Patient-Reported Responses to Sexual Orientation and Gender Identity (SOGI) Questions in Oncology

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Background

- MASCC and other organizations advocate for the routine collection of SOGI data
 - Lack of data exacerbates invisibility
- No consensus exists on how to best query patients about SOGI
 - Must be accurate, non-intrusive, and non-stigmatizing
 - Patient privacy must be ensured

Methods

- Recruited patients with cancer from an outpatient oncology unit
- Double-blind, randomized assignment of patients to complete 1 of 2 surveys
 - Surveys contained 7 identical SOGI questions
 - Differed in question order
 - Early vs late use of terms such as "queer"
 - Developed with input from national organizations, patient advocates, and advocacy groups
 - Sought patients' *responses* to SOGI questions
 - From 1 (very uncomfortable) to 5 (very comfortable)
 - Write-in-Comments

Primary Endpoint

*Comfort (scale 3-5) with the most diverse question** Secondary Endpoints

- Associations between comfort and demographics
- Qualitative thematic analysis

*Do you consider yourself to be... [with options of] cisgender man, cisgender woman, gender non-conforming, genderqueer, non-binary, man/male, transgender man/trans man, transgender woman/trans woman twospirit, woman/female, not listed (specify), I don't know

SOMEWHAT COMFORTABLE

SOMEWHAT

VERY

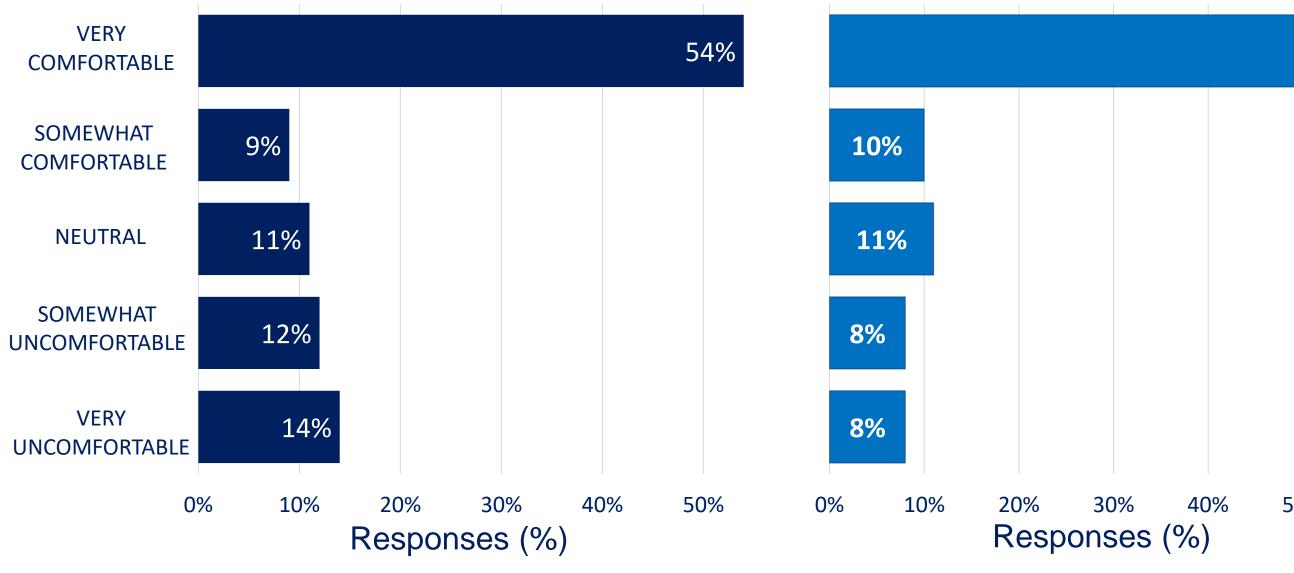
Emotional reactions to questions

3.

Comfort with SOGI Questions

✤ 440 participants; 93% participation rate

Which of the following best represents how you think of yourself?... [with options of] straight, lesbian, gay, bisexual, queer/pansexual/demisexual, asexual, not sure/questioning, I prefer to self-identify, prefer not to answer



*Univariable and Multivariable analyses did not reveal any differences based upon age, sex

Qualitative Analyses: 4 THEMES

"uncomfortable because this question is essentially gender binary;"

"all identities could be found;" "ridiculous question for a normal person" 2. Emotional reactions to SOGI collection

"bending over backwards to be politically correct;" "queer is a no go"

"shows respect for someone's self-identity"

Concern for privacy and relevance to cancer care

"This is private;" "not sure why this is needed/necessary"

"I fear if they know I'm in a same sex marriage, I won't get the best treatment"

4. Constructive remarks

"didn't know what cisgender was – please define"

Conclusions Patients with cancer are willing to participate in SOGI research Patients are comfortable with SOGI collection, despite... Negative personal views of SOGI 62% Patient age, sex assigned at birth Question/answers with potentially controversial terms Question order Why SOGI matters, descriptions of terms are helpful adjuncts to any SOGI questionnaire Based on context, SOGI collection may: help patients feel seen and heard help clinicians mitigate inequities However, it could also contribute to further stigmatization or even compromise safety of sexual/gender diverse patients Collect SOGI when benefits to patients outweigh safety risks

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