# ARE WE ASKING THE RIGHT QUESTIONS?

# Measuring Health-Related Quality of Life and Experiences with Healthcare Satisfaction and Communication among Sexual and Gender Minority Cancer Patients: A Mixed-Methods Systematic Literature Review

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## INTRODUCTION

**Sexual and Gender Minority (SGM)/ LGBTQIA+ individuals in cancer care[1]**

- Unique challenges: minority stress, stigma, and systemic exclusion.
- Negative impact: health-related quality of life (HRQoL), healthcare satisfaction, communication experiences.
- Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are essential tools to assess these dimensions.

**GAP: It remains unclear whether existing research uses inclusive, validated, and responsive instruments tailored to diverse SGM cancer populations.**

## METHOD

**Database Search**

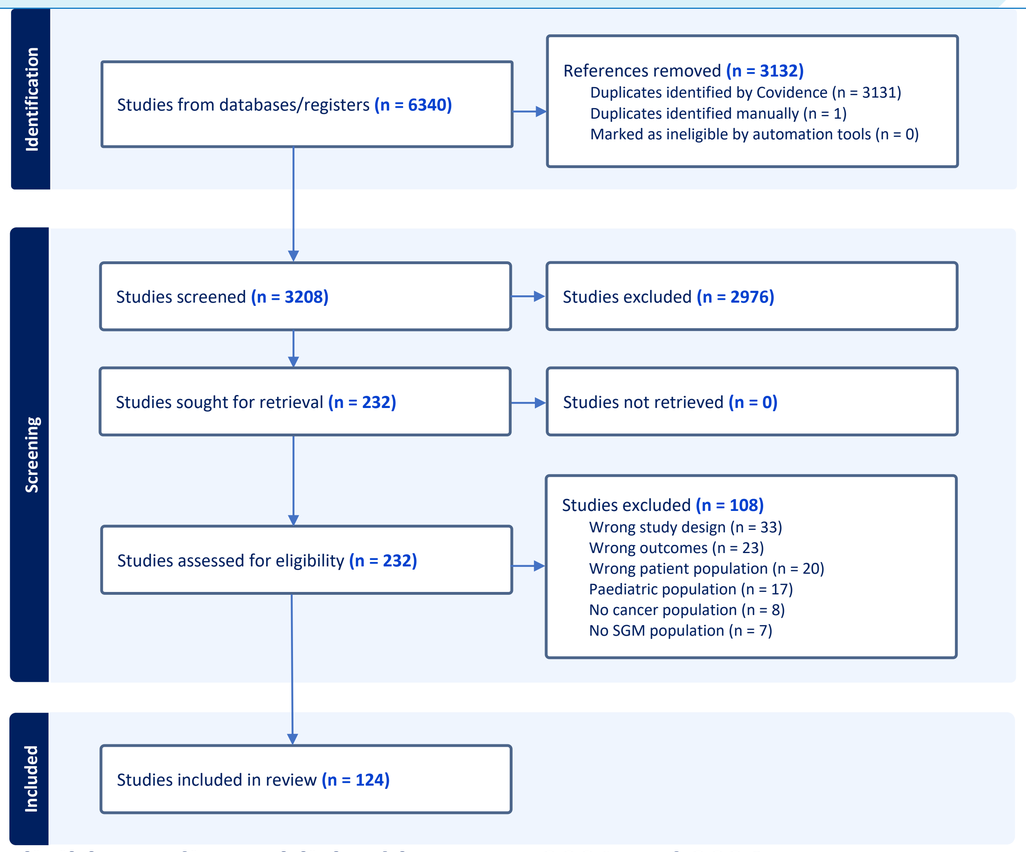
- 1) Medline, 2) Embase, 3) Web of Science, 4) CINAHL, 5) PsycINFO
- Search period: Inception – July 17, 2024

**Search strategy**

- Librarian-developed Boolean strategy: "*quality of life*", "*sexuality*", "*communication*", "*questionnaires*", "*sexual and gender minority*", "*cancer*"

**Quality assessment**

- Mixed Methods Appraisal Tool (MMAT)[2]




- **124 eligible studies published between 2001 and 2024.**

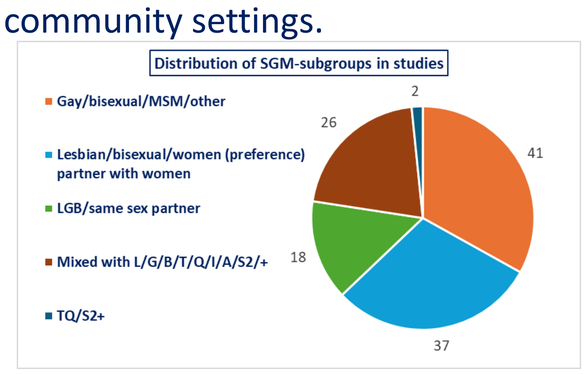
## AIM

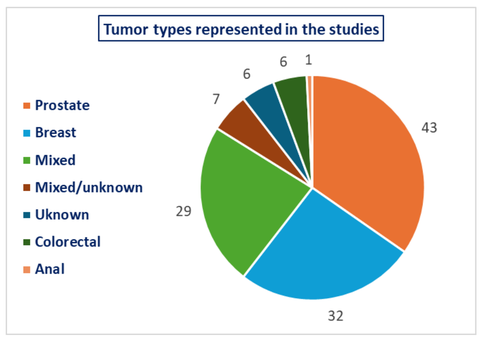
This mixed-methods systematic review[3] aims to:

1. **Synthesize existing evidence on how HRQoL and experiences with healthcare satisfaction & communication of SGM cancer patients are evaluated using PROMs and PREMs;**
2. **Identify the specific issues they report.**

## RESULTS

- Most studies were conducted in the United States (n=97).
- Quantitative descriptive (n=50) and qualitative (n=38) designs predominated, with recruitment via online platforms, clinics, and community settings.




- Only 46 studies employed SGM-specific measurement strategies, using stand-alone questionnaires and/or item lists.
- Qualitative studies highlighted additional critical domains: minority stress, chosen family, community support, partner recognition, intersectionality, changes in sexual identity, disclosure of sexual orientation and gender identity, and inclusive healthcare.

> *"'My partner came with me every three weeks for a couple of hours and not once did anyone ask: "Who is he?" or involve him. But there were straight couples there where the partner was being involved. It just seemed: "Why can't they be more friendly?" so the last thing I wanted to do was have a debate about them recognising me as a gay man."*
> (Julian, gay man, 55-64)[4]

> *"They call it the pavilion of women. So, when I get there, I'm a man in the women's pavilion. While I was waiting for the operation, there were two women with me asking, 'Are you having an operation?' I didn't feel like explaining.''*
> (Max , 54, French Canadian, breast cancer, trans man)[5]

## CONCLUSION

Despite increasing attention to SGM populations in oncology research, gaps persist in the inclusivity and specificity of PROMs and PREMs.

→ **Existing tools often lack validation for diverse SGM subgroups and may omit key domains.**

→ **Prioritization of the development and implementation of tailored instruments reflecting the lived experiences of SGM cancer patients is needed.**

## REFERENCES

1. Ussher, J.M., et al., Front Oncol, 2022. 12: 832657.
2. Hong, Q.N., et al., Mixed Methods Appraisal Tool (MMAT), version 2018.
3. Stern, C., et al., JBI Evid Synth, 2020. 18(10): 2108-2118.
4. Fish, J., et al. Cancer Nurs Pract. 2019. 18 (2), 36-41.
5. Taylor E.T., et al. LGBT Health. 2016. 3(1):79-89.

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