CAEP Position Statement

Enhanced Sociodemographic Variable Collection in Emergency Departments

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Introduction

Social determinants of health are non-medical factors that influence health outcomes[1]. These include gender identity, sex assigned at birth, sexual orientation, race, ethnicity, Indigenous Identity, age, education, socioeconomic status, and others. These factors uniquely interact for each individual and can influence health outcomes positively or negatively. Emergency medicine (EM) includes the provision of care for emergent health conditions, but also provides general unscheduled healthcare for those facing access barriers, which may be more prevalent in marginalized populations. Knowing the distributions of social determinants of health in EM patient populations in Canada is required to understand existing inequities and to monitor the effectiveness of interventions designed to promote equity, diversity, decolonization, and inclusion in healthcare. This has been identified as a priority in addressing racism and colonialism in emergency medicine in Canada[2]. There is a gap in understanding which social determinants of health are currently collected for EM patients across Canada. A recent national survey of Canadian EDs found that only 20% of responding sites collected data on race or ethnicity[3], although a response rate < 33% left uncertainty in the actual proportion of sites that collect these variables. Heterogeneity in variable definitions, processes of collection, as well as data management and reporting standards can limit an ability to combine or compare data across jurisdictions and to identify areas for further research and improvement.

International recommendations from the World Health Organization call for all countries to expand their capacity to measure and monitor inequities in their health information systems[4].The lack of well established, uniform practices for collecting equity-based data in Canadian EDs reflects existing patient, healthcare worker and systemic barriers as well as the potential harm of collecting and using this data improperly[5–7]. The collection of equity-based socio-demographic data without a clear focus on addressing equity gaps risks perpetuating existing systemic discrimination. For example, misuse of race-based data has led to misuse of race as a biological factor rather than a social construct[5]. To avoid past missteps in the collection and use of equity-based data and to focus on the collection and application of this data to address equity gaps, we need to apply existing ethical frameworks to sociodemographic data collection in the emergency department.
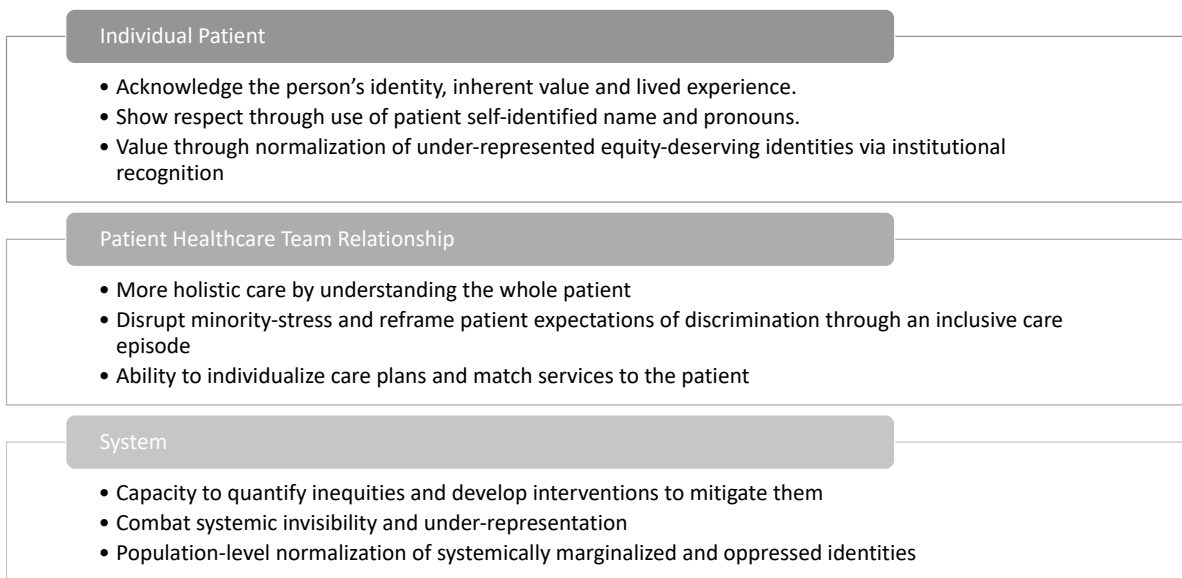
In Canada, most acute hospital admissions occur through EDs where patients are registered and sociodemographic data is collected[6]. Best practices along with potential risks, benefits, barriers, and facilitators of routine sociodemographic variable collection in emergency departments (EDs) have been identified with recommendations to optimize accuracy and safety of disclosure for patients[7]. Engagement with equity-deserving communities should be centered in enhanced equity-relevant data collection planning and processes in adherence with established frameworks for data governance[8,9]. Standardization and harmonization of demographic variable definitions and collection practices should be pursued to support the evaluation of inequities at the population level[10]. Building on a systematic review and qualitative evidence synthesis[7] we conducted a national needs assessment to inform this Canadian Association of Emergency Physicians (CAEP) Position Statement on the routine collection of social determinants of health in Canadian EDs.

Potential Benefits

There are multiple patient- and system-level benefits from enhanced sociodemographic variable collection. The triage and registration interface is the first point of contact for patients entering the ED. Interpersonal interactions at this point set the tone for the rest of the medical encounter. Patients from systemically oppressed and marginalized populations can suffer compounding stress from these encounters, in addition to the condition that has brought them to the ED seeking care. The Minority Stress Model describes how stigma, prejudice, and discrimination experienced over time interact to create an increased burden of illness and worse health outcomes for people from equity-deserving groups[11]. Inclusive encounters—such as self-identification of gender, offering non-verbal data collection options, and ensuring the clinical team knows the patient's used name and pronouns—however, can serve to break this cycle and establish a supportive therapeutic relationship with the patient and the ED healthcare team. There are numerous described benefits from enhanced sociodemographic data collection in EDs in addition to the ability to monitor inequities and design strategies to mitigate them (**Figure 1**)[7].

Given the national crisis in EM resources and staffing, the delivery of equitable care to systemically marginalized and oppressed populations is threatened now more than ever. Barriers to access and good healthcare outcomes face all Canadians during times of strain but are further amplified in systemically oppressed and marginalized populations. Measuring social determinants of health is the first step in designing strategies to promote equity and inclusion. Reliable system-level data is required to monitor the effectiveness of these efforts. We believe the benefits of enhanced routine sociodemographic variable collection in EDs outweigh the costs. Additional benefits include representation of underrepresented groups in clinical data and research, institutional normalization of equity-deserving identities, and opportunities to enhance holistic patient care. Patient- (aka human) centered care is our goal, and efforts to center the needs of our diverse patients and provide improved care will make careers in EM more fulfilling and may mitigate ever-increasing levels of burnout.

Figure 1 – Benefits of Enhanced Sociodemographic Variable Collection

Individual Patient

- Acknowledge the person's identity, inherent value and lived experience.
- Show respect through use of patient self-identified name and pronouns.
- Value through normalization of under-represented equity-deserving identities via institutional recognition

Patient Healthcare Team Relationship

- More holistic care by understanding the whole patient
- Disrupt minority-stress and reframe patient expectations of discrimination through an inclusive care episode
- Ability to individualize care plans and match services to the patient

System

- Capacity to quantify inequities and develop interventions to mitigate them
- Combat systemic invisibility and under-representation
- Population-level normalization of systemically marginalized and oppressed identities

Methods

We conducted a national environmental scan of Canadian ED sociodemographic variable collection practices at the Provincial and Territorial level. We identified Provincial and Territorial representatives with knowledge and experience of their jurisdictional EM health information systems for each Province and Territory in Canada (except the Northwest Territories where a representative could not be identified). We created a data collection form using the SurveyMonkey program (surveymonkey.com), which was deployed between June-September 2023. Data items were determined collaboratively by co-investigators. Each representative facilitated completion of a data collection form (**Appendix 1**) for each EM health information system in their Province or Territory. We reported environmental scan results as counts (with proportions).

Results

Respondents from 10 provinces and 2 territories responded to our survey from June 1 to September 28, 2023 reporting 12 different health information systems in use across Canada. In three jurisdictions the same system was reported (Cerner) but differences in software version or optional sociodemographic collection capacity were not captured. There was heterogeneity in coverage for each health information system ranging from a single ED (n=9, 30%), to a single institution or hospital network with a small number of EDs (n=9, 30%), to a health information system that represents numerous EDs (n=12, 40%).

Overall, most jurisdictions reported either no routine collection, or variation in collection and documentation of most sociodemographic variables (**Appendix 1**). Sociodemographic data was most commonly collected by registration clerks (commonly n=22, 88%; sometimes n=1, 4%, rarely n=2, 8%) , followed by triage nurses (commonly n=4, 16%; sometimes n=11, 44%; rarely n=10, 40%), with EM

physicians being the least likely to participate in this data collection (commonly n=2, 8%; sometimes n=7, 28%; rarely n=16, 64%) (**Appendix 2**). Few jurisdictions offered cultural humility training specific to the identities collected for their staff (registration clerks n=9, 36%; triage nurses n=4, 16%; EM physicians n=5, 20%)), although most respondents were unsure if data collectors of sociodemographic variables received any specific cultural humility training (**Appendix 3**). Across Canada 12 (48%) health information systems import some sociodemographics from other health visits (e.g., primary care or specialty clinics). Age (n=25, 100%), location of primary residence (n=22, 88%), sex-assigned-at-birth (n=20, 80%), religion (n=18, 72%), and relationship status (n=16, 64%) were each reported to have a standardized place and format for documentation in a majority of systems (**Appendix 4**). Gender identity (n=9, 36%), patient pronouns (n=8,32%), honorifics (n=8, 32%), race (n=4, 16%), ethnicity (n=2, 8%), Indigenous Identity (n=6, 25%), language spoken at home (n=12, 48%), sexual orientation (n=3, 12%), housing status (n=5, 21%), disability (n=0, 0%) and migrant status (n=0, 0%) were reported to have a standardized place and format for documentation in few systems(**Appendix 4**). In most health information systems, gender identity (n=17, 68%), used name if different from legal name (n=14, 56%), pronouns (n=18, 72%), and honorifics (n=21, 84%) are <u>not</u> documented where name and sex are usually found in the medical record (**Appendix 5**). Respondents identified that their health information system and data collection processes were rarely able to differentiate sex-assigned-at-birth from gender identity with only two systems (8%) reporting an ability to do so.

Only two jurisdictions (8%) included an explanatory statement explaining to patients why their sociodemographics were being collected and how their data would be used. No jurisdictions obtained explicit informed consent for disclosure of information; it was reported as implicit in all cases. Only two (8%) health information systems reported that data collectors used a standardized script when collecting sociodemographic data. One jurisdiction (4%) offered non-verbal options for patients to disclose their sociodemographic data. The best practice of *self-identification*[7] for patients reporting their identities (where patients are asked which options they identify with) was used in 8 jurisdictions (32%) as opposed to auto-population from other sources or assumptions by the data collector. The best practice of *universal screening*[7] where all patients are asked all sociodemographic questions each time they register was endorsed by six (24%) systems.

Discussion

We performed a national environmental scan of health information systems used by emergency departments, capturing data from the majority of regions in Canada. We found that there was wide variability in practices regarding the collection of sociodemographic variables, however overall, these data were infrequently collected. These findings highlight the inadequacy of data collection required to identify gaps in medical care for marginalized populations. Further, our data indicates harm to patients through routine ED practices, through insensitive data collection processes and failure to clearly provide clinical teams with patient pronouns.

Our findings expose an ongoing implementation gap across Canada between data-driven best practices in sociodemographic variable collection in EDs[7] and recommendations by the WHO[4] and the Canadian Institutes of Health Information (CIHI)[12]. Despite this gap there are EM innovators across Canada with some EDs implementing training and processes to support the collection and analysis of

social determinants of health. In Toronto, the Sinai Health System and Toronto Central Local Health Integration Network published a comprehensive guide to demographic data collection in healthcare settings[13]. In Manitoba, inequities noted during the early days of the COVID-19 pandemic led to the development of a Province-wide initiative to collect patient self-identified race, ethnicity and Indigenous Identity data at registration and in all EDs[12] proving that enhanced sociodemographic data collection can be successfully implemented in health systems, even while under strain. Importantly, this process was planned in consultation with Indigenous and racialized community groups who are involved in ongoing engagement and governance of the data [14].

Recommendations
We make the following recommendations to enhance the collection of sociodemographic data from patients routinely in EDs across Canada:
1) EDs should routinely collect sociodemographic variables that have been identified as social determinants of health.
    - Minimum recommended variables based on a national consensus process conducted by CIHI are[12]:
        - age,
        - education,
        - gender identity,
        - sex-assigned-at-birth,
        - geographic location,
        - income,
        - Indigenous Identity,
        - race.
    - Additional variables that may be relevant to ED care include language, housing, religion, and disability[7].
2) EDs should collect patient information that facilitates person-centered care with cultural humility. At minimum these should include:
        - patient pronouns,
        - used name if different from name on government identification,
        - honorifics,
        - a patient-identified substitute decision maker.
3) Consistent with the recommendations of OCAP[9] and EGAP[8], the collection of sociodemographic data should be conducted in an effort to address equity gaps and should be conducted in collaboration with impacted communities.
4) The medical record and identifying bracelets should clearly communicate to clinicians the patient's pronouns, gender identity, and used name.
5) Variable definitions should be standardized and consistent with national recommendations to facilitate harmonization of data and potential for valid comparisons between jurisdictions[15].

6) To ensure safe and accurate disclosure of personal sociodemographic information Emergency Departments should prioritize the following principles adapted from our recent systematic review and qualitative evidence synthesis[7] (**Table 1**).

Table 1 – Best Practices for Routine Sociodemographic Variable Collection in EDs

1. **Offer non-verbal collection methods for patient disclosure of sociodemographic variables primarily.** - A verbal guided option should be available to those who prefer or require an alternative to non-verbal disclosure. - Accessibility of both non-verbal and verbal methods should be considered including availability in multiple languages and or accessibility formats.
2. **Ensure patient privacy is protected during information sharing (whether disclosure is non-verbal or verbal).** - Electronic screens or paper forms should only be viewable to the individual entering the data. - There should be adequate privacy for verbal information sharing such as a private room, adequate barriers, etc.
3. **Allow patients to self-identify.** - Use inclusive categories for social identities if providing multiple choice options for patients to select. - Include options for another identity not listed. - Provide options for patients to decline disclosure.
4. **Develop standardized explanatory scripts* to introduce sociodemographic variable collection that include the following:** - A plain language explanatory statement, available in the most common languages of the patients in the jurisdiction, that explains that these questions are asked of all patients (aka universal screening), and how this information is intended to be used. - An explanation of the benefits of disclosure & collection for the individual and the system. - A clear explanation of the voluntary nature of disclosure and an explanation that a choice <u>not</u> to disclose this information will not negatively impact patient care.
5. **Provide written information (electronic or paper) to patients that includes:** - The institution's anti-discrimination policies. - A summary of whatever relevant privacy rules, regulations or laws exist. - A list of resources in the applicable jurisdiction that provide specialized healthcare support specific to identity factors being asked. - Availability of any specific advocacy services integrated into the ED (e.g., Indigenous Health Service). - Patient relations office contact and services offered.
6. **Provide anti-oppression, implicit bias, social justice, and trauma-informed care training to all ED staff.** - Require this training as a condition of employment. - Resource programs adequately to provide this training on an ongoing basis.

7. Develop processes that eliminate the need for repetitive disclosure of gender identity, patient pronouns, and used name if different from legal name. - Examples may include name tags with inclusive options, a dry-erase board in the patient care space to contain relevant details, or integration into existing electronic or paper health information systems in such a way that relevant details are available to all health care providers. - Provide patients with the opportunity to review and modify retained sociodemographic information from previous visits or linked health records.
8. Create inclusive and welcoming physical spaces by including: - Featured ambassadorial symbols (e.g., Indigenous medicine wheel, PRIDE flag, etc.). - Post existing non-discrimination policies for public viewing. - Make audio and/or visual announcements promoting diversity, reviewing population-specific resources (e.g., population-specific liaison/advocacy services) and confirming non-discrimination policies. - Make non-gendered bathrooms available.
9. Facilitate staff engagement and measure institutional outcomes by: - Recognizing and rewarding staff who model inclusive care. - Committing to regular audits evaluating key outcomes with respect to health equity, make these results public. - Regularly monitor completeness of data collection.
10. Consistent with the principles of EGAP and OCAP, engage community advocates in the approach to the collection and stewardship of sociodemographic variables[8,9]. - Work together to mitigate the potential harms of misuse of this data and to promote the use of the data to address equity gaps in care. - Establish regular practices for revisiting the collection and use of this data to maintain transparency with community members and to address any unintended negative consequences of this data collection.

Templates can be accessed at: http://torontohealthequity.ca/tools/

Conclusions

We performed a national environmental scan to investigate the health information systems processes for sociodemographic variables in EDs. We found that collection of these data was infrequently performed, unstandardized, variable between regions, and insufficient for clinical care. We recommend that EDs implement routine and nationally standardized collection of sociodemographic variables in order: (1) to identify and address equity gaps in health delivery and outcomes for systemically marginalized and oppressed groups in our communities; and (2) to provide person-centered care with cultural humility, while 3) engaging regular with community groups in order to maintain transparency and mitigate any adverse unintended consequences of this data collection.

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