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"It's Just Good Science": A Qualitative Study Exploring Equity, Diversity, and Inclusion in Canadian Arthritis Research

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Objective. Despite knowledge that health outcomes vary according to patient characteristics, identity, and geography, including underrepresented populations in arthritis research remains a challenge. We conducted interviews to explore how researchers in arthritis have used equity, diversity, and inclusion (EDI) principles to inform their research.

Methods. Semistructured interviews were conducted with individuals who 1) have experience conducting arthritis research studies, 2) reside in and/or conduct their research in Canada, and 3) speak English or French. Participants were recruited using purposive and respondent-driven sampling. Interviews were conducted over video call and audio recordings were transcribed. Template analysis was applied to interview transcripts to explore participant experiences and perceptions of EDI in arthritis research.

Results. Participants (n = 22) identified that a lack of representation in arthritis research translates to the inability to provide comprehensive care. Participants emphasized considering EDI early in all arthritis research to effectively affect a study. Themes were categorized as benefits, barriers, and facilitators. The perceived benefits were the ability to generate knowledge and reduce health disparities. Barriers included mistrust from historically exploited populations, unintended consequences, lack of access to research opportunities, and logistical challenges. Facilitators included building community partnerships, curating diverse research teams, incentivizing researchers and funder support, and fostering humility in research environments.

Conclusion. Improving representation in research is needed to improve health outcomes for diverse groups of people living with arthritis. Identified barriers to EDI in research must be addressed and partnerships and supports must be facilitated to achieve more representation in arthritis research within Canada.

INTRODUCTION

Health outcomes for people with arthritis are influenced by many elements, including biologic (e.g., genetics), social, and environmental factors, referred to as the social determinants of health (SDOH).[1] Disparities in SDOH also are associated with exclusion and low participation from particular communities in underrepresented patients in research. Specifically, within rheumatology, studies have overrepresentation of White, middle-aged, female participants.[2–4] Although most studies will summarize participant demographics and the inclusion of age and sex is standard, reporting of additional demographic factors is rare and not standardized across studies, and there is typically no stratification of effect across groups, making it challenging to compare findings. The final, perhaps most pressing issue is that current recruitment and reporting standards limit our ability to apply evidence to practice for communities facing health inequities.

In Canada, rural and remote, Indigenous, older adults with frailty, first-generation immigrant and refugee, low-income and vulnerably housed, and diverse gender and sex populations experience inequities in arthritis care, such as diagnostic delays

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SIGNIFICANCE & INNOVATIONS

- To our knowledge, this is the first study in Canada aiming to understand researcher perspectives on equity, diversity, and inclusion (EDI) in arthritis research and propose mitigation strategies for identified barriers.
- Qualitative findings showed that, although the benefits of using an EDI lens are evident to researchers, barriers remain toward improving representation in Canadian arthritis research, namely, a lack of resources and perceptions from underrepresented communities. Balancing intentionality with feasibility is crucial, and researchers may need to target specific factors (e.g., race, sex, gender, socioeconomic status, etc.) for which representation is important for the research question.
- The need for inclusivity and diversity in research has gone from recognition to action, and Canada is positioned to be a leader in this. To this aim, our findings suggest researchers may benefit from comprehensive guidance, both from rheumatology societies as well as funding agencies, on applying EDI to their own work.

and suboptimal access to interventions, namely, medications and surgery.[5] However, these populations continue to be underrepresented in research. In the growing movement toward improving consideration of equity, diversity, and inclusion (EDI) in research to reduce health disparities, guidance from those who have engaged participants from diverse communities is beneficial for meeting EDI mandates while also looking to favorably affect outcomes. To add to existing efforts, it is important to consider ways to improve representation when conducting research that aims to be generalizable to the population of those living with arthritis in Canada. Therefore, our objective was to explore how arthritis researchers in Canada have used EDI to inform their research.

MATERIALS AND METHODS

Study design. This qualitative study was conducted under a pragmatic paradigm, a philosophy suggesting that knowledge is based in experiences and that what is considered to be the "truth" is what is most useful.[6,7] The perspectives of researchers in rheumatology (both MD and PhD research scientists) related to EDI in research within Canada were solicited via semistructured interviews, an approach that aligns with the pragmatic paradigm, and we followed the consolidated criteria for reporting qualitative research (Supplementary Table 1). This study received institutional ethics approval (BREB# H21-03200).

Eligibility criteria and recruitment. Participants were eligible if they 1) had experience conducting research studies (e.g., clinical, observational, qualitative, health economics, etc.) in arthritis; 2) resided in and/or conducted their research in Canada; and 3) spoke English or French. Participants were identified using a purposive and respondent-driven (snowball) sampling approach with aim of representation across genders, career stage, and province of residence. We began recruitment by asking members of the research team for recommendations and then used snowball sampling to achieve our target sample. Recruitment via email occurred between May and November 2023. All study participants provided informed consent for participation.

Data collection. We conducted and recorded one-on-one semistructured interviews lasting ~60 minutes via video call using the Zoom platform. All interviews were conducted by MMT, a woman of color and graduate student researcher (author positionality statements in Supplementary Table 2). Participants were informed about the study goal and the interviewer's role within the project. The interview guide was developed by all members of the research team to explore the role of EDI in inflammatory arthritis research, with semistructured questions to allow for investigating further topics (Supplementary Table 3). We conducted two pilot interviews with members of the research team to refine the interview guide. Pilot interview findings were incorporated in the final analysis; participants were aware their interviews could be included as part of the study, and informed consent was obtained for this purpose. We interviewed participants until data saturation (new data repeat previous expressions in data) and inductive thematic saturation (no identification of new codes or themes) were achieved.[8] All data were handled by MMT and MADV. The interviews were audio-recorded, transcribed verbatim, and coded for overall analysis. Raw transcripts were created using Sonix, an online transcription service (https://sonix.ai), then reviewed for accuracy by MMT.

Analysis. A codebook approach to thematic analysis was used, specifically template analysis, which allows for deductive and inductive coding and is aligned with the pragmatic paradigm.[9] The data were analyzed by MADV, MH, and MMT using a combination of deductive and inductive coding, organized with NVivo software. Inductive coding began with identifying and collating raw codes (preliminary themes using participants' exact words) derived directly from the data to develop a single coding scheme.[10] Through classifying, constant comparison, and memo writing, we transformed codes into subthemes (middle-order themes to transform basic themes into similar concepts) and eventually themes to capture global patterns in the data. A combination of latent and semantic coding was used to capture surface-level meanings as well as underlying assumptions of what was being expressed by participants. To ensure dependability of the coding after the generation of initial themes, MADV, MH, and MMT discussed the initial coding framework over several meetings. Once satisfied with the coding framework, MMT coded all transcripts using strategies to ensure trustworthiness, including reflexive journaling, and discussing themes with the research team.[11] After analyses, a narrative summary of the main findings was developed.

RESULTS

We interviewed 22 arthritis researchers (45.5% women and 54.5% men) in Canada. Demographic details of participants are in Table 1. For each of the three themes, reflective quotations highlighted benefits, barriers, and facilitators for prioritizing EDI in rheumatology research. Additional supporting quotations can be found in Table 2.

Theme 1: benefits of prioritizing EDI in rheumatology research. All participants agreed that prioritizing EDI in rheumatology research is beneficial. From their sentiments, two subthemes were constructed.

Increasing knowledge to improve generalizability and quality of care. Researchers highlighted that prioritizing EDI could provide us with more information on how arthritis affects patients differently to provide better care.

> "I think overall it's probably very underappreciated how important these factors are […], in patients with rheumatoid arthritis or psoriatic arthritis or ankylosing spondylitis who are of a non-[White] background. It's very difficult for us to advise. Similarly for patients who are pregnant, these people are actively excluded from studies."—*Participant 20*

Having more representation among study participants was perceived to improve the opportunity to find answers on how and why patient outcomes differ, as well as factors that limit access to care for patients.

> "[A benefit of including EDI in research is] getting answers to why some people don't do as well as others. We have multiple examples, not only in arthritis, that people that have poor access, people with certain type of barriers to their health care don't do well and some of these are not very well understood."—*Participant 10*

Furthermore, by having more representative study samples, participants felt that the generalizability and clinical impact of research could be improved.

> "If we don't include [EDI], we can't generalize our findings because our findings are only generalizable to the people who are included in the research."—*Participant 17*

Overall, participants agreed on the value of considering EDI in arthritis research, highlighting that it goes beyond an "ethical responsibility" and improves our ability to provide better care, with one participant stating that "it's just good science."

Reducing health disparities. Many participants spoke to the ultimate goal of research being to reduce health disparities, i.e., unfair differences in health outcomes, and highlighted this as a key benefit of considering EDI.

> "I think really the goal of all of our research should be to reduce health disparities. […] the benefit of considering [EDI] and including it in research is actually trying to address those disparities and at least make sure that we're not making these things worse."—*Participant 1*

Table 1. Demographic characteristics of participants

Demographic information	n (%), n = 22
Province of residence	
Alberta	3 (13.6)
British Columbia	10 (45.5)
Manitoba	1 (4.5)
Nova Scotia	1(4.5)
Ontario	3 (13.6)
Quebec	4 (18.2)
Gender	
Male	12 (54.5)
Female	10 (45.5)
Current employment	
Clinician scientist	15 (68.2)
Researcher	7 (31.8)
Career stage	
Early (<5 y)	2 (9.1)
Middle (5–15 y)	8 (36.4)
Late (>15 y)	12 (54.5)
Type of inflammatory arthritis studied (select all that apply)	20 (90.9)
Rheumatoid arthritis	2 (9.1)
Juvenile idiopathic arthritis	2 (9.1)
Ankylosing spondylitis	5 (22.7)
Systemic lupus erythematosus	6 (27.3)
Psoriatic arthritis	5 (22.7)
Gout	3 (13.6)
Other	6 (2.73)
Type of research primarily conducted (select all that apply)	
Experimental studies/clinical trials	10 (45.5)
Observational studies	21 (95.5)
Qualitative research	5 (22.7)
Health economics research	6 (27.3)
Other	2 (9.1)

Table 2. Additional quotations supporting thematic analysis*

Global theme	Subtheme	Quotations
Benefits of prioritizing EDI in rheumatology research	Increased knowledge to improve generalizability and quality of care	“*I think if we can look at a disease through the lens of the interactions with racial background or interactions with sex, we start to learn more about the disease and how it functions. And I think that will lead to better outcomes and better interventions for everybody if we have a better understanding of it.*”—Participant 20
	Reducing health disparities	“*Because if you're going to create clinical insights and recommendations or guidelines and those guidelines are only relevant to 50% of the population, then there's a whole subset that aren't being included and that can lead to obviously the exclusion is huge.*”—Participant 2
		“*If we're only including the dominant group in our research, only doing research that benefits the dominant group and only disseminate research to the dominant group, it's one of the system-level inequities and discrimination in our society because we're not actually doing research that benefits everybody in society.*”—Participant 14
Barriers to prioritizing EDI in rheumatology research	Mistrust from historically exploited populations	“*I have to approach every patient in my clinical care, assuming they've had prior bad experiences. And I have some making up to do for experiences that the patients have had with other health care providers until we build that relationship of trust.*”—Participant 14
		“*Yes, we want to be inclusive, but we also have to be respectful that different people have different backgrounds, that for them, research may not necessarily have the same meaning as it does to us.*”—Participant 18
	Lack of access to research opportunities	“*I have to constantly remind a lot of people, my staff, my colleagues, that people participating in research are doing us the favor, because it often doesn't feel that way [...] You know, we're doing the interviews in French and English between 9 and 5 because that's what's easiest for us.*”—Participant 12
		“*So I think the other thing too, again as I mentioned, because we work in this multiethnic area, many of these people of these different groups have lower socioeconomic status. And to them, research is not meaningful. They have to get on with their job [...] they don't have this luxury of participating in research.*”—Participant 18
	Logistical challenges	“*It always comes back to more resources [...] And if you're you have limited resources, you're going to take the, you know, more low-lying fruit.*”—Participant 18
	Unintended consequences	“*I totally can appreciate the concern that if we modify criteria or change recruitment practices to try and include more vulnerable populations are we actually then almost like exploiting those populations for the benefit of others, of more privileged individuals?*”—Participant 1
		“*I think especially in like clinical care settings or even in teams that aren't used to taking a health equity perspective, if you don't know how to collect and analyze certain types of data, then you could do it wrong and end up having an unanticipated consequence on the findings.*”—Participant 2
Facilitators to support EDI prioritization in rheumatology research	Building community partnerships	“*So, we needed to always have champions. So when we go into the Black community, we would partner with leaders in the community and we would talk to them about how to prepare our materials, how to hold informational sessions. They would help us to understand what would be important to their constituents, what kind of reassurances they would be looking for. And just, you know how to create a partnership, a meaningful partnership.*”—Participant 12
	Curating diverse research teams	“*If you have a team that's diverse and it shows maybe more openness, it may be easier to have people agree to participate in your in your work.*”—Participant 10
	Incentivizing researchers and funder support	“*We're not going to see the degree of change that we want to see unless there's a sort of a mandatory aspect to some of these things.*”—Participant 1
		“*[We need] better understanding from funders that we don't develop trust overnight with communities. And that we need some time and some resources to be able to do it.*”—Participant 12
	Fostering humility in research environments	“*But at the same time, I can also appreciate how some people would really be hesitant and worried about making mistakes in this realm again, because of the current climate of cancel culture that we that we live in. And I can see how [...] I guess, just maybe not feeling like it's a safe space to make mistakes in*”—Participant 1
		“*If you get it wrong, then you have the chance to correct it. If you don't do it, then we are going to be in the dark all this time.*”—Participant 6

* EDI, equity, diversity, and inclusion.

As well, participants expressed that, by using an EDI lens to design research, there is an opportunity to have an impact on factors we are able to change as opposed to focusing on genetic factors alone, which is critical for chronic conditions such as arthritis.

> "You could have a study design, addressing that specifically and getting answers on some of these things that are modifiable, right? You may not be able to change your genes, but you might be able to change your socioeconomic factors or write, report or find some interventions, right?"—*Participant 10*

Theme 2: barriers to prioritizing EDI in rheumatology research. From the experiences of researchers, four barriers were identified as affecting current approaches to prioritizing EDI in Canadian rheumatology research. These barriers are described below and include: Mistrust from historically exploited populations, Lack of access to research opportunities, Logistical challenges, and Unintended consequences

Mistrust from historically exploited populations. Harmful stereotypes, racism, and exclusion in health care and research settings have led to mistrust about the intentions of researchers and care providers within certain communities. Participants specifically highlighted the need to consider underrepresented populations when considering this barrier. This mistrust was also perceived to lead to conflicting priorities between patient participants and researchers/providers because research may have negative connotations for many communities.

> "So, for instance, like the Black community, it's been documented that they distrust the medical community, especially if the […] clinical provider is not in their community. I think that creates a lot of mistrust and that stems from historical kind of roots."—*Participant 2*

Particularly when considering collecting information from participants, mistrust should be addressed by providing rationale for why this information is required or important for researchers to know.

> "I know in my culture there can be a little bit of distrust when it comes to others trying to gather information […] It's like, 'why do you want this information?'"—*Participant 16*

Participants also spoke to the need for researchers and providers to consider how unconscious biases may be influencing their own work and focus on rebuilding trust with their patients in safe, trauma-informed environments.

> "One key way is to just challenge whenever I have assumptions because usually that's where your unconscious biases creep out. So never assume that a patient can't afford a treatment […] Don't assume that they don't want drugs or are drug-averse because they're from a group that traditionally has been labeled as not liking drugs."—*Participant 14*

Lack of access to research opportunities. When speaking about lack of access, participants noted this referred to not only who has the opportunity to participate in research, specifically considering participant burden, but also who hears about the opportunity to participate in research.

> "Yeah, well, we think we include everybody, but we don't acknowledge that for some certain part of the population, it's harder to be part of the study, to be part of research."—*Participant 3*

With respect to participant burden, researchers spoke to the challenge of being able to appropriately compensate patients for the time taken to participate in the study, as well as additional financial and nonfinancial costs (such as child care, transportation, taking time off work to participate, living in rural or remote settings, etc.).

> "If you think about a clinical trial, like a traditional pharmaceutical company sponsored clinical trial, they typically require a lot of monitoring, you have to go to and you have to show up in-person for a visit every 2 to 4 weeks, and it's quite intensive. So, if you live in a remote place or you work in a job which doesn't allow you the ability to leave the job to go to these visits, you might not get access to whatever medication is offered in that trial, right?"—*Participant 17*

Logistical challenges. All participants spoke to logistical challenges for researchers to accommodate participant needs, including sufficient funding, effort, time, and resources, as a key barrier for their own ability to consider EDI in research. Actively aiming toward having better representation in research was perceived to be expensive, in both tangible and intangible ways.

> "Doing well is expensive. You know, expensive not just for money, but expensive in terms of time and energy."—*Participant 8*

Language was highlighted as a key logistical challenge preventing many patients from participating in research, and participants spoke to how available translation resources are not always comprehensive enough to address this.

> "Speaking English is often a criterion for many research studies. So, I think people […] maybe don't feel welcomed or interested in participating."—*Participant 7*

Furthermore, careful consideration is needed for how researchers are collecting and analyzing information, both in terms of rigor and ethical ramifications. Data collection requires considering how researchers are able to balance potentially competing objectives of recruiting more difficult-to-reach patient participants (e.g., data ownership, data protection, etc.) with concerns about achieving statistical power and being able to categorize and present data. Related to this, participants spoke to how to collect data appropriately if they perceive having a lack of expertise in EDI.

> "How do you collect that data? So, you know, if you don't work with a sex and gender or an EDI specialist, what are the questions?"—*Participant 18*

There is also a need to consider what analyses are possible when subgroups are small.

> "If you don't have enough representation in your sample, then you can't really do these analyses and these subgroups because your samples are too small."—*Participant 14*

Unintended consequences. The final barrier participants identified was a fear of unintended consequences that could worsen health disparities. This stemmed from the issue of "*drive-by research*," wherein researchers conduct studies in underserved communities, uncover problems, and fail to solve them. Specifically, researchers spoke to not feeling knowledgeable enough to work with underrepresented communities, despite having the intention.

> "I don't feel I'm knowledgeable enough to be able to conduct Indigenous research. So […] some researchers are just afraid that they do something wrong […] they don't know the culture."—*Participant 13*

Several participants spoke to the need to consider the nuance of having an absence of data on the recommendations made for clinical practice in certain populations, as this could lead to incorrectly interpreting data.

> "It would be great if we did have more evidence in these populations, but we shouldn't assume that there's going to be biologic differences in how the drugs work unless we have evidence to support that. […] I mean, it's almost like are you worsening inequities by making that assumption?"—*Participant 4*

However, other participants highlighted that the fear of unintended consequences should not be used as a reason to not consider EDI in research.

> "I think that might be a convenient excuse. I mean, I think if you approach it with a genuine spirit and you want to learn and you're open and you say, 'Look. Help me understand.'"—*Participant 12*

The overarching concern was how to balance increasing diversity in study samples while ensuring that one or a small number of patients are not being used to represent all patients with similar patient profiles (e.g., two patients of the same race and gender identity can have different health outcomes, preferences, life experiences, etc.).

> "I do think it's important that we recognize that we have diversity in our populations, but I actually also think it's a bit dangerous because people think the

> voice of one person is enough for the entire group that they represent."—*Participant 17*

Although generalizability was viewed as a benefit overall, participants felt it was important to be intentional about who is being recruited and transparent about the evidence gained from research.

Theme 3: facilitators to support EDI prioritization in rheumatology research. To address existing barriers, researchers highlighted four facilitators to be leveraged when prioritizing EDI in Canadian rheumatology research.

Building community partnerships. The first facilitator identified by participants was the need to develop community partnerships, particularly having a "champion" or organization to help build relationships and bridge the gap between researchers and underrepresented communities. By focusing on building these relationships, it was perceived that researchers could establish trust with more difficult-to-reach populations and address the aforementioned barrier of mistrust from historically exploited groups.

> "What we learned was that our champions were so much more powerful than anything that we could say or do, right? We had to earn their trust."—*Participant 12*

Participants also acknowledged that building these partnerships will take time, which can be a challenge for researchers but is a necessary step that could allow for more careful consideration of the way research is conducted.

> "There's greater acknowledgment that things just take time, and we need to put more effort into community building and being part of the community a bit more, which is good because it forces researchers to take more thoughtful approaches"—*Participant 2*

In order to successfully build community partnerships, working with patients and/or advisory boards was perceived to be critical.

> "[…] a big part of it is actually to talk to the people that we want to incorporate in that and understand how we can support them to include them better."—*Participant 3*

Curating diverse research teams. Participants identified that using an EDI lens in research should be integrated throughout all phases of studies (i.e., design, recruitment, data collection analysis, and knowledge translation) but that it begins with considering who is conducting the research. It was perceived that having more diverse research teams could encourage better representation in studies.

> "It starts with not even the data collection, but who we're including in our research teams, right? So, do we have diverse individuals who are on the staff for informing the design of measures, design of the study, design of the grants? Do we have diverse patients or consumers who are involved in providing insights into lived experience?"—*Participant 2*

Participants felt that having diverse perspectives on research teams allows for better consideration of how to recruit patients from different communities, as well as identifying potential barriers to participation and solutions.

> "So more diverse staff in our environment who can just alert us to things that we might be doing inadvertently that would discourage others—may discourage people from participating."—*Participant 12*

Incentivizing researchers and funder support. Because many of the logistical challenges identified were financially driven (i.e., requiring more time and resources to adequately address patient needs to participate in research), participants tended to consider financial support as critical for considering EDI in rheumatology research in general, as well as in their own studies. Participants spoke to the role of external decision-makers in improving consideration of EDI in research, specifically the need for recognition from funding organizations and regulatory agencies.

> "If we can get funders to also appreciate that these principles mean that we need to be funding at higher levels, [and that] we need to be resourcing teams to be able to do this and expecting teams to be able to do it. It's one thing to expect research teams to incorporate EDI principles. It's another matter to actually resource it and fund it."—*Participant 20*

Furthermore, participants spoke to the need to incentivize researchers to better consider EDI in their work, but that it may need to begin as a mandated approach to be effective.

Fostering humility in research environments. Participants spoke both directly and indirectly about the need to create safe spaces in research environments, which would require a sense of humility from researchers. Some participants highlighted how the language around EDI could be distracting from the importance, as many researchers value the importance but tend to feel challenges in trying keep up with changing terminology.

> "The first place my head goes is like, 'Oh my God, am I addressing them by the right pronouns?'"—*Participant 16*

However, the overarching consensus was the need to acknowledge research limitations with a mindset of being transparent and improving over time.

> "I will still say, it's better to try and get it wrong and then admit that you're wrong and that you didn't have the right people […] I think that's the matter of science, is that you try something, it doesn't work. Then we try it in a different way. We never advance science by not looking into it."—*Participant 6*

In order to combat the "current climate of cancel culture that we live in" (Participant 1), participants emphasized needing to balance between the importance of considering EDI and their ability to do so, which could require additional educational opportunities and training. Ultimately, the ability of researchers to be open and willing to learn and to create safe spaces to conduct research were perceived as key to being able to consider EDI in participants' research.

Thematic synthesis. From the interview data, we constructed a figure (Figure 1) that highlights how the barriers (Theme 2) participants identified corresponded to their suggested facilitators (Theme 3). Horizontal arrows depict the direct connections between barriers and facilitators, whereas the dashed lines indicate potential linkages between barriers and facilitators. Barriers and facilitators that are connected to one another are indicated by brackets. The barrier of mistrust from exploited communities corresponds to the need to rebuild trust and create safer research environments for patient participants, particularly from underrepresented communities, and this often requires including partners that communities can trust. The lack of access to research opportunities for underrepresented patients could be improved by having diverse research teams, which bring richer perspectives on how different patient populations may respond to the opportunity to participate in research (including recruitment strategies, patient barriers to participation, understanding cultural differences, etc.). Many of the logistical challenges mentioned by participants could primarily be resolved by having more resources to conduct research with EDI considerations, particularly around appropriate compensation for patient participants, but also for issues such as language barriers. Finally, the fear of unintended consequences that could potentially increase health disparities is linked to the need to foster humility in research environments and create safe spaces where researchers in Canada can consider EDI and be transparent about the limitations and be open to learning from others with different expertise.

DISCUSSION

This qualitative study was conducted to explore how researchers in rheumatology have applied EDI principles to inform

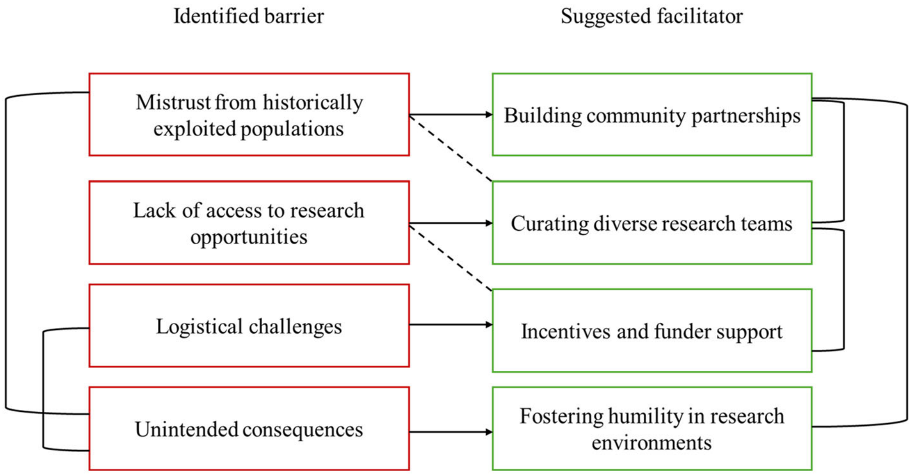

Figure 1. Identified barriers and corresponding facilitators for mitigation.

their research. Participants agreed that EDI is important to consider, but there is a need to balance intentionality with feasibility. Furthermore, to have the most impact, it is critical to consider EDI early and at all stages of the research process, from study team composition through to study design, recruitment, analysis, and knowledge translation.

The challenges of including underrepresented populations in research have been recognized in many different fields and specialties.[12–14] Known barriers to participation for underrepresented populations were aligned with our findings, such as lack of awareness about research opportunities, mistrust, lack of diversity among the research team leading to patients not feeling represented, research not being conducted in the community, and logistical issues.[14] Existing strategies to address these barriers were similar to suggestions from our study participants, including tailoring recruitment approaches to different communities (e.g., media campaigns, recruiting in places of worship, etc.), reducing/limiting indirect and direct costs to participation, transparency and education to improve awareness, translating research materials into multiple languages, and recruiting diverse research team members.[12–14]

Although several important barriers and facilitators were discussed by participants in this study, some relevant concepts were not explored in-depth. One barrier that was not explicitly discussed by participants in this study was the perception of funders and peers toward individual researcher efforts to promote representativeness in their work. This barrier has been recognized as hindering EDI prioritization in other fields and speaks to a larger issue for the research community to conducting research that will be funded versus conducting research that can create meaningful change.[15] The need for funding organizations to have rigid methods for proposed projects limits the ability to provide the flexibility and adaptability necessary for EDI prioritization in research. Addressing this barrier may involve increasing diversity in power positions such as members of review panels for different funding organizations.

Additionally, the role of other interested parties beyond the patient and provider (i.e., caregivers, family members and friends, peers, community advocates, religious and political leaders, etc.) were not discussed, which may suggest a need to expand researchers' scope of who needs to be involved when considering how to recruit and retain patient participants in studies. Using flexible, person-centered strategies may help mitigate barriers for participation and are important for improving representation in research teams, as well as in study participants.

Based on our findings and existing research,[12–14,16] comprehensive guidance for researchers is needed for ways to feasibly consider representation in their own work. It is important to note that it is likely not possible to have representation across all SDOH (e.g., sex, gender, age, race, socioeconomic status, etc.), so researchers may need to target specific factors for which representation is key for the research question. Intentionality is critical when using approaches to improving representation and should involve providing a rationale to participants explaining why particular data need to be collected. For example, if researchers are aiming to achieve a better range of racial and ethnic representation in their study, they should consider how to focus on these factors through each stage of the study. This may require having a more racially and ethnically diverse research team to provide insights into study design, providing translation services for participants who do not speak English, and targeted recruitment strategies to reach specific communities, among other considerations. These findings may lead to discussions with funding agencies (e.g., Canadian Institutes of Health Research) to help develop guidance for researchers in Canada. A possible output from future research is the development of modules to support and provide education on EDI in research to individuals wishing to apply to federal funding sources. Future research should also involve working with patients to better understand how to address barriers to their participation in research.

A strength of this research is the contribution of patient partners, rheumatologists, and researchers to the overall study design and interpretation of results. Following guidance on thematic analysis, the researchers most immersed in the interview content led the analysis, and code development was discussed and verified with others.[17] However, there was overrepresentation of participants from British Columbia, which may limit the applicability of findings to other provinces and/or territories with limited representation. Additionally, people who agreed to participate in the study may have been better informed about or more interested in discussing EDI than those who did not respond or those who declined to participate (n = 4) and may have been more likely to have experience considering EDI in their own research. Finally, we may not have captured the range of arthritis research in our recruitment, as we did not have basic scientists, translational researchers, or other related researchers as participants.

Altogether, our findings highlight the perceived value of EDI in Canadian arthritis research to improve health disparities and our ability to provide comprehensive, high-quality care for people living with arthritis. Considering EDI should be a priority not because of a societal responsibility to improve health disparities through research, but because "it's just good science."

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AUTHOR CONTRIBUTIONS

All authors contributed to at least one of the following manuscript preparation roles: conceptualization AND/OR methodology, software, investigation, formal analysis, data curation, visualization, and validation AND drafting or reviewing/editing the final draft. As corresponding author, Dr De Vera confirms that all authors have provided the final approval of the version to be published, and takes responsibility for the affirmations regarding article submission (e.g., not under consideration by another journal), the integrity of the data presented, and the statements regarding compliance with institutional review board/Declaration of Helsinki requirements.

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