

Appendices

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Collecting information on dimensions of equity, diversity, and inclusion in electronic medical records (EMRs)

4 June 2024

[MHF product code: REP 72]

Appendix 1: Methodological details

We use a standard protocol for preparing rapid evidence profiles (REP) to ensure that our approach to identifying research evidence is as systematic and transparent as possible in the time we were given to prepare the profile.

Identifying research evidence

For this REP, we searched Health Systems Evidence and PubMed for:

- 1) evidence syntheses
- 2) protocols for evidence syntheses that are underway
- 3) single studies.

We searched [Health Systems Evidence](#) using filters for ‘health record systems’ and ‘electronic health records’ combined with open text terms for (equity OR race OR ethnicity OR demographic OR language). In [Health Evidence](#), we used an open text term for (equity OR race OR ethnicity OR demographic OR language) AND (electronic health record OR electronic medical record). In [PubMed](#), we used an open text search for (“Medical Records”[Mesh]) AND (“Racial Groups/statistics and numerical data”[MAJR] OR “Ethnicity/statistics and numerical data”[MAJR] OR “Social Determinants of Health/statistics and numerical data”[Mesh] OR “Demography/statistics and numerical data”[Mesh]). Links provide access to the full search strategy.

Each source for these documents is assigned to one team member who conducts hand searches (when a source contains a smaller number of documents) or keyword searches to identify potentially relevant documents. A final inclusion assessment is performed both by the person who did the initial screening and the lead author of the rapid evidence profile, with disagreements resolved by consensus or with the input of a third reviewer on the team. The team uses a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provides a running list of considerations that all members can consult during the first stages of assessment. In total, we screened 730 results and included 20 documents.

During this process we include published, pre-print and grey literature. We do not exclude documents based on the language of a document. However, we are not able to extract key findings from documents that are written in languages other than Chinese, English, French, or Spanish. We provide any documents that do not have content available in these languages in an appendix containing documents excluded at the final stages of reviewing. We excluded documents that did not directly address the research questions and the relevant organizing framework.

Assessing relevance and quality of evidence

We assess the relevance of each included evidence document as being of high, moderate, or low relevance to the question.

Two reviewers independently appraised the quality of the guidelines we identified as being highly relevant using AGREE II. We used three domains in the tool (stakeholder involvement, rigour of development, and editorial independence) and classified guidelines as high quality if they were scored as 60% or higher across each of these domains.

Two reviewers independently appraise the methodological quality of evidence syntheses that are deemed to be highly relevant using the first version of the [AMSTAR](#) tool. Two reviewers independently appraise each synthesis, and disagreements are resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. High-quality evidence syntheses are those with scores of eight or higher out of a possible 11, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to those pertaining to health-system arrangements or implementation strategies. Furthermore, we apply the AMSTAR criteria to evidence syntheses addressing all types of questions, not just those addressing questions about effectiveness, and some of these evidence syntheses addressing other types of questions are syntheses of qualitative studies. While AMSTAR does not account for some of the key attributes of syntheses of qualitative studies, such as whether and how citizens and subject-matter experts were involved, researchers' competency, and how reflexivity was approached, it remains the best general quality-assessment tool of which we're aware. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, an evidence synthesis that scores 8/8 is generally of comparable quality to another scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the evidence synthesis can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the evidence synthesis should be discarded, merely that less confidence can be placed in its findings and that it needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7(Suppl1): S8.)

Identifying experiences from other countries and from Canadian provinces and territories

For each REP, we work with the requestors to collectively decide on what countries (and/or states or provinces) to examine based on the question posed. For other countries, we search relevant government and stakeholder websites including national-level ministries or departments of health as well as select foundations or charitable groups. In Canada, a similar approach was used, searching the website of ministries of health and provincial health agencies. While we do not exclude content based on language, where information is not available in English, Chinese, French, or Spanish, we attempt to use site-specific translation functions or Google Translate. A full list of websites and organizations searched is available upon request.

Preparing the profile

Each included document is cited in the reference list at the end of the REP. For all included guidelines, evidence syntheses, and single studies (when included), we prepare a small number of bullet points that provide a summary of the key findings, which are used to summarize key messages in the text. Protocols and titles/questions have their titles hyperlinked, given that findings are not yet available.

We then draft a summary that highlights the key findings from all highly relevant documents (alongside their date of last search and methodological quality) as well as key findings from the jurisdictional scan.

Appendix 2: Key findings from evidence syntheses and single studies

Features of data collection	Key findings from evidence syntheses and single studies
Findings about what should be collected (e.g., dimensions of equity)	<ul style="list-style-type: none"> One recent low-quality evidence synthesis noted the importance of collecting data on gender, sex, and sexual orientation and suggested this could best be accomplished by ensuring data entry for preferred name and pronouns and a two-step question for gender identity and birth sex (1) Two older single studies and one recent single study noted the importance of collecting sexual orientation (or gender identity of sexual partner) and gender identity to improve the understanding of LGBTQ health (2; 3) <ul style="list-style-type: none"> The recent single study has implemented a two-step question for gender identity, which separates sex assigned at birth and gender identity as expressed, and noted that it better supported trans-identifying patients (4)
Findings about by whom information is collected	No findings about who is best positioned to collect information
Findings about when data is collected	<ul style="list-style-type: none"> One older single study found that patients felt it was more important to provide information about their sexual orientation and gender identity in primary care than in emergency department settings (3)
Findings about frequency of data collection	<ul style="list-style-type: none"> One recent single study found that almost half of patient records in Australia had unknown or missing Indigenous identification status recorded (5) One older single study found that in a large health system in the northeastern U.S., only 45% of electronic health records had documented sexual orientation, with less documentation among patients over the age of 50, persons with Medicare, individuals seen in suburban practices, and individuals being seen at non-residency family medicine practices (3) One recent study from the U.S. found that codes related to social determinants of health in electronic medical records are being vastly underused and are only included in an estimated 2% of records (6) One recent single study found race and ethnicity were misreported in 13% and 6%, respectively, of electronic health records (EHRs), with multi-racial and Hispanic patients being the most likely to have their demographics misreported (7) <ul style="list-style-type: none"> The study also found that gender was missing for most patients and 11% of gender identity entries present in the EHR were discordant with the patient's self-identity (7)
Findings about enablers of data collection	<ul style="list-style-type: none"> One recent low-quality evidence synthesis identified the following enablers to incorporating gender, sex, and sexual orientation data into electronic health records: create an inclusive and culturally competent environment with precise terminology and standardized data collection; adopt gender-affirming language throughout the practice; and include staff in mandatory institution-wide training programs (1) One older single study and one recent single study found that enablers to the collection of sexual orientation and gender identity data in EHRs included providing staff with training on how and why information is collected, creating resources on LGBT health, and creating data quality standards based on community and stakeholder engagement (8; 9) One older single study found checkboxes within EHRs significantly increased the collection of data on gender identity and sexual orientation (3) One recent single study found incorporating specific tabs for sexual orientation, gender identity, and social history into electronic medical records (EMRs) significantly increases documentation frequency (10) One recent single study about the collection of Indigenous identification status found general practitioners who reported always asking clients tended to be those with a higher proportion of Indigenous patients (5) One older single study found the inclusion of ethnicity data as an indicator in the U.K. Quality Outcomes Framework, and therefore a mandatory field in EHRs improved data completeness and was generally found to be comparable to census data (11)
Findings about barriers to data collection	<ul style="list-style-type: none"> One recent low-quality evidence synthesis found barriers to collection of Indigenous status in health registries included inconsistent processes and missing standards, information systems that are unable to record all ethnicity information included, lack of staff capability or capacity, and the perception among staff that collecting information on Indigenous status is not important (12)

Features of data collection	Key findings from evidence syntheses and single studies
	<ul style="list-style-type: none"> • One recent low-quality evidence synthesis found that a lack of standardization for social and behavioural determinants of health in EHRs as a significant limitation (13) <ul style="list-style-type: none"> ○ The evidence synthesis also noted that while clinicians preferred patient-reported data, it was often not possible to enter in a standardized manner • One recent single study about the collection of Indigenous identification status found general practitioners who were less likely to ask about status were those working in clinics located in inner regional and outer regional/remote areas as well as those located in the states of Victoria or South Australia (5) • One recent single study found that codes in EMRs related to social determinants of health were rarely due to uncertainty among providers about how and when to code them, especially as they are often formatted as unrestricted text rather than binary fields (6) • One recent single study found that the quality and collection of demographic data, particularly race and ethnicity, is limited by the way data is captured in EHRs and the way that data fields are structured for race and ethnicity (14) • One recent study examining EHRs found that many systems do not have entries for both sex at birth and gender identity, nor do they collect information on sexual orientation (15) • One recent study found that a lack of standardized protocols, no training, and no set places for documenting gender identity information in EHRs were all barriers to information completeness (16)

Appendix 3: Key findings from evidence syntheses

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Race/ethnicity/culture 	<p>Health registries had poor representation of Indigenous data; recommendations for improving this was the sharing of knowledge experiences between health registers and supporting Indigenous-led research and meaningful collaboration (12)</p> <ul style="list-style-type: none"> The review identified four overarching themes that acted as barriers to ascertainment of Indigenous peoples on health registers, including: ethnicity data collection and quality, systems and structures, health services, health professionals, and perceptions of individual and community barriers Data on Indigenous status was frequently incomplete in records or used variable responses Limitations in data collection systems, including non-systematic, inconsistent processes and information systems unable to record all ethnicity responses, also created challenges, as did a lack of standard protocols and legislation preventing the collection of Indigenous status With respect to health services and professionals, challenges included a lack of staff capability, staff capacity, and the perception that collecting Indigenous status was not important 	High	No	3/9	2021	No	<ul style="list-style-type: none"> Race/ethnicity/culture
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex Personal characteristics associated with discrimination (e.g., disability, sexual orientation) With what supports information is collected <ul style="list-style-type: none"> Training modules 	<p>There is an urgent need to modernize electronic health records (EHRs) to better capture gender, sex, and sexual orientation (GSSO), in hopes of addressing disparities among Sexual and Gender Minorities (SGM) (1)</p> <ul style="list-style-type: none"> The review highlighted the multi-faceted nature of incorporating GSSO data into EHRs, emphasizing the complex interplay of technological (e.g., design of EHR systems to accommodate GSSO data fields), social (e.g., the need for culturally competent care for SGM), and organizational factors (e.g., establishing inclusive policies and training programs for healthcare staff) The review identified five themes in how documentation should evolve, and these include: <ul style="list-style-type: none"> create an inclusive and culturally competent environment with precise terminology and standardized data collection and adopt explicit gender-affirming language and policies, including adhering to standards of care for 	High	No	2/9	2020	No	<ul style="list-style-type: none"> Gender/sex

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
<ul style="list-style-type: none"> ○ Definitions and glossary of terms 	<ul style="list-style-type: none"> ○ individuals who are transitioning, acknowledging patients by their chosen names and pronouns, and ensuring safe access to washroom facilities ○ culturally competent healthcare staff through regular mandatory institution-wide training programs are needed for all healthcare staff and in formal education curricula for pre-licensed health professionals ○ strategies to support the collection of gender, sex, and sexual orientation data include having a standardized data collection process, listing name and pronouns, use of a two-step question for gender identity and birth sex, as well as training clinical and non-clinical staff to ask appropriate questions and explain the reasons for collecting this information and its implications 						
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Place of residence ○ Gender/sex ○ Education ○ Socio-economic status • By whom information is collected <ul style="list-style-type: none"> ○ Physicians 	<p>There is a lack of standardized guidelines and priorities for collecting social and behavioural determinants of health for EHRs (13)</p> <ul style="list-style-type: none"> • Three frameworks describing social and behavioural determinants of health (SBDH) and applications were reviewed • Some aspects of SBDH information that were collected in the frameworks are: <ul style="list-style-type: none"> ○ socio-economic determinants ○ psychosocial risk factors ○ community and societal characteristics (e.g., income inequality) • Focus groups were also conducted with clinicians and researchers to understand how SBDH variables are prioritized for collection in EHRs <ul style="list-style-type: none"> ○ Clinicians were mostly responsible for collecting data <ul style="list-style-type: none"> ▪ Most collected data that was important to them ○ Many reported a lack of standardization of SBDH variables in EHRs ○ Clinicians preferred the idea of patient-reported data, but were not clear how this could be implemented in a standardized manner 	High	No	1/9	2018	No	None found

Appendix 4: Key findings from single studies

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Race/ethnicity 	<p><i>Date of publication:</i> 2019</p> <p><i>Place published:</i> Toronto, Canada</p> <p><i>Methods:</i> Qualitative</p>	Semi-structured interviews with 27 patients from five of six clinical sites of a family health team.	<p>In general, patients are comfortable with data collection about their race, but questions should clarify the intent of the data collection and consider whether either free-text boxes or options to choose multiple categories may help individuals with mixed heritage (17)</p> <ul style="list-style-type: none"> Patients reported that the questions were easy to understand but their interpretations differed, particularly as to whether they were asking about ancestry or their own place of birth and upbringing Most participants reported that they appreciated the wide variety of options, but some patients who are children of immigrants or those of mixed heritage reported difficulty answering the question Most patients reported not feeling uncomfortable about being asked and felt it was relevant or important 	High	<ul style="list-style-type: none"> Race/ethnicity
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex Personal characteristics associated with discrimination (e.g., disability, sexual orientation) 	<p><i>Date of publication:</i> 2016</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Qualitative</p>	Semi-structured interviews with 53 patients (with varying gender identity, sexual orientation, age, and race/ethnicity) and 38 staff members in a hospital emergency department.	<p>Patients reported that they were willing to provide their information about sexual orientation and gender identity if it was collected safely and appropriately, in addition to whether staff were willing to collect the information in the first place; however, the time and contact point when to collect was not clear (2)</p> <ul style="list-style-type: none"> Specific themes emerged from the semi-structured interviews such as the ‘who, what, where, and how’ of data collection, the environment for safe disclosure, nurse intake and/or nonverbal data, confidentiality, and staff cultural competency The participants indicated that it was unclear when it was the best time to collect information about sexual orientation and gender identity given the many contact points (e.g., entrance, registration, intake, physician encounter, discharge) 	High	<ul style="list-style-type: none"> Gender/sex
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex Personal characteristics associated with discrimination (e.g., disability, sexual orientation) By whom information is collected 	<p><i>Date of publication:</i> 2015</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Qualitative</p>	Key informant interviews with senior leadership and providers.	<p>While institutional change took five years, an academic centre in the U.S. found that educating staff and leaders was critical to the buy-in and implementation of collecting information on sexual orientation and gender identity in their electronic health record (EHR) system (8)</p> <ul style="list-style-type: none"> The institutional changes started with developing executive support; conducting key informant interviews with patient relations staff, providers, and leaders; developing presentations and workshops; creating resources on LGBT health; developing publicly accessible list of providers who self- 	High	<ul style="list-style-type: none"> Gender/sex

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> ○ Physicians ○ Nurses • How information is collected <ul style="list-style-type: none"> ○ Entered in an online portal (and then integrated to EMRs) • With what supports information is collected <ul style="list-style-type: none"> ○ Training modules ○ Definitions and glossary of terms ○ Scripts for collecting information and responding to individuals' questions 			<p>identified as being comfortable and welcoming to the LGBTQ community; and linking information to EHR</p> <ul style="list-style-type: none"> • Culture change took longer than anticipated, and ended up taking five years • The academic centre collected information on sexual orientation and gender identity through the EHR and patient health portal • Educating the staff and leaders during the initial resistance was critical to the implementation and buy-in for the inclusion of sexual orientation and gender identity data in the EHR 		
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Place of residency ○ Race/ethnicity ○ Gender/sex ○ Personal characteristic associated with discrimination • By whom information is collected <ul style="list-style-type: none"> ○ Physicians • How information is collected <ul style="list-style-type: none"> ○ Orally (and then entered into EMRs) • With what supports information is collected 	<p><i>Date of publication:</i> 2015</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Cross-sectional study</p>	<p>Adults with an outpatient visit to any of 40 family medicine and internal medicine primary care practices in a large health system in the northeastern United States in 2012. The outcome of interest was documentation of sexual partner gender, which was recorded in the social history section of the EHR.</p>	<p>There is significant variability in the recording of sexual orientation and gender of sexual partners in EHRs, but the use of checkboxes appears to support greater documentation (3)</p> <ul style="list-style-type: none"> • In 2011, the Institute of Medicine identified lack of data as a major challenge to understand the health needs of LGBTQ individuals and recommended the collection of sexual orientation and gender identity in EHRs • Though many EHRs are not designed to collect information on gender identity, they often can collect information on patient gender and gender of sexual partners, which can be used as a proxy for some risk factors • Of the sample, approximately 45% had sexual partner gender documented in the EHR • Of these, 96% had only opposite-gender partners and 4% had only same-gender partners • Sexual partner data was not uniformly documented in EHRs and documentation was significantly lower among patients over the age of 50, persons with Medicare, individuals seen in suburban practices, and individuals seen at a non-residency family medicine practice • Black patients and individuals with a preventive care visit had higher documentation rates • The greatest predictor of documentation was the use of the checkboxes for other social history elements 	High	<ul style="list-style-type: none"> • Race/ethnicity/culture • Gender/sex • Socio-economic status

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex Personal characteristics associated with discrimination (e.g., disability, sexual orientation) By whom information is collected <ul style="list-style-type: none"> Physicians 	<p><i>Date of publication:</i> 2017</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Survey and qualitative content analysis</p>	1,516 LGBT and non-LGBT patients and providers in the emergency department.	<p>Patients reported that it was important to provide information about their sexual orientation and gender identity in primary care and emergency department settings; however, providers perceived a risk of potentially offending patients with this routine data collection even though patients reported the opposite (3)</p> <ul style="list-style-type: none"> Patients perceived that data collection of sexual orientation and gender identity were more important in primary care than emergency department settings, especially as they perceived that knowing this information will allow for personalized care <ul style="list-style-type: none"> Patients frequently described the risk of bias and discrimination with this data collection Providers perceived that knowing this information will allow for improved patient-provider communication; more than half the providers cited discomfort and offense as their perceived risk 	High	<ul style="list-style-type: none"> Gender/sex
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Race/ethnicity Personal characteristic associated with discrimination By whom information is collected <ul style="list-style-type: none"> Physicians How information is collected <ul style="list-style-type: none"> Written 	<p><i>Date of publication:</i> 2019</p> <p><i>Place published:</i> Australia</p> <p><i>Methods:</i> Cross-sectional study</p>	Records from 95 primary care services within Victoria, New South Wales, Queensland and South Australia were examined to determine the completeness and agreement of Indigenous status recording.	<p>Almost half of patient records had unknown or missing Indigenous identification status recorded (5)</p> <ul style="list-style-type: none"> National guidelines for the collection of Indigenous identification status in health datasets recommends the use of a standard verbal or written question and that service providers make completion of Indigenous status a mandatory requirement of new patient registration Indigenous status was found to be complete for approximately 55% of records, with one third of clinics having greater than 75% completion rate General practitioners who reported always asking clients for their Indigenous status tended to be those with a greater proportion of Indigenous patients General practitioners who were less likely to be associated with asking patients were those working in clinics located in inner regional and outer regional/remote areas, and those located in the states of Victoria or South Australia The study also found that the limited recording may be leading to overestimation of certain conditions among Indigenous populations, particularly of infectious diseases 	High	<ul style="list-style-type: none"> Race/ethnicity/culture/language
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex By whom information is collected <ul style="list-style-type: none"> Physicians 	<p><i>Date of publication:</i> 2023</p> <p><i>Place published:</i> United States</p>	Records of patients aged 18 and over across all Veterans Affairs medical centres in the U.S. were queried.	<p>Of all five codes the combination of these codes with orchiectomy is extremely sensitive in identifying transgender women (18)</p> <ul style="list-style-type: none"> A key systemic barrier in studying transgender patients is that this population is not easily identified in electronic medical record data 	Medium	<ul style="list-style-type: none"> Gender/sex

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
	<i>Methods:</i> Cross-sectional	Individuals were included if they had a diagnosis of transsexualism, gender identity disorder in childhood, diagnosis of other gender identity disorders, and gender identity disorder. Data elements queried from the medical record included sex assigned at birth, gender identity marker listed in the patient demographic information, gender-affirmation therapy, and bilateral orchiectomy.	<ul style="list-style-type: none"> The International Classification of Diseases (ICD) serves as the global standard of health data and clinical documentation but does not include a code specific to transgender identity The study tested the sensitivity and specificity of five commonly used ICD-9 and ICD-10 codes using Veterans Affairs health records Of the five ICD codes, 100% of patients who had undergone bilateral orchiectomy were confirmed to be transgender Across all patients in whom chart review was performed, the gender field was completed for only 37% of patients while sex assigned at birth was listed for 99% of patients 		
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Place of residence Race/ethnicity/culture/language Occupation Gender/sex Religion Education Socio-economic status Social capital Personal characteristics associated with discrimination (e.g., disability, sexual orientation) By whom information is collected <ul style="list-style-type: none"> Physicians How information is collected <ul style="list-style-type: none"> Orally (and then entered into EMRs) 	<p><i>Date of publication:</i> 2020</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Retrospective cohort study</p>	Analyzed data from the 2016 National Inpatient Sample from the Healthcare Cost and Utilization Project Database to evaluate the utilization of social determinant (SDOH) Z-codes.	<p>Findings suggest that SDOH Z-codes are being vastly underutilized at the patient level and current coding is poorly reflective of the actual SDOH burdens experienced by patients (6)</p> <ul style="list-style-type: none"> SDOH Z-codes describe factors influencing health status and contact with the health system including social factors such as housing status, social support, or employment status Of 14,289,644 admissions in the 2016 and 2017 National Inpatient Sample, only 269,929 (1.9%) had an associated SDOH Z-code Possibilities for why Z-codes are not being used widely is that non-adopter clinicians do not know how and when to code them and clinicians are generally not specifically trained to do comprehensive SDOH assessments Electronic health record SDOH data are also typically unstructured (i.e., recorded as unrestricted text rather than binary fields) and may be computationally difficult to mine in their current form 	High	<ul style="list-style-type: none"> Place of residence Race/ethnicity/culture/language Occupation Gender/sex Religion Education Socio-economic status Social capital

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> With what supports information is collected <ul style="list-style-type: none"> Definitions and glossary of terms 					
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Race/ethnicity/culture/language Occupation Gender/sex By whom information is collected <ul style="list-style-type: none"> Support/administrative staff How information is collected <ul style="list-style-type: none"> Written (and then transferred to EMRs) With what supports information is collected <ul style="list-style-type: none"> Scripts for collecting information and responding to individuals' questions 	<p><i>Date of publication:</i> 2023</p> <p><i>Place published:</i> New York, United States</p> <p><i>Methods:</i> Cross/sectional study</p>	<p>A survey was administered to 117 random patients, selected from prior day admissions at a large academic medical centre. Patients or respective guardians self-reported race, ethnicity, preferred language, and gender identity data, selecting from current EHR options.</p>	<p>Large discrepancies exist between self-reported race, ethnicity, preferred language, and gender identity data and that documented in the EHR (7)</p> <ul style="list-style-type: none"> Race was misreported in the EHR for 13% of patients, and ethnicity for 6% <ul style="list-style-type: none"> Multiracial and Hispanic patients were more likely to have their demographics misreported in the EHR Gender identity was missing for most patients and 11% of the gender identity entries present in the EHR were discordant with the patient's self-identity 	High	<ul style="list-style-type: none"> Race/ethnicity/culture/language Gender/sex
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Race/ethnicity/culture/language By whom information is collected <ul style="list-style-type: none"> Support/administrative staff How information is collected <ul style="list-style-type: none"> Orally (and then entered into EMRs) With what supports information is collected <ul style="list-style-type: none"> Scripts for collecting information and responding to individuals' questions 	<p><i>Date of publication:</i> 2015</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Randomized controlled trial</p>	<p>Data was collected as part of a tobacco cessation intervention for minority and low-income smokers across a network of 13 primary care clinics (n = 569).</p>	<p>The quality of demographic data in the EHR is limited by human factors in how data is captured and in the way data fields are structured for race and ethnicity (14)</p> <ul style="list-style-type: none"> Data suggests that, even in a state with policies regulating the collection of self-reported data about race and ethnicity in acute care settings, EHR data may “undercount” individuals who identify themselves as African American or Hispanic in ambulatory settings Patients were more likely to self-report as Hispanic (19.6 % vs. 16.6 %, $p < 0.001$) and African American (27.0 % vs. 20.4 %, $p < 0.001$) than was reported in the EHR 	High	<ul style="list-style-type: none"> Race/ethnicity/culture/language

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/ sex Personal characteristic associated with discrimination (e.g., disability, sexual orientation) How information is collected <ul style="list-style-type: none"> Entered in an online portal (and then integrated to EMRs) 	<p><i>Date of publication:</i> 19 June 2021</p> <p><i>Place published:</i> Not identified</p> <p><i>Methods:</i> Clinical informatics</p>	<p>One Rush University Medical Center's EHR data, specifically the records of all unplanned adolescent and adult hospital patients (≥ 12 years of age) admitted between 1 January 2020 and 31 December 2020 ($n = 49,314$).</p>	<p>Gender identity and sexual orientation data collection in EHRs contains information and disparities that may help to expand patient and provider comfort and literacy in clinical settings, indicating the relevance of this data to transgender and non-binary patients' equitable access to care, health, and utilization outcomes (9)</p> <ul style="list-style-type: none"> The study also discussed how widespread training regarding gender-affirming care and inclusive language and the development of sexual orientation and gender identity (SO/GI) data quality standards will move U.S. healthcare closer to the goals of the Meaningful Use mandate Of 49,314 individuals, 24% ($n = 11,943$) of them had gender identity data fields completed while 76% ($n = 37,371$) remained empty <ul style="list-style-type: none"> Nearly 1% ($n = 100$) of unique patients with GI data had data that reflected a transgender or non-binary status To include transgender and non-binary (TGNB) populations in informatics-based research, additional novel approaches, such as natural language processing, may be needed for more comprehensive and representative TGNB cohort discovery <ul style="list-style-type: none"> Community and stakeholder engagement around gender identity data collection and health research will likely improve these implementation efforts 	High	<ul style="list-style-type: none"> Gender/sex
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/ sex Personal characteristic associated with discrimination (e.g., disability, sexual orientation) Time-dependent relationships (e.g., caregiving responsibilities) With what supports information is collected <ul style="list-style-type: none"> Training modules By whom information is collected 	<p><i>Date of publication:</i> December 2023</p> <p><i>Place published:</i> U.S.</p> <p><i>Methods:</i> Comparative content analysis</p>	<p>Three different vended academic electronic health records (aEHRs). A data collection instrument was created to reflect gender, sexuality, and sexual orientation (GSSO) variables that were identified as ideal data elements.</p>	<p>Bias and mistreatment of those in the LGBTQ+ community persist despite some advances in incorporating simulation and content into health science curricula, highlighting the need for further gender, sexuality, and sexual orientation data collection for measuring, monitoring, and improving the LGBTQ+ populations' health, satisfaction, and quality of care (15)</p> <ul style="list-style-type: none"> Student exposure to inclusive GSSO concepts in an aEHR context may influence classroom conversations, particularly the importance of accurate clinical documentation, digital visibility for marginalized communities, and the impacts of bias on healthcare outcomes Data elements and documentation options for sex and gender were either absent or appeared to be a conflating of gender and sex rather than treating them as conceptually different data elements None of the three aEHR systems analyzed had specific documentation fields for sexual orientation 	High	<ul style="list-style-type: none"> Gender/sex

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> ○ Allied health professionals 			<ul style="list-style-type: none"> • The analysis of only three aEHRs is a limitation that reflects only a sample of available EHRs, and authors noted that progressively changing norms language related to GSSO could result in language within the study becoming outdated 		
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Gender/ sex ○ Personal characteristic associated with discrimination (e.g., disability, sexual orientation) • How information is collected <ul style="list-style-type: none"> ○ Entered in an online portal (and then integrated to EMRs) • With what supports information is collected <ul style="list-style-type: none"> ○ Written (and then transferred to EMRs) • By whom information is collected <ul style="list-style-type: none"> ○ Nurses 	<p><i>Date of publication:</i> 19 December 2022</p> <p><i>Place published:</i> Rochester, New York</p> <p><i>Methods:</i> clinical informatics</p>	<p>788 patients were included in this analysis (368 in the control period and 420 in the experimental period). The survey was administered to patients over a three-month period by Department of Radiation Oncology (DRO) staff to new adult patients. Sexual orientation and gender identity demographic data was entered into EMRs by nursing staff. Data was extracted and analyzed for all patients before and after the three-month period.</p>	<p>Collecting gender identity and sexual orientation data via a demographic form in an outpatient radiation oncology setting was well received by a majority of patients and could lead to the provision of higher quality, tailored care (19)</p> <ul style="list-style-type: none"> • Ten patients (2.9%) identified as gay or lesbian and 100% identified as cisgender • The majority of patients were not upset by the form, with only 11 patients (5.2%) stating that any specific question caused them distress 	High	<ul style="list-style-type: none"> • Gender/sex
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Gender/ sex ○ Personal characteristic associated with discrimination (e.g., disability, sexual orientation) • How information is collected <ul style="list-style-type: none"> ○ Entered in an online portal (and then integrated to EMRs) • By whom information is collected 	<p><i>Date of publication:</i> 16 October 2020</p> <p><i>Place published:</i> U.S.</p> <p><i>Methods:</i> Semi-structured interviews</p>	<p>27 stakeholders from prominent gender-affirming care providers across the United States. Interviews were conducted between August 2014 and April 2015 in the U.S. Key informants were asked to describe their electronic health record system and how it affected care for their patients.</p>	<p>While gender identity data capture in electronic health records can offer quality improvements at the clinical level, new approaches are needed to address the vulnerabilities that may arise in both visibility and implementation (4)</p> <ul style="list-style-type: none"> • Data capture is effective for increasing patient counts and making quality improvements but limited in terms of enhancing gender-affirming care depending on provider size, type, and competencies • Five informants were affiliated with clinics that had implemented the two-step question and incorporated the data fields into their EHR system, and nearly all 27 were aware of it as an alternative approach to a single question <ul style="list-style-type: none"> ○ Many agreed that it better describes trans-identified patients and could help with cultural competency as the two steps indicate (at minimum) an institutional-level distinction 	High	<ul style="list-style-type: none"> • Gender/sex

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<ul style="list-style-type: none"> ○ Allied health professionals ○ Support/administrative staff 			<p>between sex assigned at birth and gender identity (GI) and expression</p> <ul style="list-style-type: none"> • The visibility paradox emerging from the data fields in GI data capture is that the increased clinical visibility of trans persons in medical settings can also reduce the visibility of other gender diverse persons, including trans, non-binary, and cisgender • A limiting factor to this study is that interviews were conducted in 2014–15, and since this time the landscape of this issue has likely changed 		
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Place of residence ○ Race/ethnicity/culture/language • How information is collected <ul style="list-style-type: none"> ○ Written (and then transferred to EMRs) 	<p><i>Date of publication:</i> June 2015</p> <p><i>Place published:</i> United States</p> <p><i>Methods:</i> Hospital-reported race and ethnicity data and patient-reported data were compared and quantified</p>	<p>California inpatient data was compared with databases containing self-reported race and ethnicity (R/E) data to determine accuracy. Hospital discharge data from 1,052,238 maternal birth hospitalization patients and 14,918 cancer patients was included.</p>	<p>Comparison of hospital-reported versus patient-reported race and ethnicity data shows some disagreement (20)</p> <ul style="list-style-type: none"> • Agreement between hospital-reported race and ethnicity data and self-reported race and ethnicity data was measured • Self-reported race and ethnicity data for the maternal patient cohort was 86% with hospital-reported data and 90% in the cancer cohort 	High	<ul style="list-style-type: none"> • Place of residence • Race/ethnicity/culture/language
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Race/ethnicity/culture/language 	<p><i>Date of publication:</i> December 2014</p> <p><i>Place published:</i> United Kingdom</p> <p><i>Methods:</i> Ethnicity recording from hospitals was compared with the 2011 U.K. censuses</p>	<p>3,544,589 patients registered in the Clinical Practice Research Datalink up to July 2012 who had documented ethnicity data and 51,965,028 patients registered in Hospital Episode Statistics up to April 2012.</p>	<p>Ethnic data recorded in hospitals in the U.K. is comparable to census data (11)</p> <ul style="list-style-type: none"> • This study examined the agreement between ethnicity records from hospitals and census data using the Clinical Practice Research Datalink (CPRD) and Hospital Episode Statistics (HES) • 27.1% of patients in the CPRD from 1990–2012 have their ethnicity recorded, with 78.3% of those registered since April 2006 having their ethnicity recorded <ul style="list-style-type: none"> ○ The Quality Outcomes Framework (QOF) was introduced in 2006, causing this increase in data completeness ○ The ethnic data in the CPRD was comparable to census data 	High	<ul style="list-style-type: none"> • Race/ethnicity/culture/language
<ul style="list-style-type: none"> • Dimensions of equity <ul style="list-style-type: none"> ○ Gender/sex ○ Personal characteristics associated with 	<p><i>Date of publication:</i> 2021</p> <p><i>Place published:</i> Not identified</p>	<p>The sample consisted of 25 healthcare providers, including physicians, physician assistants, and nurse practitioners, selected</p>	<p>Healthcare providers often do not routinely ask patients about their gender identity for many reasons including a lack of training and fear of offending patients (16)</p> <ul style="list-style-type: none"> • The study highlighted how current healthcare provider practices lack standardized protocols for effectively garnering 	High	<ul style="list-style-type: none"> • Gender/sex

Dimension of organizing framework	Study features	Summary of study sample and intervention	Declarative title and key findings	Relevance rating	Equity considerations
<p>discrimination (e.g., disability, sexual orientation)</p> <ul style="list-style-type: none"> By whom information is collected <ul style="list-style-type: none"> Physicians Nurses Allied health professionals How information is collected <ul style="list-style-type: none"> Orally (and then entered into EMRs) 	<p><i>Methods:</i> Qualitative semi-structured interviews</p>	<p>from diverse clinical specialties within a large urban academic health system.</p>	<p>and documenting gender identity information in electronic health records</p> <ul style="list-style-type: none"> The RedClin EHR includes modules and sections with structured text that allows recording of social names, gender identity, sex at birth, legal sex, and other data fields The entries become part of the display in RedClin and electronic prescriptions of drugs and vaccines 		
<ul style="list-style-type: none"> Dimensions of equity <ul style="list-style-type: none"> Gender/sex Personal characteristics associated with discrimination (e.g., disability, sexual orientation) By whom information is collected <ul style="list-style-type: none"> Physicians Nurses Support/administrative staff How information is collected <ul style="list-style-type: none"> Orally (and then entered into EMRs) With what supports information is collected <ul style="list-style-type: none"> Definitions and glossary of terms Prompts within EMRs 	<p><i>Date of publication:</i> 2021</p> <p><i>Place published:</i> Not identified</p> <p><i>Methods:</i> Retrospective cohort design</p>	<p>The sample included 1,150 patient encounters in the Pediatric and Adolescent Gynecology Clinic, with 221 encounters before and 929 encounters after the implementation of electronic medical record changes.</p> <p>The intervention involved incorporating tabs for sexual orientation and gender identity documentation into the electronic medical records' social history section, implemented in September 2017, aiming to improve the frequency and accuracy of documentation in pediatric and adolescent gynecology clinic interactions.</p>	<p>After the implementation of electronic medical record changes in a pediatric and adolescent gynecology clinic, a threefold increase in sexual orientation documentation and a remarkable increase in gender identity documentation was observed (10)</p> <ul style="list-style-type: none"> The study's findings highlights that incorporating specific tabs for sexual orientation and gender identity into electronic medical records significantly increases documentation frequency Overall rates remained below 50%, highlighting the ongoing need for improvement in capturing equity, diversity, and inclusion information in medical forms and EMRs 	High	<ul style="list-style-type: none"> Gender/sex

Appendix 5: Detailed jurisdictional scan about approaches to collect information on dimensions of equity, diversity and inclusion in electronic medical records

Jurisdiction	Organization	Key messages
Global	World Professional Association for Transgender Health	<ul style="list-style-type: none"> The World Professional Association for Transgender Health released guidelines for the transgender health electronic medical record (EMR) working group, which include the following recommendations: <ul style="list-style-type: none"> preferred name, gender identity, and pronoun preference, as identified by patients, should be included as demographic variables provide a means to maintain an inventory of a patient's medical transition history and current anatomy any system should allow a smooth transition from one listed name, anatomical inventory, and/or sex to another, without affecting the integrity of the remainder of the patient record a system should exist to notify providers and clinic staff of a patient's preferred name and/or pronoun (if either or both of these differ from the current legal documented name/sex)
British Columbia	British Columbia Ministry of Health	<ul style="list-style-type: none"> The British Columbia Ministry of Health has a catalogue of health information standards for use in EMRs and beyond <ul style="list-style-type: none"> Policies and standards are being developed to promote equity, and a Demographic Standard is currently in development A Gender and Sex Standard is well-defined in The Gender, Sex and Sexual Orientation (GSSO) Health Information Standard and Guidance <ul style="list-style-type: none"> Pronouns: It is recommended that clinicians use gendered pronouns when confirmed; pronouns are not optional Gender identity: Patient-reported and not clinician-assigned; it can be elicited with questions such as "What is your gender identity?" or "What is your gender?" Health services sex or gender marker (also known as "legal gender or sex" among other names): Designed for health information systems that do not differentiate between sex and gender Sex assigned at birth: It is recommended that access to sex assigned at birth information be hidden or limited to those providing direct clinical care (e.g., to facilitate interpretation of medical imaging or laboratory tests) Administrative gender: Provides patients the option to decide the gender to be recorded for government documentation purposes; can be elicited by asking, "What gender do you want on your documentation?" Gender information can be collected through four mediums each with their strengths and weaknesses: paper, online, telephone, and in person Additional gender, sex, and sexual orientation information can be collected in an open-ended manner after collection following a common standard/format as they are more difficult to code The two-step method provides an evidence-based method to collect gender identity and sex assigned at birth information by asking all patients a question pertaining to each of these dimensions sequentially (e.g., "What is your gender?" followed by "What was your sex assigned at birth?"); patients can opt to not answer Gender information for official identification can employ the markers: "X" for gender that is not exclusively female/male; "U" for unknown; "W" in favour of "F" when possible B.C. Social Determinants of Health Standards can be collected by B.C. health system providers; they include: <ul style="list-style-type: none"> cultural identity and immigration status Indigenous identity socio-economic status housing insecurity food insecurity

Jurisdiction	Organization	Key messages
		<ul style="list-style-type: none"> ○ occupation and employment including higher risk work history ○ language ○ social capital/adhesion
Alberta	Alberta Netcare (Government of Alberta)	<ul style="list-style-type: none"> ● The Provincial Client Registry at a minimum collects information about gender, but also optionally collects information on language and home address (which are entered into the system) ● Gender is mandatory data to collect at time of registration, while sex at birth is collected when clinically relevant ● The health system does not currently collect race-based data, but recent reports from the Alberta Anti-Racism Advisory Council have included recommendations related to tracking race-based health outcomes
Saskatchewan	Government of Saskatchewan	<ul style="list-style-type: none"> ● Not reported in detail (i.e., no publicly available information found on demographic data collection methods)
Manitoba	Government of Manitoba	<ul style="list-style-type: none"> ● Manitoba is the first province to collect self-declared race-based patient data through Shared Health and other health service delivery organizations (often upon registration at a Manitoba hospital on a voluntary basis) ● They collect information on race, ethnicity, and Indigenous identity based on definitions that were co-developed with the communities ● They also collect information on sex and postal code on an annual basis based on data from the Manitoba Health Insurance Registry and provided by Manitoba Health
Ontario	Government of Ontario	<ul style="list-style-type: none"> ● Though not specific to health, the Government of Ontario published in 2018 (and updated in 2021) a complete standard and guidance for race-based data collection for government and other public sector organizations, including steps to follow for data collection, management, and use
	Ontario Health	<ul style="list-style-type: none"> ● The Black Health Plan notes that the Ministry of Health and Ontario Health should prioritize the systematic collection of race-based data through the Ontario Health Insurance Plan (OHIP) healthcare registration and renewal process, analyse these data, and published the data and the results to help the health system decrease inequities, however no specific recommendations for how to collect this information is provided ● One of the areas for action in the Health Equity, Inclusion, Diversity and Anti-Racism Framework is to collect, report and use equity data, the framework recommends: <ul style="list-style-type: none"> ○ Ontario Health is to mandate equity data collection across all Ontario Health portfolios, all health service providers organizations, and service provider organizations using automated processes and standardized data sets to collect, analyze, and report information ○ Ontario Health is to work with government to establish a key minimum dataset of equity elements that will be collected using standard tools, and build capacity to centrally manage a data warehouse to enable greater efficiency of collection, application, and linking of data ○ Ontario Health is to require data and analysis to be used to inform decisions including identification of appropriate programs/services and allocation of resources to reduce disparities in workplace and service delivery
Québec	Québec Health Booklet	<ul style="list-style-type: none"> ● Not reported in detail (i.e., no publicly available information found on demographic data collection methods)
Nova Scotia	Government of Nova Scotia	<ul style="list-style-type: none"> ● Nova Scotia has recently released an option to provide race and language information online, by phone, or when patients renew their healthcare ● The Fair Care Project is an effort to collect and interpret race-based data ● Race and linguistic identity collection uses the Canadian Institute for Health Information (CIHI) standard for race-based and Indigenous identity data collection and health reporting
Prince Edward Island	Government of Prince Edward Island	<ul style="list-style-type: none"> ● In 2020, the P.E.I. government developed its first plan to move all health records into EMRs with a \$9.5 million budget.

Jurisdiction	Organization	Key messages
		<ul style="list-style-type: none"> In 2023, now 176 community health providers, doctors, or nurse practitioners along with their allied health professionals are on the electronic system; this represents most family doctors present in P.E.I. However, there are no mentions of approaches on how data related to equity, diversity, and inclusion is collected in EMRs
Newfoundland and Labrador	None identified	Not reported in detail (i.e., no publicly available information found on demographic data collection methods)
Northwest Territories	Government of Northwest Territories	Not reported in detail (i.e., no publicly available information found on demographic data collection methods)
Yukon	Government of Yukon, Yukon hospitals, Yukon Medical Association	Not reported in detail (i.e., no publicly available information found on demographic data collection methods)
Nunavut	Government of Canada	<ul style="list-style-type: none"> Last modified 5 August 2022, the Government of Canada website describes an action plan for Nunavut's virtual care, to expand upon the shift towards virtual care that became necessary in 2020 due to the pandemic Included is a plan for the Nunavut Patient Portal, which plans for the implementation of the Meditech Patient and Consumer Health Portal and the Virtual Visit Solution modules within Nunavut's territorial Meditech clinical information system (CIS) environment <ul style="list-style-type: none"> Neither Meditech nor the government of Nunavut currently have public information available about Nunavut's territorial Meditech CIS or electronic health records Nunavut's healthcare plan coverage form includes patient sex and ethnicity, but not gender <ul style="list-style-type: none"> The form specifies that individuals who indicate Inuit or Registered Indian ethnicity must provide, in the case of Inuit, a Beneficiary Card
Australia	My Chart	<ul style="list-style-type: none"> Australia uses My Chart, a national electronic health record system, which prompts individuals to self-report demographic and other information Self-reported information includes: <ul style="list-style-type: none"> contact numbers and emergency contact details current medicines allergy information personal health notes indigenous status Veteran or Australian Defence Force status advance care plan or contact details of your custodian preferred language country of birth Some concerns about the lack of adaptable field for marginalized populations led to individuals 'opting' out of informational transfer into their My Charts and have resulted in other organizations
Canada	Canadian Institute for Health Information	<ul style="list-style-type: none"> The CIHI produced guidance on the use of standards for race-based and Indigenous identity data collection and health reporting in Canada, which includes information on what data to collect and safe processes for the collection and governance of data
New Zealand	Health New Zealand	<ul style="list-style-type: none"> Health New Zealand has established protocols for collecting, recording, and using data on the ethnicity of people treated by or working in the New Zealand health sector The standards set out the following for data collection that falls within diversity, equity, and inclusion information:

Jurisdiction	Organization	Key messages
		<ul style="list-style-type: none"> ○ person name, including the full name of the person, any name by which the person is known (as well as preferred name indicator, the name of the person at birth if different, as well as the name information source and date name is effective ○ birth date and place including information source ○ gender, as self-identified by the person and free text for gender detail ○ ethnicity, as classified by the individual and a free text for ethnicity detail ○ language, based on a drop-down list of those spoken or understood by the person ● Health New Zealand has also established protocols for collecting and recording Māori descent and iwi affiliation in the health and disability system <ul style="list-style-type: none"> ○ Three key elements of the definition provided by Stats NZ in the statistical standard are: <ul style="list-style-type: none"> ▪ iwi affiliation must be self-identified ▪ people may identify with more than one iwi ▪ iwi affiliation may change over time ● Protocols for collecting Māori descent and iwi affiliation data include: <ul style="list-style-type: none"> ○ respondents who indicate they have Māori descent should be asked the iwi affiliation questions ○ respondents who indicate that they do not have Māori descent should not be asked the affiliation question ○ respondents who do not know should be asked as there may be individuals who suspect they are descended from Māori but do not know their biological ancestry ○ there is a standard set of questions that must be used and that appear in both English and Māori ○ if a reference list of iwi names is given, this list should include a statement that says, “This list is for guidance only and may not include all iwi or iwi-related groups” ○ respondents must identify their own Māori descent and iwi affiliation regardless of collection method; no proof is required ● With respect to frequency, a respondent’s descent and affiliation generally endures over time; if there is no recorded data the respondent should have the opportunity to provide this data and similarly, if the information has not been updated in the last three years, the respondent should have the opportunity to confirm and/or update their data or be given information on where and how they can confirm or update it
United Kingdom	National Health Service	<ul style="list-style-type: none"> ● The National Health Service has created guidance to ensure data quality of protected characteristics and other vulnerable groups ● Four established principles of this work include: <ul style="list-style-type: none"> ○ always enable patients to self-report information about their identities and life circumstances ○ never make assumptions in the questions patients are asked about their identity and circumstances, and the data that is recorded ○ embed these ways of working across all staff roles, service design, and processes to provide trauma-informed care that makes patients feel safe and empowered to share personal information ○ routinely use and feedback the data collected to ensure that everyone working is clear on the value of it and using it to advance equity ● Specific data to be included in medical records include gender identity, sexual orientation, disability, ethnicity, and accommodation status ● Gender identity <ul style="list-style-type: none"> ○ Collecting gender identity includes two data items – the gender identity code (male, female, non-binary, other, not known or not stated) and gender identity same at birth indicator (yes, no, not known, not stated)

Jurisdiction	Organization	Key messages
		<ul style="list-style-type: none"> • Sexual orientation <ul style="list-style-type: none"> ◦ Sexual orientation can be recorded as any of the following: heterosexual, female homosexual, male homosexual, bisexual, sexually attracted to neither gender, sexual orientation unknown, sexual orientation undecided, sexual orientation not given • Disability <ul style="list-style-type: none"> ◦ The guidance recommends that organizations collecting disability data have received training to understand disability rights ◦ Disability codes include: behavioural and emotional, hearing, manual dexterity, memory or ability to concentrate, mobility and gross motor, perception of physical danger, personal and continence, progressive conditions and physical health, sight, speech, other (not listed), no disability, not stated • Ethnicity <ul style="list-style-type: none"> ◦ NHS organizations are mandated to use ethnic monitoring questions and response codes and emphasize the importance of allowing the individual to self-report ◦ Ethnicity data categories include: White (British), White (Irish), White (other background), mixed (white and black Caribbean), mixed (white and black African), mixed (white and Asian), mixed (any other background), Asian or Asian British (Indian), Asian or Asian British (Pakistani), Asian or Asian British (Bangladeshi), Asian or Asian British (any other Asian background), Black or Black British (Caribbean), Black or Black British (African), Black or Black British (any other Black background), other ethnic groups (Chinese), other ethnic groups (any other ethnic group), not stated, not known • Accommodation status <ul style="list-style-type: none"> ◦ Accommodation status is an indication of the type of accommodation that a patient currently has and should be based on the patient's main or permanent residence ◦ Guidance suggests the use of a trauma-informed approach to be used and that patients not be pushed to provide a postcode ◦ Guidance also suggests the patient self-identify their accommodation status, knowing that accommodation status is not static ◦ Accommodation data categories include: owner occupier, tenant (local authority, arm's length management organisation), tenant (private landlord), living with family, living with friends, university or college accommodation, accommodation tied to job (including Armed Forces), mobile accommodation, care home without nursing, care home with nursing, specialist housing, rough sleeper, squatting, sofa surfing, staying with friends/family as a short-term guest, bed and breakfast accommodation to prevent or relieve homelessness, sleeping in a night shelter, hostel to prevent or relieve homelessness, temporary housing to prevent or relieve homelessness, admitted patient setting, criminal justice setting, other
United States	LGBT Foundation	<ul style="list-style-type: none"> • LGBT Foundation released a good practice guide to monitoring sexual orientation and trans status • The guidance notes that sexual orientation monitoring should follow the sexual orientation monitoring information standard and use self-identification and self-disclosure <ul style="list-style-type: none"> ◦ The guidance notes that when this is not possible the individual should be categorized as not known (not recorded) ◦ As not all descriptors are compatible with what is available in IT systems, individuals are advised to use multiple terms to describe themselves • Guidance suggests using the following questions: <ul style="list-style-type: none"> ◦ Which of the following options best describes how you think of yourself? ◦ Is your gender identity the same as the gender you were assigned at birth?

Jurisdiction	Organization	Key messages
		<ul style="list-style-type: none"> • The guidance notes the following steps to help staff to feel more comfortable and willing to ask questions: <ul style="list-style-type: none"> ○ understand and communicate the importance and purpose of monitoring people's sexual orientation and trans status ○ have a confidentiality policy that is easily accessible and well understood by everyone ○ create a space for open and judgement free communication so that people feel comfortable to share personal information ○ do not make assumptions ○ ask about sexual orientation and trans status routinely ○ improve visibility such as wearing rainbow lanyards or rainbow badges, putting up posters of LGBT organisations, and having visible inclusion policies ○ LGBT inclusion and awareness training is instrumental in helping services to carry out the above steps
	Healthwatch	<ul style="list-style-type: none"> • Healthwatch produced guidance on how to collect demographic data from people, including advice on when to ask demographic questions, how to ask demographic questions, and how to tackle tricky communication situations • With respect to timing, the guidance notes that demographic information can be collected during outreach and engagement activities and through surveys, questions, and qualitative research • Demographic questions can be asked at the beginning or end of conversations with people but should always include information on how data will be used • Three ways that data can be gathered include: <ul style="list-style-type: none"> ○ make notes of relevant information that the person volunteers in the course of recounting their experience ○ ask demographic questions throughout the conversation ○ combine asking about personal circumstances with providing relevant signposting • The guidance notes that it is not always realistic to collect personal information and suggests the following: <ul style="list-style-type: none"> ○ make sure there is an attempt to collect at least some basic demographics across all possible interactions (e.g., gender, ethnicity, age and disability) ○ after the basics, prioritize demographic/personal circumstances questions that are relevant to your current insights and community engagement priorities ○ when in doubt, ask as many demographic questions as is reasonable within a possible interaction • Additional suggestions for supporting information collection include: <ul style="list-style-type: none"> ○ take a moment to introduce the demographic questions before asking them ○ reassure people that it is okay not to answer but they are encouraged to do so • When respondents fill in forms on their own ask demographic questions at the end and include a short explanation of why you are collecting the data and how you will use it
	Department of Health and Human Services	<ul style="list-style-type: none"> • At a minimum for surveys conducted or sponsored by Health and Human Services, it is required to collect information on race, ethnicity, sex, primary language, and disability status
	Department of Veterans Affairs	<ul style="list-style-type: none"> • For Veterans, data collection on functional status are routinely collected by nurses at clinic triage at some medical centres • While Veterans Affairs is undergoing an electronic health record modernization such as ensuring data collected on socio-economic status and race and ethnicity, specifics were difficult to find

Appendix 6: Detailed jurisdictional scan about approaches to collect information on dimensions of equity, diversity and inclusion in electronic medical records

Document type	Hyperlinked title
Evidence synthesis	Missing race/ethnicity data in Veterans Health Administration based disparities research: A systematic review
Commentary	Capturing patients, missing inequities: Data standardization on sexual orientation and gender identity across unequal clinical contexts
	Electronic health records and transgender patients—Practical recommendations for the collection of gender identity data
	Collection of gender identify data using electronic medical records: Survey of current end-user practices
	Using sexual orientation and gender identity data in electronic health records to assess for disparities in preventive health screening services
	Considerations for collecting data on race and Indigenous identity during health card renewal across Canadian jurisdictions
	Incorporation of socio-economic status indicators into policies for the meaningful use of electronic health records

Waddell K, Bhuiya A, Ali A, Cuirea P, Phelps A, Chen K, Grewal E, Wilson MG. Rapid evidence profile #72: Collecting information on dimensions of equity, diversity, and inclusion in electronic medical records (EMRs). Hamilton: McMaster Health Forum, 4 June 2024.

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References

1. Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex, and sexual orientation documentation in electronic health records. *Journal of the American Medical Informatics Association* 2020; 27(11): 1774-1783.
2. German D, Kodadek L, Shields R, et al. Implementing sexual orientation and gender identity data collection in emergency departments: Patient and staff perspectives. *LGBT Health* 2016; 3(6): 416-423.
3. Nguyen GT, Yehia BR. Documentation of sexual partner gender is low in electronic health records: Observations, predictors, and recommendations to improve population health management in primary care. *Population Health Management* 2015; 18(3): 217-222.
4. Thompson HM. Stakeholder experiences with gender identity data capture in electronic health records: Implementation effectiveness and a visibility paradox. *Health Education and Behaviour* 2021; 48(1): 93-101.
5. Ford BK, Kong M, Ward JS, et al. Incomplete recording of Indigenous identification status under-estimates the prevalence of Indigenous population attending Australian general practices: A cross sectional study. *BMC Health Services Research* 2019; 19(1): 567.
6. Truong HP, Luke AA, Hammond G, Wadhwa RK, Reidhead M, Joynt Maddox KE. Utilization of social determinants of health ICD-10 Z-codes among hospitalized patients in the United States, 2016-17. *Medical Care* 2020; 58(12): 1037-1043.
7. Proumen R, Connolly H, Debick NA, Hopkins R. Assessing the accuracy of electronic health record gender identity and REaL data at an academic medical center. *BMC Health Services Research* 2023; 23(1): 884.
8. 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. *Academic Medicine* 2015; 90(2): 154-60.
9. Thompson HM, Kronk CA, Feasley K, Pachwicz P, Karnik NS. Implementation of gender identity and assigned sex at birth data collection in electronic health records: Where are we now? *International Journal of Environmental Research and Public Health* 2021; 18(12): 6599.
10. Sokkary N, Awad H, Paulo D. Frequency of sexual orientation and gender identity documentation after electronic medical record modification. *Journal of Pediatric Adolescent Gynecology* 2021; 34(3): 324-327.
11. Mathur R, Bhaskaran K, Chaturvedi N, Leon DA, vanStaa T, Grundy E, Smeeth L. Completeness and usability of ethnicity data in UK-based primary care and hospital databases. *Journal of Public Health* 2014; 36(4): 684-692.
12. Wright K, Tapera RM, Stott NS, Sorhage A, Mackey A, Williams SA. Indigenous health equity in health register ascertainment and data quality: A narrative review. *International Journal of Equity Health* 2022; 21(1): 34.
13. Lasser EC, Kim JM, Hatf E, Kharrazi H, Marsteller JA, DeCamp LR. Social and behavioral variables in the electronic health record: A path forward to increase data quality and utility. *Academic Medicine* 2021; 96(7): 1050-1056.
14. Klinger EV, Carlini SV, Gonzalez I, et al. Accuracy of race, ethnicity, and language preference in an electronic health record. *Journal of General Internal Medicine* 2015; 30(6): 719-723.
15. Byrne M, Borzalski C. Analysis of inclusive gender, sexuality and sexual orientation data elements in academic electronic health records. *Computational Information and Nursing* 2023; 41(12): 975-982.
16. Nadler LE, Ogden SN, Scheffey KL, Cronholm PF, Dichter ME. Provider practices and perspectives regarding collection and documentation of gender identity. *Journal of Homosexuality* 2021; 68(6): 901-913.
17. Kiran T, Sandhu P, Aratangy T, Devotta K, Lofters A, Pinto AD. Patient perspectives on routinely being asked about their race and ethnicity. *Qualitative Study in Primary Care* 2019; 65(8): e363-e369.
18. Nik-Ahd F, Waller J, De Hoedt AM, et al. Seeing the unseen: how can we best identify transgender women within the Veterans Affairs healthcare system's electronic medical record? *The Journal of Sexual Medicine* 2023; 20(4): 559-567.
19. Doucette C, Milano MT, Kamen C. Patient perceptions of sexual orientation and gender identity data collection in an outpatient radiation oncology setting. *International Journal of Radiation Oncology Biology and Physiology* 2023; 116(1): 68-78.

20. Zingmond DS, Parikh P, Louie R, Lichtensztajn DY, Ponce N, Hasnain-Wynia R, Gomez SL. Improving hospital reporting of patient race and ethnicity—Approaches to data auditing. *Health Services Research* 2015; 50(Suppl 1): 1372-1389.