McMaster University | HEALTH FORUM

Rapid Evidence Profile

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

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[MHF product code: REP 72]

Context

- Collecting demographic data is critical to improving health equity and to supporting organizations and providers to better plan and deliver care, including to:
  - identify and address differences in care for specific populations
  - distinguish which populations are not achieving optimal outcomes from interventions
  - assess whether culturally competent care is being provided
  - develop additional patient-centred services to improve health outcomes.
- Creating standardized processes for collecting this information can help to ensure that it is accurately collected respectfully and inclusively.

Box 1: Evidence and other types of information

+ Global evidence drawn upon

Evidence syntheses selected based on relevance, quality, and recency of search

+ Forms of domestic evidence used (🍁= Canadian)

Data analytics

Evaluation

Qualitative insights

+ Other types of information used

Jurisdictional scan (All Canadian provinces and territories as well as five countries: AU, CA, NZ, UK, US)

*** Additional notable features**

This rapid evidence profile was prepared in the equivalent of three business days

Questions

- What is known about ways to elicit and record equity, diversity, and inclusion information in medical forms and electronic medical records (EMRs)?
- What guidance has been produced for recording equity, diversity, and inclusion information in electronic medical records at the provincial and territorial level in Canada and at the national level within each of the 'Five Eyes' countries?

High-level summary of key findings

- We found 20 evidence documents, of which we determined 19 (three evidence syntheses and 16 single studies) to be highly relevant to the questions.
- Most of the identified evidence focused on the collection of information for three dimensions of equity: race/ethnicity/culture/language, gender/sex, and personal characteristics associated with discrimination including sexual orientation.
- Much of the identified evidence focused on quantifying gaps and misreporting in the collection of information as well as on barriers and enablers to data collection.
- Identified barriers included:
  - no established standards for inputting data
  - information systems that limit input options
  - lack of staff capability or capacity
  - staff perceptions that the collection of this information is not important.
- In contrast, identified enablers included:

- the use of precise terminology
- mandating the collection of specific information
- using data collection standards
- mandating training programs
- using checkboxes or specific tabs within electronic health records (EHRs).

- From the jurisdictional scan, we identified provincial-level guidance from four Canadian provinces – British Columbia, Manitoba, Ontario, and Nova Scotia – and national-level guidance from all 'Five Eyes' countries that support the collection of information on dimensions of equity, diversity, and inclusion.

Box 2: Approach and supporting materials

We identified evidence addressing the question by searching Health Systems Evidence, Health Evidence, and PubMed. All searches were conducted on 8 April 2024. The search strategies used are included in Appendix 1. In contrast to synthesis methods that provide an in-depth understanding of the evidence, this profile focuses on providing an overview and key insights from relevant documents.

We searched for full evidence syntheses (or synthesis-derived products such as overviews of evidence syntheses) and protocols for evidence syntheses.

We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using the first version of the AMSTAR tool. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. The AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial, or governance arrangements within health systems or implementation strategies.

A separate appendix document includes:
1) methodological details (Appendix 1)
2) key findings from included evidence syntheses and single studies (Appendix 2)
3) details about each identified synthesis (Appendix 3)
4) details about each identified single study (Appendix 4)
5) details from the jurisdictional scan (Appendix 5)
6) documents that were excluded in the final stages of review (Appendix 6).

This rapid evidence profile was prepared in the equivalent of three days of a 'full court press' by all involved staff.

Framework to organize what we looked for

- Dimensions of equity
  - 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)
  - Features of relationships
  - Time-dependent relationships (e.g., caregiving responsibilities)
- By whom information is collected
  - Physicians
  - Nurses
  - Midwives
  - Pharmacists
  - Allied health professionals
  - Support/administrative staff
- When information is collected
- How information is collected
  - Written (and then transferred to EMRs)
  - Entered in an online portal (and then integrated to EMRs)
  - Orally (and then entered into EMRs)
- With what supports information is collected
  - Training modules
  - Definitions and glossary of terms
  - Scripts for collecting information and responding to individuals' questions
  - Prompts within EMRs

What we found

We identified 20 evidence documents that examined ways to elicit and record equity, diversity, and inclusion information in medical forms and electronic medical records. Of these documents, we considered the following to be highly relevant:

- three evidence syntheses
- 16 single studies.

We should note that we did not include commentaries as part of this profile given the lack of transparency in their development, however we have listed many commentaries in the list of excluded documents in Appendix 6, some of which may be helpful in developing approaches to collect information on the many dimensions of equity.

Coverage by and gaps in existing evidence syntheses and domestic evidence

Most of the identified evidence focused on the collection of information for three dimensions of equity: 1) race/ethnicity/ culture/ language; 2) gender/sex; and 3) personal characteristics associated with discrimination, namely sexual orientation. One evidence synthesis addressed the collection of information on broader social determinants of health including occupation, education, and socio-economic status.(1)

The included evidence focused on information collection by clinical staff in primary care, community care, and hospital settings including physicians, nurses, and administrative staff. However, none of the included evidence compared the benefits or harms of information collection by different types of health professionals or staff members. Much of the evidence was silent on when information should be collected, but some guidance is provided from the jurisdictional scan, particularly for those just beginning to collect these types of data.

Much of the evidence focuses on information provided orally by patients and entered in an EMR by a clinician and provides some evidence for what supports can facilitate information collection.

Key findings from included evidence documents

In general, findings from the included evidence provided insight into four areas:

- what data should be collected (e.g., dimensions of equity)
- when/where data should be collected (e.g., what setting of care)
- gaps or misreporting of data
- enablers and barriers to data collection.

Findings about what should be collected

In general, all included evidence syntheses and single studies focused on the importance of collecting information about race/ethnicity including Indigeneity, as well as gender and sex, to support improved representation and understanding of the health of diverse populations. Most evidence syntheses and single studies note that best practice is for patients to self-identify based on explicit, well-formed questions rather than for providers or administrative staff to assume any information.(2-4)

One recent low-quality evidence synthesis, two older single studies, and two recent single studies all focused on the importance of collecting data on gender, sex and sexual orientation in efforts to improve our understanding of LGBTQAI+ health. The evidence documents describe that patients are generally supportive of the collection of this information and described the use of a two-step question for collecting information on gender identity and birth sex, noting that this approach better supported trans individuals.(5-8)

One recent single study described how patients in a primary care practice were generally supportive of collecting data on race and ethnicity. However, the same study noted that there was some confusion with the ways that questions were asked (e.g., whether interest was in their place of birth or their ancestry) and suggested that free text or allowing multiple option choices may better support individuals with mixed ethnicities.(9)

Findings about when data is collected

One older single study found that patients were more willing to provide information about their sexual orientation in primary care than in emergency department settings.(6)

Findings about gaps and misreporting of data

The included evidence documents identified significant gaps in the collection of information on dimensions of equity. In Australia, one single study found almost half of patient records had unknown or missing Indigenous identification.(10) In addition, a large health system in the northeastern U.S. found only 45% of EHRs had documented sexual orientation, with less documentation among patients over the age of 50, those with Medicare, and those seen in suburban practices.(6) One recent study found optional codes in EMRs related to social determinants of health are being vastly underused and are only included in an estimated 2% of patient records.(11)

Evidence documents also identified challenges with misreporting. A recent single study in the U.S. found that even when race was documented, it was incorrect in between 6 and 13% of the EHRs, with multi-racial and Hispanic patients being the most likely to have their demographics misreported.(3) The same study also found 11% of gender identities in EHRs were discordant with the patient's self-identity.(3) Other studies reported similar discrepancies in race and ethnicity data of between 10 and 14%.(12)

Findings about barriers and enablers to data collection

Two recent low-quality evidence syntheses and four recent single studies identified the following barriers to collecting information on dimensions of equity:
- no established standards for inputting data, particularly for open data fields/patient-reported data (1; 4; 11; 13; 14)
- information systems that limit input options, particularly for ethnicity (including Indigenous status) and language, and missing entries for gender identity and sex at birth (13-15)
- lack of staff capability or capacity (13)
- staff perceptions that this information is not important.(13)

In contrast, one recent low-quality evidence synthesis, two older single studies, and three recent single studies identified the following enablers:
- using precise terminology in questions and adopting gender-affirming language (16)
- mandating the collection of specific information (17)
- developing data collection standards (preferably in consultation with local stakeholders and community members) (2; 16; 18)
- mandating training programs that clearly explains why the collection of this information is important and how it should be conducted (2; 16; 18)
- using checkboxes or specific tabs within EHRs to remind individuals about the collection of specific types of data.(6; 19)

Key findings from the jurisdictional scan

For the jurisdictional scan, we looked for what information on dimensions of equity, diversity, and inclusion was being collected in provincial and territorial health records. We also looked at the federal level in each of the 'Five Eyes' countries – Australia, Canada, New Zealand, U.K., and U.S.

Key findings from Canadian provinces and territories

Across Canadian provinces and territories there is significant variability in the extent to which information on the dimensions of equity, diversity, and inclusion are being collected. However, this finding may reflect in part the variation in the centralization and decentralization of EHRs in each province (e.g., where some provinces have provincially established interoperable records, such as Alberta, whereas many others do not, such as Ontario).

We identified data standards in four provinces that are being used to guide the collection of information on dimensions of equity, diversity, and inclusion.

In British Columbia, the Ministry of Health has developed a gender and sex standard for use in EMRs, while a demographic standard and social determinants of health standard are currently under development. The gender and sex standard suggests the use of a two-step question to clarify administrative gender (e.g., what gender they would like on their documentation and sex assigned at birth). The standard further suggests the use of open-ended questions collected via one of paper, online, telephone, or in person.

Manitoba collects self-declared race-based data upon registration at a Manitoba hospital (though on a voluntary basis). Codes for race, ethnicity, and Indigenous identities were co-developed with local communities.

In Ontario, though not health-system specific, 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. In addition, the Black Health Plan notes the importance of collecting race-based data through the Ontario Health Insurance Plan (OHIP) registration and renewal process. An ongoing area of action in Ontario as part of the Health Equity, Inclusion, Diversity and Anti-Racism Framework is for Ontario Health to mandate equity data collection across all of its portfolios and health service provider organizations, as well as to work with the Ministry of Health to establish a key minimum dataset of equity elements – extending beyond race - that will be collected using standard tools.

Nova Scotia has recently announced the Fair Care Project, which is a voluntary effort to collect and interpret race-based data based on the Canadian Institute for Health Information data standard.

Other provinces did not appear to be collecting this type of information at a provincial level, though there may be efforts taking place at more local or organizational levels. With respect to the territories, we did not identify any information from the Northwest Territories or from the Yukon. However, in Nunavut, the healthcare coverage form requires that patients identify their sex (but not gender) and ethnicity, and also asks individuals to indicate their Indigenous status.

Key findings from each of the 'Five Eyes' countries

We identified data standards in all five countries that cover dimensions of equity, diversity, and inclusion in electronic medical records.

Australia has a national health records system which prompts individuals to report on demographic and other information including sex and gender. Demographic information has been based off of the standards for cultural and language diversity. In addition, the 'My Health' record collects information about whether an individual identifies as Aboriginal and/or Torres Strait Islander and/or as a Veteran or a member of the Australian Defence Force.

In Canada, though there is no national EHR, a national body – the Canadian Institute for Health Information (CIHI) developed guidance on the use of standards for race-based and Indigenous identity data collection and health reporting in Canada. This guidance also points to additional resources related to best practices in data collection and data governance including First Nations Principles of OCAP (ownership, control, access, possession) and EGAP (engagement, governance, access and protection) principles for Black communities. In addition, an ongoing Canadian Institutes of Health Research funded project is in the process of developing a screening tool for poverty and related social determinants that is being piloted across the country.

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, which also includes additional equity considerations such as gender, name, and language preferences. Health New Zealand has also established protocols for collecting and recording Māori descent and iwi affiliation in the health and disability system. Healthcare providers are encouraged to confirm this information with their patients every three years.

The National Health Service in the U.K. National Health Service has established guidance to ensure data quality of protected characteristics and other vulnerable groups, which includes the collection of information on gender identity, sexual orientation, disability, ethnicity, and accommodation status among others. In addition, HealthWatch – the national patient and citizen engagement organization in the U.K. – has produced guidance on how to collect demographic data including when to ask demographic questions, how to ask demographic questions, and how to tackle challenging communications.

Finally, in the U.S., the Office of Management and Budget has set out race and ethnicity questions that must be reported by federal agencies and recipients of federal funds. The Affordable Care Act provides a data standard for racial categories, while the Centres for Medicare and Medicaid have established compendiums for disability data collection methods. EHRs within the Veterans Affairs health system are in the process of being modernized, which will include standardized data collection for socio-economic status, race, and ethnicity; however, additional details were not identified.

Next steps based on the identified evidence

- The COVID-19 pandemic shone a spotlight on the importance of collecting health information on dimensions of equity, diversity, and inclusion and much of the literature points to the challenges of collecting this information without supportive infrastructure and clear standards in place.
- Guidance and data standards such as those highlighted in the jurisdictional scan can help to ensure the right data is being collected safely and respectfully, but ongoing evaluations and audits of EHRs can help to further evaluate the extent to which these supports are effective.

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