

Potential Harms Associated with Routine Collection of Sociodemographic Information in Hospitals: Rapid Review Protocol

Prepared for: IQ@TOH

Prepared by: Campbell and Cochrane Equity Methods Group

Background

It is important for health systems to investigate performance using an equity perspective. This capability will enable the development of specific solutions addressing service gaps in disadvantaged groups. The Campbell and Cochrane Equity Methods Group recommends the PROGRESS (Place of residence, Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socioeconomic status, Social capital) framework as an aide-memoire for the concepts enabling analyses with an equity lens. Health systems need to consider the optimal method for routinely capturing this information.

Routine data capture works best if it can be incorporated into existing work flows. For most of the PROGRESS indicators, there are strong clinical indications to obtain the information to guide clinical decisions. For these concepts, it is sensible to collect the information during routine clinical processes, such as during patient registration or during the provision of a medical history by the patient to a provider. On the other hand, for several PROGRESS indicators (specifically race, religion, and income), the relevance of the information for clinical decision making may not be apparent to patients. In addition, some experts have expressed concerns that collection of this information may cause patient distress, especially for patients from vulnerable populations.

Given the uncertainty of immediate clinical benefit derived from the collection of this information, it is possible the information will be difficult to obtain. Further, the data collection itself could interfere with the trust relationship between patients and providers. For the characteristics that are of questionable clinical value, it is important to thoroughly understand these potential risks. This information will guide the data collection process including who asks for the information, how the information is categorized, and under what circumstances is it collected.

We propose to perform a rapid review of the literature to address the issue of potential or actual harms experienced by patients or their families when they are asked to provide information about their race, religion, and income during routine healthcare visits. This information will inform the design of the Ottawa Hospital's data collection procedures for these concepts.

Methods

Review format: Rapid review

Population: Patients presenting to healthcare providers - hospitals or clinics

Intervention: Routinely solicited information on race, religion, and/or income – by survey or by direct questioning

Comparator: no comparator required

Outcomes: Provider's, patient's, and/or family's experience of adverse outcomes including, for example: a perception of persecution; a perception the information will be used for negative purposes; other reasons for failure to provide information.

Study Designs: Included studies will include observational studies

Search methods: The search strategies will be developed by a medical librarian. Deduplicated citations will be uploaded into Distiller Systematic Review Software for screening. Searching will be limited to Ovid MEDLINE and <https://www.healthevidence.org/>.

Study screening and selection:

Titles and abstracts of uploaded citations will be assessed for eligibility using an accelerated screening method. This means that a study included by one reviewer will go straight to full text screening but studies excluded by one reviewer need to be screened by a second reviewer. At full text screening, studies will be assessed by two reviewers.

Only English studies will be included in this summary.

Data extraction

Data extraction forms will be developed and pilot tested using Excel. Data will be extracted by one reviewer and verified by a second reviewer. Data will be extracted for:

- Country
- Study design
- Data collection method (e.g. survey, in person)
- Data collected (e.g. race, religion, income)
- Population (e.g. patients, caregivers)
- Outcome (e.g. type of harm)

Evidence synthesis

We will provide evidence tables to summarize the included studies for the following data:

- Type of data collected
- Method of data collection
- Outcomes for patients and family members
- Outcomes for providers