Straight until proven otherwise; improving sexual orientation and gender identity disclosure in healthcare, and its application in Manitoba.

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Abstract

Background: The 2SLGBTQIA+ community experiences disproportionately poor healthcare outcomes when compared to their cisgender-heterosexual counterparts. This disparity is thought to be primarily due to a lack of disclosure of sexual orientation and gender identity (SOGI) to healthcare providers. Failure of providers to ask patients' their SOGI is thought to be the greatest barrier to disclosure.

Objective: Discuss the best methods to collect SOGI data from a logistical standpoint, and from a patient and provider perspective.

Method: Narrative literature review using PubMed and Scopus databases

Results: Nine articles were reviewed and their results categorized into four outcome measures: SOGI fields in electronic medical records, data collection method, patient perspectives on SOGI data collection, provider perspectives on SOGI data collection.

Conclusions: Adding SOGI to electronic medical records is an important step in improving disclosure. Both patients and providers prefer an indirect method of data collection such as survey format. Patients want to know why their SOGI is being collected. Provider education in delivering queer-competent care is required. Many of these findings could be implemented in the existing healthcare infrastructure in Manitoba.

Introduction

It is well known that the Two Spirited, Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual + (2SLGBTQIA+) population experiences disproportionate barriers in healthcare and poor healthcare outcomes when compared to their cisgender-heterosexual (cishet) counterparts. 2SLGBTQIA+ people have lower rates of breast and cervical cancer screening;

higher rates of STIs; increased rates of mental health issues; more eating disorders; increased substance use disorder; polycystic ovarian syndrome; black market hormone use; heart disease; and vascular disease (1). This community also experiences disproportionate rates of domestic violence with decreased access to shelters; higher rates of homelessness; and decreased access to fertility therapy (2).

The reasons for these disparities are multifactorial and often intersectional with other social determinants of health including race, socioeconomic status, geographic location, religion, age, etc. (3). While many 2SLGBTQIA+ people experience overt homophobia in primary care, data suggests that inequitable care stems from a lack of disclosure of sexual orientation and gender identity (SOGI) to healthcare providers (4). Rates of non-disclosure were reported as 35% to 65% among a sample of lesbian, gay, bisexual, transgender, and queer (LGBTQ) adolescents (4)(5).

Many studies have focussed on ascertaining 2SLGBTQIA+ patients' perspective on disclosing SOGI to providers. Research has shown that the main barrier to disclosure of SOGI to providers is that providers don't ask. In one study involving LGBTQ patients most believed that disclosure to a healthcare provider was important but had not disclosed. When asked what providers could do to improve disclosure, 64% of patients said "just ask me" (4).

Patients often don't understand the importance of informing their healthcare provider of their SOGI, and since they are not asked they do not feel the need to disclose (5). It is evident that providers need to initiate conversations about SOGI considering the numerous health disparities that disproportionately affect sexual and gender minority (SGM) patients. Unfortunately, one study found that 49% of patients had never discussed sexual health with a provider. In a subset of lesbian, gay, bisexual, and transgender (LGBT) patients that had disclosed, the topic had only been raised by the provider in 21% of cases (4). Another study found that the average physician spends less than one minute talking about sexual health with their adolescent patients (6).

Routine collection of SOGI data is not required in Canada. A 2018 report by the Canadian Institute for Health information recommended that healthcare providers begin asking their patients for this information, however as of 2022 this is not a standardized practice (7).

Evidence suggests that nondisclosure presents the biggest barrier for equitable access to healthcare for the 2SLGBTQIA+ community (4). Although there is an abundance of research into the health disparities that effect the 2SLGBTQIA+ community, less research explores solutions to this problem. A relatively small number of primary research studies and quality improvement projects have been conducted with the goal improving SOGI disclosure in healthcare. There has yet to be a literature review that summarizes or integrates these results. The objective of this literature review was to assess the best methods to collect SOGI data from a logistical standpoint, and from a patient, and provider perspective. This is then discussed in the context of the existing healthcare system in Manitoba.

Definitions

2SLGBTQIA+

Two spirited, lesbian, gay, bisexual, transgender, queer and questioning, intersex, asexual, and other non-cishet identifying people.

SGM

Sexual and gender minority

SOGI

Sexual orientation and gender identity

Cisgender

Gender identification that is congruent with the sex assigned at birth (e.g. Assigned female at birth and identifies as a woman and uses she/her/hers pronouns).

Cishet

A colloquial term used to describe patients that identify as cisgender and heterosexual.

Queer

The term queer has different connotations among different generations of 2SLGBTQIA+ people. For the sake of this paper the term queer will refer to individuals that identify themselves as part of the 2SLGBTQIA+ community.

Methods

This paper is a narrative literature review. Primary research was found using PUBMED and Scopus. Search terms were: "Sexual orientation and gender identity" or SOGI AND data collection AND health*. Qualitative, quantitative, and mixed-methods primary research between 2010-2022 was accepted. Articles were appraised using a standardized data collection form that included country, sample type, sample size, intervention used to improve SOGI disclosure, outcomes, themes, and strengths/limitations (Appendix A).

The objective of this literature review was to determine the best way to collect SOGI information from a logistical perspective as well as the patient and provider perspectives. In order to meet this objective it was necessary to develop outcome measures to categorize the data collected from each primary source. The outcome measures developed were as follows: results of adding SOGI categories to electronic health records (EHR)/electronic medical records(EMR);

efficacy of a given SOGI data collection method; patient perspectives on the collection of SOGI data; and provider perspectives on the collection of SOGI data. These findings were then discussed in the context of broader research regarding the health of SGM people, and in the context of the Manitoba healthcare environment. Strengths and limitations of the research used for this study was also discussed.

Results

Search Results

Search criteria yielded 222 results. Duplicates were removed for a total of 159 results. Titles and abstracts were reviewed for 159 articles and 28 articles were selected for further analysis. Of the 28 articles selected for a full text read-through, 3 articles were removed due to full text not being available online. An additional 16 articles were ruled out due to irrelevant content or failure to meet the “primary research” criterion (Figure 1).

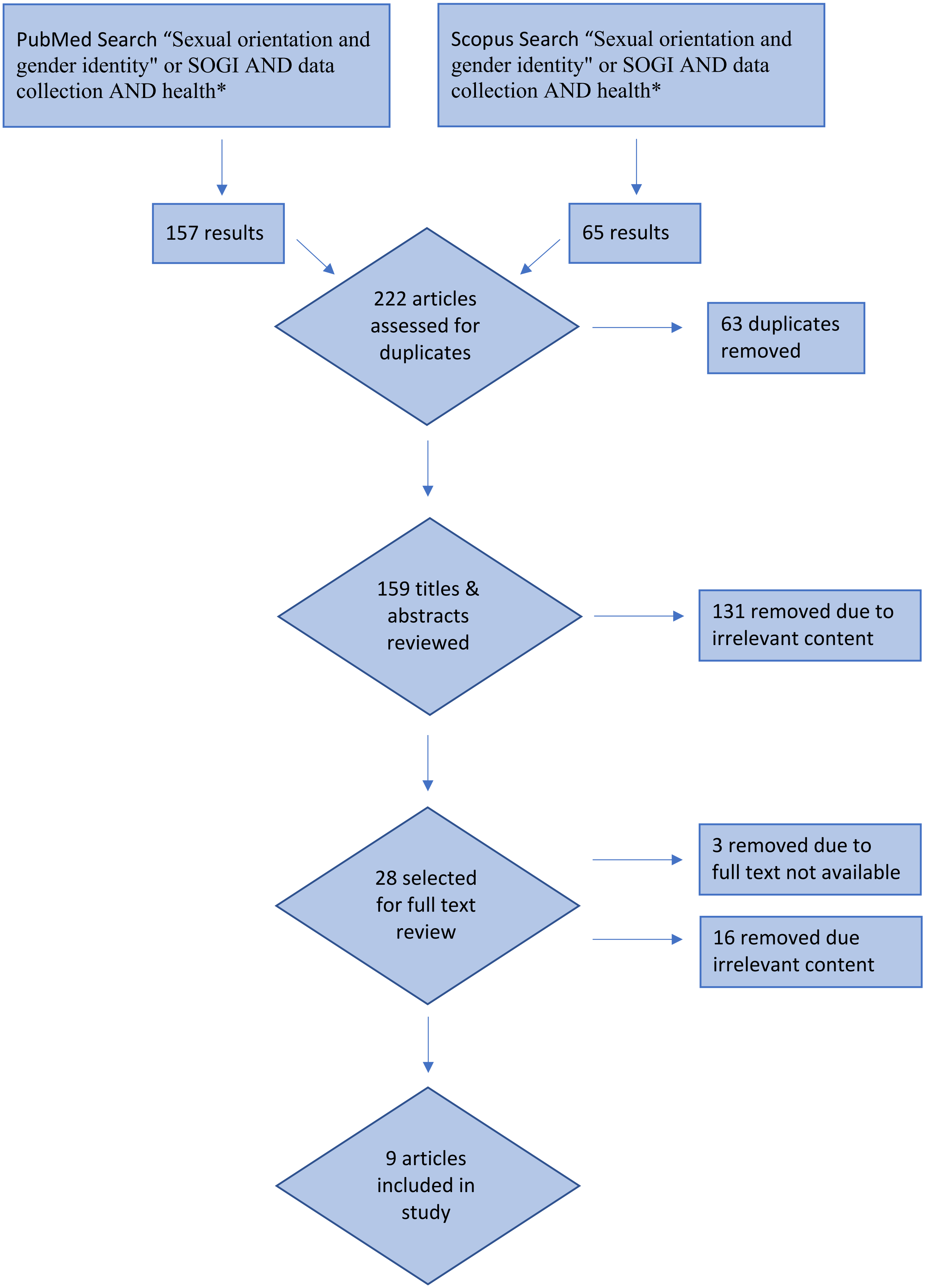

Figure 1. Flowchart of literature review process.

Outcome measure 1: Results of adding SOGI categories to EHR/EMRs

A 2021 study in the Journal of Pediatric and Adolescent Medicine conducted a retrospective chart review analysing the rate of SOGI documentation before and after the addition of SO and GI fields to the EMR. They found that sexual orientation documentation increased from 13.7% to 45.1%, and gender identity documentation increased from 1.4% to 46.5% (8).

In 2020 the results of a large American quality improvement project were published. This project, titled "Transforming Primary Care for lesbian, gay, bisexual, and transgender people: A collaborative quality improvement initiative" involved 10 federally qualified healthcare centres (FQHCs) in rural and urban environments. It implemented a plan-do-study-act approach to improve SOGI documentation and subsequently improve STI screening among the SGM population. This project added SO and GI fields to their EHR, provided coaching and education to the healthcare centres, identified project leaders within each centre, and publicly announced their commitment to the project. This project led to an increase in SOGI documentation from 13.5% to 50.8%. The success of this project was attributed to its holistic approach as well as the public commitment to the project which was thought to improve accountability of the centres (9). Despite the improved data collection, the addition of SO and GI fields alone did not necessarily translate to the accurate collection of sexual risk information.

Finally, a quality improvement study from the University of California Davis Health Systems (UCDHS) provided anecdotal findings that changing the EHR alone was not sufficient to significantly improve SOGI documentation. Also following a plan-do-study-act method, UCDHS provided education to health care providers and publicly announced their commitment to meeting the "Human Rights Campaign" requirements for health equality. Although this study did not provide statistical evidence of improvement, their anecdotal findings suggested that the combination of EHR modification, provider education, and a public declaration of their project all contributed to an improvement in SOGI documentation and patient care (10).

Outcome measure 2: SOGI data collection method

A Canadian study at St. Michael's Hospital in Toronto implemented a two-question survey to collect SO and GI data. A total of 15,221 patients were surveyed with a 93.6% response rate. They found that 166 participants selected a gender identity other than what was on their health card, and of these 166 participants 63 had a formal diagnosis of gender dysphoria. Participants noted that they found the number of SO and GI options to choose from was affirming. Others indicated that they would have appreciated a definition of each identity on the survey to ensure they were picking the one that best reflected their identity. Transgender patients were more likely to choose their current gender identity (male, female, non-binary, etc.) rather than transgender. Participants also noted a need for an "other" category on the survey, in case none of the terms accurately reflected their SOGI. Some participants felt that being asked to identify their SOGI brought back past traumatic experiences of their interactions with healthcare (11).

A matched-cohort study conducted in the US investigated patient preference for SOGI data collection methods. A total of 540 adult (18+) patients were asked their SOGI either verbally or using a standardized form. Results indicated that both SGM patients and cishet patients were more comfortable disclosing their SOGI using a standardized form (12).

A study of 225 oncology patients required participants to fill out self-report studies on their preferred method of SOGI data collection. In this instance 70% of patients preferred to be asked verbally about their gender, and 69% preferred verbal questions for their sex assigned at birth. Most patients preferred an online reporting forum for their pronouns and their sexual orientation (13).

Outcome Measure 3: Patient perspectives on the collection of SOGI data

Patient interviews and focus groups elicited detailed feedback regarding patients' perspective on SOGI data collection. A common finding was that SGM patients want to know why they are being asked their SOGI (14)(15). Participants felt more comfortable answering SOGI questions if they believed it was routinely asked of all patients (15). Patients also voiced concerns that once they disclosed their SGM identity they would be treated differently or discriminated against by providers, or that providers would make assumptions about their sexual practices based on their SOGI (15). Having an established relationship with the provider helped patients to feel more comfortable revealing their SOGI (15).

Additional contextual factors influenced a patient's willingness to disclose their SOGI. Patients wanted to know how their SOGI data would be used (14). Patients looked for contextual signs of safety in their environment such as safe space and pride posters, and felt more comfortable revealing their SGM if they could identify SGM staff (14). Finally, patients preferred to be asked their SOGI in the context of discussing their health, rather than in an administrative context (14).

Outcome measure 4: Provider perspectives on the collection of SOGI data

Provider resistance to the collection of SOGI data was found across multiple studies (9)(10). Providers objected because they did not feel comfortable asking SOGI questions without proper training, as well as the additional administrative burden of collecting this data (10). This data comes from two quality improvement projects which allowed them to make modifications to their projects throughout its course. In both instances additional training increased providers' willingness and comfort in asking SOGI questions (9,10). One project used clinical "champions" to facilitate the education arm of the project, as well as group lectures and coaching sessions to address specific concerns (9). The other QI project implemented grand rounds that were eligible for CME credits and mandatory workshops for general internal medicine, family medicine, obstetrics and gynaecology, and pediatric residents (10). In both projects education of providers led to favourable outcomes; providers were more comfortable and less resistant to asking SOGI questions.

A case study titled "The San Francisco Health Network SOGI Systems-Change Initiative" analyzed the results of a systematic approach to collect SOGI data (16). Providers received training to collect SOGI data and patients were advised of the initiative prior to having their data collected. Data was collected in survey form, which was available in five languages. Findings indicated that providers preferred this method of self-report data collection, and that after training 88% of providers were comfortable using patients' preferred pronouns. SOGI data was collected in 26.8% of all patient encounters (16).

Discussion

The findings of this literature review have implications for future healthcare practices in improving disclosure of SOGI data. SGM people frequently report that when they interact with healthcare they are assumed to be heterosexual(5,17). This assumption places the onus on SGM patients to disclose their SOGI to access appropriate healthcare. The onus to disclose is not faced by the cishet population. Patients also report encountering assumptions based on their appearance or their gender identity (2,17). These heteronormative assumptions have been associated with healthcare avoidance by SGM individuals (3). Given this data it is easy to see the importance of fostering an environment in which sexual orientation and gender identity is asked rather than assumed.

This literature review has provided insight into three focus areas: how to engage and train healthcare providers to collect SOGI information; when and how to ask patients their SOGI information; and how to record SOGI information. The remainder of this discussion will answer these questions. The application of these results will then be discussed within the context of the Manitoba healthcare system.

How to engage and train healthcare providers to collect SOGI information

Quality improvement projects that employed a plan-do-study-act model with a comprehensive education component had the greatest success in implementing SOGI data collection (9,10). Evidence suggests that up to 80% of providers believe that asking SOGI information will offend patients, yet most patients report being unbothered by these questions (18). QI studies were able to address these misconceptions as they arose. The QI project at the UCDHS initially intended to only update their EHR, but encountered resistance from staff who stated they were uncomfortable asking SOGI questions without training. Resistance to this program slowly dissipated by using a combination of grand rounds and mandatory education for residents on 2SLGBTQIA+ health disparities, the role for SOGI data collection, and how to collect such data (10). Similarly the QI project involving ten federally qualified health centres encountered initial staff resistance, however at the end of the project all ten centres agreed that the training in LGBTQ terms, concepts, and health disparities helped them collect SOGI data(9). This study was largely successful, increasing SOGI data collection from 13.5% to 50.8% (9). Finally, in the San Francisco case study, 88% of providers reported that they were comfortable collecting SOGI data and using correct pronouns following training to do so (16).

Public commitment was also found to be beneficial in improving SOGI collection. Public announcement of the FQHCs project was thought to improve provider engagement in the project. Initially this QI project only involved 10 FHQC sites, however an additional 69 sites encompassing 431 providers adopted similar programs throughout the duration of this project(9). The UCDHS project also reported that their commitment to Health Equality Inventory evaluation from the Human Rights Commission led to a sense of institutional pride, consequentially improving commitment to the project(10).

The data from these projects suggest that a flexible and supportive approach to improving SOGI disclosure rates is likely to be the most efficacious. Different clinics face different barriers, have different staff, and serve different patient populations. When providers were given the opportunity to learn about the queer community and motivated by public commitment they were more likely to engage in the projects. Improving healthcare for queer patients is long overdue, however the challenges of implementing a new way to practice should not be overlooked or discounted. The research suggests that healthcare providers are willing to adopt new practices if they have the support and motivation to do so.

When and how to ask SOGI information

Both the patient and provider perspective should be considered when deciding how to collect SOGI information. Creating a safe environment for SGM patients to disclose and discuss their SOGI is as important as ensuring providers feel comfortable asking. Fortunately, both providers and patients prefer a survey or online collection format to help mitigate discomfort for both parties (12,14,19). SGM patients expect to encounter discrimination and microaggressions from their healthcare providers once they disclose their SOGI(5). Patients reported feeling less vulnerable to discrimination and more in control of their autonomy when a survey format was used to collect SOGI information (14). In one study a simple two-question survey asking SO and GI had a 93.6% response rate, suggesting that an intervention which is simple for both patient and provider could be a highly effective and acceptable way to capture SOGI information (11).

This literature review also found that the timing in which SOGI was asked was important to patients. Patients preferred to be asked in a healthcare context rather than an administrative context, and only if it was relevant to their care (14,15). Patients also want to know why they are being asked, whether or not it is routine, and how their data will be used (14,15). These findings suggest that there may be contexts in which SOGI data should not be collected if it is not directly related to care. It is likely that this applies more to the collection of sexual orientation data than the standardized collection of gender identity and pronouns, which has been shown in multiple studies to be widely accepted by patients (20). In contrast and in keeping with previous research, patients only want to disclose their sexual orientation when it is relevant to their care, suggesting that family practice is an ideal place to implement routine collection of SOGI information (21).

As expected the findings of this literature review mirrored previous research suggesting that creating an inclusive environment was also key to facilitating SOGI disclosure (14). Previous research has amassed additional suggestions for improving disclosure among SGM patients. One young patient suggested that having brochures outlining topics that queer patients should discuss with their provider would be an effective way to facilitate disclosure. Other suggestions included inquiring about sexual activity with all genders, creating a 2SLGBTQIA+ safe environment using appropriate signage, asking patient's their pronouns, and using terms like "partner" rather than "boyfriend" or "girlfriend" (2,21). Patients also want their providers to be familiar with unique needs to the 2SLGBTQIA+ community, including safe sex practices and gender affirmation therapies (2). The promise of confidentiality was also a critical factor influencing SOGI disclosure, especially in youth and in rural settings (4,22). In all instances, heteronormativity and assumptions about a patient's SOGI created barriers to care (5,22).

The findings of this literature review indicate that the best way to collect SOGI information may be on an intake survey that asks other biopsychosocial determinants of health questions, with a statement of confidentiality and an explanation of how data will be used. According to patients these surveys should also list a number of different identities/orientations with appropriate definitions of each, and an "other" free-form category(11). Based on previous research, practitioners should also take care to use appropriate pronouns, use inclusive terms, ensure confidentiality, increase visual safe-space cues, and remain educated on topics pertinent to the 2SLGBTQIA+ community.

How to record SOGI information

EHR modification alone had an impressive impact on SOGI collection in multiple studies. EHR modification was linked with substantial increases to SOGI collection rates in one centre (13.7% to 45.1% for SO, 1.4% to 46.5% for GI)(8). Other studies had even more substantial results when combined with other interventions such as provider education (9,10). While it is evident that EMRs will benefit from system modifications to allow for the collection of SOGI data, research indicates that there are several additional factors that must be considered.

Modifying EMR systems to identify SGM individuals does not accurately explain their behaviour or risk information(9). This concern is echoed by patients who worry that assumptions about their behaviour will be made based on their SOGI (15). Previous research has indicated that these concerns are shared by providers, who worry that including SOGI in EMR without additional contextual information may create a barrier to care. Identifying SOGI is important, however providers also need to know their patients' sexual behaviours and anatomy. Providers worry that if EMRs only collect SOGI without additional sexual and gender health information patients may be at an even greater risk of facing health disparities (23). Finally, from a patient perspective an EMR system that categorizes patients in a way that does not feel representative of their true identity can be further marginalizing (24).

These results indicate a need for EMR modifications that capture data relevant to health care providers while still respecting gender and sexual diversity. Evidence from the USA demonstrates that EMRs can be modified to include these categories. Patient perspectives indicated the need for flexibility in the ways in which this data is collected and presented to accurately reflect their SOGI and their sexual behaviours. Patients need to receive preventative healthcare on an individualized level. Individualized healthcare needs to account for factors beyond patients' SOGI such as sex and gender of partners, number of partners, protection methods, gender affirmation goals and timelines, as well as the intersectional socioeconomic issues that affect each patient. Further research is needed to identify specific modifications that could be made to EMRs to accurately capture this data without overwhelming providers with an administrative burden that would limit its use. Additionally, while sexual behaviour and anatomical information can and should be collected on the intake of new patients to a practice, additional research is needed to determine the best way to collect this data from existing patients without causing further marginalization.

Application in Manitoba

The success of many of the projects and studies discussed is this literature review has been attributed to improving provider education of 2SLGBTQIA+ healthcare while simultaneously implementing SOGI data collection initiatives. In Manitoba, providing education regarding queer competent care to attendings, physician assistants, and nurse practitioners presents the greatest challenge, as these parties are no longer engaged in a formal education curriculum. Previous research has shown that grand rounds and seminars that are eligible for continuing education credits have been an effective way to engage providers. Grand rounds present one opportunity to increase education, however their reach is limited by provider schedules and interest. Providing 2SLGBTQIA+ informative literature to primary care providers may also be an effective avenue to facilitate education. Educating residents, fellows, and students is the best option, both in terms of delivery and impact. Residents, fellows, and students represent the future generation of medicine and are still formally involved with an educational curriculum. The QI project at UCDHS implemented mandatory sessions titled “How to Talk to Patients About Sexual Orientation and Gender Identity” for a select group of residents that frequency interact with 2SLGBTQIA+ patients. These sessions were well received and reported to be helpful by the residents (10). Residents in Manitoba engage in mandatory education sessions as part of their curriculum, making similar sessions to those delivered at UCDHS a feasible option. The 2021 annual report from the College of Physicians and Surgeons stated that in the last 10 years 33% of medical practitioners in Manitoba were educated in Manitoba(25).

This makes the Rady College of Medicine the largest individual educator of healthcare providers in Manitoba. Rady College of Medicine therefore has the unique opportunity to offer 2SLGBTQIA+ education as part of the medical foundations learned by future healthcare providers.

At present there is no standardized process to collect SOGI data in Manitoba. Clinics use different EMRs to track their patient data, and it is up to each clinic to decide if/how to capture SOGI data and how to record it. It is not standard practice to collect SOGI data in Manitoba hospitals. The healthcare landscape of Manitoba provides a unique opportunity to implement change. Healthcare in Manitoba is largely centralized in Winnipeg, and overall is subdivided into only five regional health authorities. Such centralization means that a large quality improvement project could theoretically be initiated. In Winnipeg there are seven Access Centres that belong to the Winnipeg Regional Health Authority. These Centres offer healthcare and other social services to meet the needs of the community in which they are located. Access Centres already have experience and resources that cater to marginalized communities. Given their existing structure, Access Centres may be an appropriate place to implement a pilot project that incorporates the findings of this literature review, such as the use of intake surveys that collect SOGI information.

Finding a way to appropriately screen the 2SLGBTQIA+ community for relevant health issues is a field that needs additional research. In Manitoba “Primary Care Quality Indicators” or PCQIs are used to ensure special populations are receiving appropriate healthcare services unique to their needs. PCQIs have been developed by Manitoba physicians, specialists, and public health to encourage primary care providers (PCPs) to engage in preventative health screening, chronic disease management, and mental health and addictions management.

Providers are encouraged to attach PCQIs to appropriate patients. These PCQIs will then prompt the provider to inquire about the PCQI topic on an appropriate schedule (26). For example, a PCQI for diabetes prompts the physician to ensure the patient is having routine eye checks, foot checks, and bloodwork every year. The efficacy of PCQI implementation is twofold. First it financially incentivizes the PCP to identify patients belonging to specific patient populations, and second it ensures timely follow up on health issues specific to a given population.

Theoretically a 2SLGBTQIA+ PCQI could be an effective way to use SOGI data to improve healthcare outcomes for the queer community. It is important to recognize that poor healthcare outcomes for 2SLGBTQIA+ people are due to more than just healthcare avoidance. This can be demonstrated using the example of cardiovascular health. In a 2020 statement the American Heart Association (AHA) attributed many of the adverse health outcomes of the queer community to “minority stressors”(27). Minority stressors are unique challenges faced by a specific population, for example family rejection, violence, discrimination, etc. According to the AHA, one effect of minority stressors is the increased likelihood that people will engage in unhealthy coping methods that increase cardiac risk factors (27). Minority stressors is just one of the connections that the AHA draws between the 2SLGBTQIA+ community and increased risk of cardiovascular disease. This demonstrates how biopsychosocial factors contribute to physical health, and creates an avenue for intervention.

Currently PCQIs exist for preventative health, diabetes, asthma, congestive heart failure, hypertension, coronary artery disease, osteoporosis, COPD, and mental health and addictions. A PCQI for patients that identify as sexual or gender minorities could prompt providers to offer STI screening more routinely, screen for cardiovascular disease, eating disorders, substance use disorder, and mental health issues more frequently, and inquire about other issues affecting specific 2SLGBTQIA+ communities such as safe access to gender affirming therapies. A similar targeted approach was effective in the QI project implemented in FQHCs, when SOGI data was collected and then used to screen for STIs in the LGBT population. In this instance STI screening in the queer patient population improved by 132.4% after SGM patients were identified . However this also demonstrates how categorizing based on SOGI alone may increase biases and assumptions against these groups. It is therefore important to balance screening for health issues that disproportionately affect 2SLGBTQIA+ patients with appropriate safeguards to reduce implicit bias.

Any projects implemented in Manitoba would require input from the local queer community and organizations supporting the queer community such as Klinic, Nine Circles, and Rainbow Resource Centre. This input is needed to ensure the healthcare needs of the queer community are met without further stigmatizing these patients. Input is also needed from health authorities and PCPs to ensure the suggested project is feasible. The results of this literature review demonstrate that there is potential for increased SOGI data collection to lead to better screening and ultimately better healthcare outcomes for the queer community.

Strengths and limitations

Strengths

The articles used for this literature review included projects that involved buy-in from the 2SLGBTQIA+ community as well as healthcare providers and public health in their design. Urban and rural projects were included, as was a wide age range including adolescents, adults, and seniors. Many projects included large and diverse samples, both in terms of patient demographics (race, gender identity, sexuality, socio-economic status, age) and in terms of type of healthcare interaction (obs/gyne, oncology, family medicine, emergency medicine). Through this literature search multiple outcome measures were attainable, providing patient and provider perspective as well as data on EHR/EMR interventions and data collection methods.

Limitations

The main limitation of this project and of other similar projects is that there is no way to account for patients that are sexual and gender minorities but not comfortable disclosing this to their provider. This limitation inevitably skews results as it fails to fully assess if any of the interventions increase SOGI disclosure among individuals that would have previously been hesitant to disclose. Similarly, this literature review is not able to comment on whether the collection of SOGI information resulted in better healthcare outcomes for the queer communities being studied.

The other major limitation of the research used in this literature review is the inconsistency in methodology between studies. Each study employed its own approach rather than following a common framework. Although conclusions can still be drawn from this body of work, there is a limited ability to make direct comparisons between findings or employ statistical analysis. Some studies also had a large proportion of cisgender heterosexual participants which could also skew the results. Finally, the data used in this literature review is primarily from American studies.

Future research recommendations

Future research should focus on each individual aspect of collecting SOGI data that was discussed above: how to engage providers; how and when to collect SOGI information; how to record information; and how to use information. Current primary research regarding SOGI data collection is largely qualitative and often retrospective, limiting its generalizability and creating opportunities for bias or error. Future research using matched-cohort methodology and larger sample sizes would be beneficial to determine the impact of given interventions on SOGI disclosure and healthcare outcomes. Additional Canadian research is also needed.

Conclusions

Sexual orientation and gender identity disclosure is an important step to ensure 2SLGBTQIA+ patients receive appropriate healthcare. Despite most queer patients being ready and willing to disclosure their SOGI, they are rarely asked and therefore rarely disclose. Failure to disclose SOGI results in the provision of heteronormative care, which decreases queer patients' access to culturally appropriate care and causes higher rates of healthcare avoidance. Multiple solutions to this problem have been investigated and trialed in the format of quality improvement projects or research studies. Findings suggested that quality improvement projects have a high success rate in improving SOGI disclosure. Projects involving provider education, using surveys to collect data, and having EMRs that could collect SOGI information were most successful. Adding SOGI to electronic medical records is an important step in improving disclosure. Patients are more likely to disclose if they understand why their SOGI is being asked and if they are asked in a context in which they feel comfortable. A possible application of these findings in Mantioba could be through a quality improvement pilot project targeting the Access Centres and using the existing Primary Care Quality Indicators system.

1. Milner GE, McNally RJ. Nonadherence to Breast and Cervical Cancer Screening Among Sexual Minority Women: Do Stigma-Related Psychological Barriers Play a Role? Heal Psychol. 2020;
2. Bass B, Nagy H. Cultural Competence in the Care of LGBTQ Patients. StatPearls. 2021.
3. Utamsingh PD, Richman LS, Martin JL, Lattanner MR, Chaikind JR. Heteronormativity and practitioner–patient interaction. Health Commun. 2016;31(5).
4. Meckler GD, Elliott MN, Kanouse DE, Beals KP, Schuster MA. Nondisclosure of sexual orientation to a physician among a sample of gay, lesbian, and bisexual youth. Arch Pediatr Adolesc Med. 2006;160(12).
5. Rossman K, Salamanca P, Macapagal K. "The doctor said I didn't look gay": Young adults' experiences of disclosure and non-disclosure of LGBTQ identity to healthcare providers HHS Public Access. J Homosex. 2017;64(10).
6. Snyder BK, Burack GD, Petrova A. LGBTQ youth's perceptions of primary care. Clin Pediatr (Phila). 2017;56(5).
7. In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality A Focus on Age, Sex, Gender, Income, Education and Geographic Location. Ottawa; 2018.
8. Sokkary N, Awad H, Paulo D. Frequency of Sexual Orientation and Gender Identity Documentation After Electronic Medical Record Modification. J Pediatr Adolesc Gynecol. 2021;34(3).
9. Furness BW, Goldhammer H, Montalvo W, Gagnon K, Bifulco L, Lentine D, et al. Transforming primary care for lesbian, gay, bisexual, and transgender people: A collaborative quality improvement initiative. Ann Fam Med. 2020;18(4).
10. Callahan EJ, Sitkin N, Ton H, Eidson-Ton WS, Weckstein J, Latimore D. Introducing sexual orientation and gender identity into the electronic health record: one academic health center's experience. Acad Med. 2015 Feb;90(2):154–60.
11. Pinto AD, Aratangy T, Abramovich A, Devotta K, Nisenbaum R, Wang R, et al. Routine collection of sexual orientation and gender identity data: A mixed-methods study. CMAJ. 2019;191(3).
12. Haider A, Adler RR, Schneider E, Uribe Leitz T, Ranjit A, Ta C, et al. Assessment of Patient-Centered Approaches to Collect Sexual Orientation and Gender Identity Information in the Emergency Department: The EQUALITY Study. JAMA Netw open. 2018 Dec;1(8):e186506.
13. Alexander K, Walters CB, Banerjee SC. Oncology patients' preferences regarding sexual orientation and gender identity (SOGI) disclosure and room sharing. Patient Educ Couns. 2020;103(5).
14. 'Suen LW, 'Lunn MR., 'Sevelius JM., 'Flentje A., 'Capriotti MR., 'Lubensky ME., et al. Do Ask, Tell, and Show: Contextual Factors Affecting Sexual Orientation and Gender Identity Disclosure for Sexual and Gender Minority People. LGBT Heal. 2022;9(2):73–80.
15. Ogden SN, Scheffey KL, Blosnich JR, Dichter ME. "Do I feel safe revealing this information to you?": Patient perspectives on disclosing sexual orientation and gender identity in healthcare. J Am Coll Health. 2020;68(6):617–23.
16. Rosendale N, Fishman A, Goldman S, Pardo S, Scarborough A, Bennett A. Systematic Collection of Sexual Orientation and Gender Identity in a Public Health System: The San Francisco Health Network SO/GI Systems-Change Initiative. Jt Comm J Qual Patient Saf. 2020;46(10).

17. Morris M, Cooper RL, Ramesh A, Tabatabai M, Arcury TA, Shinn M, et al. Training to reduce LGBTQ-related bias among medical, nursing, and dental students and providers: A systematic review. BMC Med Educ. 2019;19(1).
18. Rullo JE, Foxen JL, Griffin JM, Geske JR, Gonzalez CA, Faubion SS, et al. Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial. Health Serv Res. 2018 Oct;53(5):3790–808.
19. Pinto AD, Aratangy T, Abramovich A, Devotta K, Nisenbaum R, Wang R, et al. Routine collection of sexual orientation and gender identity data: a mixed-methods study. C Can Med Assoc J = J l'Association medicale Can. 2019 Jan;191(3):E63–8.
20. Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, et al. Do ask, do tell: high levels of acceptability by patients of routine collection of sexual orientation and gender identity data in four diverse American community health centers. PLoS One. 2014;9(9):e107104.
21. Fuzzell L, Fedesco HN, Alexander SC, Fortenberry JD, Shields CG. "I just think that doctors need to ask more questions": Sexual minority and majority adolescents' experiences talking about sexuality with healthcare providers. Patient Educ Couns. 2016;99(9).
22. Logie CH, Lys CL, Dias L, Schott N, Zouboules MR, MacNeill N, et al. "Automatic assumption of your gender, sexuality and sexual practices is also discrimination": Exploring sexual healthcare experiences and recommendations among sexually and gender diverse persons in Arctic Canada. Heal Soc Care Community. 2019;27(5).
23. Dichter ME, Ogden SN, Scheffey KL. Provider Perspectives on the Application of Patient Sexual Orientation and Gender Identity in Clinical Care: A Qualitative Study. J Gen Intern Med. 2018 Aug;33(8):1359–65.
24. Scheffey KL, Ogden SN, Dichter ME. "The Idea of Categorizing Makes Me Feel Uncomfortable": University Student Perspectives on Sexual Orientation and Gender Identity Labeling in the Healthcare Setting. Arch Sex Behav. 2019 Jul;48(5):1555–62.
25. Manitoba TC of P and S of. 2021 Annual Report. 2021.
26. Manitoba Provincial Government. Primary Care Quality Indicators. https://www.gov.mb.ca/health/primarycare/providers/pcqi.html. 2020.
27. Caceres BA, Streed CGJ, Corliss HL, Lloyd-Jones DM, Matthews PA, Mukherjee M, et al. Assessing and Addressing Cardiovascular Health in LGBTQ Adults: A Scientific Statement From the American Heart Association. Circulation. 2020 Nov;142(19):e321–32.

Appendix A

Article Title	Year and Country Journal	Method	Sample Type	Sample Size	Objective	Intervention	Outcomes	Themes	Strengths/ Limitations
Frequency of Sexual Orientation and Gender Identity Documentation After Electronic Medical Record Modification	2021- USA *Journal of pediatric and adolescent gynecology*	Retrospective chart Review	Outpatient pediatric and adolescent gynecology clinical practice Ages 14-18 inclusive	Sample 146 Population 1150	Investigate if EMR modification improved SOGI disclosure	Implementation of SOGI documentation tabs into EMR	Significant increase in SOGI documentation after EMR change. SO: 13.7% to 45.1% GI: 1.4% to 46.5%	Documentation was still at less than 50% of patients. Most documentation was in social history Documentation did increase disclosure Documentation does not equate to meaningful intervention	**Strength**: Documented race and type of visit - no significant relationship. Sample size was to the appropriate power of the population Random selection of encounters **Limitations**: Type of clinic might have made pre-disclosure rates abnormally high (gyne) Patients all female or AFAB. Participants were "out" enough to participate in LGBTQ study, data is skewed and doesn't include a closeted LGBTQ sample.
Transforming primary care for lesbian, gay, bisexual, and transgender people: A collaborative quality improvement initiative	2020 -USA *Annals of Family Medicine*	Pre-Post intervention study. 1 year timeline.	Federally qualified health centers	10 Centers	Increase STI and HIV screening among MSM and MTF women	Blended "practice improvement collaborative initiative" and "Project Extension for Community Health Outcomes" 1.Coaching to create inclusive environments. 2. Collecting SOGI data 3. Risk based sexual histories 4.Screening LGBT people for	Culturally affirming practice increased by 42.9% Identifying LGBT liaisons increased by 300% SOGI documentation increased by 276.3% (13.5-50.8%) STI screening improved: 86.5% syphilis 109% Chlamydia and Gonorrhea 132.4% HIV The intervention expanded from 10 clinicians at 10 clinical	No financial incentive was required for participation Education was beneficial Regular virtual check-ins and coaching was helpful. Publicly announcing dedication to this project may have improved follow-through.	**Strengths:** Rural and Urban Engagement from LGBT community **Limitations:** Clinics were already interested in LGBT healthcare. no control group did not include all gender groups including gender queer or "other". Participants were "out" enough to participate in LGBTQ study, data is skewed and doesn't include a closeted LGBTQ sample.

						STIs. Each clinic received coaching calls, free resources online, clinic-developed question forms, training on LGBT health disparities twice monthly, outreach with LGBT organizations, LGBT advisory groups, virtual monthly reports, a clinical champion	sites (ie, 1 clinician at 1 clinical site per FQHC), to 431 clinicians at 79 clinical sites, although adoption varied greatly among FQHCs Staff resistance can be a problem Translation can be a problem Other FQHCs agreed that creating a more culturally affirming clinical environment through training staff in LGBT terms, concepts, and health disparities helped them with successfully collecting SOGI data and providing risk-based sexual health screening. All FQHCs encountered challenges with capturing sexual risk information in structured formats within EHRs, - unable to report these data.		
Routine collection of sexual orientation and gender identity data: a mixed-methods study	Canada 2019	Survey and semi-structured interviews (not anonymous)	St Michaels in Toronto	15221	Improve SOGI disclosure	Survey asking patients their SOGI Two questions on the survey.	93.6% rate 166 patients chose a gender identity not congruent with their sex on their health care. 103 did not have a dx of gender dysphoria disorder. Patients with a dx of gender dysphoria disorder were more likely to select prefer not to answer or "don't know" about GI Many transgender patients choose "male" or "female" as their GI rather than transgender Interview results: Many patients reported that	Need to include male and female as well as "male (FTM)" and female (MTF) Survey method had a very high response rate. Need an "other" section for SOGI data	**Strengths** Advisory groups created buy-in from LGBT community, hospitals and family health centres, and patients **Limitations** Not inclusive of all SOGIs Single institution in a very LGBTQ friendly area. Did not include provider or survey/interview administrator training. Participants were "out" enough to participate in LGBTQ study, data is skewed and doesn't include a closeted LGBTQ sample.

							having many SOGI options to select from was affirming. Many patients wanted explanations of each identity on the survey. Some LGBTQ people found the questions brought up their past trauma of discrimination in healthcare/personal lives.		
Assessment of Patient-Centered Approaches to Collect Sexual Orientation and Gender Identity Information in the Emergency Department: The Equality Study	USA- 2018 *Journal of the American Medical Association Network Open*	Matched Cohort Study	Four emergency departments in the Eastern United States	540 patients aged 18 or older.	To assess the optimal patient-centered approach for SOGI collection in the emergency department (ED) setting.	SOGI data was collected on ED patients using verbal questions or using a standardized form. SGM and cis-het patients were matched and comfort/satisfaction with collection method was compared.	Significantly more SGM patients felt comfortable reporting their SOGI when asked using a standardized form. No signifiant difference for cis-het patients.	Standardized forms provide a more comfortable way for SGM minority patients to disclose SOGI	**Strengths** Study design was formulated using a multidisciplinary team including LGBTQ health advocates. Large sample size Data was collected over one year Data was collected at both academic and community sites Nurses doing collection of data received LGBTQ education prior to collection. Data was adjusted for other variables such as race. **Limitations** Participants were “out” enough to participate in LGBTQ study, data is skewed and doesn’t include a closeted LGBTQ sample. Sample excluded substance abuse and psychiatric patients. These issues disproportionately affect the LGBTQ community and therefore should have been included to accurately reflect the queer community.

Systematic Collection of Sexual Orientation and Gender Identity in a Public Health System: The San Francisco Health Network SO/GI Systems-Change Initiative	USA- 2020 *Joint commission journal on quality and patient safety*	Case Study	Patients and Providers involved in the San Francisco Health Network	7807 providers 53418 patients. 60285 unique encounters	Determine number of providers trained and change in SOGI data collection	Data collection only undertaken by providers that had been trained to do so. Patients were to be advised of the initiative to collect this data prior to collection Collection of name and pronoun Providing provider education All data collected via survey form. Survey available in 5 languages.	Providers preferred to collect data by self-report system 88% of providers surveyed felt comfortable using correct pronouns after training. 26.8% of encounters collected SOGI data.	A very low number of unique encounters involve SOGI disclosure even with this intervention Surveys are more comfortable for providers, which may improve initiative uptake.	**Strengths** Community buy in and staff input Comprehensive survey **Limitations:** No pre-intervention data collected No control group Poor metrics reporting Participants were “out” enough to participate in LGBTQ study, data is skewed and doesn’t include a closeted LGBTQ sample.

Do Ask, Tell, and Show: Contextual Factors Affecting Sexual Orientation and Gender Identity Disclosure for Sexual and Gender Minority People	2022- USA *LGBT Health*	Focus Groups Cognitive Interviews Results were transcribed and coded for analysis	Sexual and Gender minority (SGM) identifying individuals from US recruited from the PRIDE study and using social media/flyers. Aged 18+. Fluent in english.	74 individuals	To understand what contextual factors affect SOGI disclosure for SGM people	Thematic analysis: SGM perspective on factors affecting their willingness to disclose SOGI.	Participants wanted to know why they were being asked SOGI data even in healthcare Participants expressed concern with being asked if it wasn't relevant to the immediate treatment (eg relevance in the context of a broken arm) Participants wanted to know how their SOGI would be used. Participants prefer to be asked in a health context as opposed to an administrative context Participants use different words to describe their SOGI based on context Participants look for environmental ques of safety before disclosing their SOGI Seeing other SGM people working in an environment where the question is being asked increased the likelihood of disclosure Format of question was also relevant. Participants were more comfortable with a survey/tablet format because it provided less chance of discrimination and stigma. Also protected their autonomy	Participants have a general distrust of any institution asking their SOGI Participants expect to encounter homophobia and discrimination When asked about SOGI, participants are hypervigilant to nonverbal cues from the asker.	**Strengths** Provides context and direct opinions / perspectives of SGM individuals **Limitations** Not specific to healthcare setting Small sample size and based on individual experiences rather

Oncology patient's preferences regarding sexual orientation and gender identity (SOGI) disclosure and room sharing.	2020 USA *Patient education and counselling*	Self report surveys Results were stratified and analyzed based on patient perceptions of sharing SOGI information and demographics	Oncology patients	225	Assess oncology patient perspectives on answering SOGI questions. Determine comfort with room sharing based on SOGI identifiers	Thematic analysis: Preferred mode of disclosure Comfort in sharing room Text	70% of patients prefered verbal questions for gender 69% preferred verbal questions for sex at birth Online reporting was preferred for asking pronouns and sexual orientation. 15-20% of patients reported there was no need to ask their SOGI data Heterosexuals were relatively okay with sharing a room with a patient with a different SO. Females were less comfortable sharing a room with MTF Males were comfortable sharing a room with FTM	Preference for online /non-face to face reporting. Many patients do not understand the importance of SOGI data	**Strengths** Provides patient perspective **Limitations** Largely heterosexual and cisgender patient populations.
Introducing Sexual Orientation and Gender Identity Into the Electronic Health Record. One Academic Health Center's Experience	2015 USA University of California, Davis, Health System's (UCDHS's) *Academic*	Quality Improvement Project	Patients at California Davis Health System	n value unknown	Determine if the QI project improved SOGI disclosure rates	QI to improve SOGI documentation in EHR Task force creation of faculty, med students, hospital	Initial plan was to just update EHR. However found that this was not sufficient to increase SOGI data collection Initially strong objections from staff due to discomfort with questions and lack of training.	Modifications to EHR alone were not enough to improve SOGI Provider discomfort is a barrier which can be overcome with appropriate training Patients are receptive of being asked	**Strengths** -QI model allowed for adjustments and continuous improvement in response to needs -Focused on provider perspective **Limitations** No numerical data on success rates

	Medicine					administrators Education implemented in response to staff resistance. Grand rounds and brief information. Grand rounds were usable for CME credit Education on LGBT health disparities Education on ways that SOGI data can help reduce health disparities Health Equality Inventory evaluation by Human Rights Campaign was requested leading to a public commitment to change Internal press releases about the project Presentation of goals and results at senior leadership meetings introduced a two-hour,	Initial response to goals and results presented at senior leadership meetings was met with minimal engagement which improved overtime. No complaints regarding questions within 13 months of program running Anecdotal evidence shows that meeting the HRCs standards for SOGI requirements has given “institutional pride”	SOGI	No data on efficacy of survey vs verbal questions

						mandatory workshop for general internal medicine, family medicine, pediatrics, and obstetrics–gynecology residents about asking SOGI. included role play scenarios. Residents reported finding this helpful Created an avenue for patient complaints if they encountered a non-lgbt friendly provider. Created a list of LBGT friendly providers online, Patients had two options to provide data, an online questionnaire or verbally. Patients also had the option to not disclose.			

"Do I feel safe revealing this information to you?": Patient perspectives on disclosing sexual orientation and gender identity in healthcare	2019 USA *Journal of American college health*	Focus groups with thematic analysis	Undergraduate and graduate university students in an urban city in the USA	70 survey respondents 34 focus group participants	Identify considerations in SOGI disclosure from the patient perspective	Thematic analysis of factors influencing disclosure	Respondents were hesitant to reveal SOGI data if they didn't understand its relevance to their care Participants better understood the relevance of asking their gender identity (as it relates to body parts and pronouns) than they did sexual orientation. Some participants noted that they were more comfortable answering SOGI data if it was obvious that it was routinely asked of patients. Patients indicated they would be more comfortable providing their SOGI data if they had an established relationship with the provider. Patients are worried they will be treated differently or judged by their provider if they disclosure non cishet SOGIs. This worry is based on both previous experience with providers and hypervigilance regarding discriminiation. Patients are worried that if they disclose their SOGI the provider will make assumptions about their behaviour or medical requirements (often based on previous experience)	Patients feel more comfortable discussing SOGI if it is relevant to care Patients feel more comfortable discussing SOGI if seems routinely asked Patients are less likely to reveal SOGI if they perceive that it will be negatively received. Patients are less likely to disclose their SOGI to a new provider.	**Strengths** Free form questions and focus groups allowed researchers to elicit in-depth patient perspectives **Limitations** Small sample size Population limited to university students 41% of participants were heterosexual