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AN ACCREDITED CONTINUING EDUCATION SERIES WITH THE EXPERTS

Addressing Disparities in Cancer Care and Incorporating Precision Medicine for Minority Populations







Disparities of Cancer Care in the LGBTQ Community



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Faculty Disclosures

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Learning Objectives

- Review racial difference in the outcomes in patients with cancer, including patients with both hematologic and solid tumors
- Evaluate sociodemographic, physician, and hospital factors that can help identify potentially
 modifiable patient and health care system factors that may underlie persistent racial disparities in
 receipt and quality of therapy
- Develop efforts to improve access to care, enhance diversity in the healthcare workforce, navigate minority cancer patients through the healthcare system, and enhance adherence to cancer-specific best practice





Advancing Sexual & Gender Minority Health Research and Data Collection

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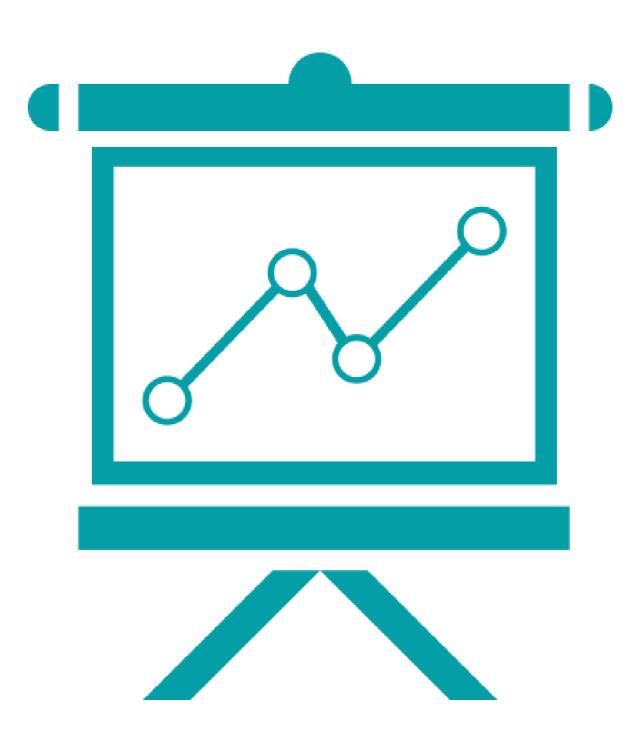
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Overview of Presentation

- Background
- Sexual & Gender Minority
 Research Office
- SGM Research Strategic Plan
- NIH SGM Grants Portfolio
- Cancer & SGM Populations
- SGM Data Collection
- Relevant Resources
- Connect with Us





Constructs to Consider

- Sex –determined via biological factors (such as external facing genitalia) and often assigned at birth; ca be non-binary (e.g., male, female, intersex)
- Gender Identity an individual's innate and personal sense of gender and how they identify along the gender spectrum; gender identity can deviate from sex (e.g., transgender, cisgender, gender nonconforming)
- Sexual Orientation an individual's emotional, romantic, and/or sexual attraction or behavior towards other people (e.g., heterosexual, gay, bisexual, asexual)

Important Definitions Regarding Sex

- Birth Sex/Sex Assigned at Birth: typically determined via presence/absence of male or female sex organs at birth
- Intersex: individuals who identify as intersex have either a congenital variation in either sex chromosomes, gonadal development, sex hormone synthesis or function, and/or appearance of external genitalia that fall outside of binary notions of male and female. Variations are referred to as differences of sex development (DSD) or intersex traits

Important Definitions Regarding Gender

- Gender non-conforming/non-binary: an individual whose gender identity, characteristics, and/or behaviors do not conform to binary constructs and social stereotypes of sex
- Transgender/trans: individuals whose gender identity is different from their sex assigned at birth
- Cisgender/cis: individuals whose gender identity aligns with their sex assigned at birth

NIH Definition of SGM

"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 samesex 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."

SGM as a Health Disparity Population

- In October 2016, NIMHD announced SGM as an officially designated health disparity population for NIH
- This designation has since facilitated the creation of tailored research projects, programs, and activities intended to tackle the distinct issues encountered by SGM individuals
- Ascertainment of SGM status in ongoing and planned population studies has been enhanced

Sexual & Gender Minority Research Office



SGMRO – What We Do

- Coordinate sexual and gender minority (SGM) health research activities across NIH
- Represent NIH at conferences and events focused on SGM research
- Serve as a resource for the extramural and NIH communities about SGMrelated research activities
- Connect extramural researchers with key NIH contacts
- Convene conferences and workshops to inform priority-setting and research activities
- Collaborate with NIH Institutes and Centers on the development of SGM health research reports
- Manage information dissemination related to SGM research
- Leverage resources and develop initiatives to support SGM health research

SGMRO – How We Accomplish Our Goals

- Sexual & Gender Minority Research
 Coordinating Committee (RCC): representatives
 from across the Institutes and Centers
- Sexual & Gender Minority Research Working
 Group (RWG): representatives from extramural institutions; reports to the Council of Councils
- Cross-Agency Collaboration:
 - HHS LGBT Coordinating Committee
 - Measuring SOGI Research Group of the Federal Committee on Statistical Methodology
 - HHS Data Council



Sexual & Gender Minority Research Strategic Plan



New NIH SGM Strategic Plan

- Focuses on FY 2021 FY 2025
- Includes activities across the agency (not just the SGMRO)
- Serves as a blueprint for SGMRO priorities and collaborations



Operational Strategic Goal Areas



Operational Goal 1: Advance rigorous research on the health of SGM populations in both the extramural and intramural research communities



Operational Goal 2: Expand SGM health research by fostering partnerships and collaborations with a strategic array of internal and external stakeholders

Operational Strategic Goal Areas



Operational Goal 3: Foster a highly skilled and diverse workforce in SGM health research

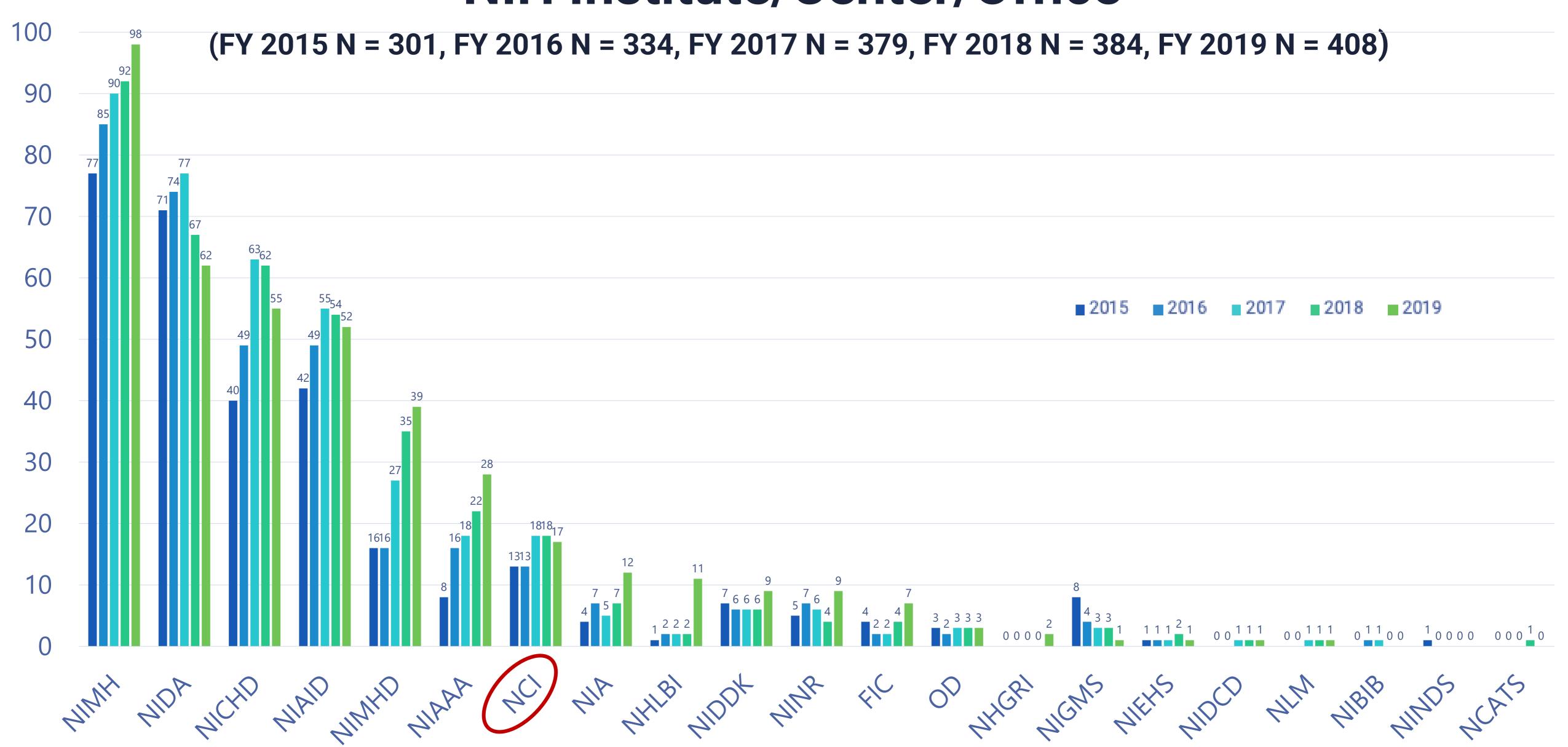


Operational Goal 4: Encourage data collection related to SGM populations in research and the biomedical research workforce

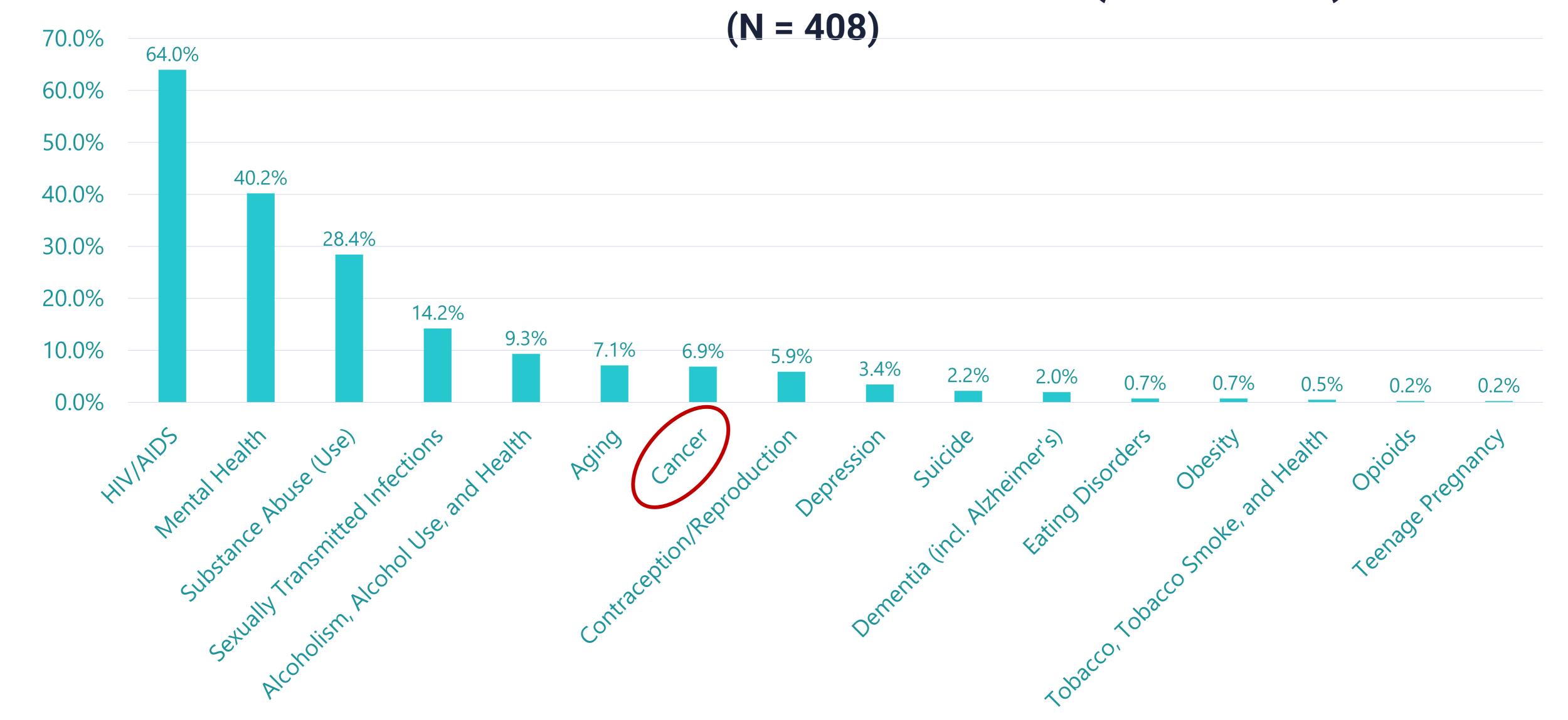
NIH SGM Grants Portfolio



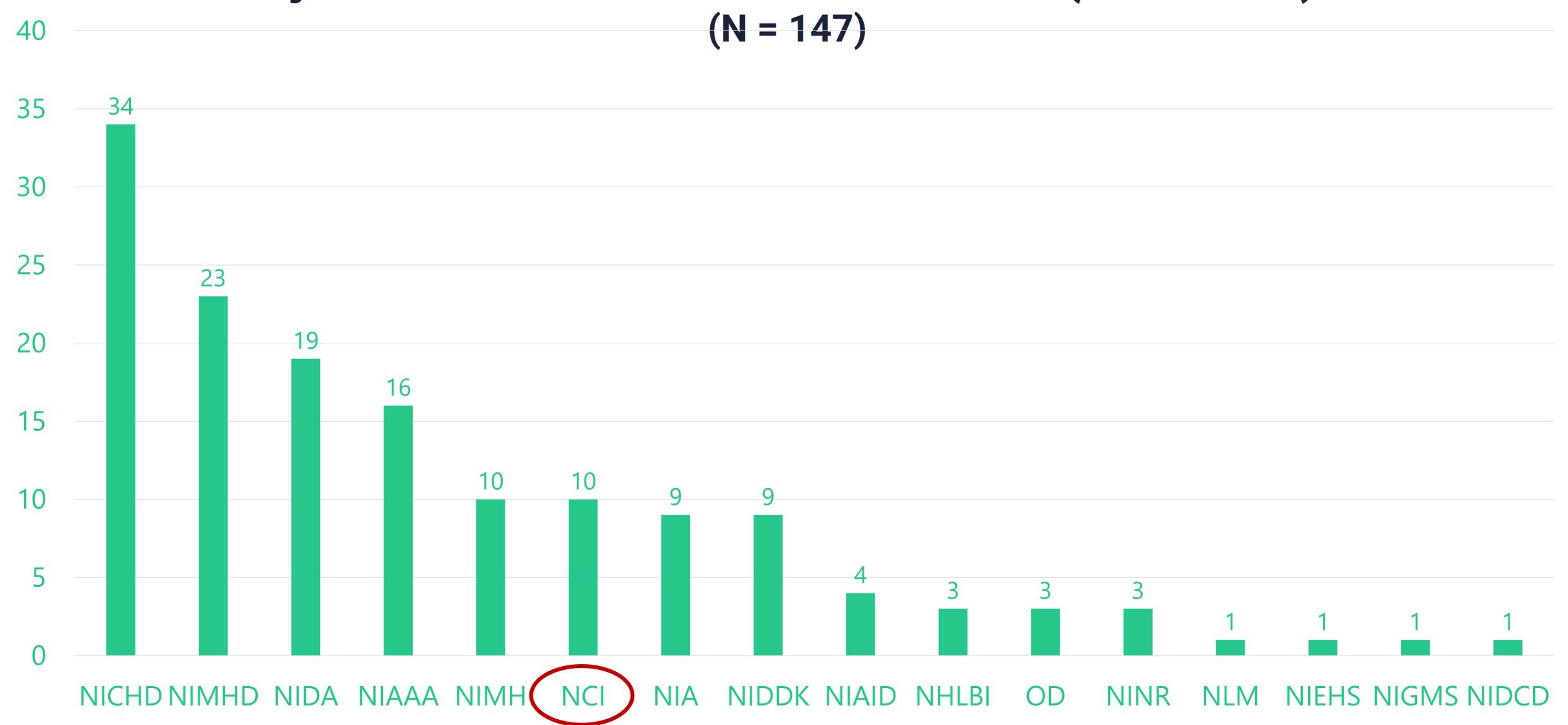
Number of SGM-Related Projects by NIH Institute/Center/Office



Proportion of SGM Projects by Disease Area/Health Condition (FY 2019)



Number of Non-HIV/AIDS Related SGM-Related Projects by NIH Institute/Center/Office (FY 2019)



Portfolio Analysis Key Takeaways

- 35.6% increase in the number of funded SGM-related projects from 2015 to 2019
- The total number of Non-HIV/AIDS projects reached its highest level ever in FY 2019
- 83.8% increase in the number of non-HIV/AIDS funded SGM-related projects from 2015 to 2019
- 18 NIH ICOs funded SGM health related work in FY 2019

Recently Funded Research Projects (Examples)

- Restore: Improving Sexual Outcomes of Gay and Bisexual Prostate Cancer Survivors – NCI
- Evaluating Companion Diagnostics to the anal Pap test to improve prediction of AIN2+ in HIV-infected MSM – NCI
- The Role of Transgender Embodiment on Breast and Uterine Cervix Cancer Screening – NCI
- Barriers to Knowledge of Family History and Family Communication among Sexual Minorities and the Implications in the Context of Hereditary Cancer Syndromes – NHGRI
- Increasing Uptake of Evidence Based Screening Services though a Community Health Worker-led multimodality - NIMHD

Cancer & SGM Populations

Cancer in SGM Populations

- Limited research on SGM populations and cancer
- National cancer registries do not collect sexual orientation and gender identity (SOGI) data
- Evidence suggests that incidence of certain cancers is higher among SGM populations
- Cancer screening rates among SGM populations overall are often low and significant gaps in screening recommendations exist for these populations^{9,10}
- SGM populations encounter significant barriers to care, including a lack of culturally competent providers

Cancer Health Disparities Among SGM Populations

Lesbian and bisexual women:

- Report higher rates of breast cancer in comparison to heterosexual women¹
- Cancer survivors report fair or poor health compared to other survivors³

Bisexual women:

 At greater risk for endometrial and ovarian cancers; less likely to undergo cancer screening procedures²

Transgender women:

 At risk of developing breast cancer if prescribed gender affirming hormone therapy⁸

Cancer Health Disparities Among SGM Populations, Cont.⁴

Transgender adults:

- Cancer outcomes may be worse for transgender adults than cisgender adults for some cancers
- More likely to be diagnosed with lung cancer at later stages
- Less likely to receive treatment for pancreas and kidney cancers
- At increased risk of death for prostate cancer, non-Hodgkin lymphoma, and bladder cancer

Cancer Health Disparities Among SGM Populations, Cont.

- **Gay men** are more likely to report having prostate and colorectal cancers when compared to heterosexual men^{5,6}
- HIV-negative men who have sex with men (MSM) are 20x more likely to have anal cancer when compared to other men
- HIV-positive MSM are up to 40x more likely to have anal cancer than other men

Issues in Cancer Care Experiences Among SGM Populations

- SGM patients are deeply affected by providers' LGBTQ-specific knowledge and skills, assumptions, and mistreatment¹¹
- Most oncologists do not feel confident in their knowledge of the SGM-specific health needs
- Majority of cancer institutions do not include questions pertaining to SOGI on intake forms¹²
- Disclosure of sexual orientation and gender identity is related to more positive health outcomes¹³

Issues in Cancer Care Experiences Among SGM Populations, Cont.

- Current models of cancer care are inadequate in accounting for transgender and gender nonconforming cancer experiences¹⁴
- SGM cancer patients want their providers to: 15,16
 - Discuss how treatments may affect SGM patients
 - Discuss impacts on sexuality
 - Avoid heterosexist assumptions
 - Recognize the importance of partners in decision making

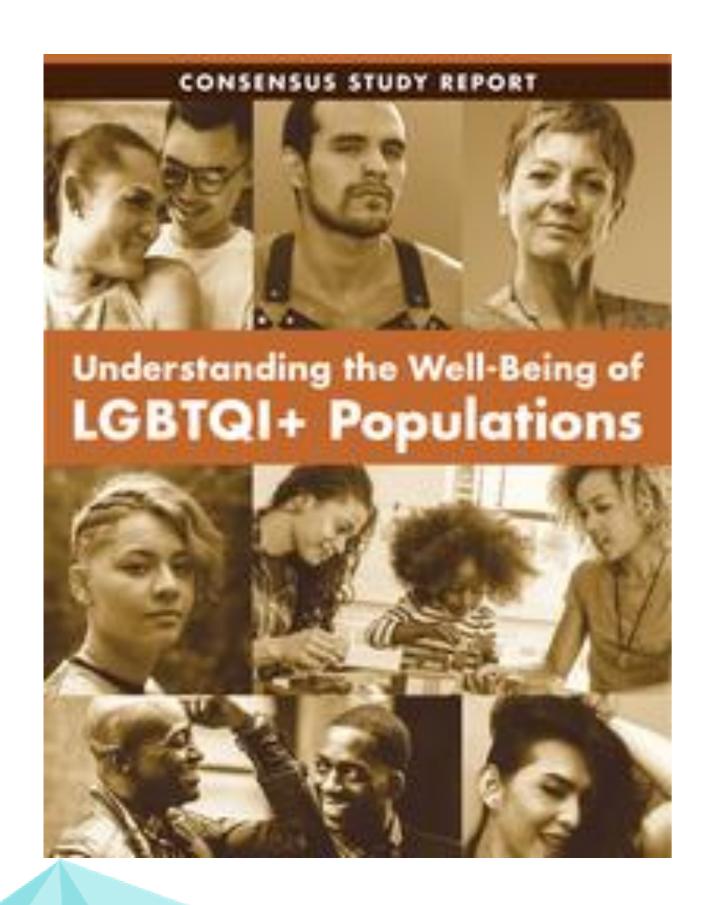
Key Takeaways

- More data is needed to better assess and resolve SGM cancer disparities
- SOGI data collection must occur in national cancer registries for adequate surveillance
- Cultural competency training for providers is critical
- Patients have demonstrated high levels of acceptability in routine collection of SOGI data in clinical settings and disclosure drives positive health outcomes

SGM Data Collection



Understanding the Well-Being of LGBTQI+ Populations (2020)



- National Academies (NASEM) Consensus Study Report released in 2020 and co-funded by the NIH SGMRO
- Report reviews available evidence and identifies future research needs related to the well-being of sexual and gender diverse (SGD) populations across the life course and across 8 different domains
- Recommendations include addition of SOGI measures to all data collection efforts and instruments, and highlight the need for methodological research to develop, improve, and expand measures that capture the full breadth of sexual and gender diversity

Current Challenges in SGM Data Collection

- Lack of data about SGM populations
- Lack of standardization across measures for collecting:
 - Non-binary sex (to capture the intersex population)
 - Gender identity
 - Sexual orientation
- Lack of standard measures in order to adequately:
 - Pool data across studies
 - Develop clear guidance for researchers, particularly those who do not conduct SGM-specific research, and others

Issues in Collecting SOGI Information^{17,18}

- Conflating sex, sexual orientation, and gender
- Utilizing binary gender construction and not incorporating gender neutral language
- Not acknowledging that sexual orientation and gender identity can change over time
- Lack of "other" options in SOGI response categories

Patient Experiences with SOGI Data Collection

- Patients across four large health centers understood the importance of SOGI data collection and would be willing to answer questions developed to collect SOGI data in health settings¹⁹
- Patients who answer questions regarding sexual orientation identity questions may feel safer discussing their health and risk behaviors²⁰
- Multiple studies have shown discordance between patient and provider beliefs regarding SO data collection. Many providers believe patients would be offended or refuse to answer, when in reality, patients are okay with disclosing this information^{21,22}

Examples of SGM Data Collection at NIH

- All of Us Research Program (https://databrowser.researchallofus.org/survey/the-basics)
 - Asks sex assigned at birth, gender identity, and sexual orientation in demographics protocol
 - Comprehensive, but not appropriate for standard federal surveys or administrative data collection
- PhenX Toolkit
 (https://www.phenxtoolkit.org/protocols/view/11801?origin=search)
 - Mirrors All of Us Research Program

Examples of SGM Data Collection at NIH

- Adolescent Brain Cognitive Development (ABCD) Study (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6584307/)
 - Asked sex assigned at birth, sexual orientation, and gender identity for cohort of 9 to 10 year old children
- NCI Health Information National Trends Survey (HINTS) (https://hints.cancer.gov/view-questions-topics/all-hints-questions.aspx)
 - Asks male or female (does not specify sex assigned at birth or gender identity) and sexual orientation

Upcoming NASEM Report

- Consensus Study Panel to determine recommended measures across three constructs: non-binary sex, gender identity, and sexual orientation
- Recommendations will be made across three domains:
 - Research (including large Federal surveys)
 - Administrative Data Collection (e.g., grant and job applications)
 - Clinical Settings (e.g., clinical trials, physician offices, community health centers)
- Report will also include guiding principles

Fenway Health Recommendations on SOGI Data Collection in Clinical Setting²³

Figure 3a. Recommended SO/GI Questions

you think of yourself as (Check one):
Straight or heterosexual
Lesbian, gay, or homosexual
Bisexual
Something else
Don't know
Choose not to disclose

What is your current gender identity? (Check one):	
	Male
	Female
	Transgender Male/Trans Man/ Female-to-Male (FTM)
	Transgender Female/Trans Woman/ Male-to-Female (MTF)
	Genderqueer, neither exclusively male nor female
	Additional gender category, please specify:
	Choose not to disclose
What sex were you assigned at birth? (Check one):	
	Male
	Female
	Choose not to disclose

Fenway Health Recommendations on SOGI Data Collection in Clinical Setting²³

- Allow for patient self-report during registration, either remotely prior to the visit or on-site
- Group questions with other demographic questions to normalize the process
- If SOGI is not reported, providers can ask during social or sexual history during the visit
- All clinical staff should be trained to communicate effectively and respectfully with patients about the reasons for collecting SOGI data and how data will be used

Relevant Resources



SGM Health/Cancer Related Resources

- National LGBT Cancer Network
- The National LGBTQIA+ Health Education Center (Fenway Institute)
- Federal Committee on Statistical Methodology Measuring SOGI Research Group
- Sage Advocacy & Services for LGBT Elders

Methods and Measurement in Sexual & Gender Minority Health Research



DPCPSI » About SGMRO » Resources » SGM Methods & Measurement



The NIH Sexual & Gender Minority Research Office (SGMRO) recognizes the growing need to develop better measures and methods to accurately capture and understand the health of sexual and gender minority (SGM) populations. The information provided highlights work within the field of SGM methods and measurement. These resources are not exhaustive. They may be useful for those looking to better understand how to capture SGM populations in research and clinical settings but do not represent standards required by NIH.

Data and Measurement Frameworks

Data Sources

Access publicly-available, nationally-representative data sources that can be used answer your SGM-related health research questions.

Quick Links

- Data Sources
- Examples of Sexual Orientation and Gender Identity (SOGI)
 Questions
- Federal Register Notice
 PDF version pdf
- Publications
- SGM Related Projects (via NIH RePORTER)

Related Federal Reports

- Current Measures of Sexual
 Orientation and Gender Identity
 in Federal Surveys pdf
- Evaluations of Sexual
 Orientation and Gender Identity
 Survey Measures: What Have
 We Learned? pdf
- Sexual Orientation in the 2013

https://dpcpsi.nih.gov/sgmro/measurement









Connect with Us

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Sign-up for NIH SGM Listserv: https://tinyurl.com/NIHSGMLIST

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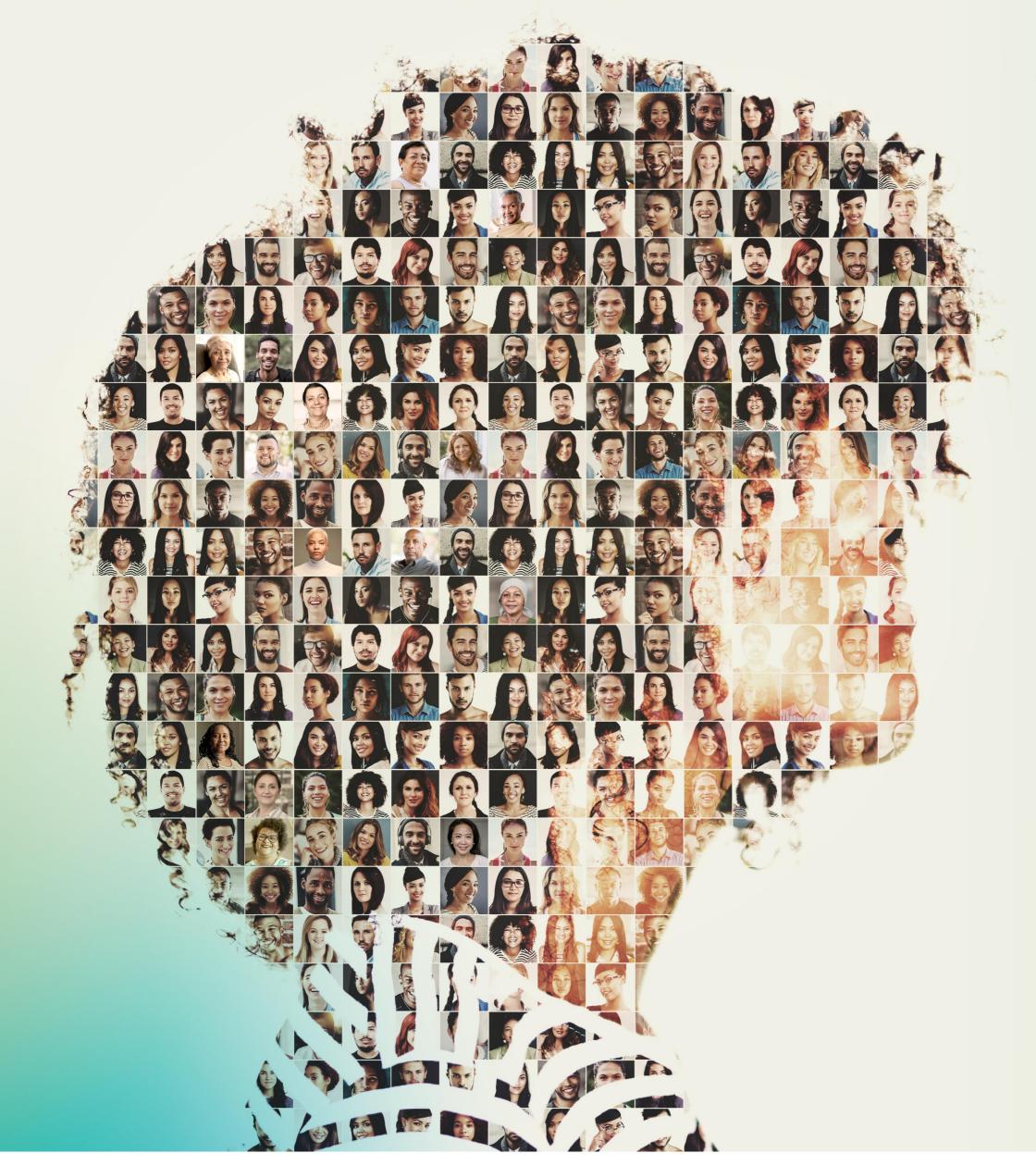
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