

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



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## WEBINAR 5: Disparities Among SGM Populations

R E S O U R C E   G U I D E

# TABLE OF CONTENTS

Introduction to Disparities Among SGM Populations [3](#)

Cancer Disparities Among SGMs [4](#)

Addressing These Disparities [5](#)

Sexual Gender Minority Research Office at NIH [6](#)

Addressing SGM Data Collection Needs [7](#)

References [8](#)



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# Introduction to Disparities Among SGM Populations



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Cancer incidence and outcomes vary considerably between racial and ethnic groups. Inequalities in wealth that lead to differential exposure to risk factor and structural barriers to high-quality cancer prevention, early detection, and treatment; and differences in death rates between non-Hispanic (NH) Black and NH White men and women are well documented.<sup>1</sup>

There is limited research on sexual and gender minority (SGM) populations and cancer largely due to the lack of sexual orientation and gender identity (SOGI) data collection as national cancer registries do not currently collect SOGI data. Existing, yet limited, data suggest that the incidence of certain cancers may be higher among SGM populations. SGM populations encounter significant barriers to care, including a lack of culturally competent providers. Cancer screening rates among SGM communities overall are often low and significant gaps in screening recommendations exist for these populations. Lack of culturally competent care and screening guidelines can lead to delays in cancer diagnosis and treatment resulting in decreased survival and quality of life. To better assess and address disparities encountered by SGMs in cancer care, enhanced data collection is vital. Current challenges in data collection relate largely to the lack of standardization of measures for sex assigned at birth, sexual orientation, and gender identity, as well as the exclusion of these measures in cancer research. The Sexual & Gender Minority Research Office (SGMRO) at the National Institutes of Health is working to help address gaps in cancer research among SGMs. As part of their efforts, the Office is currently funding a National Academies Consensus Study Panel on SOGI data collection that will culminate in a report outlining recommended measures, with specific guidance for their use, in research (academic and federal), administrative data collection, and clinical settings. The expected release date of the report is December 2021.



- Limited research on SGM populations and cancer
- National cancer registries do not collect sexual orientation and gender identity (SOGI) data
- Evidence suggests that the incidence of certain cancers is higher among SGM populations. Documented examples include:
  - Sexual minority women (SMW) are at greater risk for breast, endometrial, and ovarian cancers compared to heterosexual women<sup>1,2</sup>
  - Transgender adults are more likely to be diagnosed with lung cancer at later stages, less likely to receive treatment for pancreas and kidney cancers, and are at increased risk of death for prostate cancer, non-Hodgkin lymphoma, and bladder cancers when compared to cisgender adults<sup>3</sup>
  - Gay men are more likely to report having prostate and colorectal cancers when compared to heterosexual men<sup>4,5</sup>
- Cancer screening rates among SGM communities overall are often low and significant gaps in screening recommendations exist for these populations<sup>6,7</sup>
- SGM populations encounter significant barriers to care, including a lack of culturally competent providers<sup>8,9</sup>
  - SGM patients are deeply affected by providers' LGBTQ-specific knowledge and skills, assumptions, and mistreatment<sup>10</sup>
  - Most oncologists do not feel confident in their knowledge of SGM-specific health needs<sup>11</sup>

- Enhanced data collection is needed to better understand and address SGM cancer disparities<sup>12</sup>
- 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<sup>13,14</sup>
- Current models of cancer care are largely inadequate in accounting for SGM populations (especially transgender and gender nonbinary individuals) and must be adapted to address the unique concerns and experiences of SGMs<sup>15</sup>



## Current Challenges in SGM Data Collection

- Lack of standardization across measures for collecting non-binary sex, gender identity, and sexual orientation, which makes it difficult to:
  - Pool data across different studies
  - Develop clear guidance for researchers, particularly those who do not conduct SGM-specific research, and others on how to collect these data



## Issues in Developing Measures for SGM Data Collection<sup>16,17</sup>

- Conflation of sex assigned at birth, sexual orientation, and gender in data collection
- Utilization of a binary (and incorrect) gender construction and lack of gender-neutral language
- Failure to recognize that sexual orientation and gender identity can change over time
- Lack of “other” options in SOGI response categories



- The SGMRO sits within the Division of Program Coordination, Planning & Strategic Initiatives, within the Office of the Director at the National Institutes of Health
- SGMRO is responsible for advancing and coordinating SGM health research and related initiatives across the numerous Institutes, Centers, and Offices at the agency. Other key responsibilities include:
  - Serving as a resource for the extramural and NIH communities about SGM-related research activities
  - Convening conferences and scientific workshops to inform priority-setting and identify research opportunities/gaps
  - Manage information dissemination related to SGM research
  - Leverage resources and develop initiatives to support SGM health research and its scientific workforce within the NIH and beyond
- SGMRO is responsible for the development and implementation of the NIH-wide SGM Strategic Plan. The plan:
  - Includes scientific opportunities, goals, and activities across NIH to advance health research and overall wellbeing of SGMs
  - Serves as a blueprint for SGMRO priorities and collaborations
  - Outlines four key operational goal areas:
    - Advance rigorous research on the health of SGM populations in both the extramural and intramural research communities
    - Expand SGM health research by fostering partnerships and collaborations with a strategic array of internal and external stakeholders
    - Foster a highly skilled and diverse workforce in SGM health research
    - Encourage data collection related to SGM populations in research and the biomedical research workforce

# Addressing SGM Data Collection Needs



- SGMRO is currently funding a National Academies of Sciences, Engineering, and Medicine (NASEM) consensus study on data collection related to sex assigned at birth, sexual orientation, and gender identity
  - o This study convened a panel of experts to provide recommendations for specific measures for use in:
    - Research and Surveillance (e.g., academic, federal)
    - Administrative data collection (e.g., workplace surveys)
    - Clinical settings (e.g., patient intake forms)
  - o The consensus study panel report will also include comprehensive guidelines for the appropriate use and adaptation of these recommended measures

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