Equity, diversity and inclusion are foundational research skills

Failure to consider the principles of equity, diversity and inclusion in biomedical and human behaviour research harms patients, trainees and scientists. On the basis of experience and evidence, we make actionable, specific recommendations on how equity, diversity and inclusion can be considered at each step of a research project.

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Budding scientists in human behaviour and the biomedical sciences take introductory courses in study design, ethics and statistics — skills considered foundational for research — but receive little or no instruction on how to identify and mitigate racism, sexism and other forms of discrimination in their studies. Failing to incorporate principles of equity, diversity and inclusion (EDI) into research has led to study retraction[1], and the consequences of such failure can be devastating for marginalized communities — including persistent health disparities, mistrust and disengagement with academia, and death[2]. Principles of EDI must be incorporated throughout the research process (Table 1). Although many of these EDI considerations are applicable to all research disciplines, we focus here on human and biomedical research.

Incorporating EDI at conceptualization

Conducting a literature review is often the first step when conceptualizing a study. Similarly, researchers should also perform a historical review of their field through an EDI lens. This should include an understanding of the land that their institution occupies, how definitions or diagnoses have been used to oppress groups[3], how to use inclusive language, what forms of oppression were present in in landmark studies, and the history of celebrated figures in their academic field[4]. Beyond the notable, well-publicized examples of oppression in research — such as the Tuskegee Study or the case of Henrietta Lacks — there are instances of research-related harm to marginalized groups across biomedical disciplines[4,5]. Reviewing these issues at the outset should inform the remainder of the study, from study design to dissemination, to avoid perpetuating marginalization.

Recruitment of diverse teams

Lead scientists should understand the value of diversity and their role in developing capacity among under-represented groups for research when they recruit their teams. The exclusion of certain demographic groups from research is well-documented[6]. The reasons for under-representation are multifactorial and span all stages of the research career, from direct discrimination (for example, based on race or sex) to raising real but underappreciated barriers by not financially compensating team members. In turn, the lack of diversity among researchers perpetuates a lack of representation, mentorship and research into neglected fields.

Investigators can address historical exclusion by seeking collaborators, research assistants, patient partners and trainees from underrepresented groups. If researchers cannot identify appropriate candidates, they can use alumni networks, publicly available resources or student associations to recruit potential team members. Although a lack of skills is not a key contributor to the noted under-representation of some groups in academia, investigators may need to invest time and resources to develop needed skills among team members who have been excluded from previous opportunities. Investigators should financially compensate trainees for their time, to avoid unintentionally excluding those of lower socioeconomic status from participation.

Simply increasing the number of people from marginalized communities in academia may not reduce health disparities in these communities if individual researchers are 'lost' to their communities through assimilation[7]. Investigators should therefore engage in capacity building in communities. Researchers must practice cultural competency when training or evaluating people from marginalized communities. Mentorship is a key component in capacity building, and researchers need to dedicate time and effort towards this essential element of EDI. Furthermore, patient partners and community members should be invited to join the study team, striving to represent the diversity of the general population. Non-academics who participate on the study team should be compensated and their contributions must be acknowledged during publication and dissemination, as would be expected for any member of the study team.

Engagement of diverse populations

Defining a study population is crucial for creating an equitable research study.

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Table 1 | EDI considerations for each stage of a research study, with explanations and examples

Study phase	EDI principle	Example/explanation
Conceptualization	Involve communities to inform the research question.	*Researched to Death* is a synthesis of 11 studies examining violence against Indigenous women in Canada, which found that all had similar recommendations, none of which had been implemented 15 years after publication. The authors argue against further prevalence studies without investment in solutions to address this well-documented violence[10].
	Conduct an EDI literature review.	'Professionalism' has been used to justify exclusion and oppression of Black physicians, especially Black women physicians[3]. This understanding may have informed the design of this now-retracted study that examined the professionalism of physicians on social media[1].
Study team	Build capacity among individuals and communities.	Intentionally recruit team members from historically excluded groups using student groups and alumni networks. Compensate team members appropriately to ensure that low socioeconomic status groups are not excluded from academia.
	Include community partners.	A collaboration between academics and Indigenous community members in Canada addressed type 2 diabetes among First Nations youth 'in a good way'[11].
Study population	Evaluate inclusion and exclusion criteria with an EDI lens.	Exclusion of pregnant women from COVID-19 vaccination trials led to a lack of data to guide pregnant healthcare workers when deciding whether to be vaccinated during the COVID-19 pandemic[2].
	Design an inclusive recruitment process.	Monitor recruitment into the study and address barriers for under-represented groups during recruitment.
Data	Use inclusive language when collecting demographic data.	Exclusive or stigmatizing language may lead to inaccurate categorization of groups or non-participation of participants from marginalized groups.
	Accurately measure the true variable of interest.	Use scales to measure sex, sexism, gender identity, gender roles, and/or gender expression, depending on the study question.
	Report demographic categories accurately.	Report on smaller demographic categories (for example, transgender women, transgender men) so that results can be pooled across studies.
	Consider additional ethical considerations for data stewardship.	First Nations people in Canada have developed a set of governing principles for research data — OCAP (ownership, control, access, and possession) — to protect themselves from ongoing colonialization through research[7].
Knowledge translation	Provide accessible data to communities.	Follow a framework to create a two-way dialogue about research findings and their meanings for communities[12].
	Leverage research team networks and skills to advocate with communities.	Using epidemiologic evidence of racial disparities in COVID-19 prevalence and mortality to characterize 'micro-outbreaks' of COVID-19, creating nuanced, population-based strategies.

Inclusion and exclusion criteria may intentionally or unintentionally create studies whose results are not applicable for certain groups. The exclusion of pregnant people from COVID-19 vaccination trials, resulting in a lack of evidence to guide a substantial proportion of healthcare workers during the pandemic, is a notable contemporary example[2]. Investigators should consult with stakeholders and those with EDI expertise to evaluate each inclusion and exclusion criterion using an EDI lens. Assumptions about the biological or scientific validity of criteria that exclude specific groups should be explored; for example, pregnant people can provide informed consent to participate in drug studies, especially for life-threatening diseases. Each community will have different histories that inform their relationships with science and medicine; researchers should familiarize themselves with resources to guide their work in the communities relevant to their study.

Intervention trials often explicitly or implicitly exclude people who do not speak English, have no fixed address, have substance use disorders or do not have insurance. Similarly, observational or registry data often exclude women and older individuals. To increase diversity in study populations, investigators can include translators in their budget, use community-based participatory action research methods, oversample from under-represented populations and/or hire community members for the study team. Teams studying diseases can aim for a participation/prevalence ratio (PPR) of 0.8 to 1.2 to ensure that their study population represents the distribution of the disease in the general public. Data monitoring committees can alert recruiters to imbalances in demographics of participants to help identify exclusion before enrolment is completed.

Preventing marginalization in data

Analysis of research data by participant sex is a requirement for many granting agencies, given the known harms from failing to account for sex-differences in medical research. Despite the growing awareness of these harms, sex and gender-based analysis is still often incorrectly performed or not included at all[8]. While guidelines for sex- and gender-based analysis exist, inaccurate or imprecise collection of sex and gender data from study participants limits the analysis. For example, many administrative datasets use only binary gender and/or sex options. Investigators should not assume participant sex or gender, and instead should familiarize themselves with best practices for asking about sex

assigned at birth, sexual orientation and gender identity during data collection. Transgender and gender-diverse people are frequently overlooked during the design of data collection forms, which may lead them to withdraw from a study, leading to missed associations during analysis. Reporting outcomes using more granular categories of sex and gender may allow individual data to be pooled across studies even when sample size is too small to allow statistical comparison with larger groups.

In addition, investigators may not properly differentiate whether their variable of interest is sex, sexual orientation, gender identity, gender roles, gender expression or gender relations[9], each of which may have different associations with health outcomes. Researchers then unintentionally use surrogate variables rather than examining the true causal factor; for example, using race to approximate racism or sex rather than body size.

Similar issues are seen with the collection and analysis of data on race, ethnicity, ability and other characteristics related to EDI. Researchers should consider that data produced from historically excluded groups may need to be held to a higher standard of ethics and principles. This is, in part, due to oppression and injustices perpetrated by scientific communities when these groups have participated in research, including coerced participation in studies, withholding of results, and the use of data to demean participants and justify disparities rather than to resolve health inequities. An important example of this harm is the 'thrifty gene' studies conducted on Indigenous people in Canada in the 1990s, when researchers claimed to have identified a gene that predisposed Indigenous people to diabetes[5]. This study was used for decades to support the false notion that race is a biological concept and to justify a lack of action by Canada to address the social determinants of health in Indigenous communities, including racism, poverty and lack of access to healthy food[5]. First Nations people in Canada have developed a set of governing principles for research data — OCAP (ownership, control, access, and possession) — to protect themselves from ongoing colonialization through research[7]. These guidelines can serve as a framework for the collection and use of data from marginalized groups, although researchers should also engage with other relevant communities to ensure that specific cultural requirements for data are met.

Equitable research after publication

Most health researchers are familiar with the often-cited statistic that it takes 17 years from publication of an important result for an intervention to become common practice. While this is clearly less than ideal for most medical therapies, it is egregious when research reveals worse outcomes for an already marginalized group. Researchers, especially those with privilege, have an obligation to address the health disparities that arise due to racism, sexism or other forms of discrimination that they uncover during their studies.

Knowledge translation is a series of evidence-based and theory-informed strategies to reduce time lags between research and real-world application. Using an EDI lens, knowledge translation can take the form of advocacy to improve access, reduce barriers, redesign medical devices, reformulate medications or change systems to reduce inequity. The diversity of the target population should be considered when adapting existing knowledge translation strategies to meet community needs, rather than adopting a homogenous, one-size-fits-all approach. Researchers should ensure that their final data are accessible to marginalized communities — both literally and considering the language, culture and scientific literacy of the research subjects — by budgeting time and resources to report back to these stakeholders.

Stakeholders should be engaged early in the study design to plan for dissemination of the study results and potential uses of the data; this may also lead to adaptation of the study question and design, or data collection or analysis, depending on the needs of the community. When research unexpectedly reveals a disparity, national patient organizations or community leaders should be engaged to discuss the next steps, using a community-based approach. Researchers should leverage their skills and networks to assist stakeholders to use the data generated by their projects to advocate for needed change. It is simply not enough for a researcher to publish on an inequity or disparity, advance their career and move on to the next study.

The ethical obligation of health research

Systems-level accountability, involving the multiple intersecting levels of health research structures, is needed to ensure that health researchers continue to adopt and evaluate these recommendations. Accountability should be established by requiring EDI considerations in ethics review applications and funding applications, and for publication. Incorporation of EDI into research programs is a first step in reducing healthcare disparities for historically excluded groups, which is a matter of justice and therefore an ethical obligation.

Universities must longitudinally incorporate EDI into undergraduate and postgraduate scientific courses, and formally evaluate these skills, as they do for other foundational scientific topics such as ethics and statistics. Continuing professional development to build these skills in senior educators, investigators and leaders is also likely to be necessary.

Universities and funding agencies must provide the resources needed to incorporate EDI throughout the entire research process; including funds to consult experts, compensate team members and community partners appropriately, and disseminate results in marginalized communities. Continuing to allow health research to benefit only privileged groups is inexcusable. ❐

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Competing interests

The authors declare no competing interests.