Fairness is Excellence:
The Ontario SPOR SUPPORT Unit's Equity Framework

This framework explains principles and practices for promoting equity in patient-oriented research, and the equity-related requirements for researchers working with the Ontario SPOR SUPPORT Unit (OSSU). This document also describes resources and services that the OSSU can provide researchers. The framework is part of the OSSU's broader efforts to promote equity in patient-oriented research.

Equity means fairness. Health equity means fairness in health outcomes and throughout the health sector including within health care, training, education, and research. There are multiple forms of discrimination, each with a different history and different manifestations today. The right to health is a human right (1).

Topics addressed in this framework

- General principles for addressing health equity in research
- Some reasons researchers should take health equity seriously
- Selecting research topics and developing proposals
- Engaging with patients and the public
- Supporting, retaining and finding research staff and trainees
- Conducting research
- Analysing results
- Exchanging knowledge including reporting results

General principles for addressing health equity in research

1. Health research should benefit everyone
2. Health researchers can decide to prioritize health equity
3. The actions of health researchers can promote or undermine health equity
4. Health equity requires dedicated effort and resources
5. Health researchers should "walk the talk" and ensure that the research enterprise is itself fair

Some reasons researchers should take health equity seriously

Research can help to address health inequities. Using an equity lens in health research can help interrupt discriminatory practices and address inequities. Health care and health outcomes differ based on racialization, gender, income and other factors. Research can also exacerbate health inequities and reinforce discriminatory practices. Health research takes place within societies marred by racism, sexism, language discrimination and other forms of discrimination in the legal, government, education and other sectors. Health research has been misused to justify and support discriminatory practices and policies. Today, some still claim that biological differences based on "race" explain differences in health outcomes, and a substantial gender gap in pay and rank exists in health care and health research (2,3).

Health care and health research institutions are anchor institutions that can support progress by setting an example that others may choose to follow. Health researchers can promote health equity by prioritizing health equity in selecting research questions or topics, adhering to fair hiring processes, conducting research properly and attending to equity when communicating about research to promote action. The research enterprise must itself be fair.

Selecting research topics and developing proposals

One of the most valued aspects of research is the freedom to choose study topics and questions, an important aspect of academic freedom. This freedom means that researchers can choose research topics that help advance health equity. Shared resources including government funding are used by the research endeavor, so many researchers strive to improve health for everyone including those who are disadvantaged.

Researchers can select topics that address health inequities. Researchers can decide to do research that help address disparities in health outcomes for racialized people or address women's health. Researchers can choose to include language identity variables to help address disparities in access to health services for linguistic minorities. Advancing health equity is challenging work and it is unlikely to occur by happenstance.

It is best to focus on health equity from the outset rather than to add-on equity related analyses to studies toward the end of a study. As described below, such afterthought analyses can be counterproductive. If, for example, gender is an important characteristic, then gender needs to be properly assessed by design.

Many research topics apparently have little or nothing to do with health equity from the outset. For example, studies of whether a medicine or surgical intervention improve health outcomes may seem unrelated to health equity since the intervention is expected to improve health for everyone. But such studies can be designed to test interventions that will be widely accessible, to assess them in diverse study populations that reflect the diversity of Canada, and to measure outcomes of general importance.

If a study really has nothing to do with health equity, this should be made clear and no attempt should be made to make a study appear to address equity if it is in a tokenistic manner.

Health researchers should avoid research topics or questions based on discriminatory premises. The false premise that genetic or biologic differences between people of different "races" underlies some studies that find apparent differences in health outcomes such as mortality. In fact, race is a social construction and differences in health outcomes between people of different "races" are related to social factors including discrimination based on race. Some commonly used clinical prediction rules such as those for predicting cardiovascular risk, kidney function, and fragility fracture risk, also incorporate "race" in questionable ways; such tools should be avoided (4).

Just as researchers are expected to refer to and cite the relevant literature such as relevant systematic reviews in a research proposal or manuscript, the relevant literature related to equity should also be prominently summarized. This could include a discussion of relevant disparities and their history.(5) Some scholars and academic institutions have expertise and experience addressing health inequities and working with disadvantaged populations. When forming a research team, health researchers should ensure the team includes not only those with technical expertise such as in biostatistics, but also those with expertise in advancing equity in health research. Proposals should demonstrate a thorough understanding of relevant equity issues and in experienced hands this can be communicated concisely.

Prioritized	• Health equity is a main focus of the research project or proposal
Acceptable	• Health equity issues are explicitly mentioned and meaningfully addressed
Unacceptable	• Health equity issues are either not mentioned or not meaningfully addressed • The topic or question is based on or perpetuates discrimination such as sexism or racism

Engaging with patients and the public

Engaging patients and members of the public in the research enterprise can help ensure that researchers are asking questions that are important to the intended beneficiaries of health research.(6) Excluding racialized people and language minorities, for example, from engagement efforts could exacerbate inequities by centering research on topics that are less important to those left out. It might make sense for members of groups disproportionately affected to be over-represented in research aimed at addressing a health issue.

Avoid blaming people who experience disadvantages for being "hard to reach". The responsibility for engaging with people who reflect the diversity of Canada lies with researchers. Time and resources are required for engagement to be done well. This includes making it easy for people to participate regardless of their first language.

Prioritized	• Engagement will clearly prioritize people who experience disadvantages
Acceptable	• Engagement plan recognizes need to engage people who experience disadvantages
Unacceptable	• Plan does not mention how people who experience disadvantages will be engaged • Engagement plan is likely to substantially under-represent people who experience disadvantages • Unexplained lack of patient or public engagement plan or inadequate explanation of engagement

Supporting, retaining and finding research staff and trainees

Inclusive research environment

Before recruiting disadvantaged individuals, it is important to ensure that the work environment is appropriate and inclusive. It makes sense to recruit members of disadvantaged groups only if they are likely to want to remain a part of a research team. Most institutions have policies against discrimination, but more than documents are needed. Processes should be in place to support disadvantaged people. Opportunities for professional development and advancement should be equitably available. Some institutions operate on the tacit assumption that discrimination such as sexism, racism and first language of communication do not exist. In some cases, it is either unclear how instances of discrimination should be addressed, or usual but unworkable channels such as reporting to direct supervisors are supposed to address discrimination.

Researchers should be able to clearly explain specific steps taken to make the work environment inclusive and how concerns about discrimination will be handled.

As the supervisor-trainee relationship involves a stark power imbalance, it is especially important to ensure trainees are invited into an inclusive environment with access to individuals other than their supervisor with whom they could raise concerns about discrimination. Contact persons and relevant policies or procedures for all the relevant institutions (e.g., hospital and university) should be clear to the trainee.

Team members should be provided with training opportunities such as Indigenous cultural safety training and integrating a sex and gender based analysis (SGBA+) lens in health research.

Prioritized	• The institution and team have demonstrated an inclusive environment that is supportive of disadvantaged individuals and that is poised to handle specific instances of discrimination
Acceptable	• The institution and team have a plan for making their environment inclusive and for dealing with specific instances of discrimination
Unacceptable	• The inclusiveness of the environment is not mentioned • There is no meaningful plan for making the environment inclusive • There is no plan for handling specific instances of discrimination

Hiring and selection

Position openings should be communicated widely and effort should be dedicated to reaching disadvantaged individuals. Postings should focus on the actual requirements of the position and avoid unnecessary requirements that may deter some potential applicants. Postings should explicitly mention efforts to promote equity during the selection process and accommodations for special needs. Selection or hiring committees should represent the populations served and members should be trained in how to promote fairness. Policies and processes should be in place to address problematic conduct by selection committee members.

Formal selection processes may be less prone to bias and discrimination than informal hiring of "known candidates", but bias and discrimination can affect any hiring process no matter how well structured. Those involved in selection committees should be properly trained in how to recognize and address discrimination. Thus, it is important to monitor for the effects of discrimination in both recruitment and retention by tracking the diversity of team members such as gender and racialization.

Research trainees including summer students, practicum students and graduate students are often linked with potential supervisors informally. Where appropriate, recruitment and selection processes should be formalized in ways that promote fairness. The inclusion of disadvantaged trainees should be tracked. Supports, awards and funding should be allocated to trainees through fair and transparent processes.

Prioritized	• People who experience disadvantages will be prioritized in selection processes
Acceptable	• The hiring or selection process recognizes the need to include people who experience disadvantages
Unacceptable	• Hiring or selection processes are likely to miss or exclude people who experience disadvantages • The hiring and selection plans are not mentioned

Conducting research

Recruitment should include people who experience disadvantages as appropriate to the topic and research question. Potential barriers to participation including language, should be addressed. Researchers should assess the success of recruitment methods periodically to ensure that efforts to include disadvantaged people are succeeding; changes should be made as needed. The fact that some groups such as Black and Indigenous people have been targeted by extreme forms of research misconduct should be taken into consideration when designing both recruitment approaches and the informed consent process. Participants should know the extent to which people who experience disadvantages have been involved in designing the project.

Data collection approaches should be flexible enough to limit the burden on disadvantaged individuals. The setting and timing of interviews should take into account differing circumstances and schedules. Participants should know exactly why information such as about gender or ethnicity is being collected and how it will be used.

Data stewardship should respect the involved individuals and communities. Approaches to data ownership and access should respect everyone involved and exceed standards including those described in *Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada*. Participants should be able to access data collected about them.

Participants and others affected by the research should know how to raise concerns about discrimination.

Special attention is needed when research participants are mostly disadvantaged people and those involved in conducting the study are not. Ideally these situations will be avoided since research teams (including engaged patients and members of the public) should be comprised equitably.

Specific guidance is available for applying an equity lens to clinical trials (7–9), systematic reviews (10), and clinical practice guidelines (11).

Prioritized	• Study recruitment and data collection and stewardship will clearly address health equity as there is an explicit plan for supporting disadvantaged individuals and accommodating disabilities
Acceptable	• Some attempts will be made to address health equity in the conduct of the study
Unacceptable	• It is unclear whether or not the study will be conducted appropriately or if health equity was considered • The conduct of the study is likely to harm people who experience disadvantages

Analyzing results

In studies focusing on health equity, the primary analysis will usually address equity by design. For example, in a clinical trial of an intervention aimed a mitigating the harm of an inequity, the comparison between groups will answer a question about equity.

In studies that do not focus on health equity, care is needed to analyze results in manner that is valuable and that avoids harm (12). Many studies have shown associations between poor health outcomes and low income, for example; the value of additional studies like this are questionable if the findings are not explicitly connected to promoting equity. The analysis plan should appropriately address sex or gender and language differences as appropriate to the research question. Studies that show an association between being a member of a particular "race" and health outcomes can reinforce the falsehood that biological differences between races explain differences in outcomes when social factors including racism are often ignored. That is, the process of racialization and racism are more important than any biological differences that may or may not exist. Purported biological differences between "races" such as in renal function or prostate cancer risk often do not exist when carefully examined (4). Drawing attention to differences between "races" can stigmatize people and so this should only be done when there is a clear reason.

Qualitative studies can provide valuable insights into the experience of disadvantaged people. Qualitative analyses should use approaches that appropriately incorporate the experiences and views of disadvantaged people.

Prioritized	• The analysis plan clearly takes into account and addresses health equity considerations in the pre-specified primary or secondary analyses
Acceptable	• The analysis has the potential to take into account health equity considerations and differences between populations
Unacceptable	• The analysis plan ignores relevant health equity considerations • The analysis will likely perpetuate discrimination or employs discriminatory categories • The analysis will merely illustrate a difference between groups but for no clear purpose

Exchanging knowledge including reporting results

Knowledge exchange should ideally begin before research projects formally start. A first step could be to ensure that research team listens to people who experience disadvantages. Engagement with disadvantaged people early on can help to ensure that the entire project, including the knowledge exchange plan, is rooted in existing knowledge.

Existing partnerships will facilitate the sharing of research findings and results. This means that partnerships should be formed well before it is time to share results. People who experience disadvantages should play an active role in exchanging knowledge.

The knowledge exchange plan should recognize that "neutral" sharing of "objective" findings can harm people who are already disadvantaged. Biases can be perpetuated, and people or groups can be stigmatized. Knowledge exchange plans should describe how the risks of sharing research findings will be mitigated. The rationale for mentioning specific groups should be clear. Care should be exercised when reporting "race" or "ethnicity", and the reason for choosing sex or gender should be clear. Groups or individuals likely to be affected by the release of research findings should be consulted prior to publication.

Find the language and terms that are most appropriate to your project by speaking to those with relevant experiences or knowledge. Instead of using vague terms such as "vulnerable" groups, clearly explain who is being referenced (13). Instead of using terms that blame individuals or groups for being "hard to reach" or for their "mistrust" in the

system, use language that accurately describes that nature of discrimination and inequity. Report results in languages that ensure they are accessible to a wider audience. Address other barriers to accessing the results such as journal paywalls.

When a project is complete, researchers should reflect on whether it promoted (or undermined) health equity. Remedial action should be considered as appropriate and lessons learned should be discussed and shared with others, including those who were supposed to benefit from the research.

Prioritized	• Knowledge exchange will clearly involve and respect people who experience disadvantages in a way that will promote health equity
Acceptable	• Knowledge exchange will respect people who experience disadvantages and may promote health equity
Unacceptable	• Knowledge exchange plan does not consider equity considerations • Knowledge exchange will likely harm people who experience disadvantages

Supports offered by the OSSU

Researchers have a responsibility to invest time and resources in advancing health equity. Researchers should not expect someone else to tell them what to do. The OSSU can assist researchers who are committed to advancing health equity in several ways:

(1) Curating and linking to external resources
(2) Providing knowledge syntheses such as this framework
(3) Supporting working groups focused on indigenous health; sex and gender based analysis (https://www.womensresearch.ca/research-areas/sgba/), and francophone considerations
(4) Connecting researchers with a supportive community centred advancing health equity
(5) Hosting events focused on health equity and providing training
(6) Supporting equity advancing research initiatives including with funding
(7) Helping to link researchers with potential collaborators interested in health equity

Key Resource

Government of Canada. Best Practices in Equity, Diversity and Inclusion in Research

https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/edi-eng.aspx

Additional resources

Patient-Centered Outcomes Research Institute

https://www.pcori.org/research-results/2018/building-health-equity-leaders-network-disseminate-use-evidence-transform

National Institute for Health Research (United Kingdom) INVOLVE

https://www.invo.org.uk/current-work/diversity-and-inclusion/

Health Quality Ontario

https://www.hqontario.ca/What-is-Health-Quality/Health-Equity-and-Quality/Our-Work/Northern-Ontario-Health-Equity-Strategy

Women's Xchange

https://womensxchange.womensresearch.ca/about-us/about-womens-xchange.html

Dimensions Charter

https://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/Dimensions-Charter_Dimensions-Charte_eng.asp

National Collaborating Centre for Social Determinants of Health

https://nccdh.ca/resources/entry/lets-talk-racism-and-health-equity

Knowledge Translation Intersectionality Guide

https://knowledgetranslation.net/wp-content/uploads/2020/08/Intersectionality_KT_Guide_20200317_FD.pdf

Learning Health Systems framework

Brooks D, Douglas M, Aggarwal N, Prabhakaran S, Holden K, Mack D. Developing a framework for integrating health equity into the learning health system. Learn Health Sys. 2017 Jun;1:e10029. doi: 10.1002/lrh2.10029.

Style guide

https://healthsci.queensu.ca/academics/edi/style-guide

Methods

The development of the framework involved an environmental scan of similar documents used by peer institutions internationally, a review of the relevant literature and consultations with key OSSU stakeholders and decision makers. Framework development was assisted by four community members who elected not to be named. Framework development was be led by Dr Nav Persaud and done in partnership with Dr Jennifer Walker, Dr Alain Gauthier, Dr Paula Rochon, Dr Patricia O'Campo, Robyn Rowe, Dr Robin Mason and Camille Eugénie Demers.

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