; Wallace et al 2013)

Social Determinants of Health

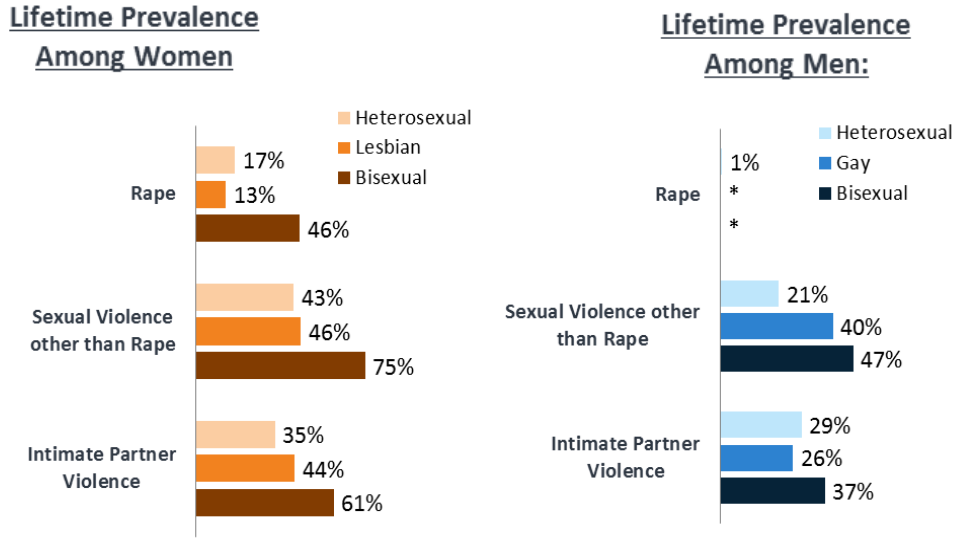
Social & Community: Discrimination & Violence



NPR/Robert Wood Johnson Foundation/Harvard T.H. Chan School of Public Health, Discrimination in America: Experiences and Views of LGBTQ Americans, January 26 – April 9, 2017. Q93a/b/e, Q94. Each question asked of half-sample. Total N=489 LGBTQ U.S. adults.



Sexual Violence by Sexual Orientation



Sexual Violence other than rape includes being made to penetrate, sexual coercion, unwanted sexual contact, and non-contact unwanted sexual experiences. Perpetrator can include an Intimate Partner.
Intimate Partner Violence includes physical and sexual violence, threats of physical or sexual violence, stalking, and psychological aggression by a current or former intimate partner

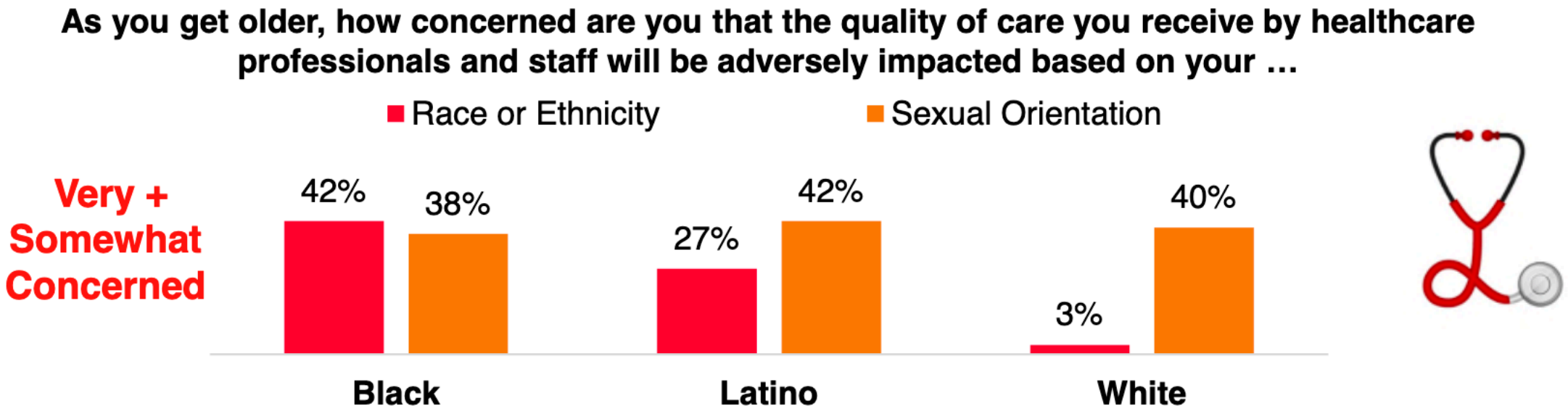
Social Determinants of Health

Health, Healthcare, and Social Services

Source: Lambda Legal. When health care isn't caring: Lambda Legal's survey of discrimination against LGBT people, N = 4,916

Social Determinants of Health

Health, Healthcare, and Social Services



Source: AARP, 2018

Social Determinants of Health

Health, Healthcare, and Social Services

Health and Comorbid Conditions

- Coronary Heart Disease
- Asthma
- Arthritis and pain
- Cancer
- HIV (1:6 MSM)

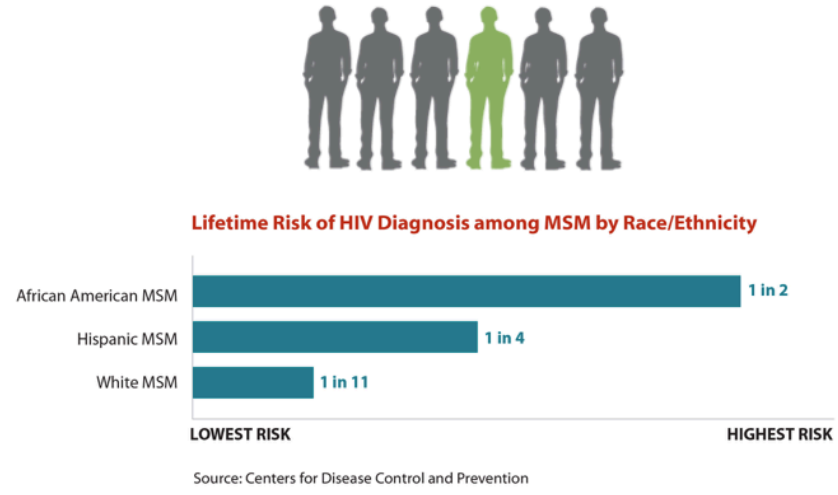


TABLE 2—Chronic Health Conditions Among Women and Men Aged 50 Years or Older, by Sexual Orientation: National Health Interview Survey, United States, 2013–2014

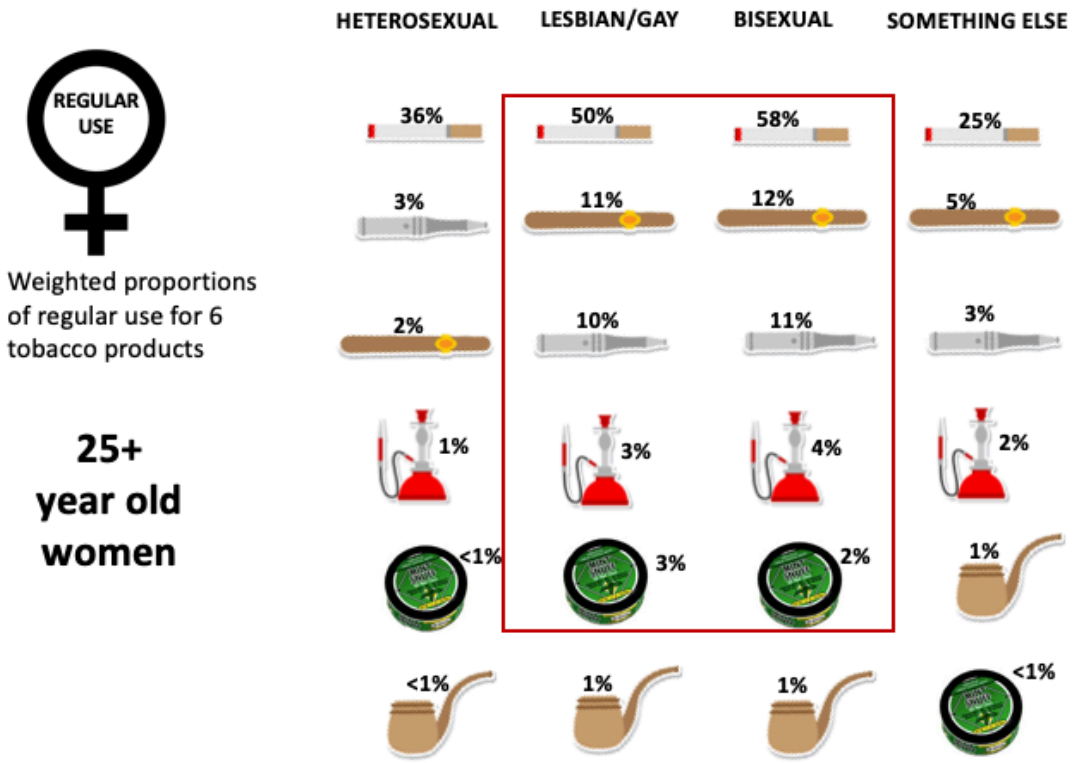
	Women			Men		
Health Indicator	Heterosexual (Ref), % or Mean (95% CI)	Lesbian/Bisexual, % or Mean (95% CI)	Adjusted OR or IRR (95% CI)	Heterosexual (Ref), % or Mean (95% CI)	Gay/Bisexual, % or Mean (95% CI)	Adjusted OR or IRR (95% CI)
Chronic conditions						
Stroke	5.1 (4.9, 5.3)	6.8 (5.2, 9.0)	2.12 (1.57, 2.87)[a]	5.5 (5.2, 5.7)	2.5 (1.6, 4.0)	0.56 (0.27, 1.17)
Heart attack	4.3 (4.1, 4.4)	6.4 (4.5, 9.0)	2.28 (1.58, 3.29)[a]	8.7 (8.4, 9.0)	8.0 (6.3, 10.0)	1.08 (0.83, 1.40)
Angina pectoris	3.0 (2.8, 3.1)	2.8 (1.9, 4.1)	1.29 (0.88, 1.90)	4.8 (4.6, 5.0)	6.9 (5.0, 9.4)	1.69 (1.21, 2.35)
High blood pressure	50.0 (49.6, 50.5)	39.0 (35.1, 43.0)	0.88 (0.74, 1.04)	51.3 (50.7, 51.9)	46.4 (42.7, 50.3)	0.94 (0.80, 1.10)
Chronic obstructive pulmonary disease	6.0 (5.8, 6.2)	5.2 (4.0, 6.7)	1.08 (0.83, 1.41)	5.7 (5.5, 6.0)	5.3 (4.0, 6.9)	1.06 (0.71, 1.57)
Asthma	13.7 (13.4, 14.0)	18.0 (15.7, 20.5)	1.28 (1.12, 1.53)	9.0 (8.7, 9.3)	9.9 (8.0, 12.2)	1.06 (0.77, 1.44)
Arthritis	44.7 (44.2, 45.2)	50.3 (46.0, 54.6)	1.57 (1.32, 1.88)[a]	34.2 (33.6, 34.8)	28.9 (25.6, 32.5)	0.84 (0.71, 1.01)
Low back/neck pain	39.8 (39.3, 40.3)	53.0 (48.4, 57.5)	1.78 (1.46, 2.17)	35.5 (35.0, 36.1)	40.2 (36.6, 43.8)	1.21 (1.04, 1.41)[b]
Diabetes	15.9 (15.6, 16.2)	10.6 (8.8, 12.7)	0.77 (0.63, 0.96)	18.7 (18.3, 19.1)	14.2 (11.6, 17.2)	0.85 (0.68, 1.07)
Obesity	30.6 (30.1, 31.1)	35.4 (31.4, 39.4)	1.18 (0.98, 1.41)	30.9 (30.4, 31.5)	24.2 (21.2, 27.5)	0.67 (0.55, 0.80)[a]
Cancer	16.3 (15.9, 16.7)	14.6 (12.1, 17.6)	1.07 (0.88, 1.30)	16.2 (15.8, 16.7)	19.0 (16.2, 22.2)	1.41 (1.17, 1.69)
Weakened immune system[c]	10.1 (9.6, 10.5)	17.2 (12.2, 23.7)	1.69 (1.16, 2.46)	5.0 (4.6, 5.3)	15.2 (11.6, 19.6)	3.16 (2.25, 4.43)[a]
No. of chronic conditions[d]	2.3 (2.3, 2.3)	2.4 (2.3, 2.6)	1.18 (1.11, 1.25)	2.2 (2.2, 2.2)	2.1 (1.9, 2.2)	0.98 (0.93, 1.04)

(Source: Fredriksen-Goldsen et al 2017)

Cancer Care (unmet) Needs

Cancer Care Needs

- Risk factors (tobacco, alcohol, HPV, obesity, nulliparity)
- Screening
- Experiences in cancer care
- Sexual rehabilitation following cancer treatment
- Gender affirmation hormone therapy (before, during, after cancer treatment)



(Source: Wheldon et al, 2018)

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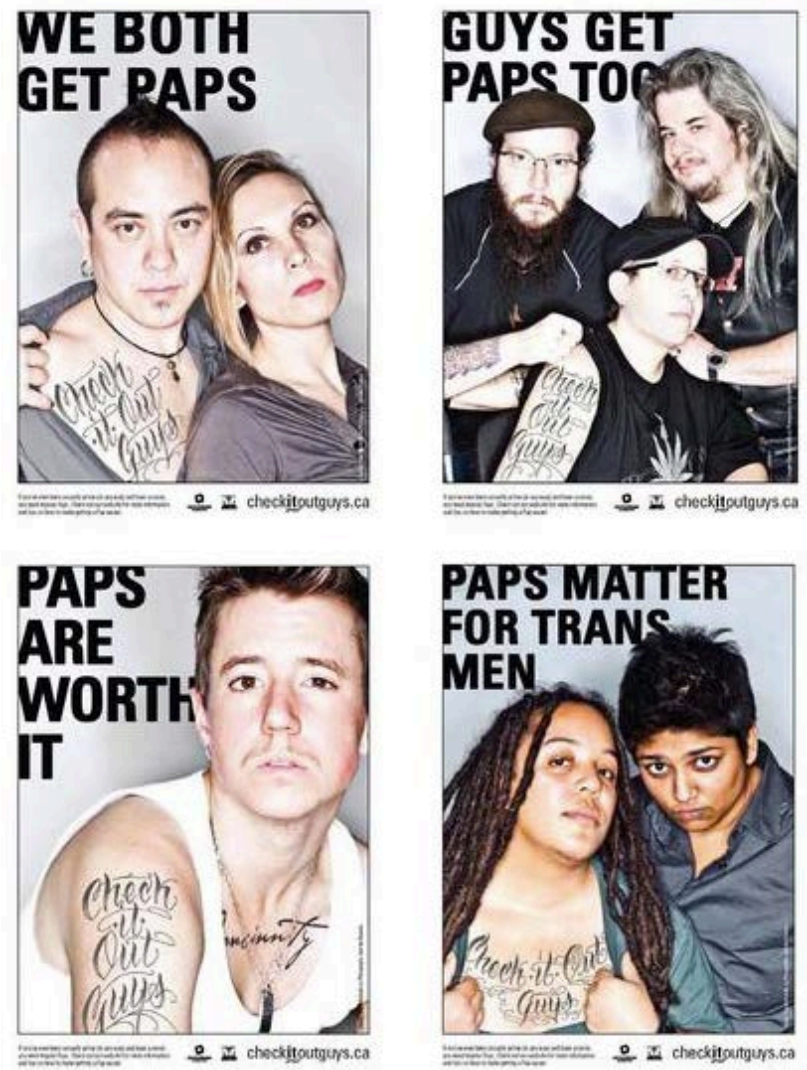

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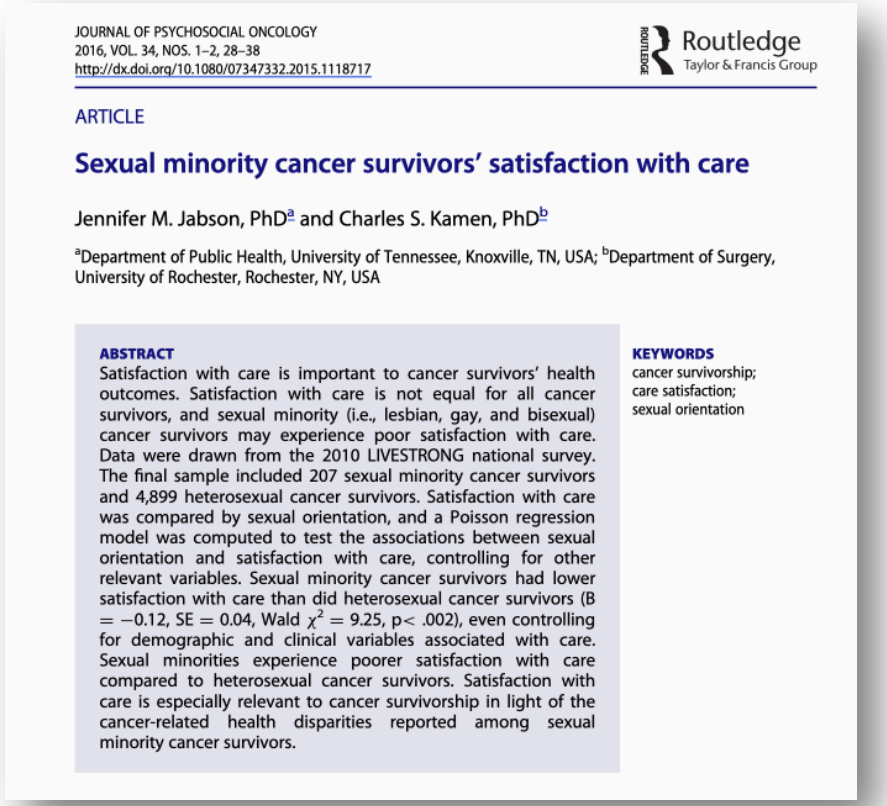

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http://dx.doi.org/10.1080/07347332.2015.1118717

Routledge
Taylor & Francis Group

ARTICLE

Sexual minority cancer survivors' satisfaction with care

Jennifer M. Jabson, PhD[a] and Charles S. Kamen, PhD[b]

[a]Department of Public Health, University of Tennessee, Knoxville, TN, USA; [b]Department of Surgery, University of Rochester, Rochester, NY, USA

ABSTRACT

Satisfaction with care is important to cancer survivors' health outcomes. Satisfaction with care is not equal for all cancer survivors, and sexual minority (i.e., lesbian, gay, and bisexual) cancer survivors may experience poor satisfaction with care. Data were drawn from the 2010 LIVESTRONG national survey. The final sample included 207 sexual minority cancer survivors and 4,899 heterosexual cancer survivors. Satisfaction with care was compared by sexual orientation, and a Poisson regression model was computed to test the associations between sexual orientation and satisfaction with care, controlling for other relevant variables. Sexual minority cancer survivors had lower satisfaction with care than did heterosexual cancer survivors (B $= -0.12$, SE $= 0.04$, Wald $\chi^2 = 9.25$, $p < .002$), even controlling for demographic and clinical variables associated with care. Sexual minorities experience poorer satisfaction with care compared to heterosexual cancer survivors. Satisfaction with care is especially relevant to cancer survivorship in light of the cancer-related health disparities reported among sexual minority cancer survivors.

KEYWORDS

cancer survivorship; care satisfaction; sexual orientation

"…sexual minority cancer survivors reported less satisfaction with care than heterosexual cancer survivors"

-Lack of shared decision making

-Unmet needs

Cancer Care Needs

- Risk factors (tobacco, alcohol, HPV, obesity, nulliparity)
- Screening
- Experiences in cancer care
- Sexual rehabilitation following cancer treatment
- Gender affirmation hormone therapy (before, during, after cancer treatment)

We started talking about anal intercourse and he [urologist] said, 'ah look I can't go there I want to stop, you know, I'll stop the conversation' – and I thought well, okay, well it's important to me but I obviously can't talk to you about it.

(Source: Rose et al, 2016)

"Rick" gay man, 59 years old
Prostate Cancer

Cancer Care Needs

- Risk factors (tobacco, alcohol, HPV, obesity, nulliparity)
- Screening
- Experiences in cancer care
- Sexual rehabilitation following cancer treatment
- Gender affirmation hormone therapy (before, during, after cancer treatment)

Contents lists available at ScienceDirect

Journal of Clinical & Translational Endocrinology

journal homepage: www.elsevier.com/locate/jcte

Review

Hormone therapy in transgender adults is safe with provider supervision; A review of hormone therapy sequelae for transgender individuals

Jamie D. Weinand, BS, BA, Joshua D. Safer, MD *

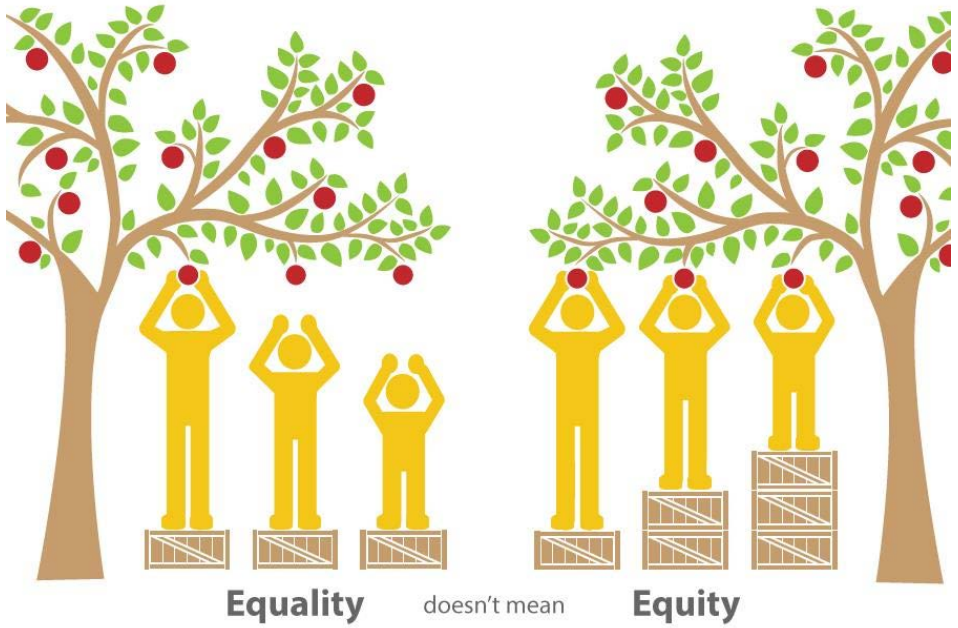
Transgender Medicine Research Group, Section of Endocrinology, Diabetes and Nutrition, Boston University School of Medicine, Boston, MA, USA

"Hormone therapy has not been shown to increase transgender individuals' cancer risk."

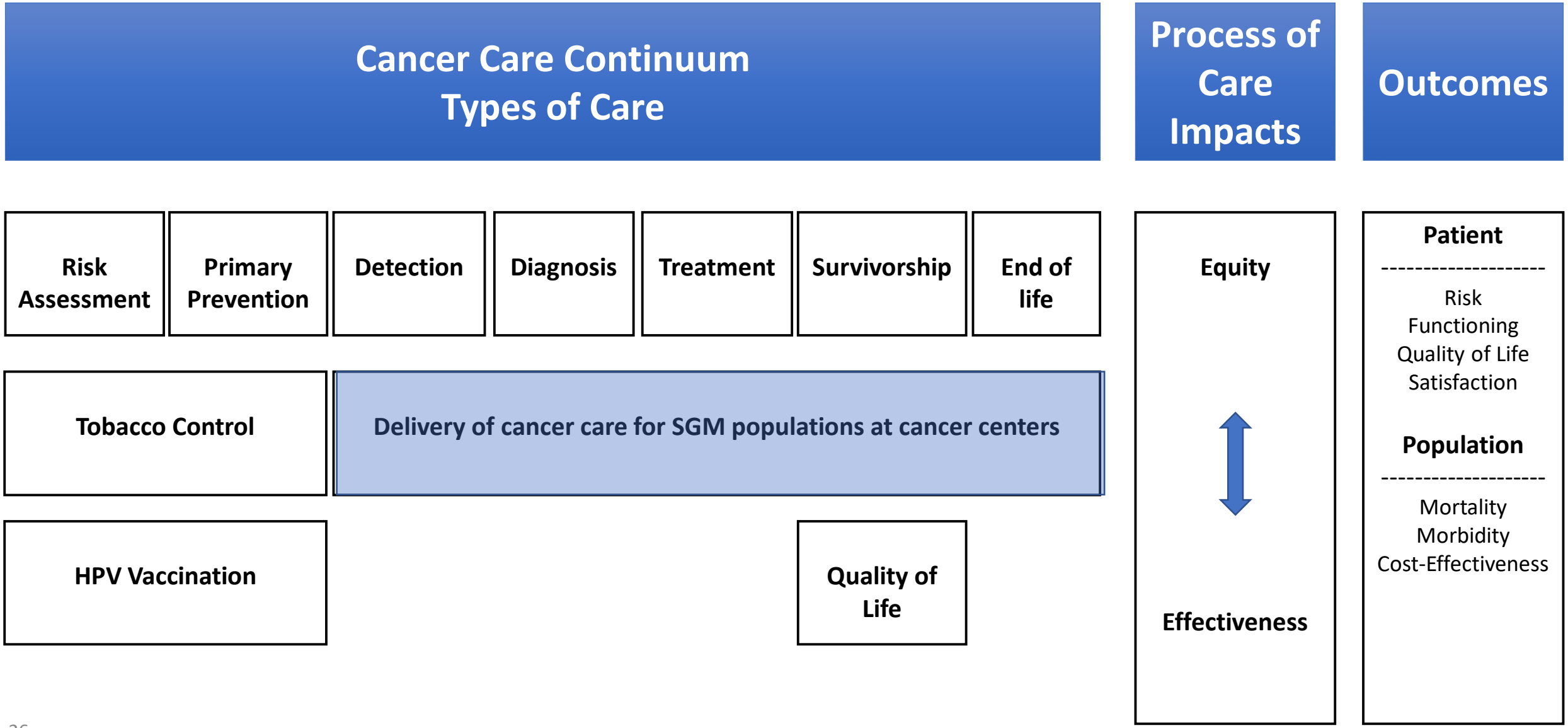
Research focus: Cancer Care Equity

1. What are the **needs** of SGM populations across the cancer care continuum?

2. How can the **delivery** of care be adapted or augmented to meet these needs?



Program of Research

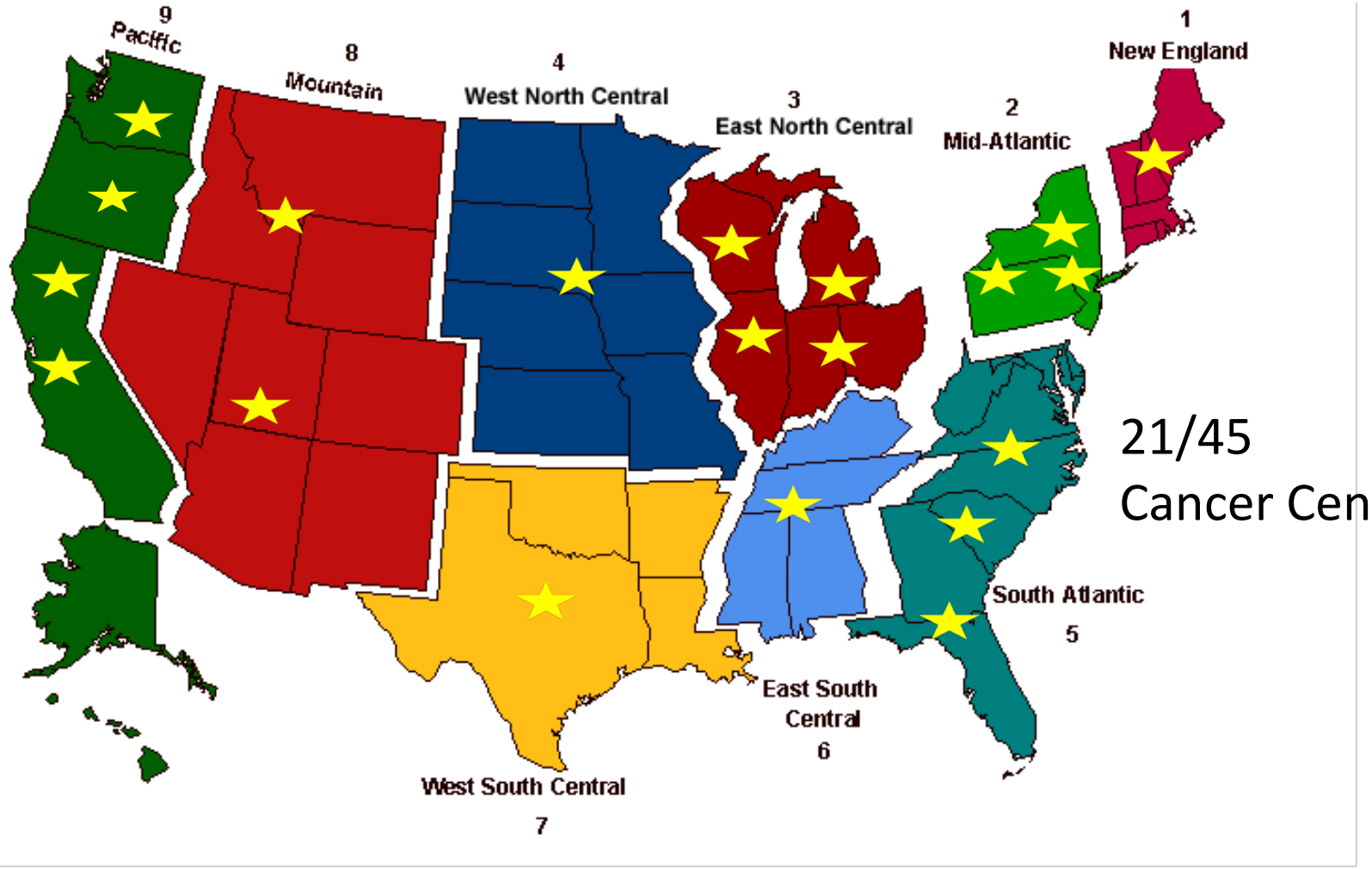


Taplin et al, 2012

Purpose: To identity existing policies and guidelines at National Cancer Institute-Designated Cancer Centers focused on the provision of culturally competent care for SGM cancer patients and survivors

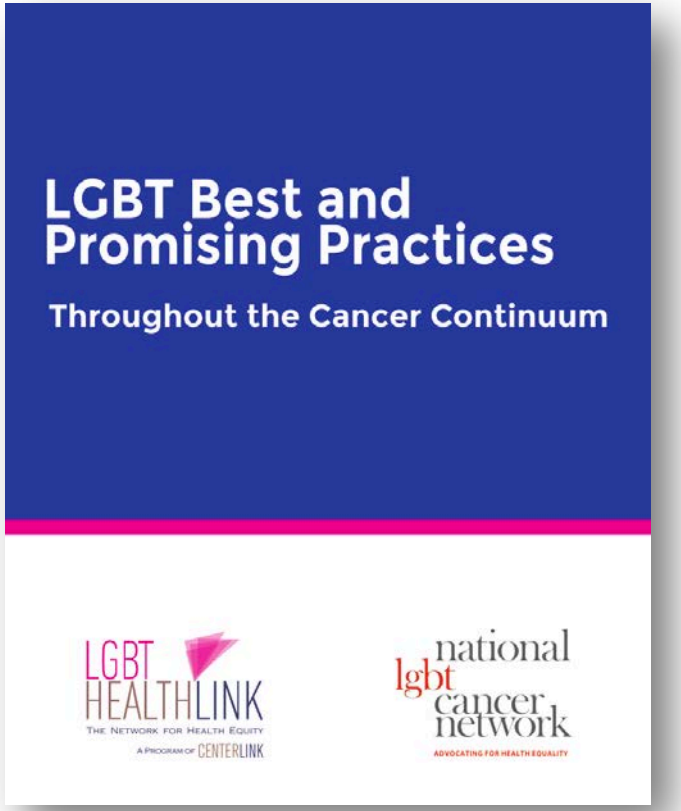

• Structured interview guide
• ~20 min phone calls
• Diversity representative
• Descriptive qualitative content analysis
MOFFITT
CANCER CENTER

Geographic Representation in 9 Census Divisions



21/45
Cancer Centers Represented

Best Practices Framework



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ABSTRACT

ASCO is committed to addressing the needs of sexual and gender minority (SGM) populations as a diverse group at risk for receiving disparate care and having suboptimal experiences, including discrimination, throughout the cancer care continuum. This position statement outlines five areas of recommendations to address the needs of both SGM populations affected by cancer and members of the oncology workforce who identify as SGM: (1) patient education and support; (2) workforce development and diversity; (3) quality improvement strategies; (4) policy solutions; and (5) research strategies. In making these recommendations, the Society calls for increased outreach and educational support for SGM patients; increased SGM cultural competency training for providers; improvement of quality-of-care metrics that include sexual orientation and gender information variables; and increased data collection to inform future work addressing the needs of SGM communities.

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INTRODUCTION

Sexual and gender minorities (SGMs), including individuals who are lesbian, gay, bisexual, transgender, and intersex (LGBTI), bear a disproportionate cancer burden. Such disparities in cancer-specific outcomes among SGM populations stem from the unique cancer risks, needs, and challenges faced by SGM populations, including discrimination and other psychosocial issues, as well as gaps in patient-provider communication and quality of care. For example, lesbian and bisexual women have higher rates of obesity and a greater risk of breast cancer, gay men have a greater risk of anal cancer, and people who are LGBTI are more likely to smoke cigarettes than their heterosexual cisgender counterparts.[1] In addition, SGM populations exhibit low rates of uptake of cancer screening, in part because of lower rates of insurance coverage, exclusion from traditional cancer screening campaigns, and previous experiences of discrimination when interacting with health care systems and providers.[2-4] As a result, SGM patients with cancer may be more likely to present with late-stage disease.[5] It is also likely that inadequate evidence-based knowledge and patient-provider communication lead to suboptimal care and survivorship care planning. Because of fear of discrimination and stigmatization, SGM populations often do not disclose their sexual orientation to their health care providers, and this may create additional barriers to care.[6] In addition, medical students and faculty who identify as SGM have reported persistent discrimination in the workforce.[7] Finally, lack of information on sexual orientation and gender identity (SOGI) at the individual patient level and in large databases leads to gaps in the knowledge base about the disease burden, quality of care, opportunities for improvement, and research needs in SGM populations.

For this statement, ASCO has used the terminology adopted by the National Institutes of Health (NIH), "sexual and gender minorities," to be both inclusive and consistent. As described by the NIH, the term "encompasses lesbian, gay, bisexual, and transgender (LGBTI) people, as well as those whose sexual orientation and/or gender identity varies, those who may not self-identify as LGBTI (eg, queer, questioning, two-spirit, asexual, men who have sex with men, gender-variant), or those who have a specific medical condition affecting reproductive development (eg, individuals with differences or disorders of sex development, who sometimes identify as intersex)."[8(p1)]

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Collect and use SOGI data in EHR

- Enhance patient navigation and care coordination
- Facilitate research on disparities
- Quality Improvement

Organizational and environmental

- Support from administrators
- Engage local community
- Disseminate and enforce antidiscrimination policies
- Creating welcoming environment including intake forms, restrooms, waiting areas

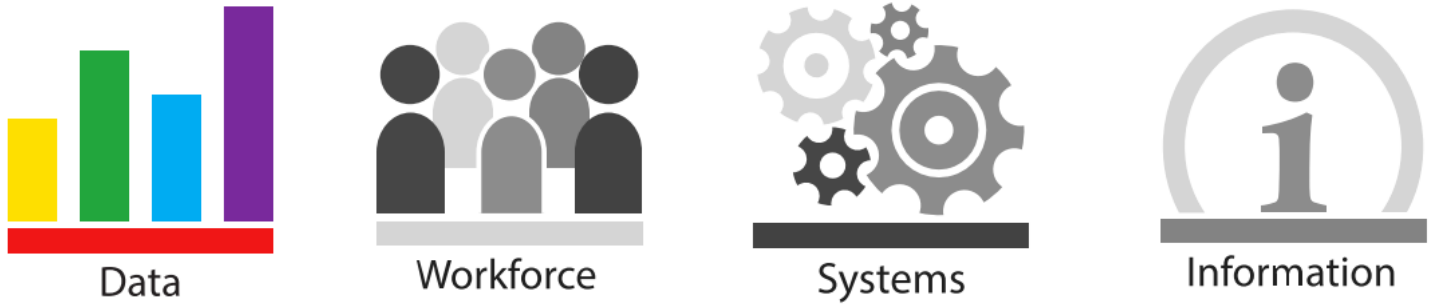
Cultural sensitivity training

- All levels of providers and any staff members who interact with patients and/or caregivers including clerical staff, technicians, patient navigators, pharmacy staff, housekeeping staff, and food service

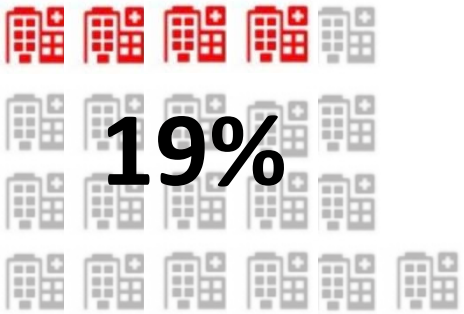
Patient education and support

- Educational resources tailored to the needs of SGM patients
- Improve access to support services through survivorship programs, support groups, bereavement programs

Collecting LGBT data as a core demographic variable



Gender Identity vs. Sex at Birth

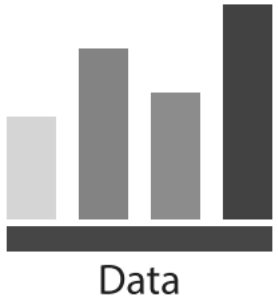


Sexual orientation

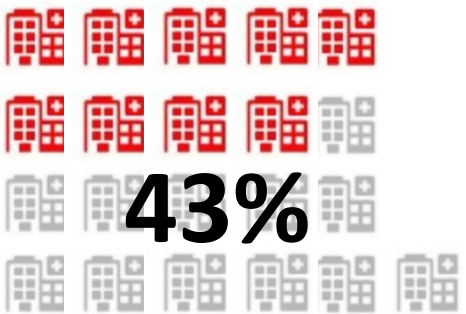
More commonly collected in clinics focusing on sexual health or HIV/AIDS.

Recorded in open ended field; not as patient demographic

Training and continuing education on LGBT cancer topics



SGM Cultural Competency Training



Not Institutionalized

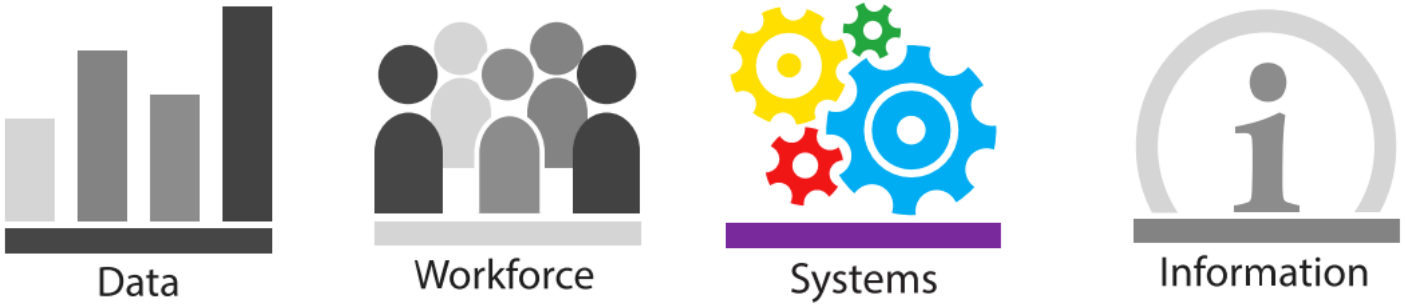
Voluntary

Sporadic

Initiated by an individual or group with specific interest

LGBTQ Elders of Color")

Altering the health care environment



Welcoming Environment

19% Gender-neutral language on forms

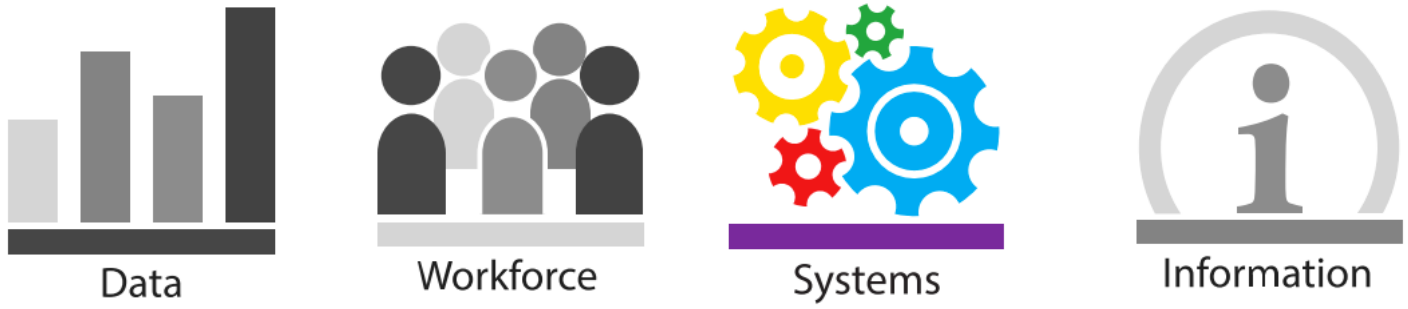
57% Preferred name and/or gender pronoun

100% Post non-discrimination policies

33% do NOT do anything specific for SGM populations

They ”treat every patient equally”

Addressing inequalities in administration and policy



86% Advisory board or committee to advise on SGM policy issues

- 10 to 30 members
- Clinical & administrative members (few with community members)
- Patient issues
- Employee focused

Addressing inequalities in administration and policy

<u>Few (19%) had policies that specifically addressed SGM issues</u>

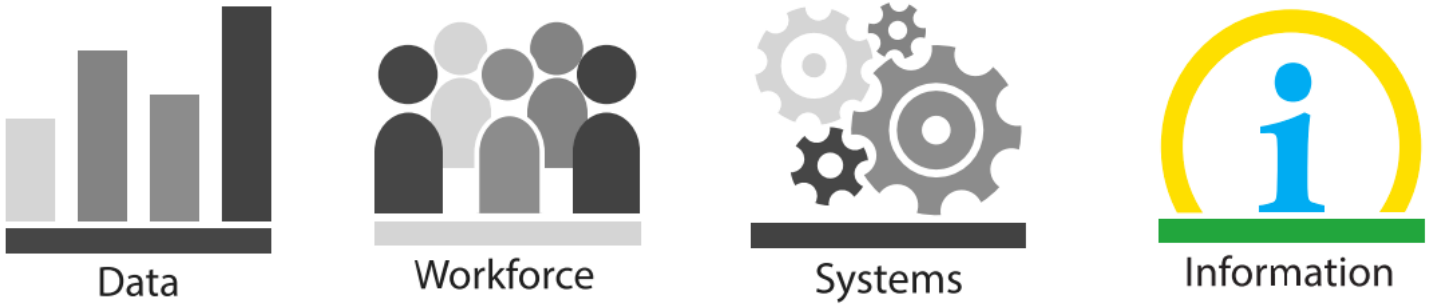
*Healthcare decision making from same-sex partners

*Visitation/overnight guests

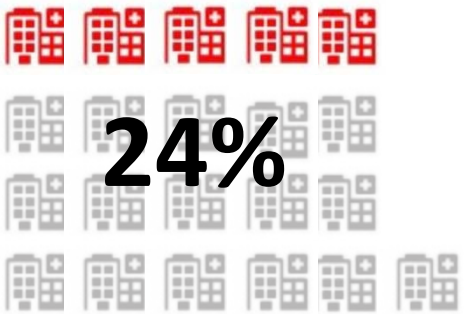
*Gender affirmation for employees

*Procedures to record gender identify from patients

Lack of SGM specific patient education materials

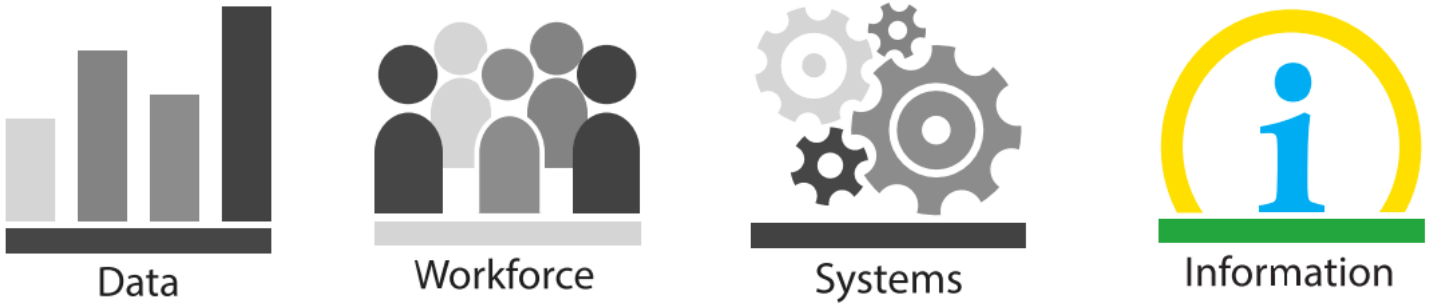


SGM patient inclusive educational materials



SGM materials were "specialized and separate" in sexual health or urology clinics

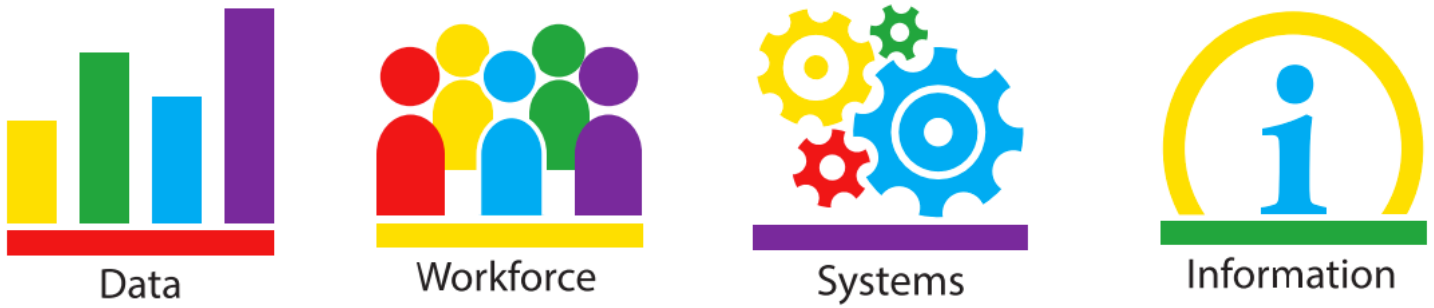
Limited survivorship resources



SGM Survivorship Group

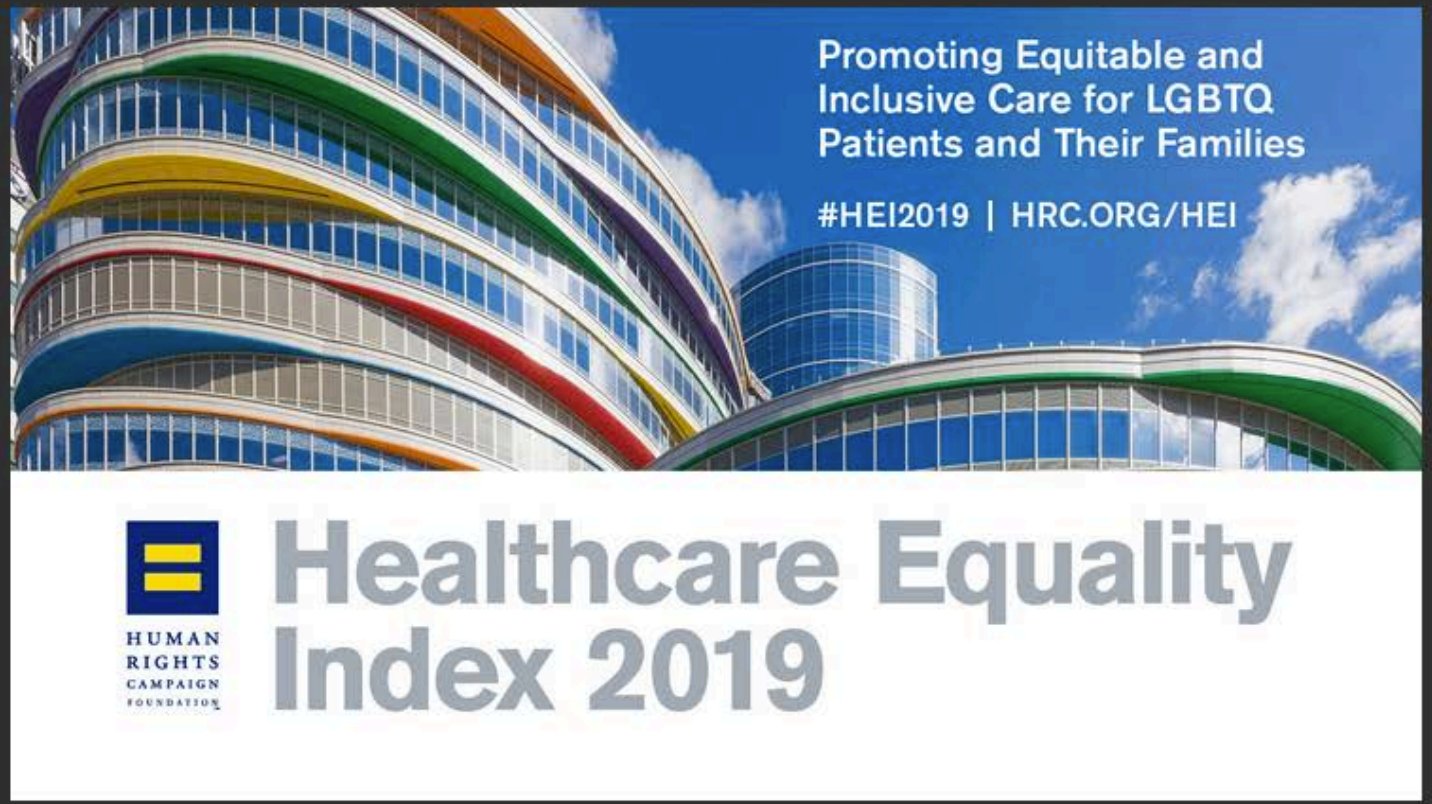
"…we are trying to get a more formal approach to survivorship but I don't know that there have been any efforts specifically geared toward LGBTQ survivorship."

Room for Improvement at the Organizational Level



- SOGI Data collection not systematic
- Trainings not institutionalized
- Forms and materials not inclusive/SGM community largely not engaged
- Lack of specific SGM patient programs

National Benchmarks



In its 12th year, the Healthcare Equality Index (HEI) is the national LGBTQ benchmarking tool that evaluates healthcare facilities' policies and practices related to the equity and inclusion of their LGBTQ patients, visitors and employees. The HEI 2019 evaluates more than 1,600 healthcare facilities nationwide.

Download the HEI 2019 ›

Call to Action

1. **Avoid assumptions** about gender and sexuality
2. Include sexual orientation and gender identity in **non-discrimination policies** for patients and staff
3. **Engage** diverse SGM communities
4. Take advantage of cultural sensitivity **trainings** for LGBT populations (e.g., National LGBT Cancer Network)
5. Form SGM **advisory committee** to implement actions 1-4
   - Include clinicians and administrators from across the organization, as well as community advocates in implementation process

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