

# ASKING PATIENT SEX & GENDER

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Please find following a summary of a literature search and relevant results.

## QUESTION

What are the best practices in asking clients/patients questions about sex and gender (as distinct variables from each other) at intake?

## SEARCH LIMITS

English-language, last 10 years.

## SEARCH METHODOLOGY

A systematic search was conducted for literature. The results were screened by two librarians using [Covidence](#). See the Appendix for the PRISMA chart, search terms, and Medline search strategy.

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## DATABASES SEARCHED

- Medline – index of peer reviewed articles across health sciences and medicine.
- Embase – index of biomed and pharmacological peer reviewed journal articles.
- Emcare – index of nursing, allied health, critical-care medicine and more.
- Cochrane Library – collection of databases containing high-quality independent evidence.

## LITERATURE RESULTS

All articles can be provided in full text – click on the link for each citation or email [library@monashhealth.org](mailto:library@monashhealth.org) with a list of articles you require.

### PEER-REVIEWED LITERATURE - IN REVERSE CHRONOLOGICAL ORDER

Articles are grouped by theme:

- Patient Experience (p. 2)
- Electronic Medical Records (EMRs) (p. 3)
- Paediatric Population (p. 5)
- Clinician Experience (p. 6)

*Each article summary contains excerpts from the abstract and an online link.*

### PATIENT EXPERIENCE

Iv Kyrakis, C. B., et al. (2023). **Imaging Care for Transgender and Gender Diverse Patients: Best Practices and Recommendations**, *Radiographics*, 43(2), e220124. [Click for full-text.](#)

Inclusive practice in a radiology department starts with ordering and scheduling the examination, facilitated by staff education on appropriate use of a patient's chosen name, gender identity, and pronouns. Contemporary electronic health record systems have the capacity for recording detailed sexual orientation and gender identity data, but staff must be trained to solicit and use this information. A welcoming environment can help TGD patients to feel safe during the imaging experience and may include institutional nondiscrimination policies, gender-neutral signage, and all-gender single-user dressing rooms and bathrooms. Image acquisition should be performed using trauma-informed and patient-centered care.

Bindman, J. et al. (2022). **Health Care Experiences of Patients with Nonbinary Gender Identities**. *Transgender Health*, 7(5), 423–429. [Request full-text.](#)

Recommendations for the provision of gender-affirming health care for nonbinary patients include nonbinary-inclusive intake forms and electronic health records, having providers be proactive in eliciting preferred names and pronouns, and requiring education for providers and staff at all levels on the provision of nonbinary-inclusive gender-affirming health care.

Allison, M. K., et al. (2021). **Experiences of Transgender and Gender Nonbinary Patients in the Emergency Department and Recommendations for Health Care Policy, Education, and Practice**. *The Journal of Emergency Medicine*, 61(4), 396–405. [Click for full-text.](#)

Participants recommended education for current and future ED clinicians and staff to improve knowledge of best practices for trans/NB health care. Recommendations were also made to improve ED policy for inclusive and affirming intake processes, intake forms, and electronic health record (EHR) documentation, including documentation and use of patients' chosen name and pronouns.

Puckett, J. A., et al. (2020). **Perspectives from Transgender and Gender Diverse People on How to Ask About Gender.** *LGBT Health*, 7(6), 305–311. [Click for full-text.](#)

TDG participants suggested separate questions for sex assigned at birth and gender and separate questions for gender and whether participants identified as TGD.

Maragh-Bass, A. C., et al. (2017). **Is It Okay To Ask: Transgender Patient Perspectives on Sexual Orientation and Gender Identity Collection in Healthcare.** *Academic Emergency Medicine*, 24(6), 655–667. [Click for full-text.](#)

Patients see the importance of providing GI more than SO to providers; nonetheless they are willing to disclose SO/GI in general. It is crucial for providers to address their concerns with SO/GI disclosure, which include LGBT education for medical staff and provision of a safe environment.

## EMRS

Alpert, A. B., et al. (2022). **Experiences of Transgender People Reviewing Their Electronic Health Records, a Qualitative Study.** *Journal of General Internal Medicine*, ePub ahead of print. [Click for full-text.](#)

Four themes were noted. (1) Using the wrong name, pronoun, or gender marker for patients is common in the EHR, erodes trust, and causes trauma. (2) Various aspects of clinicians' notes contradict, blame, or stigmatize patients, across multiple axes of oppression. (3) Limitations of EHR capabilities create barriers to quality care. (4) Certain medical customs set the stage for marginalizing, objectifying, and pathologizing transgender people.

Baker, K. E., et al. (2022). **Will clinical standards not be part of the choir? Harmonization between the HL7 gender harmony project model and the NASEM measuring sex, gender identity, and sexual orientation report in the United States.** *Journal of the American Medical Informatics Association*, 30(1), 83–93. [Request full-text.](#)

We propose construct entities and value sets that best align with both publications to allow the implementation of EHR data elements on gender identity, recorded sex or gender, and sex for clinical use in the United States. We include usability- and interoperability-focused reasoning for each of these decisions.

Kronk, C. A., et al. (2022). **Transgender data collection in the electronic health record: Current concepts and issues.** *Journal of the American Medical Informatics Association*, 29(2), 271–284. [Click for full-text.](#)

We present recommendations and common pitfalls involving sex- and gender-related data collection in EHRs. Our recommendations leverage the needs of patients, medical providers, and researchers to optimize both individual patient experiences and the efficacy and reproducibility of EHR population-based studies.

McClure, R. C., et al. (2022). **Gender harmony: improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation.** *Journal of the American Medical Informatics Association*, 29(2), 354–363. [Click for full-text.](#)

The Gender Harmony Model is a logical model that provides a standardized approach that is both backwards-compatible and an improvement to the meaningful capture of gender identity, recorded sex or recorded gender, a sex for clinical use, the name to use, and pronouns that are affirmative and inclusive of gender-marginalized people.

Lau, F. (2021). **An Action Plan to Modernize Gender, Sex, and Sexual Orientation Information Practices in Canadian Electronic Health Record Systems.** *Canadian Journal of Community Mental Health*, 40(3). [Request full-text.](#)

This brief report contains a summary version of the proposed action plan to modernize gender, sex, and sexual orientation (GSSO) information practices in Canadian electronic health record (EHR) systems.

Lau, F., et al. (2020). **An Environmental Scan of Sex and Gender in Electronic Health Records: Analysis of Public Information Sources.** *Journal of Medical Internet Research*, 22(11), e20050. [Click for full-text.](#)

There are variations in sex and gender concepts across Canadian EHRs and the health information standards that support them. Although there are efforts to modernize sex and gender concept definitions, we need decisive and coordinated actions to ensure clarity, consistency, and competency in the definition and implementation of sex and gender concepts in EHRs.

Lau, F., et al. (2020). **A rapid review of gender, sex, and sexual orientation documentation in electronic health records.** *Journal of the American Medical Informatics Association*, 27(11), 1774–1783. [Click for full-text.](#)

The literature on GSSO documentation in EHRs is expanding. While this trend is encouraging, there are still knowledge gaps and practical challenges to enabling meaningful changes, such as organizational commitments to ensure affirming environments, and coordinated efforts to address technical, organizational, and social aspects of modernizing GSSO documentation.

Ahmad, T., et al. (2019). **Incorporating Transition-Affirming Language into Anatomical Pathology Reporting for Gender Affirmation Surgery.** *Transgender Health*, 4(1), 335–338. [Click for full-text.](#)

This group proposes inclusive diagnostic terminology for pathology reporting and puts forward recommendations for procedural descriptions in the pathology report.

Grasso, C., et al. (2019). **Planning and implementing sexual orientation and gender identity data collection in electronic health records.** *Journal of the American Medical Informatics Association*, 26(1), 66–70. [Click for full-text.](#)

This report addresses concerns by presenting recommendations for planning and implementing high-quality SO/GI data collection in primary care and other health care practices based on current evidence and best practices developed by a US qualified health centre and leader in LGBTQ health care.

Imborek, K. L., et al. (2017). **Preferred Names, Preferred Pronouns, and Gender Identity in the Electronic Medical Record and Laboratory Information System: Is Pathology Ready?** *Journal of Pathology Informatics*, 8, 42. [Click for full-text.](#)

Preferred name, pronoun preference, and gender identity have the most immediate impact on the areas of pathology. A broader challenge is that, even as EMRs add functionality, pathology computer systems (e.g., LIS, middleware, reference laboratory, and outreach interfaces) may not have functionality to store or display preferred name and gender identity.

Cahill, S. R., et al. (2016). **Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health.** *LGBT Health*, 3(2), 100–102. [Request full-text.](#)

Providers should also collect sex assigned at birth data as well as current gender identity data. Training of clinical staff in collection and use of SO/GI data, education of LGBT patients, and SO/GI nondiscrimination policies are critical for successful implementation.

Deutsch, M. B., et al. (2015). **Electronic health records and transgender patients--practical recommendations for the collection of gender identity data.** *Journal of General Internal Medicine*, 30(6), 843–847. [Click for full-text.](#)

This manuscript provides a description of identifiers associated with gender identity, and makes practical and evidence based recommendations for implementation and front-end functionality.

## PAEDIATRIC

Goldhammer, H., et al. (2022). **Pediatric sexual orientation and gender identity data collection in the electronic health record.** *Journal of the American Medical Informatics Association*, 29(7), 1303–1309. [Request full-text.](#)

Discusses the methods that pediatric primary care organizations can use to collect and document sexual orientation and gender identity information with children and adolescents in EHRs. These recommendations take into consideration children's developmental stages, the role of caregivers, and the need to protect the privacy of this information.

Kidd, K. M., et al. (2022). **Operationalizing and analyzing 2-step gender identity questions: Methodological and ethical considerations.** *Journal of the American Medical Informatics Association*, 29(2), 249–256. [Click for full-text.](#)

The 2-step method of assessing gender identity asked about gender identity (eg, “What is your gender identity?”) and sex assigned at birth (eg, “What was your sex assigned at birth?”) separately.

Guss, C. E., et al. (2020). **"It'd Be Great to Have the Options There": A Mixed-Methods Study of Gender Identity Questions on Clinic Forms in a Primary Care Setting.** *The Journal of Adolescent Health*, 67(4), 590–596. [Click for full-text.](#)

In interviews with adolescents, the questions regarding name, pronoun, gender identity, and assigned sex at birth were acceptable and interpretable to adolescents of diverse gender

identities. Participants described the questions as beneficial to all patients and perceived them as an indicator of a welcoming clinic environment.

Indyk, J. et al. (2020). **Ensuring Gender Affirming Care: Utilizing the Electronic Health Record to Improve Care of Gender-Diverse Patients in a Large Pediatric Hospital.** *Pediatrics*, 146, 304–305.

[Click for full-text.](#)

The aim was to collect and communicate information about gender identity (distinct from birth sex), affirmed name and pronouns. Our interventions included an EHR-based SOGI “smart-form” for data collection, downstream decision support tools and educational and instructional modules to educate staff about the importance of collecting and utilizing this information.

Fowler, K.G., et al. (2018). **Healthcare Experiences of Transgender and Gender Diverse Youth: A Qualitative Analysis.** *Journal of Pediatric and Adolescent Gynecology*, 31(2), 182. [Click for full-text.](#)

[Click for full-text.](#)

Use of sensitive and affirming language by health-care providers improves transgender youths’ perception of safety and welcome in healthcare settings. An added consideration is the common co-occurrence of Gender Dysphoria (GD) and Autism Spectrum Disorders (ASD). This study samples the perspectives and reactions of a broad range of gender diverse and transgender youth with the aim of capturing the types of language and communication that is most acceptable and affirming in this population.

## CLINICIAN EXPERIENCE

Mullins, M.A., et al. (2022). **“It really does not matter to me, they can be two purple unicorns”: Barriers and facilitators to sexual orientation and gender identity (SOGI) measurement in the NCI Community Oncology Research Program (NCORP).** *Journal of Clinical Oncology*, 40(28 Suppl), 170. [Click for full-text.](#)

All oncologists expressed a low relative priority of sexual orientation data for oncology care. Gender identity had higher. At the oncology care team level, perceived irrelevance to oncology care was related to discomfort in asking SOGI, fear of patient discomfort, and limited awareness of SOGI in electronic health records. Suggested solutions included: normalizing asking SOGI questions, giving patients privacy to complete SOGI, and clarifying relevance of SOGI for clinical purposes. Understanding how SOGI improves patient experiences was a facilitator for collection.

Nadler, L. E., et al. (2021). **Provider Practices and Perspectives regarding Collection and Documentation of Gender Identity.** *Journal of Homosexuality*, 68(6), 901–913. [Click for full-text.](#)

Providers did not have a protocol and absent dedicated locations in the EHR for collecting and documenting patient GI Findings indicate the need for provider training and appropriate EHR fields to support GI collection and documentation.

## SEARCH TERMS

Concept	MeSH headings	Keywords
Gender or sex diverse	Gender Identity, Transsexualism, Sexual and Gender Minorities	sex identity, sex expression, sex diverse, sex diversity, sex dysphoria, assigned sex, sex minority, sex variant, sex fluid, gender identity, gender expression, gender diverse, gender diversity, gender dysphoria, assigned gender, gender minority, gender variant, gender fluid, gender orientation
Patient records	Data Collection, Interviews as Topic, Medical Records	data collecting, data collection, data representation, data record, data recording, record keeping, electronic health record, informatics, EHRs, patient history, patient information, personal history, personal information
Best practice	Consensus, Consensus Development Conference, Consensus Development Conferences as Topic, Critical Pathways, Guideline, Guidelines as Topic, Practice Guideline, Practice Guidelines as Topic, Health Planning Guidelines	guideline, practice guideline, consensus development conference, NIH, position statement, policy statement, practice parameter, best practice, standards, guidance, recommendations, practice guideline, treatment guideline, clinical guideline, CPG, critical pathway, critical protocol. Clinical pathway, clinical protocol, practice pathway, practice protocol, care standards, care path, care pathway, care map, care plan

MEDLINE SEARCH STRATEGY

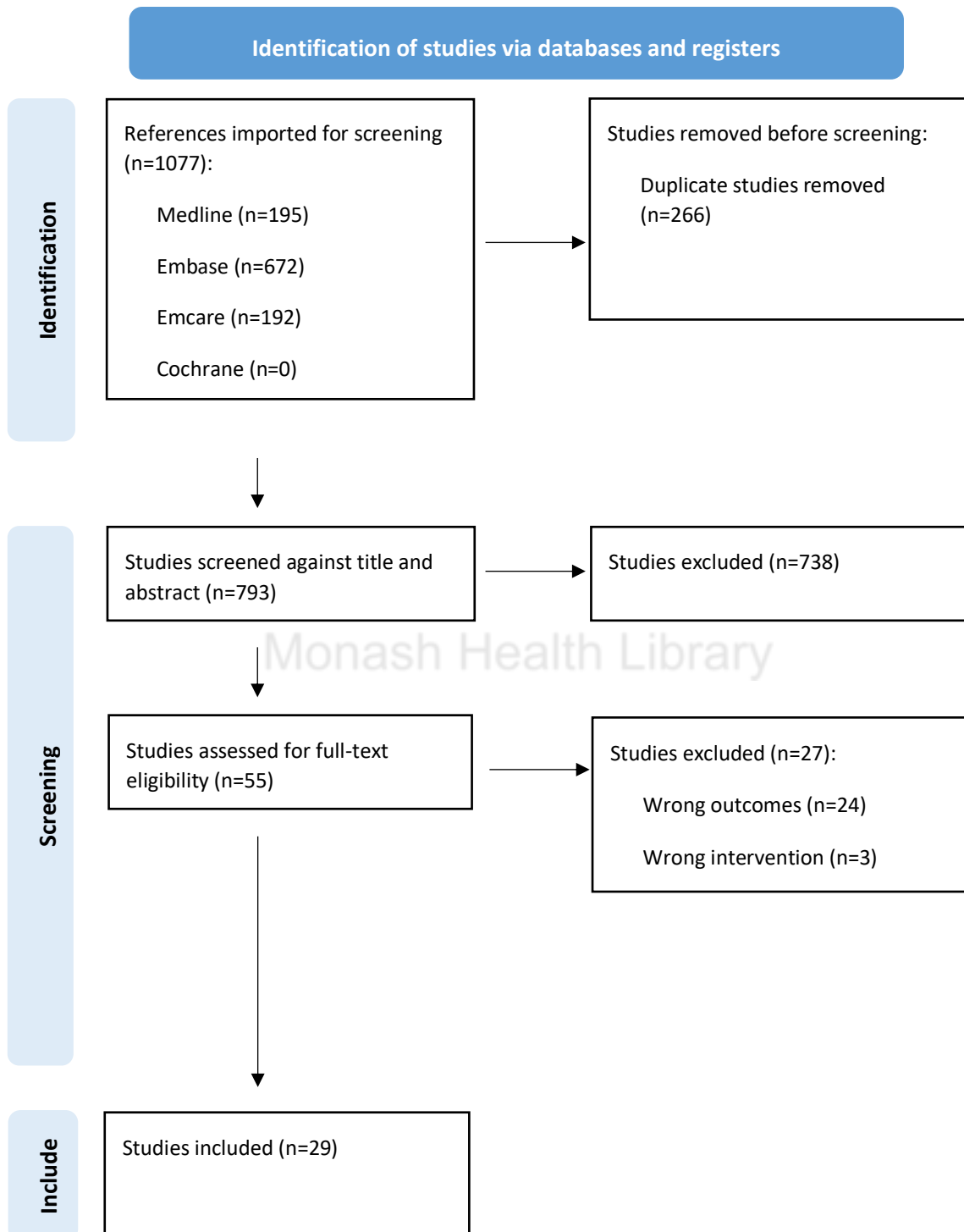
Ovid MEDLINE(R) ALL <1946 to January 20, 2023>

- 1 Gender Identity/ or Transsexualism/ or exp "Sexual and Gender Minorities"/ 36347
- 2 ((sex adj1 (identity or expression or divers\* or dysphoria or \$assign\* or minorit\* or variant or fluid)) and (gender adj1 (identity or expression or divers\* or dysphoria or \$assign\* or minorit\* or variant or fluid or orientation\*))).mp. 509
- 3 1 or 2 36476
- 4 \*data collection/ or \*interviews as topic/ or exp medical records/ 180122
- 5 (data adj4 (collect\* or represent\* or record\*)).mp. 616562
- 6 (record keeping or electronic health record\* or informatic\* or EHRs).mp. 75552
- 7 ((patient or personal) adj3 (history or information)).mp. 57026
- 8 4 or 5 or 6 or 7 849611
- 9 exp consensus/ or exp consensus development conference/ or exp consensus development conferences as topic/ or critical pathways/ or exp guideline/ or guidelines as topic/ or exp practice guideline/ or practice guidelines as topic/ or health planning guidelines/ or (guideline or practice guideline or consensus development conference or consensus development conference, NIH).pt. or (position statement\* or policy statement\* or practice parameter\* or best practice\*).ti,ab,kf,kw. or (standards or guideline or guidelines or guidance or recommendat\*).ti,ab,kf,kw. or ((practice or treatment\* or clinical) adj guideline\*).ab. or (CPG or CPGs).ti. or consensus\*.ti,kf,kw. or consensus\*.ab. /freq=2 or ((critical or clinical or practice) adj2 (path or paths or pathway or pathways or protocol\*).ti,ab,kf,kw. or (care adj2 (standard or path or paths or pathway or pathways or map or maps or plan or plans)).ti,ab,kf,kw. 1232581
- 10 3 and 8 and 9 230
- 11 limit 10 to yr="2013 -Current" 195



APPENDIX

PRISMA CHART



This report contains curated literature results against a unique set of criteria at a particular point in time. Users of this service are responsible for independently appraising the quality, reliability, and applicability of the evidence cited. We strongly recommend consulting the original sources and seeking further expert advice.