

## **EQUITY IN HEALTH RESEARCH**

**EQUITY IN HEALTH RESEARCH: MOTIVATIONS, CHALLENGES, AND  
EDUCATIONAL IMPERATIVES**

By KATHLEEN HOWCROFT, BA (Hons)

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements  
for the Degree Master of Science

McMaster University © Copyright by Kathleen Howcroft, July 2024

MASTER OF SCIENCE (2024)  
(Health Science Education)

McMaster University  
Hamilton, Ontario, Canada

TITLE:

Equity in Health Research: Motivations,  
Challenges, and Educational Imperatives

AUTHOR:

Kathleen Howcroft, BA (Hons)  
(McMaster University)

SUPERVISOR:

Dr. Anita Acai, PhD

SUPERVISORY COMMITTEE:

Dr. Albina Veltman, MD  
Dr. Sandra Monteiro, PhD

NUMBER OF PAGES:

xii, 153

## **Lay Abstract**

Health sciences researchers are increasingly interested in incorporating equity, diversity, and inclusion (EDI) principles into their work, yet many lack the appropriate education. This knowledge gap poses risks, particularly for research involving equity-deserving communities. This thesis explores EDI adoption in health research using a qualitative descriptive approach. Researchers who self-identified as conducting EDI-related research or using an EDI lens participated in semi-structured interviews analyzed using conventional content analysis. Participants' motivations involved personal experiences of inequity and professional pressures. The challenges they experienced included systemic pressures that can lead to tokenism and harmful research practices, evolving terminology and landscapes, emotional burdens, and bureaucratic resistance and opposition. By understanding advice and resources from current researchers, including better emotional and institutional support, this study takes a crucial first step toward improving EDI education among health sciences researchers. This effort aims to prevent harmful research practices, thereby improving the quality of health research.

## Abstract

**Introduction:** There is growing interest among health sciences researchers in incorporating equity, diversity, and inclusion (EDI) principles into their work. However, there is a lack of established best practices. This knowledge gap poses a risk of harm, particularly for equity-deserving communities. This study aimed to identify the needs of health sciences researchers conducting EDI-related research and to learn from their experiences.

**Methods:** This study used qualitative description through semi-structured interviews with health sciences researchers who self-identified as conducting EDI-related research or using an EDI lens in their research. Participants included faculty, staff, and students with diverse identities, experiences, and research areas. The interviews were transcribed then analyzed using conventional content analysis.

**Results:** Motivations for conducting EDI-related research were a mix of personal experiences and professional pressures. Participants avoided labeling themselves as “experts,” emphasizing the importance of lived experiences in their research. However, lived experience alone was not a substitute for formal research expertise; both were needed on research teams. Challenges included systemic pressures, representation issues, evolving terminology and landscape, emotional burdens, and bureaucratic barriers resisting and opposing EDI-related research. Early-career researchers struggled with power dynamics in academia and finding supervision aligned with their interests and

ethics. Participants shared valuable advice and resources to support higher-quality research including the creation of brave spaces for conversations around EDI to help alleviate the emotional burden on researchers, the importance of team-based approaches to ensure diverse perspectives and critical representation on research studies, and several ways EDI considerations can be embedded in educational and institutional processes.

**Conclusion:** This study addresses the gap in formal EDI research education in the health sciences—an oversight that risks harmful research practices. The outcomes can be used to develop educational resources that promote critical thinking and best practices, thereby improving the quality and impact of health research.

## **Acknowledgements**

First and foremost, I want to express my deepest gratitude to Dr. Acai. Without her, I wouldn't be the person or researcher I am today. Dr. Acai, I have never encountered a more dedicated supervisor. Your commitment to empowering students and promoting equity through education and research makes McMaster University a better place. Every person who works with you is better because of it. The importance of mentorship cannot be overstated—having someone as exceptional and supportive as you on my team, cheering me on, and providing guidance makes an immense difference. Your support has instilled in me the confidence to tackle the most daunting challenges and the resilience to keep pushing forward. Your impact on my life is immeasurable, and words cannot fully express how thankful I am.

I would also like to extend my heartfelt gratitude to Drs. Albina Veltman and Sandra Monteiro for their unwavering support as both committee members and mentors. Their tireless advocacy for improving the experiences of equity-deserving communities within academic and healthcare settings has been invaluable. Dr. Veltman's decision to embrace research to help address inequities is truly inspiring. Thank you for exemplifying the many ways leaders can use their platform to improve the lives of others.

During this project, I grappled with many uncertainties about the best approach to my research and the many decisions throughout. In these moments, Dr. Monteiro created an environment where I felt encouraged to ask questions, learn, and grow, all while feeling supported and appropriately challenged. Thank you for embodying the qualities of

an exemplary researcher and, more notably, for teaching me the importance of creating safe spaces for others.

Starting an asynchronous Master's program was initially daunting. I wanted a community among peers, and I feel so fortunate to have met the most supportive cohort who inspired me and filled me with hope for the future of academia and healthcare. Thank you, Ali, Ally, Michelle, Marina, Sakshi, and Spencer, for the many laughs and constant support. I know you all will move on to do incredible things, and I look forward to supporting your careers from afar. To Dr. Acai's Research Group, I have learned so much from each of you over the past two years. A special thanks to Alek Montes, who dedicated many hours of his time to supporting this work.

To my mom, my first teacher, the best teacher I know, and the person responsible for my unwavering commitment to improving education: I have learned so much about how education can empower and transform lives, and the responsibility educators have to support all learners. Thank you for dedicating 30+ years of your life to educating the next generation; I look forward to carrying on your legacy. And to my dad, who effortlessly builds relationships with everyone he meets, thank you for teaching me the importance of learning from and listening to others. You make everyone around you feel seen and heard, qualities I hope to embody as both an educator and researcher.

Finally, to the participants in my study who were brave and generous with their time, thank you for your trust. You give me hope for a better future.



## TABLE OF CONTENTS

<b>Reflexivity Statement</b>	1
<b>Autoethnography</b>	4
<b>Chapter 1: Introduction</b>	19
1.1 Health Equity Tourism	19
1.2 Tokenism	22
1.3 Perverse Incentives	24
1.4 What is EDI?	25
1.5 Existing Literature on Best Practices	27
1.6 Research Objectives	31
1.7 Thesis Overview	32
<b>Chapter 2: Methods</b>	33
2.1 Setting	33
2.2 Study Design	33
2.3 Participants, Sampling, and Recruitment	34
2.4 Data Collection	36
2.5 Ethical Considerations	37
2.6 Data Analysis	38
2.7 Member Checking	38
<b>Chapter 3: Results</b>	39
3.1 Demographics	39
3.2 Categories and Concepts	40

<b>Chapter 4: Discussion</b>	118
4.1 Addressing Challenges in EDI-Related Research: Recognizing and Using Existing Resources	119
4.2 Defining EDI-Related Research	121
4.3 Psychological Implications for Conducting EDI-Related Research	122
4.4 Embedding EDI-Considerations into Education	124
4.5 The Role of Scientific Gatekeepers in Promoting EDI	128
4.6 An Interdisciplinary Approach to EDI	129
4.7 Limitations	130
4.8 Key Take-Aways	132
<b>Chapter 5: Conclusion</b>	134
<b>References</b>	136
<b>Appendix 1</b>	148
<b>Appendix 2</b>	150
<b>Appendix 3</b>	151

## LIST OF FIGURES

- Figure 1:** Overview of the five categories and their respective concepts. 40
- Figure 2:** Four ways in which participants described integrating EDI into their research. 41

## LIST OF ABBREVIATIONS

<b>CBPR:</b>	Community-Based Participatory Research
<b>CIHR:</b>	Canadian Institute of Health Research
<b>CRT:</b>	Critical Race Theory
<b>DORA:</b>	Declaration on Research Assessment
<b>EDI:</b>	Equity, Diversity, and Inclusion
<b>EGAP:</b>	Engagement, Governance, and Protection
<b>2SLGBTQIA+</b>	Two Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and Additional people who identify as part of sexual and gender diverse communities.
<b>OCAP:</b>	Ownership, Control, Access, and Possession
<b>PI:</b>	Principal Investigator
<b>RCT:</b>	Randomized Controlled Trial
<b>SAGER:</b>	Sex and Gender Equity in Research

## **Declaration of Academic Achievement**

The work described in this thesis was completed by Kathleen Howcroft (the primary author) and supervised by Dr. Acai. The data were transcribed with the help of Alek Montes, a research volunteer in Dr. Acai's Research Group at McMaster University. Analysis and generation of codes was completed with help from Alek Montes and Drs., Acai, Monteiro, and Veltman. The selection of quotes was performed by Kathleen Howcroft with assistance from Alek Montes.

## **Reflexivity Statement**

In research, acknowledging and addressing inherent bias is a fundamental responsibility, and positioning oneself is the first step in this process (Olmos-Vega et al., 2022). Recognizing positionality as a researcher is critical as it acknowledges that context should be provided (Olmos-Vega et al., 2022). I am a white, cisgender, heterosexual, young, able-bodied woman who conducts mostly mixed-methods and qualitative research. This positionality within academia, and greater society, grants me unearned privileges and advantages, impacting how I engage with and conduct my research and the opportunities and resources I have access to. As an early-career researcher, I am acutely aware that I am still developing expertise, and I am committed to being a lifelong learner.

When I started this research study, I was interested in research on equity, diversity, and inclusion (EDI) in the health sciences. I was aware of some of the inequities that existed in health research, especially those related to sex and gender, and I wanted to contribute to making academia a better place for others. However, my understanding was limited by my experiences and perspectives. My initial approach to this work was naive and ignorant, and in hindsight, potentially problematic. The diverse perspectives and lived experiences of my research team, as well as many others with whom I have interacted with and learned from throughout my Master's degree, have been critical in challenging and refining my approach to research; demonstrating the importance of collaborative and inclusive research practices. My research team supported me in putting aside my ego by creating a brave space that was necessary for the level of

introspection and critical reflection required to do equity-related research ethically (Arao & Clemens, 2013).

This study has been the most uncomfortable yet transformative of my career. A sticky note on my wall with the words “I feel like a child again” encapsulates the overwhelming nature of this experience. My engagement with this research project required me to “unlearn” many of the traditional approaches to research that I had been taught, and “relearn” ways of approaching research that were more collaborative, reflexive, and ethical. Doing this work has been a true process of education, and to this day, I am still learning.

In scientific research, subjectivity has traditionally been viewed as an indicator of lower-quality research, conflicting with the ideals of a “good researcher” that emphasize objectivity and the researcher as the expert. This standard perpetuates a false sense of detachment, where research is seemingly untouched by personal biases. However, in other disciplines, there are research methods that embrace the self as a vital element when conducting research (Duarte, 2017). One methodology, autoethnography, which emerged from anthropology, recognizes that subjectivity can offer important insights into the complexity of human experience (Chang, 2016). An autoethnography “situates the researcher within the context of a culture, sub-culture, or group, and studies one’s experience along with that of other members of the group” (Duarte, 2017, p. 2). As part of my thesis, I engaged in an autoethnography as a method for both reflexive practice and to study my experiences and how they related to my participants and the broader conversation around EDI, the results of which are presented in the next section.

Throughout my research, I grappled with the impact of my choices within my study design and how my positionality may affect my relationship with participants. Despite my desire to contribute to making research in the health sciences more equitable, my privileged identities and the absence of certain lived experience have shaped my research lens, and I recognize and value the contributions of those with direct lived experiences to this work. Many of the people I spoke with as part of this research, as well as others who were not participants, have been doing work to advance equity in the health sciences for a long time. However, because many of these researchers hold marginalized identities, some of their voices may have been silenced or ignored. Although I may not share all the same lived experiences as the participants in my research, I can leverage my privilege to amplify their voices because I believe we have a collective responsibility to build a more equitable society. To those who have come before me, your work and sacrifices have laid the groundwork for this research. Thank you for all that you have contributed—and continue to contribute—to making academia a more equitable place.



## **Autoethnography**

I don't know if other researchers feel this way, but when I am writing or presenting this work, I see the participants, I hear the participants, and sharing their experiences often makes me emotional. Maybe I am just sensitive, but for 21 people to have taken an hour out of their day to sit with me, pour their wisdom into me, and provide thoughtful suggestions for ways forward and hope for improvement—that was incredibly powerful. All I want is to amplify those voices in a way that encourages people to hear them, and I want participants in my study to know how thankful I am that they trusted me with their stories.

There have been moments throughout my graduate education when I felt embarrassed about my social sciences degree. It is not valued as heavily in the health sciences, especially given how it has informed my approach to research, as I have always favored mixed and qualitative methodologies. However, my interdisciplinary background was ultimately an advantage when pursuing my thesis project. While I was naive about how hard my project would be, I came into it aware of systemic inequities and deeply valued different perspectives. I understood how complex humans are, and it was important for me to capture this in my data. This understanding of complexity also influenced how I wanted to disseminate my research. I think storytelling is the most profound way to understand the human experience, and journalling and memoing throughout this study not only provided a space for cathartic release but also culminated in a narrative about my experience as an EDI-related researcher in the health sciences.

After asking people to share their personal experiences with me, it felt necessary for me to be vulnerable and share my own experiences with this work in return.

As part of this thesis, I aim to share both my experiences and challenges in conducting EDI-related research, just as others did with me. I hope this will initiate an honest conversation about the realities of doing this kind of work, providing insights that other researchers may relate to and potentially improving the practice of EDI-related research. My autoethnography contributes to my thesis by offering insights into the complexities of navigating one's identities in research settings, as well as conducting EDI-related research. It provides an additional lens to view my research not just as a professional commitment but as a personal journey that was deeply impactful and transformative.

Throughout my thesis, I collected personal memory data using an autobiographical timeline of significant events that shaped my experience (Chang, 2016). I also gathered observational data through memos written during the study, capturing my emotions and thoughts at the time, and external sources including a personal interview and journal entries (Chang, 2016). To triangulate and analyze these data sources, I created a chronological narrative of my experience and identified recurring ideas across the three data sets (Chang, 2016). I present the findings of this autoethnographic work below.

---

## **Beginnings: How I Got Here**

My interest in health equity began during my teenage years at a public high school in Hamilton. At 16, I was accepted into a program called Connexions, which integrated a social justice lens into subjects like English, geography, and interdisciplinary studies. My teachers saw this as an opportunity to transform how students perceived the world and themselves. As part of this program, we volunteered with local community organizations, and I encountered stark disparities in access to healthcare and was particularly impacted by the stories of other young women. These experiences motivated my decision to pursue a major in Psychology, Neuroscience & Behavior with a minor in Women's Studies (now Gender Studies) at McMaster University.

In Fall 2017, I started my undergraduate degree and enrolled in various social sciences courses as electives. Each course deepened my understanding of human complexities and social justice issues. For me, university wasn't just about gaining knowledge; it was about learning to question everything, dismantling my preconceptions, and building a more just worldview.

During my second year, I nervously arrived early for a mandatory statistics tutorial. My teaching assistant, Dr. Acai, a PhD student at the time, was working on a project related to gender disparities in parental leave among surgeons. Our conversation piqued my interest, and I applied to volunteer in the lab she was working in. I was accepted and began working on health professions education projects—many linked to addressing health inequities in some way. This experience sparked my interest in

academia, creating an opportunity to combine my passion for education with a commitment to improving healthcare through research.

Following my undergraduate degree, an opportunity presented itself for me to conduct a Master's thesis project based on data from a diversity and climate survey administered to health sciences faculty and staff at McMaster University. With Dr. Acai as my supervisor, I eagerly accepted. "Yes!" I exclaimed on the Zoom call. "How soon can I start?!" Naively, I believed I was over-prepared and never considered whether I was the right person to conduct this research.

My initial focus was to assist with the analysis of the open-ended survey comments, which I thought may lead to some interesting research questions that I could pursue as part of my Master's degree. When I opened the data file, I was pleasantly surprised to see many more comments than I had anticipated. I thought my thesis was going to be easy with all the suggestions people had provided. And then I started reading.

The comments from the survey were unlike anything I had ever read before. People had poured their trauma into raw testaments of the pain they had endured, not just in academia but in any aspect of their lives where they had experienced inequities. I was struggling under the weight of the first ethical dilemma I felt as a researcher: What was I to do with all the information I had just read? I felt deeply protective over people's experiences that I had just absorbed straight into my heart.

### **Pivoting and Persisting**

Up until this point, I had always studied people who were in different positions than me, like medical students or musicians. Suddenly, I was reading people's

experiences that mirrored aspects of my reality. I realized that certain uncomfortable situations I had blocked out as an undergraduate student were shared by others. No one had anticipated that the comments would be as sensitive and triggering, but my supervisor, committee members, and the other leaders I worked with did everything they could to provide me with support. Nonetheless, the emotional toll of the work I was engaged in was palpable. I struggled with feelings of guilt, questioning the appropriateness of wielding other peoples' traumatic stories as research findings.

When the time came for me to start designing my thesis study, I had initially wanted to conduct a study where I could ask people about the inequities they had experienced in greater detail and explore possible solutions. However, my supervisor, committee, and other colleagues pointed out that this approach was not appropriate, as it could inadvertently cause harm by asking faculty and staff to recount traumatic experiences to an outwardly privileged, junior researcher with limited agency to address them. After some deep discussions, I realized that, while daunting, I would need to pivot my thesis work for it to be ethical.

*“Redirecting my thesis feels like redirecting a river. I know it’s the right choice and I am happy to do the extra work this requires but I am stuck. I am afraid for the integrity and relevance of my research within the institution. I feel like my Master’s should make some improvement [or] lead to a much-needed change, but I fear this is not in the scope based on*

*my junior position.” -Journal Entry, June 2023*

Pivoting my research was hard. I felt frustrated and my ego was hurt, and I was stuck on this idea of only conducting research that I thought would have a “tangible benefit” to participants by helping to create resources for engaging in EDI-related research. Yet I had designed a study that could have triggered incredibly traumatic experiences for participants—experiences that I may never understand because of my privileged identities. Nonetheless, I found it difficult to move beyond the plan I had initially created for myself. Feelings of self-doubt started to creep in, and I began questioning my abilities as a researcher.

*“Do I even belong in this field? I sound whiny and privileged, but the way people speak to me makes me feel like I do not have value to them ... I don't think this field is for me because the guilt and fear I carry every day is preventing me from doing the work. I have lost myself and my values and I no longer think I'm 'good.' I think I'm confused [about] what being a good researcher even is.” -Journal Entry, December 2023*

At this point in my Master's degree, I had completed all my courses and was starting the second year of my thesis, dedicated to my research. I decided to shift the focus of my thesis to understanding the experiences of health sciences researchers conducting EDI-related research and how they were adopting EDI principles into their

work. This felt safer, as it was more aligned with my identity as a researcher. Instead of asking about inequities, I would be asking about researchers' experiences with conducting EDI-related research.

I remember waiting for the various levels of approval needed for my study when another student questioned why I wasn't further along in my thesis. This was one of the most discouraging moments of my project. I didn't have the energy to explain why this research required more time, the challenges of obtaining ethics approval, or the need for my supervisors and other institutional leaders to provide additional approval due to the sensitive nature of the topic. Nor did I mention that we had to be especially careful because of my positionality. Instead, I simply got up, went to the bathroom, and took some deep breaths.

*“And then [student] insinuated that the reason my thesis was going slowly was because I was being lazy or not taking responsibility for it. I feel at odds with academia's expectations versus the process of doing EDI work ... There is a general lack of understanding about the nuances and politics with this work that stalls its progression. Also, I am experiencing internal resistance, making myself freeze. I am having a hard time moving forward because there is a lot of risk. I understand now why problematic research gets published and why not everyone should be doing this type of work because it is so much harder than any other study I have ever done.”*

*-Journal Entry, June 2023*

Months later, after meticulously justifying every aspect of the study to multiple people, I finally received all the necessary approvals. I had been journaling for months, developed a positionality statement, interviewed myself, and was ready to start recruiting participants. At that point, I thought the hard part was over. However, the moment I hit “Send” on those recruitment emails, my project got much harder.

### **Encountering Resistance: Am I a Health Equity Tourist?**

*“I played rep sports for ten years where I got screamed at in gyms full of people, told I wasn’t fast enough, strong enough, smart enough. I have been benched more than once. I have failed things before and been rejected from jobs and other opportunities that I really wanted. But nothing prepared me for the amount of criticism I am currently experiencing.” -Memo, November 2023*

The responses to my recruitment emails—or lack thereof—were difficult for me to accept. Fifteen of my emails were completely ignored, despite being sent to people with whom I had previously worked on EDI projects with and who had been vocal both within the institution and on social media about their dedication to helping support EDI-



related research.

*“I thought I was good at taking feedback and I had thick skin, but I don’t think that anymore ... People give advice on completely the opposite way they think I should do this. They are thrilled when I present my ideas in meetings and express their interest and then I email them and email them and they never reply and I see the tweets they post and listen to them talk during activities and I want to yell, ‘Hypocrite; performer!’ All this ‘support’ the Faculty says it provides, I feel none of it. The few people agreeing to participate are the ones who are so tired and doing so much. And these people who are the most vocal didn’t even reply.”*

*-Journal Entry, November 2023*

I also had many participants spend the first ten minutes of our interview trying to understand my intentions and asking deeply uncomfortable yet necessary questions about what work I had done to become informed enough to engage with this topic.

*“I feel forced to talk about things I didn’t want to talk about because people keep telling me I’m not in a position to ask about experiences with equity. And of course, I have an incredible amount of privilege and advantage but I’m getting tired of saying that every time I speak. I never wanted to make people feel tokenized or triggered ... but people were mad*

*I even approached the topic. And I hate that shit. ... It creates a toxic environment where people are having to disclose deeply personal and sensitive experiences or identities out of fear of being cancelled for expressing their opinion. I am not going to wield something I went through that was horrific as a pass to enter a conversation ... it's inauthentic and forces others to out themselves, as well.”-Journal Entry, August 2023*

To be clear, in no way am I saying that it was not okay for people to ask about my intentions for doing this research. I understand why there is hesitancy to engage in studies like mine, and this hesitancy is justified. Among other unethical research practices, rampant health equity tourism in the health sciences has diluted the reputation and quality of equity-related research. But coming face to face with the question of whether I, myself, was a health equity tourist was incredibly difficult and one that I was not immediately ready to confront. I was not used to justifying my intentions repeatedly, and there was a narrative playing in my head that I was a bad person and everyone else thought so too. People were quick to assume poor intentions. And as much as I tried not to take this personally, it still hurt my feelings and made me question every decision I made, including whether I wanted to keep doing this research.

*“I have done everything I can to resist reinforcing the inequities perpetuated by this space. And being judgmental and assuming negative intentions prevents people from learning and growing and wanting to help*

*conduct this research.” -Journal Entry, November 2023*

Many people I was interviewing held leadership positions within my institution. I genuinely thought my chances of a career in academia were over with some people having reacted so negatively to my research. I knew the qualities of a health equity tourist as I had read all the papers I could find on this topic. And I did feel I met some of the qualities. I wanted another degree, and to do so, I needed funding. I didn't hesitate to think about the potential consequences to my participants at first, and I was not educated enough about my positionality and how to be critically reflexive when I started this research. Although I had a minor in gender studies and had been exposed to equity-related research in the health sciences, I never explicitly studied EDI in general nor did I feel like an “EDI researcher” in any way.

*“I learned about the term health equity tourism today and I am really nervous that I myself am in fact a health equity tourist. I had previous experience with sex and gender analysis and questions around health equity, but I jumped onto this project so fast. I should have asked more questions, I should have at least paused and asked myself if I was the most appropriate person for this work. Now I fear I am adding another study into a pile of low-quality work that puts people at-risk.”*

*-Memo, August 2023*

My interviews also made me realize how I never felt comfortable speaking anymore. I never felt like there were spaces where I could ask questions and provide my opinion on things; it just felt too risky, which was preventing me from doing a lot of important learning. I am outwardly privileged by my identities but there were experiences I had that related to the topics I was discussing with participants, but I didn't want to have to disclose these just to be able to conduct my interviews. I felt like I had to always be "on," as if I was performing for a crowd with others watching my every move, ready to catch me when I made my next mistake.

*"I need participants for my study. ... However, some of these people have leadership roles and are very important at McMaster. Many hold the keys to future opportunities. If they do not like the way my interview goes, will this negatively impact my career goals? I think this research is incredibly important but is it worth the rest of my career?"-Memo, December 2023*

## **Finding My Voice While Amplifying Others**

I've reflected on my thesis research experience for months, wondering what it is about this type of research that leads people to assume the worst intentions of others. Many participants in my study, particularly students and early-career researchers, discussed feeling debilitated by "cancel culture." They felt compelled to maintain an inauthentic public image and feared retribution. They also did not always feel as if they

could choose what research topics to pursue, with some researchers feeling forced to integrate EDI into their work without the appropriate expertise. This was an experience I related to, as systemic factors had similarly influenced my research focus, despite the support I received from my supervisor and committee members.

Another area where I found alignment with participants' perspectives was with respect to the deep frustration attached to performative EDI research. My goal was to contribute to a more equitable healthcare system, yet I had encountered so many examples of studies that merely talked about problems without leading to a positive change. Participants echoed my frustrations with committees, working groups, and research studies yielding minimal benefits. It often became hard not to feel frustrated. Yet, this frustration also served as motivation, underscoring my desire to move forward with my research so that those who come after me would hopefully be even better supported in their work.

Over time, I started to find my voice again. I found myself in a position of educating others about ethical research practices, despite being a learner myself. I also found myself becoming more critical and scrutinizing. For example, I was incredibly worried about how my positionality would impact my interpretations of the data I had collected. During data analysis, when a participant made a statement that others did not fully understand, my immediate response was to defend it. This reaction showed me how clearly I saw myself in my participants. I felt an overwhelming need to portray participants in a positive light because I knew how hard it was for them to talk about their experiences. I wanted to honour their courage and vulnerability. At the same time, I

wanted to make sure that I was not misrepresenting the findings in any way. I addressed my concerns about how to most authentically present participants' data with my committee as I knew my analysis had to be done slowly, carefully, and with input from multiple analysts. Luckily, my supervisor, each committee member, and a student volunteer, all of whom held different research expertise, experiences, and identities, helped analyze a subset of my transcripts. Then, I faced the daunting task of writing and disseminating the results.

*“Dr. Monteiro gave me some important advice. I need to figure out what impact I want my work to have. I want it to be cautionary but also filled with hope. Like let’s use this trend to our advantage and really reflect on how to do this work appropriately and the knowledge and skills that are important to pass on, that are important to teach, that are important to re-shape the foundational way we approach research. This is an opportunity to resist traditional research practices. This is an opportunity to reflect on the impact of language and expertise. We need to learn from other people and really understand what drives this research forward. I want it to be better—I don’t want to point out all the ways it’s bad and I also don’t want to make it seem like it’s all good.” -Memo, January 2024*

My thesis work made me feel uncomfortable and at times even fearful as I began practicing what has now become foundational to my research: constant critical reflection.

There were many moments throughout my thesis where my immediate reaction was to “build a wall” and avoid this research altogether. I think this is a natural reaction for people when they enter conversations around EDI and are met with judgment and assumed negative intentions. I was fortunate enough to have been provided with brave spaces where I could learn and grow from experienced researchers who took the time to provide education and emotional support; I never felt truly alone. The emotional labour, the ethical dilemmas, the constant self-reflection—all of these became the driving forces behind my commitment to this research.

However, not everyone has the same support networks I had during my thesis. Participants in my study, especially students and early-career researchers, expressed feelings of loneliness and a lack of access to brave spaces and supportive research communities. This autoethnography is not just my story; it is one I hope others can relate to, so they feel less alone in the challenges of EDI-related research. It is also an invitation for others to embark on their own journeys of critical self-reflection, which are essential for this type of work.

If we truly wish to make strides towards more equitable, diverse, and inclusive research practices, we must build bridges and not walls, and call others up and not out, when conducting EDI-related research. Vulnerability must be met with empathy and support, not judgement, offering grace to those striving to unlearn and relearn more just research practices. Everyone must engage in this work moving forward. By ensuring no one walks this challenging path alone, we will encourage and empower people to learn how to do this work more effectively.

## **CHAPTER 1: INTRODUCTION**

The COVID-19 pandemic and concomitant events, such as the murder of George Floyd, heightened social awareness of long-standing inequities, including those in healthcare (Boulware et al., 2022; McGrail et al., 2022; Nana-Sinkam et al., 2021). The instant and global reach of social media platforms broadcast these inequities in real-time, making them increasingly difficult to ignore (Carney, 2016). In response to growing societal concerns about health inequities, many research institutions have made public statements of commitment and updated their strategies to improve EDI (Tamtik & Guenter, 2020). Scholars in the social sciences, humanities, and increasingly in the health sciences, have dedicated their careers to identifying and addressing these inequities (Lett et al., 2022; McFarling, 2023). Despite ongoing efforts, incorporating EDI considerations into health research has only recently become a priority for many researchers. This shift is exemplified by recent institutional commitments to EDI-focused initiatives and the incentivization of this type of work (Mugo & Puplampu, 2022).

### **1.1 Health Equity Tourism**

One might wonder why it has taken so long for such a pivotal shift to emerge in health research, a field primarily dedicated to assisting vulnerable populations in accessing necessary care. However, integrating aspects of EDI into research is a complex and challenging task, particularly when researchers are suddenly expected to possess the knowledge and research skills without adequate education (Nweke et al., 2022). Incorporating EDI principles into health research extends beyond the mere introduction of



institutional policies and incentives; it demands a nuanced understanding and deliberate approach to effect meaningful change (Tamtik & Guenter, 2020). This transformation within health research holds considerable significance and is long overdue; however, institutions must approach it cautiously (Nweke et al., 2022).

Institutional commitments must transcend performative gestures and implement empirically supported measures to help researchers improve their practices, thereby enhancing research quality and fostering equitable outcomes (Ruzycki & Ahmed, 2022). Insufficient training in how to ethically integrate EDI into one's research design, topic, or career has the potential to adversely impact communities, particularly equity-deserving communities, who have been and continue to be marginalized within Canadian healthcare systems (Raphael, 2022). There is a growing number of researchers interested in studying health inequities, but many lack the necessary education and experience to conduct EDI-related research ethically. Despite this, these researchers may succeed in obtaining funding and resources, which frequently comes at the expense of opportunities for experienced researchers, especially those who are members of equity-deserving communities (McFarling, 2023).

Lett and colleagues (2022) described health equity tourism as the phenomenon of previously unengaged researchers temporarily conducting health equity research in an opportunistic way, without having developed the necessary level of expertise required to produce high-quality research. Health equity tourism is a result of institutional and funder incentivization of EDI work that allows researchers to gain recognition or rewards, whether that be funding, publications, publicity, or promotion (Lett et al., 2022). The

allure of contributing to trending research topics, such as those related to EDI, can lead to problematic research practices that perpetuate inequities in healthcare and academia.

Health equity tourism carries with it the risk of the same white saviouristic tendencies present in the field of global health, where researchers from more privileged backgrounds assume they are rescuing or “helping” people from marginalized or disadvantaged communities, often without a genuine understanding of the communities’ needs (Banerjee et al., 2023). Challenges in global health include the dominance of high-income countries acting as “the knowledge holders,” which can lead to harmful decision making, especially when health experts from low- and middle-income countries are excluded or disempowered from equitably contributing to this research (Binagwhaho, Ngarambe & Mathewos, 2022). Addressing health inequities through research requires embedding EDI principles to dismantle the white supremacy mentality that upholds the colonial legacy of global health research (Binagwhaho, Ngarambe & Mathewos, 2022). Conducting research that fails to benefit the communities studied is unethical and perpetuates harmful inequities that dilute the quality of the field of health research. This approach not only damages trust but also discourages communities from engaging in future research (Cooper & Crews, 2022).

When recommendations are made by researchers who fail to consider the varying social determinants of health, including the capabilities and circumstances of different communities, they can unintentionally widen existing inequities (Raphael, 2022). An example of this occurred during the COVID-19 pandemic, during which there was a surge in health equity research aimed at addressing the challenges faced by certain equity-

deserving communities (Benach et al., 2022). Often, these research studies capitalized on knowledge held by these communities but provided very little benefit to the communities themselves. Translation of the study findings into practice were either non-existent or reinforced a problematic power dynamic where researchers presumed to know what was best for communities they did not belong to, suggesting useless recommendations that eroded trust in researchers and healthcare systems (Bajos et al., 2022; Büyüm et al., 2020; Cooper & Crews, 2022). In some cases, these studies even perpetuated false narratives, harming the communities being studied (Yearby, 2021).

## **1.2 Tokenism**

To ensure mutual benefit and equitable outcomes within health research, diverse research teams with appropriate representation from the communities being studied are imperative. Collaborators need to have the ability to make decisions and feel their experiences and insights are valued. Romsland and colleagues (2019) and Morrison and Dearden (2013) studied how to involve collaborators within research, including specific strategies to create an equitable research environment. Both studies concluded that health researchers need to undergo training on how to appropriately involve collaborators, as failing to do so risks the well-being of community members. This training would help sustain community partnerships that are essential for EDI-related research.

Romsland and colleagues (2019) defined tokenism “as a false appearance of inclusiveness,” where the collaborator is presented as having influence over decisions regarding the research study, but they are unable to equitably participate (p. 2). If, on a research team, a person was invited because of their lived experiences but not provided

with the autonomy to equitably contribute to research decisions, this would be considered tokenism. Collaborating with communities requires researchers to thoughtfully navigate power dynamics and create conditions for psychological safety (Wallerstein et al., 2018). According to Gaventa and Cornwall (2015), reflexive questions about who is able to participate in the creation of knowledge, for what purpose, and where the power is held, are crucial in ensuring authentic collaboration, rather than tokenism. When community members are included in research without genuine empowerment, it can lead to feelings of exclusion and powerlessness, as their decision-making powers are overridden (Wallerstein et al., 2018). This reinforces problematic power dynamics where researchers are considered the “experts” on the needs and experiences of communities they may not belong to. It is essential for researchers to be trained and continuously reflect on ways to foster equitable collaboration.

Research practices in the health sciences, particularly studies on EDI-related research, are moving towards more community-based participatory research designs (CBPR), a positive systemic shift towards valuing lived experiences not just as a formality but as a critical component of the research process (Tajima, 2021; Wallerstein et al., 2018). In CBPR designs, the goal is for researchers to collaborate to serve the community, rather than pursue questions that address their own interests. One strategy for collaboration is through peer researchers. Peer researchers are members of the community being studied and are paid to be part of the research team (Ross et al., 2023). The intent is that peer researchers foster a deeper level of community engagement by having a more integral position on a research team to represent their community’s needs. In theory, peer

researchers should be provided with the support to equitably contribute to research projects and receive financial compensation. However, the experiences of peer researchers revealed that despite these intentions, challenges persist in achieving truly equitable and non-tokenistic collaboration (Ross et al., 2023). Peer researchers reported negative experiences navigating respectability, often viewing their intersectional experiences as having “negative value” or resulting in “no benefit” to their communities (p. 739). These findings highlight the complexity of emerging “inclusive” research practices and the risks of tokenism, including harm for community members when researchers are not trained on how to equitably collaborate with others.

### **1.3 Perverse Incentives**

Perverse incentives are an economic term defined as “incentives that encourage people to make one decision instead of another for monetary reasons,” which can cause considerable damage when taken up within academia (Stephan, 2012, p. 29). Specifically, within health research, perverse incentives include the prioritization of funding, publications, and professional recognition over the genuine needs of the communities being studied. The consequences include unethical research practices, perpetuation of inequities, and minimal benefits for communities (Stephan, 2012).

Equitable collaboration with communities and other researchers requires time and resources to appropriately compensate everyone involved and ensure the research outcomes address the real needs and priorities of communities. However, perverse incentives in academia, which prioritize quick results, are incompatible with CBPR designs (Edwards & Roy, 2017). This disadvantages the professional careers of

researchers who prioritize impactful research designs that often do not align with traditional academic metrics of success. Perverse incentives motivate researchers to pursue studies that serve their careers over those that benefit the communities they work with.

Perverse incentives can drive hypercompetitive research environments that can motivate unethical behaviors, undermining the quality of research and harming both researchers and participants' well-being (Edwards & Roy, 2017). To address these issues, funding agencies and research institutions must incentivize ethical outcomes over quantitative metrics. Hypercompetition also deters marginalized communities from pursuing positions or remaining in academia, impacting the diversity of perspectives and experiences crucial for ethical, impactful research and a representative academic environment (Edwards & Roy, 2017).

#### **1.4 What is EDI?**

To foster ethical research practices, it is crucial to understand and implement principles of EDI into health research. EDI is an acronym for the terms equity, diversity, and inclusion, which encompass many different facets of identity and lived experiences that impact a person's relationships with people and structures within society. These relationships can differ based on the area of society and stage of life one is in.

Equity refers to “ensuring fair treatment, access, opportunity, and advancement for all people, while at the same time striving to identify root causes and eliminate barriers that have prevented the full participation of some groups” (Kohl et al., 2022, p. 1). Diversity is “the variety of characteristics that makes everyone unique” (Kohl et al.,

2022, p. 1). These characteristics can include race, ethnicity, gender identity, gender expression, sexual orientation, socioeconomic status, caregiver status, neurodiversity, age, body size, household stability, religion, culture, citizenship, language, education, disability, and other characteristics outside of identity, including diversity in “thought, experience, [and] talent” (Kohl et al., 2022, p. 1).

Diversity is a term that is becoming increasingly used within academia as an indicator of “successful EDI.” Yet, this term is often superficially interpreted to serve as a visual checklist focused on the number of people with different visible identities as opposed to their experiences. While having people of different visible identities is important, EDI efforts must extend beyond tokenism and the performative nature of having people with different identities and experiences in the same space without active and equitable participation. Each person must be empowered to contribute their perspective, and they must feel a sense of inclusion. Inclusion refers to “practices and policies designed to provide equal access to opportunities and resources for people who might otherwise be excluded or marginalized” and is essential to creating a more equitable academic and healthcare systems (Kohl et al., 2022, p. 1).

It is important to note the distinction between EDI and Indigenous reconciliation. Although there are similarities between the two terms, EDI initiatives encompass broad demographic groups, while Indigenous reconciliation specifically addresses the historical and ongoing inequities experienced by Indigenous communities (Garson et al., 2021). This involves acknowledging the impacts of colonialism and working towards meaningful reparations and support for Indigenous communities (Garson et al., 2021). EDI initiatives,

while addressing structural inequities, do not specifically address the historical context of colonialism and its ongoing impact. Therefore, while both Indigenous reconciliation and EDI initiatives aim to create more equitable spaces, they do so through different lenses, addressing specific needs and challenges within their respective contexts (Garson et al., 2021). Although the focus of this thesis is EDI, it is important to also recognize Indigenous reconciliation as an essential consideration for addressing inequities and some Indigenous perspectives are included in the thesis.

### **1.5 Existing Literature on Best Practices**

It is evident that the recent prioritization of EDI-related research requires all researchers in the health sciences to garner a basic understanding of how to integrate EDI into their research practices responsibly. However, there is a noticeable absence of a standard level of knowledge and skills required for researchers interested in EDI-related research. The health equity tourist phenomenon highlights the pervasive lack of awareness and education among new researchers about the foundational work already accomplished, emphasizing the urgent need for comprehensive education for those interested in this area. Conducting EDI-related research necessitates that researchers have a strong foundational understanding of their topic and methodology before engaging in the research project. While guides and frameworks exist for newcomers, they are often challenging to apply.

Sex and gender differences have been historically excluded from health research, negatively impacting the generalizability of findings and enforcing health disparities for many communities (Heidari et al., 2016). In response, the Sex and Gender Equity in



Research guidelines (SAGER) were created by the Gender Policy Committee of the European Association of Science Editors, which comprised “a multidisciplinary group of academics, scientists, and journal editors” (Heidari et al., 2016, p. 6). The committee created guidelines for terminology and step-by-step recommendations on how to report sex and gender considerations throughout a research design. Although SAGER provides researchers with recommendations, the authors note how important it is for other members of the scientific community including journals, funding bodies, and ethics boards to also use the recommendations, as they play an important role in the standard of research. Specifically, these groups serve as the “gatekeepers of science,” influencing the quality of health research (Heidari et al., 2016, p. 2). These recommendations also do not consider gender-diverse people, a serious limitation that risks enforcing sex and gender inequities by failing to include all people (Heidari et al., 2016).

Intersectionality, as termed by Kimberlé Crenshaw (1989), originally sought to address the intersection of sex, gender, and race, and has been a topic within feminist scholarship for decades (Bauer, 2014, p. 11). Intersectionality theory has the potential to better account for the many characteristics and experiences that impact people’s health (Bauer, 2014). However, a challenge with using this theory is the lack of a clear method for doing so (Bauer, 2014). Analyzing many identities may not be feasible as it requires large sample sizes, and it can be challenging to recruit for such diversity amongst participants. For this reason, researchers may need to choose which identity characteristics are most impactful for their research question and distinguish between social identities and social positions, which can be difficult for less experienced

researchers (Bauer, 2014). It can also be problematic to expect participants in these studies to indicate whether their identity characteristics are privileged or oppressed, as these experiences are complex and can co-occur and change based on context (Bauer, 2014). Despite these challenges, intersectionality theory, if applied by a research team with experience and expertise with this topic and method, allows individual and group-level causes of inequities in healthcare to be studied more effectively. Bauer (2014) provided suggestions for how intersectionality theory can be applied not just to qualitative and mixed-methods research but also to quantitative research.

Incorporating critical race theory (CRT) into health research offers a framework for analyzing the effects of racism within institutions and systems, providing a means to identify and address health inequities when applied to a health research study (Graham et al., 2011). The challenge for researchers who want to use CRT is that it first requires a thorough understanding of race and racism including the historical context and the many ways in which racism exists (Graham et al., 2011). Without this foundational education, researchers risk a superficial application of CRT, which can lead to harm. Furthermore, the methodological complexity of CRT often requires the use of qualitative methodologies, which can be daunting for new researchers, even those who are educated about race and racism (Graham et al., 2011).

The Engagement, Governance, Access, and Protection (EGAP) framework provides another approach to addressing systemic racism in health research (“Home | Black Health Equity Working Group”, 2021). The EGAP framework, developed by the Black Health Equity Working Group, focuses on empowering Black communities and

emphasizing ethical data practices aimed to dismantle structural racism and advance health equity. The EGAP framework ensures that Black communities take the lead in how their data is collected, managed, and used, thereby protecting their rights (“Home | Black Health Equity Working Group”, 2021). The EGAP framework emphasizes the importance of researchers studying their own communities and using their positions to empower others, ensuring that research practices are aligned with the community’s interests.

Indigenous research methodologies highlight the necessity of integrating community values and practices into the research process to ensure they are respectful and beneficial to the communities involved (Drawson et al., 2017). Two-Eyed Seeing integrates Indigenous and Western ways of knowing, emphasizing the equal value of both perspectives to address a research question (Rankin et al., 2023). When applying this approach, it is crucial to create and sustain authentic relationships, ensure reciprocal research, and have Western researchers defer to Indigenous leadership and knowledge. These principles can be challenging to integrate into research as they challenge traditional Western research norms, where the researcher is seen as the expert and sole knowledge holder. Researchers working with Indigenous communities need to be able to create an environment for co-learning and have the skills to reciprocally integrate both Indigenous and Western knowledge systems. Working with Indigenous communities also requires collaboration and trust, which necessitates equitable partnerships to be built over time (Rankin et al., 2023).

The First Nations principles of Ownership, Control, Access, and Possession (OCAP) establish how Indigenous peoples’ data and information will be collected,

protected, used, or shared (“The First Nations Principles of OCAP”, 2023). These principles respect Indigenous sovereignty by ensuring that research involving Indigenous communities is conducted in a manner that is ethical, respectful, and beneficial. Researchers and institutions working with Indigenous data must understand and respect OCAP principles to support ethical data governance; Indigenous communities must be given the rights to control their own data (“The First Nations Principles of OCAP”, 2023). Similar principles could also be applied to other equity-deserving communities to guide researchers towards more ethical research practices and disrupt the harmful colonial research practices within Western health research.

Ultimately, while there are many frameworks and approaches for how to incorporate certain identity characteristics and equity-oriented theories into health research, each requires a considerable level of education. Many faculty and students want to engage in EDI-related research or feel obligated to do so, but lack necessary knowledge of existing theories and resources, leading to their inauthentic use and risking harmful practices. Understanding researchers’ motivations and experiences is crucial for developing future educational resources, as there is a gap in literature on the actual experiences of conducting this type of work, perpetuating a culture of isolation and unaddressed challenges.

## **1.6 Research Objectives**

This thesis aims to understand the state of EDI-related research in the health sciences, including the experiences and perspectives of current researchers. We explore the following four questions: 1) How are EDI principles being adopted in health

research?, 2) What motivates health sciences researchers to integrate EDI principles into their research?, 3) What challenges have researchers encountered?, and 4) What resources would be helpful to guide future EDI-related research studies?

### **1.7 Thesis Overview**

We aimed to study the experiences of EDI-related researchers in the Faculty of Health Sciences at McMaster University. Our qualitative descriptive methodology sought to amplify the authentic voices of researchers to inform the creation of educational resources to improve the support for and the quality of EDI-related research in the health sciences. Conventional content analysis was used to analyze the transcripts from semi-structured interviews to capture participants' direct responses to the four research questions discussed in our interview guide. Chapter 1 is an introduction, Chapter 2 describes the methods, Chapter 3 reports the findings, and Chapter 4 discusses the implications of our findings.

We chose to use collective language ("we") throughout this document to emphasize the collaborative nature of our research. The goal was to provide a platform for multiple voices, recognizing that EDI-related research transcends individual efforts. It is not a reflection of decisions made in isolation, nor should this type of research be conducted by one person alone, especially given the lead author's positionality. Our decision to use collective language acknowledges the diverse contributions and collective agency necessary for driving equity-focused research forward.

## **CHAPTER 2: METHODS**

### **2.1 Setting**

This study took place within the Faculty of Health Sciences at McMaster University. The Faculty of Health Sciences, which consists of more than 10,000 full- and part-time faculty and staff, includes many different departments such as Anesthesia; Biochemistry and Biomedical Sciences; Health Research Methods, Evidence and Impact; Family Medicine; Medical Imaging; Medicine; Obstetrics and Gynecology; Oncology; Pathology and Molecular Medicine; Pediatrics; Psychiatry and Behavioral Neurosciences; and Surgery (“About - Faculty of Health Sciences”, n.d.). These departments offer both undergraduate and graduate programs, encompassing a broad spectrum of healthcare disciplines. The Faculty’s commitment to enhancing and prioritizing EDI in addition to accessibility and Indigenous health (“About - Faculty of Health Sciences”, n.d.), made it an ideal setting for this research study.

### **2.2 Study Design**

This study used a qualitative descriptive design. Qualitative description is a naturalistic method for capturing and summarizing participants’ subjective experiences (Sandelowski, 2000). This approach emphasizes staying close to the data, allowing the researcher to document the authentic and diverse experiences of participants without the constraints of predefined theoretical frameworks (Neergaard et al., 2009; Sandelowski, 2009). Adopting a qualitative descriptive design allowed us to produce a detailed account of participants’ experiences in their own words (Neergaard et al., 2009; Sandelowski, 2000; 2009).

### **2.3 Participants, Sampling, and Recruitment**

We used key informant and snowball sampling to recruit for this study. We started by inviting key informants; researchers within our network were contacted via email and invited to participate in an interview. We considered key informants to be any researcher in the health sciences that we knew studied topics related to EDI or used an EDI lens in their research within the health sciences. We used snowball sampling by asking each participant after their interview if they knew of any other researchers within the health sciences that were eligible for our study outside of the research team's networks.

The first round of recruitment occurred during November 2023, and follow-up emails took place two weeks after the first communication that participants were sent. Respondents replied to the recruitment email if they were interested in participating. Once they expressed an interest, they were sent the letter of information and consent and the interview questions. Due to the topic's sensitive nature, we encouraged participants to review the questions they would be asked before their interview.

The inclusion criteria for this study were faculty, staff, or graduate students conducting EDI-related research or using an EDI-related lens in their research within the Faculty of Health Sciences at McMaster University. We asked participants to define their research area(s), if possible, using the Canadian Institute of Health Research's four categories, which include clinical, biomedical, health services, and population health research (Government of Canada, 2023). This was important to ensure we had different types of health sciences researchers represented in our sample.

To help researchers self-identify whether their research was EDI-related, we included the following examples in the recruitment email (although we were clear that this was not an all-encompassing list): Researchers who want to understand the health experiences of equity-deserving groups, researchers seeking to improve access to care or care itself for equity-deserving groups, researchers studying the workplace climate experienced by equity-deserving groups, and researchers recruiting participants from equity-deserving groups.

The exclusion criteria included non-English speaking participants, since the interviewer only spoke English. Participants were required to be fluent in English to ensure effective communication during interviews. Except for one participant who requested an in-person interview, all other interviews were conducted over Zoom, as this was a more accessible platform with the added benefit of automatic transcription.

A study invitation was sent to 40 potential participants. We heard back from 25 people, with four declining to participate, and 21 agreeing. Out of the four respondents who declined to participate, one did not have the capacity, and another did not feel they met the inclusion criteria. Two respondents who declined to participate met with the principal investigator (KH) to explain their decision. The first respondent was concerned about being identified as they felt they could not answer the interview questions honestly while remaining anonymous. The second respondent had concerns about how the research findings would be presented and used. Specifically, they were concerned that if the findings were presented as a checklist for engaging in EDI-related research, then this could lead to harm as readers may assume that engagement in this work is simple if one



meets a few pre-determined criteria. Both concerns emphasized the sensitive and serious nature of this research, and these considerations were foundational in our decisions on how to analyze and disseminate the results most appropriately.

While recruiting participants for this study, we recognized there were many conflicting understandings of what constitutes EDI-related research. We believe this lack of universal understanding may be contributing to some of the problematic research practices discussed in this thesis. The lack of a clear standard may imply that anyone can conduct this type of research. Another important note from participants during recruitment was the rejection of the term “EDI researcher.” Many participants in this study were not comfortable identifying with the term as it carried negative connotations about the self-awareness and ethical considerations required for the work they conduct. While they felt all the interview questions applied to them and that EDI principles were foundational to their work, they did not want to be labelled as someone who conducted “EDI research” or as an “EDI researcher.”

## **2.4 Data Collection**

The primary data collection method used in the study was semi-structured interviews, facilitated over Zoom, to further our understanding of the experiences of researchers who conducted EDI-related research within the health sciences. Participants were asked 18 questions using an interview guide (Appendix 1). The final version of the interview guide asked about the following topics: 1) Researchers’ motivation to begin EDI-related research and continue this work; 2) How EDI is integrated into their research and if this has changed at all; 3) Challenges they may have experienced; 4) Advice and/or

resources to improve the quality of EDI-related research. Participants were informed that the interview was voluntary and although it was possible that they could be identified through their responses by members of the research team, data would be de-identified prior to dissemination and all efforts would be made to preserve participants' confidentiality. Each interview lasted approximately 45-60 minutes.

## **2.5 Ethical Considerations**

The study was approved by the Hamilton Integrated Research Ethics Board (HiREB) under Project #16810. Those interested in participating were sent a letter of information and consent and the interview guide (Appendix 1). Participants were asked to read both documents. If they were still interested in participating, they were to provide written consent for their interviews to be audio-recorded via Zoom and for the researchers to use de-identified quotes in the results. The letter of information and consent described what their data would be used for, how it would be recorded and stored, and the contact information for HiREB and the research team should participants have any questions or wish to have their data removed from the study. Participants were read the consent information once more before their interview and provided with the opportunity to opt out if they were no longer comfortable participating. This included their ability to skip any questions and end the interview at any time. Following the interview, the primary investigator (KH) and student research volunteer (AM) read and corrected the transcripts automatically generated by Zoom to ensure accuracy and completeness. The transcripts were then de-identified by KH and then sent to the participant for their approval. Once the

participant confirmed they were comfortable with the transcript, it was uploaded onto a secure platform for data analysis and the audio recording was deleted.

## **2.6 Data Analysis**

The semi-structured interviews were analyzed using conventional content analysis (Hsieh & Shannon, 2005). Given the semi-structured nature of the interview guide and the clear, detailed responses from participants about their experiences in health research, their answers closely aligned with the interview topics, facilitating the creation of categories and concepts (Hsieh & Shannon, 2005). KH conducted every interview, AM observed three interviews, and AA did not conduct any interviews but regularly debriefed with KH about KH's experiences (see Appendix 2 for AM's positionality statement). Initially, KH, AM, and AA engaged in an immersive reading of the transcribed interviews, allowing for a holistic understanding and familiarity with the dataset. KH and AM initially coded every transcript. To ensure diverse perspectives were included in the data analysis, AA, AV, and SM also coded a subset of the transcripts. Following the coding stage, KH and AA held multiple meetings to group the codes into concepts which were then organized into categories. Lastly, KH and AM reviewed each transcript to select representative quotes for each category and concept, ensuring that the voices of all participants were included.

## **2.7 Member Checking**

Following analysis, we emailed a detailed summary of our findings to each participant, which included a description of each category and concept and the corresponding participant quotes. Participants were given a week to review the results and

provide feedback if they felt any of the data were identifiable or if any of their responses had been misinterpreted. Ten of 21 participants responded to the member checking. Eight of these participants indicated that they were comfortable with our interpretation and presentation of the findings and did not suggest any changes. Two participants provided points of clarification that were integrated into the findings.

## **CHAPTER 3: RESULTS**

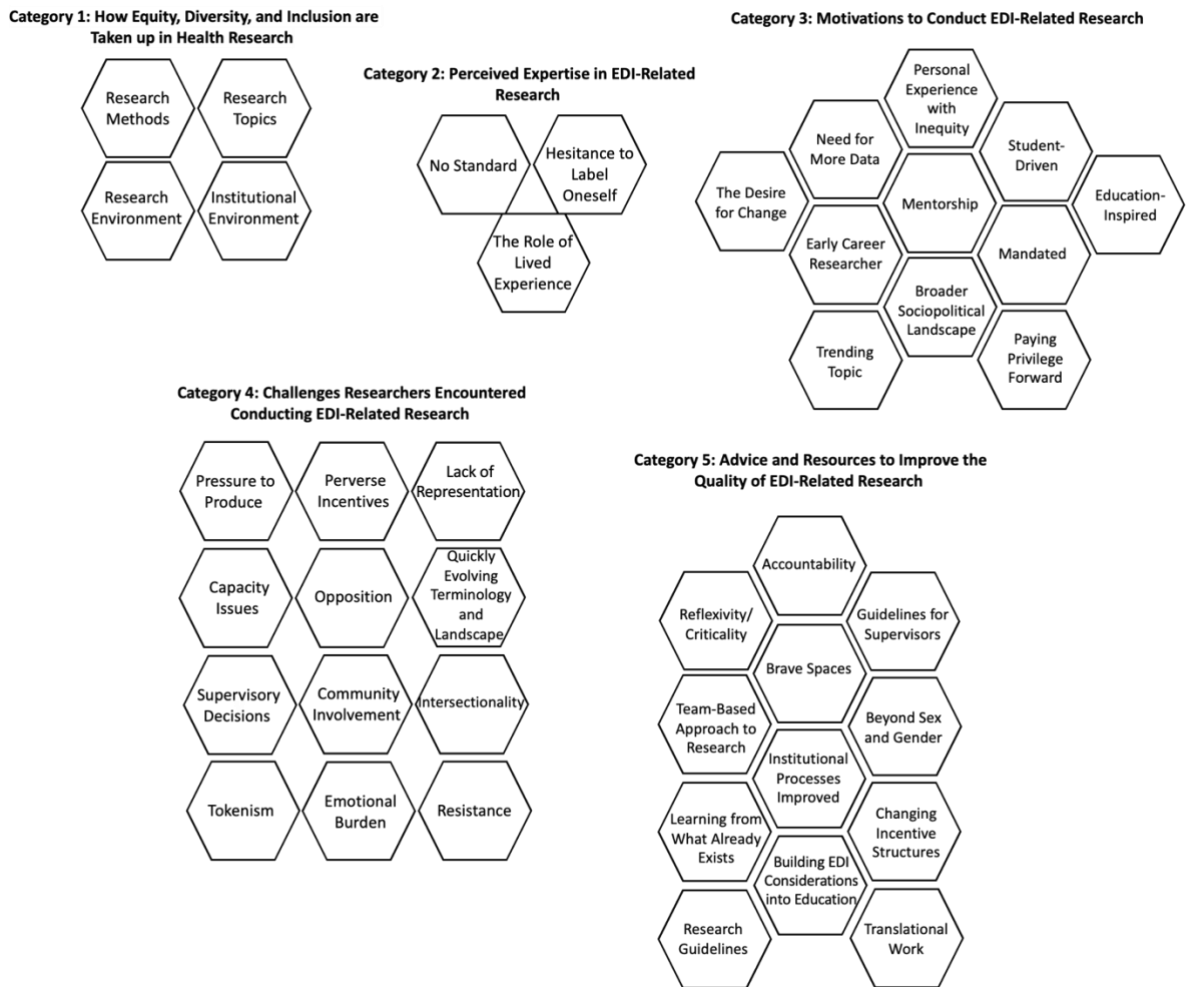
### **3.1 Demographics**

A total of 21 researchers participated in the study. Participants included four students and 19 faculty and staff members (two participants were faculty members and enrolled in educational programs). During their interview, participants were asked to share, if they were comfortable, any identity characteristics they felt were salient to their experiences conducting research. Participants described identity characteristics such as being Indigenous, racialized, white, a member of 2SLGBTQIA+ communities, heterosexual, cisgender, neurodivergent, parents, and having a disability. Participants had the opportunity to disclose whichever characteristics they felt comfortable sharing, but because many expressed concerns about being identified, we are not going to share any more detail than the list of identities. The research topics studied by participants spanned across the four CIHR categories: biomedical, clinical, population health, and health services, with health services being the most common and biomedical the least common research area. Some participants found that their research did not neatly fit into any one category or felt it spanned across multiple categories.

During recruitment, an unexpected observation emerged: students exhibited even greater reluctance to participate than faculty and staff. This hesitancy became clearer upon analyzing the data, as each student expressed a pervasive sense of vulnerability and risk, both professionally and emotionally, when engaging in conversations around EDI-related topics.

### 3.2 Categories and Concepts

Figure 1 presents the five categories and 42 concepts developed from the data.



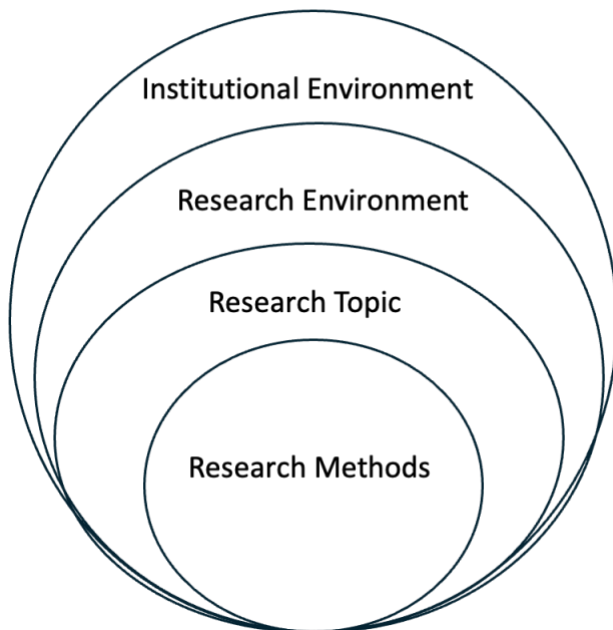
**Figure 1:** An overview of the five categories and their respective concepts. While each

category and concept are distinct, collectively, they capture the experiences of health sciences researchers conducting EDI-related research.

### **Category 1: How EDI Is Taken Up in Health Research**

Participants described four levels at which EDI could be integrated into health research. While the four concepts are distinct, they are not isolated and often intersect and influence one another.

*“It’s not just in your research question, it’s not just in the way you collect research, it’s not just the way you analyze research. Right? It is a whole embodiment of how you do research. From beginning to end.” -P09*



**Figure 2:** Participants described four distinct ways they integrated EDI into their research within the health sciences. Some researchers focused on a single aspect, while others incorporated more than one approach.

### **Concept 1: Research Methods**

Participants described incorporating EDI principles into their research methods to ensure their study's approach was inclusive and representative of the communities they studied. Participants acknowledged the limitations of certain methods when the communities they studied were not appropriately represented. Participants discussed learning from and trying to constantly improve their study's sampling and recruitment to work towards more representative findings, strategically targeting communities that are harder to reach with forms of recruitment that are less common in the health sciences. For example, participants discussed finding community champions to help with recruitment.

These were trusted members of the community who were involved in activities like community organizations and social clubs who could help facilitate recruitment by connecting with harder-to-reach populations. Participants explained that as trusted members of the community, community champions could increase participation and help develop more equitable requirement strategies by ensuring the materials are in the appropriate languages and account for cultural context. Other researchers described extending their study or conducting another study to focus on groups they were unable to reach in the past.

*“You have to think about what does this apply to and whom does this apply to and does it apply equally across all the different types of people that exist in the world? Because even those that engage in fundamental biology aren’t particularly interested in improving the health of mice. They’re interested in improving the health of humans. Which humans are going to benefit from this fundamental biology? I think a fraction of people think about that.” -P10*

Participants also highlighted that the research methods needed to capture the complex nature of human experiences in relation to health often require non-traditional and individualized approaches. Such non-traditional methods, like autoethnography, which originate from outside of the health sciences, often conflict with the “gold standard” methods in scientific research, such as randomized controlled trials (RCTs).

*“I’m not going to do an RCT if I feel like an RCT isn’t warranted for the research question. ... I’m also not going to push an RCT if folks in the community who I’m doing the work with say, ‘That’s not realistic for our setting or for our goals.’ Whereas ... like in the real hard sciences or the people who are purists might push that methodology because it’s seen, in the Westernized notion of what constitutes good evidence, as the best methodology.”-P17*

## **Concept 2: Research Topics**



Participants discussed incorporating EDI into their research through their choice of research topics, exploring health research questions that related to a topic under the “EDI umbrella.” Some participants stated that their research’s focus was on improving EDI in a particular area of health research. Others explored related topics such as advocacy, accessibility, workplace climate, or barriers to accessing care. Participants also described applying an EDI-related lens to their research questions.

*“So, EDI is a giant portion of my research, at least from what I would consider. I have a big focus on gender, specifically, because that is one of the most prominent variables and topics of discussion that comes up in my area ... There are other issues of course, but that’s primarily the one that I’m focused on. I also tend to include more, I would say, social identity questions and focus more on social identity than other researchers in this area. I always want to hear about how people’s social identities have influenced the way that they experience [redacted]. So, that is always the lens that I bring to my research.”-P11*

*“[My research is] trying to shine a light on equity-deserving groups that haven’t had as much attention or accommodation in our system.”-P12*

It was noted by participants that the Canadian Institute of Health Research, a prominent funding body, mandates considerations for sex and gender within applicants’

research proposals. This led some researchers to include this lens as part of their research question and analysis to better position themselves for funding. Others did not feel this identity characteristic was central to their research, although they did have to still include how sex and gender were being considered in their research.

*“...there was all of a sudden, a push from larger bodies like ethics boards, like the Tri-Council who say, ‘Now we need to prioritize EDI; we are looking for these requirements’ and then a genuine desire I think for people to think about these issues. But then the cross section of the two that then led to people feeling pressure to do EDI stuff or bring that lens in. And then because they need funding, they need to meet these requirements.” -P15*

### **Concept 3: Research Environment**

This concept goes beyond researchers’ methodologies and topics and focuses on the ways in which participants described promoting EDI within the physical and cultural environment in which they conduct research. Most participants discussed research groups as a key area where principles of EDI could be integrated to create more equitable research environments and outcomes.

*“So, as one example, in my research group, I really strive to ... create opportunities for people who might not normally get to participate in research. So, I’m more interested in a student who is really enthusiastic and*

*curious and has amazing lived experience and different, whatever that looks like for them, as opposed to the A+ student that has done 50 different research placements and wants to go to medical school.” -P01*

Participants expressed the importance of creating a diverse and inclusive research environment that recognizes and values all team members’ contributions.

*“I think for me being able to have a little bit of experience in different labs allowed me to see how different supervisors run things, which ones maybe are a bit more open to talking about personal positionality with their students, which ones are more open to being challenged by students, especially ones from seemingly different backgrounds. And then being able to get into the lab groups and talk to the people who work under them to see, okay, is the supervisor picking from diverse backgrounds? Do they have all sorts of different students who have different interests, different backgrounds, different ways of learning or interpreting data?” -P20*

Participants also described the deliberate effort required to create inclusive research environments. For example, one researcher described how they strategically planned to hire research personnel from the same racial background as their participants, as they felt this would strengthen their research and its translation into practice.

*“When we were recruited for the research coordinator position, we did a strategic equity plan. ... Certainly, in health care, it improves health outcomes. We felt that racial concordance between the research coordinator and the participants would also improve rapport and make it easier if there’s trauma experiences or whatever.” -P03*

Similar to P01, another participant articulated the importance of deliberately recruiting research personnel from equity-deserving backgrounds who do not typically have opportunities to work in research:

*“I try and recruit as much as I can from specific communities through the academic programs that we have. In [redacted] we have a [redacted] program, specifically geared towards racialized and LGBTQ students that normally don’t have opportunities to work in research. I always engage in that program.” -P10*

#### **Concept 4: Institutional Environment**

Lastly, participants described incorporating principles of EDI within the broader institutional environment, examining how universities and other associated institutions like hospitals and affiliated research centers can implement policies and practices that support equitable, diverse, and inclusive research practices.

*“When I think of the EDI work that I do, that’s more local and like leadership and translation and actually trying to do things differently within the department. And I don’t yet have research related to that.” -P02*

Participants also described promoting EDI by studying the climate and areas for improvement within the health sciences. Others discussed ensuring equitable access to resources, support, and opportunities amongst students, staff, and faculty that identify as members of equity-deserving communities. Participants also worked on EDI committees within their departments, faculty, and associated institutions.

### **Category 2: Perceived Expertise in EDI-Related Research**

Participants reflected on their level of expertise in conducting EDI-related research and how they perceive expertise in others. While they perceived some people to have expertise, they noted that many researchers in the health science do not and are uncritically labelling their research as addressing “EDI.”

*“...humanities-based researchers [are at] the level of expertise that I aspire to and very much so look up to. I think that in the area of health ... research, we have people who dabble in [EDI-related research] more than others. Unfortunately, I do think that a lot of the times EDI is kind of slapped onto studies and people might say that they have some level of expertise in it, and*

*they don't. But I do think that there are people with varying levels in this field.” -P11*

Participants noted that expertise encompassed a range of personal, professional, and experiential knowledge and its application within various areas of academia. Although they acknowledged the variance in researchers' expertise when it came to conducting EDI-related research, they struggled to articulate what true expertise looked like in this domain.

*“I would argue that there's been varying levels of expertise in integrating aspects of EDI into people's programs of research. In the sense that some who are very aware of the implications of what it means to study or do research in this kind of work ... versus those who are like, there needs to be an EDI component to this, let me add a sex and gender analysis tacked on because ... maybe that's the only way to do it.” -P15*

### **Concept 1: No Clear Standard**

Participants discussed the lack of universally accepted criteria for what constitutes expertise in EDI research. This ambiguity was thought to arise from the complexity and breadth of terms associated with the “EDI umbrella,” which encompasses a wide range of disciplines, methodologies, and topics.

*“I guess it’s kind of a broad question as to what does integrating EDI mean. It could be that your framework for your study is grounded in community-based, participatory research, that it adheres to guidelines that are now required for Indigenous research, for example. It could also mean that you’re working with target populations and you’re adhering to and upholding authentic voices in that participatory research study. So, there’s perhaps different ways to integrate EDI. Perhaps you’re using EDI principles, maybe you have language speakers, so all the above could be different ways of integrating EDI.” -P14*

Participants explained that the absence of clear standards makes it difficult to define and recognize expertise in conducting EDI-related research, contributing to a landscape where researchers must “walk alone.”

*“I don’t think it’s possible to be an expert in EDI. ... You can be an expert in equity for Indigenous Peoples in this kind of context, right? And you can know a lot about that thing and really be able to speak to it. And then you can be a huge racist in another context and not on purpose, because you just don’t understand the needs of women or the needs of whatever. There’s just so many intersectionalities and so many different kinds of equity that it’s only ever a process, right? So, then you develop expertise in different areas, but ... all expertise is content-specific, domain-specific. So, if I know about this it*

*doesn't mean that I can 'think critically' about this other thing. This other thing has its own expertise that needs to be built, and some of that will cross domains and some of it won't." -P15*

Participants also described considering the use of the label “EDI researcher” to decide whether to trust certain research studies. Many participants shared their experience that researchers who claimed to be “EDI researchers” and have “EDI expertise” rather than framing this as an interest, focus, or lens secondary to their main discipline, topic, or area of research interest were often the ones engaging in problematic research practices.

*“I think the thing that tends to raise a red flag for me is when people use this as a big label like, 'I'm an EDI researcher; I do diversity work; my research is about inclusion' rather than framing their research as about a specific topic, discipline, problem and noting that they have an interest in or a focus on issues related to equity, diversity, inclusion, like 'I'm a sociologist who studies gender dynamics in the workplace and I bring a critical feminist lens to think through equity issues pertaining to those doing precarious work in the hospitality industry'. That kind of language signals to me someone who is knowledgeable about this topic and has an interest in engaging in EDI work that goes beyond self-promotion or the generation of professional capital.” - P07*



## **Concept 2: Hesitance to Label Oneself**

Participants expressed hesitation about identifying themselves as experts in EDI-related research. Many felt that such a label contradicted the value of humility, which they deemed essential for genuine engagement in EDI efforts. Additionally, as noted earlier, participants perceived EDI as a broad term encompassing multiple concepts, making it unrealistic for any individual to claim expertise across its entirety.

*“I’m constantly learning and figuring new things out all the time and would be hard pressed to call myself an expert at all. At the same time, is there expertise here? ... I wouldn’t want to deny that along the way.” -P16*

Participants’ hesitations were often rooted in self-awareness of the limitations of their knowledge, which was often restricted to a single lens (e.g., sex and gender, race and ethnicity, etc.). Participants preferred to describe their engagement with EDI in terms of specific skills, areas of knowledge, or ongoing learning, rather than asserting broad expertise. Although participants were hesitant to label themselves as EDI experts, almost all of them were able to name a researcher they considered to have more expertise than themselves. Participants expressed that they “knew expertise when they saw it” but did not know how to define it.

*“Yes, I think that there are experts in this field. I think that they might have some similar conceptions to me of like, they may or may not consider*

*themselves an expert, depending on what the area is. For example, I would consider [redacted] to be an expert in EDI based issues, specifically around [redacted].” -P11*

### **Concept 3: The Role of Lived Experience**

Participants described how researchers’ lived experiences offered unique insights and perspectives that could guide more equitable approaches to research.

*“I think I still add value to the conversation when performing EDI research or research that’s considered EDI just because I wrote a lot of my research based on personal experience as a person of colour and also how well connected I am within the research topic that I’m doing.” -P08*

Participants cautioned solely relying on lived experience to guide research without recognizing its limitations that can pose challenges. Participants noted that individual experiences may not fully capture the diversity within and across communities, and that lived experience does not automatically equate to research expertise. Participants described experiencing tokenism when they were invited to join research studies but expected to assume expertise around an entire community’s experience. Some participants wanted to work on studies that related to their lived experiences, while others found this to be too personal.

*“I think in academia there’s a lot of assumed expertise. And it’s like, you wouldn’t ask a PhD researcher to go and become a doctor because there’s specific training to become a doctor, but then all of a sudden there’s this interesting nuance between people with lived experience who then can speak on an EDI matter versus someone having expertise to do research related to EDI.” -P15*

Nevertheless, incorporating lived experience alongside academic and professional knowledge was seen as a necessity for EDI research by ensuring that it is grounded in the realities of those it seeks to serve.

*“I wouldn’t go into someone’s kitchen and pretend I’m a cook. I don’t know what any of this stuff is. I’m going to sit and watch some cooking shows. Right? It’s the same idea. You can’t just jump in.” -P09*

Participants advocated for a balanced approach, where lived experience was valued as one important component of a comprehensive research strategy, complemented by research expertise. A researcher can have both lived experience and research expertise, but more often participants discussed the importance of a team-based approach to research in which different researchers bring different forms of expertise to the study.

### **Category 3: Motivations to Conduct EDI-Related Research**

There were several reasons participants decided to become involved in EDI-related research, with most participants describing several different factors that motivated them to pursue their research area.

### **Concept 1: Personal Experiences of Being Part of an Equity-Deserving Group**

Participants described how their personal experiences with inequities, whether through their own experiences or those of family and friends, motivated them to conduct EDI-related research. They spoke of a deep, personal connection to the issues at hand, driven by a desire to address the injustices they or their family or friends faced.

*“So, being a woman, I am comfortable with sex and gender-based analysis because I know that women have been excluded from research. I know pregnant people have been excluded from a lot of clinical trials in the past. The history of clinical trials is very male and ... I’m a female, so I want that to change.” -P04*

Participants also discussed that while identifying with the community or communities they studied could make it challenging to separate themselves from participants’ experiences, it also helped them better understand the context.

*“There have been so many times where I can see that the healthcare system does a disservice to ... not just people who look like me or who are me or who*

*have the same circumstances but also other individuals as well. And because it has done such ... a continuous disservice, the way a lot of minorities view health, there's such an aversion towards it right? And I am tired of seeing this constant cycle of abusing minorities and if I can have some part in helping change and push change for that system, for a selfish reason, I think it'll provide a sense of protection for these folks." -P08*

Student participants discussed having a personal motivation to find a research group that aligned with their values and to change the future of research by advocating for studies to be conducted more ethically. These participants were tired of seeing their communities negatively impacted by the healthcare system and health research.

*"I think coming into it, back in second year of undergrad, I was terrified. I didn't want to get booted out of a lab. I didn't want to perform poorly. I just kind of listened to whatever the grad student or the PI [Principal Investigator] at the time told me was applicable and then I learned how to talk about my own positionality, and I learned how to talk about my own perspective in a way that was engaging with others and not just me like information dumping. ... I think I've been able to more critically evaluate what's been pitched as an EDI lens on a research study and what actually is at the forefront of the research project. And maybe I just feel a bit more confident with speaking my own mind or maybe addressing things that I don't*

*really see the logic behind straightaway.” -P20*

Participants pointed to the delicate balance required to manage personal emotional investments and the professional detachment necessary to protect one’s wellbeing and interpretation of results.

*“I have complained about the institution’s behavior before. He [my supervisor] is well aware of the experiences I have personally had...And... he was like, ‘You know who can do this study?’ ... And I was like, ‘Wow.’ That may or may not be triggering for me; that’s not even something that he would think of.” -P11*

## **Concept 2: Need for More Data**

The lack of comprehensive data on inequities was a prevalent concern and source of motivation for participants, who felt that the absence of “hard” evidence pointing to experiences of inequity hindered the recognition of these issues as legitimate areas of concern. Participants described their research as a crucial step towards filling this gap, viewing it as both a social justice imperative and a necessary foundation for informing policies, program development, and admissions processes aimed at addressing inequities and improving equity.

*“Well, I think that health is political. And you realize that when we begin looking at race-based data, or the lack thereof, then research becomes a social justice vehicle because research evidence, building evidence and having evidence-based decisions in health in general is what runs the country in terms of research dollars, health services, and programs.” -P14*

Participants recognized how disheartening it was to continuously need to prove inequities they already knew existed but felt that people in positions of power required quantitative data to see value in creating change.

*“Without the evidence, racism remains invisible. ... Data is needed ... Without the data, then it's just somebody's opinion.” -P03*

### **Concept 3: Desire to Create Change**

Participants expressed a strong desire to contribute positively to their academic and societal environment, seeing their research in EDI as a means to create meaningful change both within and outside of academia.

*“I basically hold the philosophy that we should work in an actively interdependent way. I think that the university space can really highlight the individual, but my goals and passions are pretty relevant and in respect to what's needed in society so I try to organize my research program to be*

*responsive to people who are looking to do things that will influence change.”*

*-P16*

Participants acknowledged the inequities present in academic institutions, some of which they had personally experienced, and that needed to be improved. This motivated them to conduct research that addresses some of these inequities to create a more equitable, diverse, and inclusive institution for all. Participants appeared dedicated to creating an institution that reflected their values of inclusivity, which they hoped would improve the academy for the next generation.

*“I think it relates to my values as a person. Like, I think I want to be part of an institution that’s more just and equitable and, you know, like fair. I see a vision for higher education that includes that. And so, I just want to make it a better place for the people that come after me. Like that’s honestly what motivates me.” -P01*

#### **Concept 4: Early-Career Researchers**

The sentiment that participants became engaged in EDI work “because no one else would” was pronounced among early-career researchers, including students. Early-career researchers often felt compelled to take on EDI-related research due to a lack of available expertise or interest from others.



*“I’ve been pulled into lots of equity projects because there hasn’t been any other expertise available. But it did often feel like it was sort of by chance or by happenstance that I was brought into the work and given my role and how precarious it was as an early-career faculty member, it was also really hard to say no to some of those opportunities.” -P01*

Participants also acknowledged that funding was a major motivation for pursuing EDI-related research projects, particularly among early-career researchers. Several participants expressed discomfort with this, feeling a sense of immorality and inauthenticity in pursuing EDI-related research solely for funding opportunities.

*“My application for this research funding was built on the foundation of my PhD research funding. As I mentioned, my background is [redacted]. And I would have chosen mental health to work in because that was where I was clinically oriented. But there was no funding for it at the time. ... And so that was the area of inquiry I was thinking about. But then I got recruited to be on this team that was looking at how to improve the [redacted]. ... I hummed and hawed about it, but then the advice I got was just do it because it’s PhD funding and then you can do whatever you want afterwards. But the problem was that when you get into an area of research, then you kind of become known in that area.” -P14*

Many early-career researchers, especially students, felt a moral obligation, stemming from their worldviews and values, to incorporate EDI considerations into their research. However, due to a lack of expertise within the broader research community, they often had to educate themselves and others. While they believed this work was necessary, they also acknowledged the personal and professional risks it carried, given its highly political nature.

*“As a new researcher I just keep trying to push it in there everywhere that I push my agenda. Everywhere I go and then I just I’m waiting to be completely shut down. I’m kind of like holding my breathe a bit.” -P09*

### **Concept 5: Broader Sociopolitical Landscape**

The influence of the broader sociopolitical landscape, particularly world events that highlighted systemic injustices, was a powerful motivator for participants to study EDI-related topics.

*“Like we hear stories about the, you know, the Black Lives Matter and trans athletes getting banned from sports. ... And it’s heartbreaking. So, it [EDI] is a really important social issue, and it should be incorporated into research and other fields as well. And it’s probably not as much as it should. So that’s mostly what motivates me.” -P04*

Participants described a heightened awareness of and urgency to address EDI issues in the wake of such events, feeling a collective discomfort and a moral imperative to contribute by reflecting on how they can improve the way in which their research addresses deeply rooted inequities.

*“So, the political climate, the murder of George Floyd, some of the really sort of difficult things that happened with finding the mass graves of young Indigenous children who’d been murdered. Like that, I think nobody could ignore at that point, like we’re missing something in all that we do. ... That was really important because I think the whole world felt uncomfortable, which was a good thing.” -P05*

### **Concept 6: Mentorship**

Mentorship was a pivotal factor in guiding participants towards EDI research. Participants recounted how the interest and engagement of a mentor in EDI-related research provided them with a model to follow, offering both inspiration and education.

*“But I did have a mentor [redacted], and he was doing EDI work. So, I just fell into it. I learned from him actually how to do it. And he had community groups, people from [redacted] communities providing input into the research and commenting about it. Like even before that was a thing, really.” -P03*

This mentorship often opened doors to EDI-related research that participants might not have pursued independently. Participants highlighted the importance of learning from others and how engaging in mentorship shaped their research trajectories.

*“And so now I feel like ... there’s a momentum and a confidence moving forward, and it allows me to really support this research rather than try to lead it myself. I’m supporting people who know what I think, know a lot and are going to have expertise. And ... we’re all consulting really appropriately I think with, you know, people who do have a ton of expertise in EDI.” -P05*

Participants reflected on the many benefits of being mentored and felt it was important to pay this mentorship forward.

*“And there are people that I consider mentors that I feel like have done that and like I’m in, where I am now, and my experience is slightly better because of their work, so, I feel like that’s also what I want to do for others that come after me.” -P01*

### **Concept 7: Student-Driven**

Participants, particularly faculty who supervised learners, noted the vital role of student interest and initiative in driving EDI research. They shared examples of projects that emerged from graduate students’ passion and leadership, underscoring the importance of

supporting and nurturing student-driven research to better explore and address EDI issues.

*“I feel like I haven’t really had to convince any of the students. They just know intuitively that this is something that needs to be done and they just come to me for methodological help and practical, like how to actually implement this.... And they are taking the lead ... I’m just brainstorming with them ways that they can ask their questions better or analyze the results better or report the results better, all that kind of stuff. But I’m learning that as well as I’m going along. We’re all kind of learning it together.” -P04*

Participants, particularly faculty, described wanting to support students to study inequities within their communities. Some participants noted that they initially did not feel comfortable addressing these topics given their positionality until students who had personal experiences with inequities and were interested in studying them, sought out their supervision.

*“I have a graduate student who’s very passionate about this topic. ... I [also] have a wonderful thesis student. And so, we’ve amassed a little team and we’re doing some work [redacted] learning more about barriers and facilitators to accessing care [redacted]. And so, that’s been an example of*

*like we're directly interested in EDI.” -P05*

However, it is critical to note that from students' perspectives, the dynamic of the student holding more expertise in EDI-related topics than their supervisor, could often lead to challenging experiences (see Category 4, Concepts 10 and 11).

### **Concept 8: Education**

Educational experiences, particularly those that challenged participants to critically assess the role of science and research in society, appeared to be the catalyst for some participants to take an interest in EDI-related research.

*“I was a white person, so I didn't have to deal with racism on a personal level. But it's in the water, and it seeps into everything you do. And then when I went to university, I started studying postcolonial literature and trying to understand what the colonization experiences globally and what racism is like for people. I think literature was a huge lens for me. But for little 20-year-old me, it was like, 'Oh, that's a whole thing, like racism is not slavery; racism is alive and well.' I think that undergrad experience was a huge thing for me.” - P12*

*“I had held a very positivist perspective. Science has the answers to everything, and that illusion was torn away in this course where it really shed*

*light on the fact that science is very much skewed by politics of the era. ...  
And so that's when I started to realize the many different factors that can  
influence what is being looked at in science and the way that can be used to  
harm a lot of individuals.” -P06*

Learning moments through courses, literature, and conversations with peers that exposed the biases and limitations of traditional scientific inquiry motivated participants to incorporate an EDI lens in their research as they sought to broaden the scope and impact of their work. Participants also reflected on how through their own self-study, driven by a desire to learn more about either a topic related to health equity or methods to integrate EDI considerations, their understanding of science had been transformed.

*“And during graduate school [redacted] I was still interested in and reading  
sort of very casually engaged with feminist scholarship of science, and  
feminist critiques of science, as a hobby, something I enjoyed reading and  
found very stimulating.” -P19*

*“But I also think that my own perspective on that has changed over the years  
as I've learned more about EDI. Because when I think about it, what did I  
really know about EDI when I started? Probably not that much, right? And  
so, as my own education on this topic was increased, and I took courses in  
various places to learn more about that [EDI].” -P18*

### **Concept 9: Mandated**

The role of mandates from funding agencies or institutional policies in directing researchers towards EDI considerations was highlighted as both a practical and ethical imperative for conducting health research. Participants appreciated these requirements and training as it pushed them towards greater inclusivity and consideration of sex and gender characteristics, in particular.

*“First of all, CIHR has some really great training on sex and gender-based analysis; it’s very accessible to everyone. They really focus on that. And I’m a [redacted], so they particularly make us train on that, like how to detect what is a good sex and gender-based analysis sort of aspect to the research. And it’s actually mandatory. So, it really forces you to learn if CIHR makes it mandatory.” -P04*

However, participants expressed a concern that certain identity characteristics were mandatory to consider while others were not, which may not fully account for the intersectionality of people’s experiences. Another concern was that these considerations should be required of researchers regardless of the funding opportunity being pursued.

*“I wouldn’t say that it’s a personal interest for me; it was always an expectation of scholarship that I had an understanding of these different*



*areas of the literature. To me, that's what constitutes good EDI work- incorporated throughout examination of an issue or a phenomena, not a standalone thing to study in isolation or when it's convenient or desirable” - P07*

### **Concept 10: Paying Privilege Forward**

Many participants recognized their privileged positions within academia and society, acknowledging that being part of an academic institution and having access to higher education confers a variety of social privileges. Participants discussed the advantages their identities and current role within the faculty provides them with in terms of how they are treated by others, as well as access to funding and mentorship.

*“One is I know I come from a place of privilege because of my education and income and I’m always very cognizant of that. And I think I’ve become more aware of it.” -P13*

Participants described various ways they use their privilege to pay it forward with their peers, by advocating for students and co-workers trying to do equity-related research and using their position as a leader to provide opportunities for others who do not have the same platform and institutional clout.

*“It just feels really important. It’s always been time for me to advocate for the groups that I’m a part of, like [redacted]. And just the groups that make me feel like I don’t belong. But it’s also time for me to be an advocate, ally, and an activist for racialized people because I’ve been accruing a lot of privilege over the course of my life. In some ways. And that is something that’s owed.”*

*-P12*

### **Concept 11: Trending Topic**

Some participants described how incorporating elements of EDI into their research was a relatively recent endeavor. They discussed how EDI was not on their radar until recently when it became more of a priority within and outside of the institution.

*“I would say the best example and where it’s really come to the forefront for me is in that last line of work with [redacted]. And I think I was probably very naive, but prior to that EDI wasn’t even on my radar, and it certainly wasn’t spoken about as much as it is now. In some ways I felt like we just fell into that, doing the [redacted] by happy accident and then learnt so much from it.” -P13*

While for most researchers the outcomes of their EDI-related research were seen as positive, some researchers also noted the “trendy” nature of EDI research to have the potential to lead to harmful research practices.

*“I think academics are very good at positioning themselves to be successful. And so, they’re good at jumping on that hot buzz topic or buzzword or buzz theory that’s going to get funding, that’s going to get published, that people are going to get excited about. And we’ve seen this all over and over again. When we have a bunch of people jumping on the bandwagon for the sake of accruing professional capital, that’s when people start doing work in a shallow, haphazard, misinformed, and potentially harmful way.” -P07*

#### **Category 4: Challenges Encountered in Conducting EDI-Related Research**

Participants described a variety of challenges encountered while conducting EDI-related research in the health sciences. These challenges highlighted the conflict between personal interests in more equitable research practices and academic pressures that can deter the ethical conduct of this research. Moreover, the articulated challenges with EDI-related research spoke to the resistance and opposition entrenched in hierarchical institutions that often call into question the legitimacy of EDI initiatives and the value of their application to research spaces.

#### **Concept 1: Pressure to Produce**

Participants felt the academic environment prioritized quick research outputs that led to more grants and publications over thorough, community-engaged research that takes more time to conduct ethically. Specifically, participants noted that including

community members takes time and requires building trust for equitable engagement. It is also essential for research that is undertaken to benefit the community, which involves developing long-term relationships and partnerships. Participants described a tension between the need for impactful, meaningful work and the institutional pressure for rapid results, often at the expense of depth and engagement with EDI issues.

*“And I do believe that, you know, our institutions are based around fast timelines, quick results, and high productivity. And that is to our detriment. Because you end up losing all sorts of very interesting data because you’re not looking.” -P10*

*“This work actually has to be done slowly and carefully and mindfully. If you rush through it and don’t think about all aspects, you’re not going to do it right and you’re going to actually cause a lot of harm.” -P18*

## **Concept 2: Perverse Incentives**

Participants expressed concerns about perverse incentives in academia, where engagement in EDI-related work could lead to personal advancement through funding, promotions, and public acknowledgment. Importantly, participants noted that not all incentives being offered by the institution to support researchers engaging in EDI work are perverse. However, when incentivization leads researchers to prioritize personal gain over genuine contributions to a more equitable academic or healthcare system, this dilutes

the quality of the research and exploits the communities it aims to serve.

*“In economics, we have this theory called perverse incentives, and it’s the idea that the incentive is actually encouraging people to do the wrong thing or the bad thing. And I think academia is full of perverse incentives and that the attention to EDI has created so many perverse incentives about doing research with marginalized or historically excluded communities.” -P07*

### **Concept 3: Lack of Representation**

Participants highlighted a lack of diverse representation within academic structures, including review boards and committees, which they felt complicated the conduct of ethically sound and representative EDI research.

*“I think that a lot of the reviewers are overworked early-career faculty or perhaps senior faculty that are very, you know, like to review things in their niche area and have been doing research in a particular area for a very long time. I don’t think that the diversity is there in the reviewer pool and that shows, right?” -P01*

Participants also discussed how many areas within the Faculty were still dominated by white men, which could lead to resistance around pursuing EDI-related topics.

*“The area that I work in is male-dominated, and trying to push any sort of research with the lens of gender equity in it is incredibly difficult. Not because they don’t care in a way, but because they will never understand the things that women experience and people who are marginalized by their gender identity in their workplaces.” -P11*

Students also discussed a lack of representation within faculty who supervise research. This made it challenging for students to study their communities when they could not find a supervisor who also represented these communities and had research expertise with the methodologies they felt were most appropriate.

*“Often PIs [Principal Investigators] are high up in academia; [they] have a lot of privilege. And they’re not very representative of society or especially, you know, if you’re studying equity, they might not be representative of communities that they’re trying to study.”- P21*

#### **Concept 4: Capacity Issues**

Participants described capacity issues as a hurdle to conducting ethical EDI-related research. Students and early-career researchers felt compelled to undertake EDI-related research due to a shortage of qualified people, leading to scenarios where those with the best intentions lack the necessary resources, support, or expertise, potentially

compromising the quality and impact of the research.

*“And I’ve been part of research where that community obviously is dealing with a lot. They actually just don’t have the capacity to lead research in that area. And that is how a lot of times, you know, white researchers, that’s how they get pulled in because they want to help, and they end up kind of taking over. Right? And taking over the lead. And then it becomes kind of like this, you know, it starts to feel unfair and like we’re profiting off of it and we’re leading it when it’s not ours to lead. But I think sometimes that comes from this under-resourcing issue that I talked about at the beginning. I was the only person there, so I was invited [redacted]. And I just wonder how we get around that and how we encourage, you know, people from particular equity-deserving backgrounds to be able to do research and take ownership of that research, like what resources are needed to actually facilitate that, because I don’t think it’s just saying, ‘Yeah, here, go and do your research.’” -P01*

Faculty and staff researchers discussed their competing responsibilities that create rushed research where participants expressed a desire to do more relationship building and knowledge translation, but they did not have the capacity to conduct the study to the extent they felt it should be conducted.

*“I’ve learned that it’s like they have basically a full-time person whose job it is to do that [facilitate an advisory committee]. And our trials are so underfunded, we don’t have time for that, we don’t have the people for that, and we don’t have the skills for that. Having a whole patient advisory committee and like, you know, biweekly meetings and monthly newsletters and all kinds of stuff that they’re doing, like for a [redacted] grant, it’s just not feasible for every project. So, we have to figure out ways to scale that back and do that, you know, get some of the good quality stuff in there, but with less cost and time.” -P04*

Along similar lines, participants discussed capacity issues in community organizations they partnered with that did not have the time or the resources to engage with research or the co-design of studies because of their workload. This could make it challenging to have collaborators from the communities being studied and to spend the time required to create an equitable environment for collaboration.

*“And the idea was to support them and give them some tools and give them some funding to house the work they’re already doing. To make links between research and policy work. But I think the big challenge, which is kind of what the job has been, has been too bold, and one of them is that those people are super burnt out. Most people who are already doing the policy work are doing everything they can already, and they don’t have time to answer my*



*email and start a new project. They really want to. Every time you email them, they're like, 'Yeah, I really want to do this.' And then you're like, 'When can we meet?' And you just don't hear back ... I was doing a ton of work to try to bring these people together. And through no fault of their own ... they just can't." -P12*

Participants also discussed that potential participants from harder-to-reach communities had competing responsibilities and it was difficult to provide appropriate compensation for community members to take time to participate in research, especially with short funding timelines. This could then lead to a lack of representation within the research sample.

*"When we recruit participants in our study, we purposefully sub-recruit from hard-to-reach neighborhoods. Now those individuals, of course, are hard to reach for a reason. They're called hard to reach because they don't have time. Or the resources. And this is not high on their priority list when they need to pay rent. As opposed to coming out to a research study. So yes, there are definite challenges." -P10*

### **Concept 5: Opposition**

Participants provided examples of opposition they experienced from colleagues and people in positions of power, who publicly or privately expressed skepticism towards

their research findings. Institutional opposition was described by participants as going beyond resistance to include active, overt efforts to undermine or devalue EDI-related research. This form of opposition was characterized by participants as outright rejection, dismissal, or invalidation of their research findings. Students and early-career researchers, in particular, discussed feeling like they had to continuously convince people of the merit of their research, especially when using non-traditional methodologies to capture complex experiences.

*“There’s this one paper that I did with a very good colleague of mine ... Oh my gosh, I can’t even tell you, I think it got desk-rejected fifteen or twenty times. And the more it got rejected, the more I wanted to get it in somewhere. I think I was probably the most persistent I’ve ever been as an academic was to publish that paper. Because I knew that it was so important to get it in a journal, essentially, because of all the desk rejections that I was getting... the reason that they kept giving was that it wasn’t an interest to our readers. And I’m like, how could this not be an interest to your readers if we’re all collectively moving towards more inclusive practices in research design? For me, that was my first exposure at something that I felt was an injustice in that space. Like why is this not acceptable for you?” -P20*

When presenting EDI-related research, participants discussed being questioned about the legitimacy and value of their work, which they often found demoralizing.

*“This study was conducted at a point where I was well aware of the institutional spin requirements that exist for publishing these pieces of research. And this study was conducted with the intent of publishing it; we promised that to our participants. ... And instead of the reaction of like, ‘Oh my god, this is horrible, we need to do something,’ there was, ‘We can’t put this out into the world because it would look too bad.’ ... And it was very, very disappointing to say the least.” -P11*

### **Concept 6: Quickly Evolving Terminology and Landscape**

The challenge of keeping up to date with rapidly changing terminologies and conceptual landscapes in EDI research was commonly noted by participants. Participants described the pressure to continuously update their knowledge and the fear of making mistakes that could cause harm or misrepresent the communities they study in, emphasizing the need for continuous learning and humility in EDI-related work.

*“... this is again something I struggle with, even the classifications of what’s race versus ethnicity and what are different gender orientations and how to ask the questions properly and sensitively.” -P13*

*“It reminds me of the conversation that happened around how BIPOC [Black, Indigenous, and People of Colour] when we created this really fun acronym that rings off the top of your head. It sounds really nice, and then people were like, ‘But why are we putting them all together?’ ... It just gets very messy because you’re conflating things, especially for that one, because you know that different racialized identities have very different experiences depending on the context.” -P15*

Participants also discussed the challenge of navigating different perspectives on the best terminology within communities. Despite their efforts to use “best practice” language and defer to community members for decisions, there was always someone who preferred different terminology. This sometimes prevented or stalled participants from continuing their research.

*“And another challenge is, like I just said, the terminology just isn’t quite there. It became tricky in terms of how do I communicate this? ... I wanted to be very cautious about and mindful of the terminology that I was using and the stances that I was taking. .... And so, trying to educate myself on that and what I say, this was tricky because the community is also split on the terminology used and on the perspectives. And so, I don’t think any community has one single idea or thought.” -P06*

### **Concept 7: Supervisory Decisions**

Students and a smaller number of more experienced researchers noted the challenge of finding a supervisor or supervising students with the appropriate background and understanding for EDI-related research projects.

*“But also, there’s some not-so-good people doing EDI research. I think anytime someone gets into any line of research, you should be really careful about who’s supervising you, and very much trust your gut. There are very kind people out there. ... But there are some people who take more than they give and can even be abusive in this field.” -P12*

Participants, specifically students, felt they often had to educate their supervisors on EDI best practices, which could strain relationships and complicate the research process, highlighting a gap in supervisory training and awareness. Students felt they were having to lead EDI-related research even though they did not feel they had enough expertise to do this work appropriately, especially students with lived experiences as members of equity-deserving communities.

*“The first challenge ... is that my supervisor is a man. ... It’s very difficult to have these conversations in the environment that I’m in.” -P11*

*“When I first started out, I was never allowed to run a focus group on my own. ... But that often meant that the PI [Principal Investigator] or whoever I was working with would be the main facilitator. They’ve had the conversations, or they would be the one actively recruiting. And that comes with its own bushel of things that you need to consider. If I go into it with the mindset that I want to include a well-represented population, it’s not something that I can directly apply because it’s my PI who recruited. Maybe they recruited in a way that wasn’t equitable or maybe they recruited based on just snowballing and that in itself creates issues.” -P21*

Students also discussed the challenges with finding other students engaged in doing EDI-related research as a product of the lack of supervisors, which impacted their ability to build community and made them feel alone.

*“The second one [regarding challenges], I think, is to find a community of people and I think this comes with having a supervisor that does this form of research, having people that actually do EDI research around you for just purely emotional support, is a big one. Because if you haven’t done EDI research, you don’t know the toll that it takes on you to process the data, write about it on a day-to-day basis ... Having someone who actually does that specific kind of research, talking to people who are like, ‘Yeah, I’ve*

*heard these stories too.' It's great. It's fantastic." -P11*

### **Concept 8: Community Involvement**

Participants described systemic and logistical barriers to effectively involving patients or community members in research, pointing out the lack of training and resources as key issues. Crucially, this concept differs from Concept 4: Capacity Issues, in that it was not just that there was no time or resources to involve communities in research, but researchers also lacked the education to equitably and meaningfully involve community members in their research.

*"I don't do a whole lot of patient involvement in research. I find that challenging to do to operationalize. It sounds lovely on paper. And then when you try and operationalize it, it's extremely challenging." -P04*

Participants questioned the suitability of traditional academic settings for conducting meaningful EDI-related research, given the inherent power imbalances and risks of tokenism when engaging with community members without a commitment to long-term partnerships and training on how to design an equitable research study. One researcher described what tokenistic research feels like for research participants:

*"They [participants] felt like I participated in so many studies. I've said my piece so many times, but nothing ever changes. I don't even hear back from*

*the researcher about what did they do with this information, and I as a person or the community have not actually received benefit from all of these different studies that have been done.” -P18*

### **Concept 9: Intersectionality**

The complexity of addressing multiple identities within research contexts was a challenge for participants, who felt it was both impossible and unethical to attempt to represent all possible identity characteristics of participants.

*“When you’re talking about like quantitative research, we need to really think about how to analyze data when there’s intersecting identities from people from diverse backgrounds. So, somebody who is Indigenous but also identifies as Two Spirit, like how are we designing studies where we can look at some of those questions?” -P05*

Researchers did not feel they had the knowledge on how to appropriately capture and analyze their study participants’ experiences of intersectionality. They stressed the importance of nuanced, respectful engagement with diverse communities to avoid oversimplification and misrepresentation.

*“I think again it comes back to this intersectionality piece. ... In practice, I think it’s very challenging. And the reason I think it’s very challenging is*



*because if you're doing quantitative analysis, and you're doing any statistics or stratification or whatever ... the more you try to splice the data, the smaller your sample size is going to get, and then you create a cell that's almost nonexistent, right? Or you end up aggregating all of the data. ... I think it's still one of the things that I'm grappling with. How do we actually do this well if you need these humongous sample sizes in order to do it, and even then, we don't do it very well." -P13*

### **Concept 10: Tokenism**

Experiences of tokenism were frequently mentioned by faculty, staff, and students. This included being invited to join studies as a researcher because of identities they held and being asked to make decisions on behalf of an entire community that they did not feel they fully represented. Some participants noted that they were not provided with autonomy to express their opinions on research decisions, or their opinions were not valued by the lead researcher.

*"You just needed me to be there. I was the token—again. That's what it feels like. It may not be the intention, but that's what it feels like." -P09*

Researchers from equity-deserving groups were concerned about whether their involvement in projects was genuinely valued or merely a symbolic gesture to enhance the project's image and chances for funding, leading to skepticism about the authenticity

of the institution and individual researchers' commitment to EDI.

*“I was very upset about the concept of tokenism because I was like, ‘how many young women who happen to identify as being part of the [redacted] community, exist in this space and that you were like, this person should do this?’ Was that a PR [public relations] move? Do you actually appreciate my ability to design a good study and analyze data and present it in a way that’s very clear? Or does this look good if this person is doing this research? I was happy I signed up for the research. That’s fine; I did that research. But what I didn’t sign up for was being paraded around the institution giving presentations to old white men who were less than receptive to my results. That I did not sign up for. And that was incredibly difficult and triggering.” - P11*

Participants described EDI-related research that on a surface level seemed appropriate, but in reality, was creating harm for the communities involved in their work because the researchers were ignorant of the diversity within communities and the risks associated with having one researcher making decisions on behalf of an entire community.

*“There was a lack of representation in this type of research that was being done and there was like a lack of background knowledge ... And I think because of this disconnect it felt like from my personal experience that I had*

*to have the responsibility in filling that gap. So, there was kind of like a question on why I was hired. ... I don't know if it was also kind of a check mark. And when it comes to grant applications that 'yes, we have individuals that are of this community'. It could have been a diversity vote or very performative way of thinking. So again, it's still unclear, but that's what it felt like at the time. I felt there was a lot of responsibility that was shifted on individuals who identified within this group that may not have been qualified essentially and to [conduct] certain research tasks." -P08*

### **Concept 11: Emotional Burden**

Participants detailed the emotional challenges associated with conducting EDI-related research, including feelings of fear, discomfort, and loneliness. Research that was seen to portray healthcare systems or institutions unfavorably was often met with resistance or opposition, forcing researchers to weigh the potential risks to their careers against continuing their studies. EDI-related work was perceived as hard to present, get published, and often undervalued when looking at promotions and opportunities for advancement within the institution. The decision to pursue these topics that researchers made involved balancing ethical obligations to participants, personal values, and career risks. Researchers lacking a supportive community and network of other researchers reported feeling particularly isolated when experiencing negative emotions. The fear of perpetuating inequities, coupled with concerns about being ostracized or silenced by

peers, supervisors, and leaders within the institution, intensified the emotional burden.

*“But the risk is, maybe you say something a little too controversial. And as a new researcher, do you want to do that? And are you doing it alone? Will your team actually back you up? Will your PI [Principal Investigator] back you up? Will your supervisor back you up? That is a huge, huge risk to doing this work. It’s also taxing on your spirit, and your body, and your mind. You get passionate about the work and then it falls flat because people don’t want to pick it up or you can’t publish it or whatever the case is and then you think, ‘Well that’s feels devastating.’ And not ego devastating—it’s like community devastating.” -P09*

Furthermore, ‘cancel culture’ was perceived to have heightened the risks associated with EDI-related research, disproportionately affecting early-career researchers and students who lacked job security and who were often assigned to help with these challenging projects. Participants explained that they needed to navigate their ethical and moral responsibilities to various stakeholders without adequate support or experience on how to take care of their well-being and make decisions effectively.

*“I think right now, people aren’t willing to engage in conversation. They want to argue. And I was speaking with a colleague who was saying, you know, it used to be where if you had a perspective and someone else had a different*

*perspective, you engage in a conversation. And one outcome is you come out of that conversation more with conviction in your perspective, because hearing the other argument strengthens your ideas, or the other option is they give you a new perspective and you change your ideas, and you've evolved as a person in your thinking. Whereas now people are so ingrained in putting their personhood into their ideas that there is almost no room to engage in that conversation with folks. I do think also a lot of these topics related to EDI invoke a lot of fear in individuals out of fear of being cancelled or a fear of being judged for the perspective that they have.” -P06*

For students and early-career researchers, specifically, who often lacked the agency to make decisions on their methods, topics, and the ways in which they conduct research, explained how the emotional burdens of EDI-related research created a lack of motivation to continue conducting this work, as they wanted to avoid any further psychological harm to both themselves and the communities they were working with.

### **Concept 12: Resistance**

Participants described institutional resistance as obstacles imposed by organizational structures, like ethics committees, that hinder and stall EDI-related research and acknowledged that this form of resistance signaled a clear lack of institutional equity. This differs from the resistance from study participants and community members to participate in research, which participants felt was healthy

skepticism to protect their communities from potentially problematic research. In contrast, resistance from the institution was often seen to stall or subverts studies that have the potential to identify and address inequities necessary for genuine improvement.

*“Certain people even block the things that you want to do, and that has happened. And it’s never explicit, right? It’s never like, ‘Don’t do this or wait to do this.’ It’s more just not answering emails or simply not supporting it when the support is needed. ... In the past, I’ve definitely had challenges with research ethics boards where they don’t necessarily understand that when you’re working with a vulnerable population, a kind of hidden population, for example, snowball sampling might be a way of finding those hidden folks in a respectful way, and I’ve been blocked from using snowball sampling in cases where that was maybe the best way that we could have recruited people. And even challenging those ideas with research ethics boards, we did not win in that case.” -P18*

Participants also noted that using social justice and equity-oriented language, such as “colonialism” or “anti-racism,” could result in delayed research approval, as studies with this language generally faced greater scrutiny from review boards.

*“So, you know, you can submit to a particular committee about something that doesn’t involve or have anything that says anti-racism. And it seems to go pretty smoothly. And you don’t get a million questions. And as soon as you start making comments about how, you know, you’re going to purposely recruit, you know, equity groups because the participants are from equity groups or this and that, then there’s a million questions. I mean, a million questions and stuff gets sent to other people for their feedback. And you end up in a bureaucracy that takes six months. I mean, bureaucracy and committees are a great way to kind of stall this kind of work. And I’ve experienced a lot of that.” -P03*

Critically, this concept differs from Concept 5: Opposition, which involves someone directly questioning the merit of one’s work or the institution not granting approval. In contrast, resistance is not a blatant rejection of the research; it is more implicit, manifesting through longer review processes and questions from institutional leaders that act as stall tactics.

### **Category 5: Advice and Resources**

Participants discussed the importance of developing new resources and making existing ones more accessible to provide better training and support for health sciences researchers. They also emphasized the value of learning from resources in other disciplines. With more resources and improved educational and institutional support,

participants were hopeful that future EDI-related research would involve researchers who possess the necessary knowledge and education to conduct these studies responsibly. Central to these discussions, too, was fostering a research environment where ethical considerations and proactive measures are integrated into individual education and institutional policies.

### **Concept 1: Accountability**

Participants emphasized the importance of accountability in EDI research by embracing mistakes and making amends. Within this concept participants highlighted the need for humility and learning from other researchers' mistakes.

*“So, we were systematically excluding people of different cultures, women who are wearing dresses, women who are wearing a headscarf and people with disabilities in an [redacted]. We actually changed our entire research program [redacted]. ... We had to learn an entire new methodology because this system is way better at including people who are wearing any clothing. You can just come in wearing any clothing that you want. You can come in with your walker or your cane. ... We're better able to include people as they are appearing in [redacted], which I think is much more inclusive for, you know, race, ethnicity, culture, gender, religion, and disability.” -P04*



Participants stressed that mistakes are part of the learning process, advocating for resources that guide researchers on how to improve and move forward constructively.

Participants wanted more transparency from mentors and experienced researchers about how their approach to this work has changed over time and the reason for these changes.

*“Doing this work requires an intense amount of humility and willingness to have difficult conversations. And to admit when you’ve done wrong and done harm. Because I would think that even equity researchers who might be put on this pedestal as folks that always do something right. I think that’s also my worry that if you’re identified as an equity researcher, that means you’re always going to get it right. And quite frankly, you can get it wrong still. I think just being able to have really difficult conversations sometimes, and apologize, and understand one’s motivations is just so important.” -P17*

*“I wish that I had like a compendium of errors, mistakes that people had made because there are so many things out there where it’s like checklists of, you know, it’ll say, these are questions to ask yourself, these are things, but you kind of ignore them or gloss over them because you’re like, ‘Yeah, I ask myself that all the time, yeah, I’m super critical’. But it’s not until you actually have made an error yourself that you realize the depth of it. So, I think if we were just more honest about, you know, the challenges, the nuances, the complexities that are encountered in this work, that would have*

*been very helpful to me. It can be helpful to just learn about what are the ways that equity research has gone wrong and, you know, make those case studies basically.” -P01*

## **Concept 2: Reflexivity and Criticality in Research**

Participants emphasized the importance of integrating critical reflexivity into research practices. They suggested that researchers should regularly ask themselves, “Am I really the best person to do this research?” Participants explained how this introspection is crucial for recognizing personal biases and understanding the inherently political nature of EDI work.

*“What are some of the biases and assumptions that you’re bringing to this work? Why are you the best person to lead this project? Why are we asking the question in that way? What is the method? Why are we using this methodology? Those kinds of things ... I do think experiences shape us. I think we have to be really mindful about that. There needs to be a processing of those experiences to really understand how much they’re influencing what we focus on, but how we interpret the data that we collect.” -P17*

*“I definitely keep in mind when I’m in these moments so reviewing a study design where they might be using genderist, sexist ableist attitudes to interpret situations and then propose ideas, then that’s relevant. Thinking of*

*the different ways that I experience things and people that are of different identities would experience things.” -P02*

When students were looking for supervisors, a “green flag” was any supervisor who encouraged their students to reflect on their positionality and to critically reflect. When this was standard practice in a research group, this helped students feel more comfortable being part of that group.

*“I would say to kind of begin with overall before even getting into the research project itself, identifying as a woman and a person of colour when I first got into research, one of my first priorities was ensuring that especially in qualitative research where your own positionality plays a huge role in interpretation of data and themes and also how you interact with the populations that you’re speaking with, I wanted to make sure my supervisor or the people that I’d be working with also had diverse backgrounds. ... And then moving forward from there, the projects that I went into in terms of reflexivity, it was important for me at least that I always included my own positionality into any reflexive statements or into any discussions that we had. .... There’s always something that I personally brought up or other members of the lab brought up from their own vantage points, which is fantastic. But I think that wouldn’t have been made possible if it weren’t for foundationally*

*the labs being built on that kind of principle or the main supervisor not instilling that in us upon our initial training.” -P21*

Participants also encouraged researchers to reflect on their positionality by acknowledging how personal identity characteristics and lived experiences shape their approach to research. Participants noted the importance of understanding the researcher’s subjective perspectives that inherently influence all research, both quantitative and qualitative, and when acknowledged add important nuances and diverse perspectives to health research questions.

*“First off, recognize your positionality and be really honest with yourself. Yeah, it’s great that you have an interest in this issue, and you want to pursue this EDI lens. But see where the gaps in your positionality are, where you yourself may not be an expert on.” -P08*

### **Concept 3: Team-Based Approach to Research**

Participants described team-based approaches to EDI-related research as the best practice for ensuring different identities, experiences, and expertise are considered. By having many perspectives on a research team, participants felt these studies could better account for the complex and diverse experiences of communities. Participants emphasized the limitation of individual perspectives and the value of diverse voices beyond well-

recognized names.

*“So being able to combine those [lived experiences and research expertise] definitely is what I would say approaches true expertise within the field. I wouldn’t say one or the other is better. I don’t think you could compare someone who solely has lived experiences with someone who solely has the actual technical abilities of like data analysis, collection, interpretation, all of that. I think that combined either in a singular individual or through a team is much more valuable than just like the sum of the parts.” -P20*

However, participants, especially students and early-career researchers, cautioned that there are some spaces within academia where it remains unsafe to disclose marginalized identities or experiences of inequities. Having researchers continuously disclose potentially traumatic experiences or identities that could prevent them from future opportunities should not be an expectation.

*“We often say that we should be able to share our lived experiences in the academic setting and allow that to help influence and shape our research agendas and be transparent about that. And yet, I think it’s naive and short sighted to think that it’s actually still safe to do that. ... That’s actually a potentially vulnerable and unfair ask.” -P17*

#### **Concept 4: Identities Beyond Sex and Gender**

Participants pointed out the necessity for research processes to comprehensively address the diverse identity characteristics that impact health. Currently, there is a hierarchy of identities, with sex and gender being more commonly considered, as researchers must address these in grant applications due to funding agency mandates. However, other characteristics, such as body size, ability, or socioeconomic status, are often not considered by researchers.

*“Yeah, so when I started, I think the gender piece, especially in health professions in some of the more clinician lead projects that I’ve been on, sex and gender were always one of those categories that were always looked at.”*

*-P15*

*“I think, well, at first, I was very focused on sex and gender. ... And then over time, I started to realize, like, wow, there’s actually a lot of things beyond gender, too, like there’s race, sexual orientation, there’s ability, there’s socioeconomic status. Like these things are all important. So, I started to be more kind of broader in how I thought about equity.” -P01*

*“I have sort of a broader personal commitment to equity and justice and sort of a big umbrella way of thinking about the world. And so, this certainly influenced the fact that the research that I choose to do has an equity focus*

*and this focus on sex and gender specifically.”-P19*

Participants stressed the importance of considering the intersectional experiences of participants and other identity characteristics that are less studied. Funding and ethics applications should not only ask researchers to consider sex and gender but also require them to address how all identity characteristics and their intersections relate to their research question.

*“And I’ve attended meetings that talk about sex and gender-based analyses, gone to workshops. Making sure that I’m well informed about what’s out there. And understand the language. A lot of people don’t understand what intersectionality is, what it means. How can you incorporate it if you don’t even understand it?” -P10*

### **Concept 5: Enhancing Institutional Processes**

There was a consensus among participants on the need for improved institutional processes related to funding, ethics, journals, and other challenges and barriers to incorporating EDI considerations into health research. Participants noted in the realm of EDI-related research, the pursuit of simplistic solutions or “silver bullets” is fundamentally misguided. Also, institutional committees responsible for determining whose research gets approved, funded, or published lack diverse identities, experiences,

expertise, and critical EDI education. Addressing this lack of representation could reduce the number of problematic research studies.

*“I think representation, the way methods are carried, the amount of knowledge that individuals hold when pursuing certain research on different ethnic minorities, there’s just a lot of knowledge gaps. I feel that’s been a huge challenging and frustrating process by people who are more higher up in the research game like PIs [Principal Investigators] and people who are funding these projects as well. And I think we talked about funding earlier, but I think there’s also a lack of funding towards projects that are focused on these issues. Specifically, recognizing these healthcare disparities among these ethnic minorities but also even if there is funding a lot of these funds are being allocated towards projects that have a lack of representation. I don’t know if that’s more palatable and that looks good as a project for someone to be the lead that has a bigger name and who’s not essentially like a minority or connecting to the population that they’re focusing on. So yeah, there’s a lot of disconnects I feel.” -P08*

Participants also noted that many departments in the Faculty are currently engaged in EDI committees and are trying to improve the diversity and climate locally. If the various committees were better able to collaborate and learn from the initiatives that each are



doing, this would reduce some of the capacity issues, the unnecessary repetition, and lower the risk of potential mistakes by learning from initiatives that did not work.

*“There are other surveys that are done, climate surveys, census surveys, and you know, I would like to see that similar processes that are used so that when that data is collected, it just doesn’t stay with the central office, it goes back to the EDI committees that, you know, the multitude of them, and that the EDI committees then work as like recommendations back to the central office or the department or whatever so that they can hear the recommendations or understand the interpretations from the perspective of these various EDI committees.” -P03*

Participants also discussed the need to consider how faculty, students, and staff are integrating aspects of EDI into their roles when evaluating hiring, promotion, and renewal packages. They emphasized the importance of accounting for the time and resources required for this work when setting funding timelines and publication requirements. This approach would encourage higher-quality work, foster more community partnerships, and promote responsible research practices instead of providing perverse incentives. Without institutional support, allocating time and resources for this type of work, participants felt the type of research required to address inequities was unrealistic to expect. A system that requires researchers to independently learn how to ethically approach these topics outside of their working hours does not align with the institution’s public commitment to

improving EDI practices. Participants felt a constant conflict of their time and morals trying to navigate institutional requirements and time needed for such critical engagement in EDI practices.

*“I think people should do it and I think it’s problematic when people do it because they want a line on their CV. That’s probably more true for folks who don’t have the visible lived experience than those that do who are tasked with a lot of that work. I recognize that’s a lever for people, that’s a way to incentivize and promote that type of activity, but I also see that the merit system that the university applies is also responsible for a lot of the inequity that’s at play. So, you’re kind of like turning the sock inside out. Maybe not the best metaphor, but it kind of eats itself. You know what I mean? So how can we valorize it and make it meaningful and important? But keep it framed out as contributions to an active interdependent community that loves each other?” -P16*

### **Concept 6: Guidance for Supervisors**

Clear guidance for supervisors regarding the sensitivities around lived experiences and shared identities were emphasized. Participants highlighted the importance of recognizing that a student’s personal background does not automatically imply an interest or capacity to research EDI-related themes; in fact, it can cause harm.

*“Find someone who is an expert to be your supervisor. Or who at least has some expertise related to EDI issues to supervise your work. You have to fight so many more battles. Your supervisors theoretically should have a level of expertise above your own concerning certain topics. This one was not inside of the realm of expertise of my supervisors. ... It is incredibly challenging to even get any form of support.” -P11*

Moreover, participants expressed a desire for guidance surrounding how supervisors can best support students wishing to study a community that the supervisor does not belong to or have a relationship with.

*“There’s no oversight to implement that policy and there’s no faculty development to ensure that any faculty who’s been given the privilege of supervising graduate students knows what that means, you know, in terms of timely feedback or providing the kind of guidance that’s needed to complete their work in a time frame that the student wants. And so that policy then goes unattended ... It’s not often translated down to the level of the individual student.” -P02*

Participants who supervised students emphasized the importance of providing support and education to conduct EDI-related work ethically. While research should align with the student’s natural interests, EDI work often attracts researchers with personal

experiences of inequities, and the learning curve can be substantial. Unlike other disciplines where supervisors can simply provide a dataset for students to analyze and correct mistakes easily, EDI research—often involving mixed methods and qualitative approaches—requires careful preparation to protect both students and participants. Participants noted that supervisors have a critical responsibility to equip their students with the necessary research skills and to ensure their psychological safety. In EDI research, the potential impacts are more significant. For example, if a student asks an inappropriate question that hurts a participant, the damage cannot be undone. Similarly, if a student encounters triggering information from a participant, it can have lasting effects. Proper training is essential to minimize these risks and ensure ethical and effective research practices.

*“We’re here to give you resources and connect you to opportunities to better learn what you want to learn, but what do you want to learn and how can I be supportive in that process, is also part of the question. And fundamentals, yes. ... You should have a general understanding of community relationships, within the community that you want to work with. ... And being supportive in that by sharing resources, by sharing my own experiences, by connecting them to other people on the team that might know more than I do about something. Having them look things up and present back to me on things.” - P20*

Students provided advice for peers interested in pursuing EDI-related research. They emphasized the importance of asking potentially uncomfortable questions at the start of a supervisory relationship. This includes inquiring about the supervisor's interests and methods, their connection to the community they study, what the community gains from their research, and how they interact with the community. If a supervisor is unable to answer these questions or becomes offended, it might indicate a misalignment of values. Participants acknowledged the career risks involved, as many students need research experience, and it can be tempting to stay silent even if the research feels problematic. However, they advised trusting your instincts—if you have a bad feeling, engaging in harmful research is worse than not doing any research at all.

*“But definitely as a student don't be afraid to speak out. You're not just a scut worker in a lab trying to build your way up. I understand that there is a social hierarchy in a lab and you kind of do have to work your way up from cleaning pipettes to actually being able to contribute to the project. But being able to voice yourself and to ask the tough questions to your supervisor to the other people who are formulating the project itself is important.” -P21*

Given that EDI-related research requires more time than other research topics, it may not lead to publications within a student's time in a research group. Participants emphasized the importance of being transparent with students and ensuring that the outcomes of this

work align with what they hope to gain from their research experience.

*“And I am very aware of the fact that a lot of these students either want to go to medical school or want to go to graduate school, whatever. ... That requires publications and some sort of output but I am very real with them that they are going to do a lot of work on this, and it just might not see the light of day because people don’t want it to see the light of day, not because I’m not going to try. But even apart from that, even if it does see a journal somewhere, the process is going to be painfully slow and you’re not going to see immediate outcomes. And that’s hard for people.” -P11*

There were also examples students shared of excellent supervisory experiences in which their supervisor helped support them and ensured they had a community of people to lean on.

*“I know it was a lot of really tough things, but the reason why I say I was lucky is I had really great support when going through this conflicting time because ... I was lucky enough to have my supervisor at the time to really be my advocate and was really transparent with me with all these issues that were happening ... She was always open to be an ear and a place to vent but she actually connected me with individuals who addressed these concerns and who are [redacted] and who have done this kind of work for years to*

*communicate with me and where I can also address my concerns and that opened my eyes that a lot of those red flags that I initially had that I was overthinking were completely valid. And if I didn't have those conversations, I would really be beating myself up for, 'Oh, my concerns are not valid, I should stay quiet, I should stay complacent'. But I think I was really lucky and having those connections and support through my supervisor.” -P08*

### **Concept 7: Learning from Existing Knowledge**

Participants expressed the importance of learning from the vast wealth of knowledge within social sciences, humanities, and Indigenous research methodologies that can help inform more ethical methods to study EDI-related research.

*“It's not unlike engaging in Indigenous research, right? It is walking into a community and saying, 'this is what I know, and this is what I can offer'. What would you like? If you would like anything, because sometimes they don't want anything. It's like, 'We don't have time for this. This doesn't work for us. Come back later.’” -P10*

Participants encouraged researchers to draw on established practices and theories in other fields, avoiding the pitfalls of reinventing the wheel and ensuring that research builds on a solid foundation of existing knowledge and experience and crediting this previous work.

*“It feels like the health sciences have ‘discovered’ EDI in the last few years, especially since 2020. Sure, there’s always been people who’ve been really doing great work in this area, but I think like as the sort of the mainstream researchers in the health sciences this is kind of a new thing. As it’s gotten trendy and new scholars are jumping into it, they aren’t always engaging with the requisite care, sensitivity, or for the right motives or even with the right background preparation. But for me, the social sciences and humanities have been thinking about these ideas for a long, long time and if you have done training in sociology or anthropology or philosophy, these ideas have always been part of it and have always been part of the sort of the core canon of knowledge. I think when we look back to the health sciences researchers who have been doing this for a long time and doing this work well, we see that social scientific or humanities interest in the theories and knowledges they are bringing to their health sciences research.” -P07*

Along a similar vein, participants also stressed the importance of providing recognition for all the researchers that have come before themselves by providing appropriate credit and avoiding the narrative that EDI-related research is a new and emerging area in the health sciences.

### **Concept 8: Changing Reward / Incentive Structures**



A need for a shift in the reward and incentive structures within academia to value diverse forms of dissemination and community-engaged research was highlighted by participants. Participants discussed challenging traditional reward structures of productivity currently measured by publishing output, and instead advocating for varied dissemination methods that prioritize community-driven, action-oriented studies.

*“I need to find ways to get involved and to insulate in that load and to advance the work. And then the subsequent challenge to that is that I’m also cautious to not do that in a way that sets me up for personal benefit. I think it’s weird, for helping create a more prosocial environment, that I think that I should be rewarded in some way, and it strikes me that’s the minimum of being a good citizen, not an exemplary activity. But the university is an individual place and not necessarily an actively interdependent place so there’s a tension there about accruing the academic capital along the way, which I try very hard not to.” -P16*

Participants felt that future EDI-related research studies should focus on effecting change rather than on identifying problems, avoiding the trauma of re-identifying known issues without improvements. This would acknowledge and incentivize the importance of translational work, moving beyond identifying problems to implementing solutions.

*“When you are going to a community, who is vulnerable, who’s a population that maybe has been overstudied, or who has had bad experiences with the health care system, with the research system, to try to speak to those issues when you’re recruiting and try to develop a relationship such that there would be more trust there. That you’re not just coming into the community and you’re going to leave and nothing’s going to change. ... I think that’s important, when you’re working with these populations to not just promise, but then deliver on that.”-P18*

### **Concept 9: Translational Work: Community-Driven Research**

Participants wanted to see more knowledge translation but felt this was often incompatible with the timeline and funding on most grants and required an additional team and expertise strictly focused on how to translate the results to positively impact the community. Participants viewed knowledge translation plans as a requirement of ethical community-based research and the institution should have all researchers include this when applying for ethics approval, funding, or even drafting a publication.

*“And then I think the other thing is, related to funding that people need to consider is, if you truly want to do this work and do it well then you need translation and that is extremely expensive. Both translation to hold the groups and to have those key conversations, but also whatever comes out of it also needs to be translated back. Because you want to be doing that*

*knowledge mobilization piece and be giving information back to the [redacted] and that needs to be done in multiple languages.” -P13*

*“So, I started building a different kind of team to do knowledge translation on the first project, integrated knowledge translation, which would allow people to move in between the two projects as they see fit. And then a bigger issue is that it’s really hard to find agencies that will fund knowledge translation work. Like it’s getting easier. [Redacted] has some special pockets for it, all requiring matching funding, which can be hard to come by. So, they are in some ways not an option. And then [redacted] is interested in matching. But they’re also really competitive. But that’s it, like, I don’t know anyone else who really wants knowledge translation work. So, funding that as a specific aim is easier now than it used to be, but it’s not easy.” -P12*

### **Concept 10: Methodological Guidelines**

Participants emphasized the importance of developing guidelines for studies involving equity-deserving communities, a resource they advocated for students, faculty, and staff alike. These guidelines should promote the use of mixed methods and qualitative approaches to effectively capture the complexities of applied health research. While these methods may not always be considered the “gold standard” in scientific research, many participants argued that incorporating methods from various disciplines is crucial to avoid overlooking critical considerations and assuming understanding of participants’ concerns,

which could perpetuate inequities. Participants underscored the need to shift the culture within health sciences by challenging the notion that quantitative research alone is objective and best practice. Studies using non-quantitative methodologies should be equally valued and integrated into practice.

*“If there’s a heavy emphasis on qualitative work, it’s seen as softer, not as empirically robust, not as meaningful. I think the work that I’d like to do that I have had the most meaning from tends to take longer because it entails building trust and relationships. Like real relationships with folks who have had challenging experiences and so in a system that privileges productivity and efficiency and always wants more for less.” -P17*

Participants noted that methodological inclusiveness facilitates deeper engagement with communities. This necessitates a reciprocal, long-term commitment to community partnerships, guided not by researchers’ interests, but more importantly, community needs.

*“And so, the communities that I’m working with have multiple priorities and having a researcher come in to do research is not always on their priority list. So, you have to work with the rhythm of the community. They’re often extremely low capacity and intimidated by having to participate in a study. ... I built in having a community liaison work with our team so that we wouldn’t*

*have to overburden health care practitioners working in the clinic, in the community and so forth. But there still are challenges and I worry that my methodology and engagement isn't as robust as it could have been.” -P14*

*“Ethical research practices are not just theoretical ideals but must be embedded in the fabric of project execution, emphasizing equitable community inclusion from start to finish. Involving community members in the research analysis piece is probably something that I've spent some time doing too, something that I call collaborative coding. It's when you're analyzing your data; it's not just done from the lens of the researcher but rather involving a person with lived experience or a community member in the actual analysis so you're doing that together and [redacted]. So, we work together to code, and I learned a lot from that and would have probably missed a lot if I hadn't worked with her in terms of the richness of the data and understanding what things mean within that context which I, not being ethnically part of that ingroup, I wouldn't have picked up on that.” -P20*

Participants emphasized the necessity of adopting a reciprocal, community-oriented approach for meaningful and impactful research. They cautioned new researchers against employing methods that uphold traditional, colonial understandings of science, where researchers merely enter a community, ask questions of interest, and then leave. Instead, researchers should be educated and encouraged to develop innovative, collaborative

designs in partnership with research teams and communities.

*“We have to consider even RCTs [randomized controlled trials]. They’re considered the gold standard and rightfully so; they give quality evidence but it’s expensive. Is it feasible? Would it be palatable towards certain populations? Should we be carrying out RCTs in low-income countries knowing how much money they cost, right? Things like that. It would be great to do an RCT in a low-income country, but are we going to get the most representative data from that? And are we going to implement policies and interventions that would be helpful to these populations. So, I don’t know, we have to really examine circumstances and think more critically and think outside of the box in terms of the type of methods that we’re wanting to pursue within certain research projects.” -P08*

*“And so, I think a lot of times researchers, scientific researchers, particularly, come to their scientific studies prioritizing ideas like objectivity, and a need to be objective, like, I’m describing the real facts of reality. And that aspiration to objectivity tends to make it hard to see the ways in which the operations of human society means that nothing in science is actually that objective. For me, I think that bringing an equity lens into health research is important for ensuring that we actually account for the realities of people’s lives. And the realities of people’s lives have a lot of diversity and a lot of*

*heterogeneity and a lot of, power and privilege and oppression and marginalization. And if we aren't alert to that in the ways that we undertake health research, there's very real danger of perpetuating those.”-P19*

Participants discussed that guidelines that have been developed for research with Indigenous communities could possibly be applied and used as the foundation for broader guidelines on how to conduct EDI-related research with other equity-deserving communities.

### **Concept 11: Integrating EDI into Education Systems**

Incorporating EDI considerations and methodologies into educational systems was seen as critically important to educate the next generation of health researchers.

*“So, I think one of the big challenges that we have in health care is equity and, you know, making sure that our workforce is ready to serve the needs of all of the patients they might see, which is obviously very diverse because our society is very diverse. And also, thinking about equity in terms of the experiences of health care providers as they’re moving through the educational system. So, it’s integrated in the sense that it’s something that I think about all the time in the context of education.” -P01*

Participants expressed a desire to incorporate inclusive and representative recruitment and sampling considerations into research courses. They highlighted gaps in training regarding community-based participatory research, co-design models, and the underrepresentation of qualitative and mixed methodologies in undergraduate programs. These methods are typically introduced at the graduate level or higher, limiting early exposure for students.

Participants emphasized the need to expand undergraduate and graduate curricula to include these critical concepts and methods. They underscored the importance of teaching skills beyond traditional health research approaches like RCTs and observational studies. Additionally, participants noted a lack of emphasis on building community partnerships, advisory councils, and equitable collaboration, essential research skills currently absent from many undergraduate and graduate courses alike.

*“I think if my understanding of how patients should be co-designing research was better, we could probably better convince them. I feel like the training is lacking in that. We know that we’re supposed to do it, but not how. ... I don’t know of any classes at McMaster in graduate studies that teach you about patient engagement in research. Like there should be a whole class on that in graduate studies and it should be something that people are ... specializing in.” -P04*



### **Concept 12: Brave Spaces**

Participants emphasized the critical need for accessible and judgment-free spaces to discuss their experiences with conducting EDI-related research. They noted a current lack of such spaces, which are essential for creating an environment where researchers can safely grow and challenge their perspectives. These spaces would not only facilitate open dialogue but also provide students and early-career researchers with opportunities to connect with peers, potential supervisors, and mentors. Such interactions are crucial for guidance, learning, and building supportive networks. Acknowledging that mistakes are a natural part of learning and providing space for growth are essential for improving the quality of EDI-related research. This approach encourages people to pursue this challenging and often isolating type of research, which is vital for advancing future healthcare practices.

*“Find a community of people and I think this comes with having a supervisor that does this form of research, having people that actually do EDI research around you for just purely emotional support, is a big one. Because if you haven’t done EDI research, you don’t know the toll that it takes on you.” -*

*P11*

Researchers require access to brave spaces for discussions, both formally and informally, to cultivate expertise in EDI-related research. Participants emphasized the need for communities of practice across departments and faculties, enabling researchers at all

levels to learn from peers in varying roles within the institution. Entering these spaces requires fostering a culture of “calling people up” rather than out, encouraging environments that acknowledge mistakes, especially in language and research approaches related to EDI.

*“We are inundated with all kinds of information on these topics. You can search for any kind of video or resource. You can buy books. Okay, you can go online and order any kind of book to teach you about the history of anything. It’s all out there to be had so I don’t, personally, I would not recommend education per se. I would not recommend continuing to develop modules on why it’s important to learn about EDI. I think what we need is just space to talk and work these things out for ourselves, like not by ourselves, but like what does it mean for me and how does it affect you?... We don’t make it possible to have those conversations like with openness and humility and stuff, so I think that’s just what we need. We just need some safe spaces that are always accessible, you know, not like a workshop that you could sign up for in the faculty development program where you might journal about certain things. But actually, talking to other people to hear their stories.”-*

*P02*

## **CHAPTER 4: DISCUSSION**

This qualitative descriptive study explored how health sciences researchers incorporate principles of EDI into their research practices. It also examined their motivations for pursuing this type of research, the challenges they have faced, and the resources and advice they felt were important for improving research quality and better supporting researchers in the health sciences. To gather these insights, semi-structured interviews were conducted with health sciences researchers who self-identified as conducting EDI-related research or using an EDI lens within their work. These interviews were transcribed and analyzed using conventional content analysis, resulting in five categories and 42 concepts across the dataset.

Participants included students, staff, and faculty, providing a diverse range of experiences and perspectives. These varied viewpoints highlighted the similarities and differences in challenges faced at different stages in a researcher's career, which heavily influenced their ability to incorporate EDI principles into their research. For example, students often possessed more expertise or lived experiences but were also more likely to experience tokenism, leading to emotional burdens. In contrast, senior faculty and staff struggled more with the evolving terminology and landscape and capacity issues as their research training did not include how to effectively integrate EDI considerations.

Recommendations for improvement focused on enhancing both individual and institutional support. This dual approach is essential to ensure researchers feel a sense of ethical responsibility and emotional support incentivized by institutions who must

prioritize slower, more thoughtful research practices over quantitative metrics such as publication counts.

#### **4.1 Addressing Challenges in EDI-Related Research: Recognizing and Using Existing Resources**

Many participants identified advice and resources that directly addressed the challenges they have encountered in EDI-related research. They acknowledged some EDI-related research conducted in the health sciences but more often they recognized studies in other disciplines that needed to be better used. This included research guidelines, guidance for supervisors, frameworks for research methods and topics, and resources that help researchers recognize their positionality and engage in critical reflexivity. Acknowledging and crediting this foundational work is important for advancing EDI-related research practices.

Interestingly, several participants noted that integrating EDI has recently become a priority in their research practice. They emphasized the need for resources that support this transition. Researchers may struggle to access the resources that already exist due to time or capacity constraints, as EDI work is often an additional responsibility on top of their other commitments.

The challenges researchers face in conducting EDI-related research are multifaceted. Resistance and opposition from review boards, colleagues, and leaders within the institution often slow the approval process for EDI studies, which are then rushed and often undervalued by funding bodies and journals. This devaluation can stem from a lack of alignment with traditional research processes. The deeply rooted inequities

in academia and the healthcare system are well-known, and every participant in this study could list a myriad of issues within them. However, the advice and resources that researchers suggested were particularly interesting because most of them already exist. One resource that participants wanted is a compendium of resources related to “best practices for EDI work” to help them ethically approach their research. The Declaration on Research Assessment (DORA), for example, has been around for over a decade. DORA was developed in 2012 as part of the Annual Meeting of the American Society for Cell Biology, serving as a compendium of resources aimed at improving equity and addressing structural inequalities in academia by supporting best practices in research assessment (“Home-The Declaration on Research Assessment”, 2024). DORA is not just for individual researchers to access resources and tools that promote equity in their practice; it also provides metrics and tools that institutions or scholarly organizations can use to create more equitable policies for hiring, promotion, and funding (“Home-The Declaration on Research Assessment”, 2024).

Why is it that some researchers are unaware of the work already done? Is this a capacity issue where researchers do not have time? Is it because many of these resources are spread across different disciplines, and researchers in health sciences may be unsure how to apply them? Is there a lack of educational background in these theories and frameworks, making the resources challenging to apply? Or perhaps researchers do not know which resources to trust? Whatever the reason, there is an urgent need to make these resources accessible and to require researchers to engage with them. This could involve providing time and training to become familiar with the relevant literature and

engaging in discussions about these topics. Ensuring that researchers have the capacity and support to use these resources effectively is crucial for advancing EDI-related research practices.

#### **4.2 Defining EDI-Related Research**

EDI-related research within the health sciences is characterized by its complexity and broad scope, making it challenging for participants to clearly define. In this study researchers could recognize experts in EDI and describe how they integrate EDI considerations into areas of their research career, including their methodologies, topics, research environments, and the institutional environment in which they work. However, no participant in this study felt comfortable self-identifying as an expert in EDI-related research. This hesitancy, in addition to some participants' direct resistance against the term "EDI researcher," suggests that labeling oneself this way is potentially inappropriate and misleading due to the broad range of methodologies and topics encompassed by the acronym "EDI." This represents an interesting conundrum. While EDI may not be its own field of research, researchers with varying degrees of expertise are pursuing topics directly related to this area. If no one wants to claim or clearly define expertise in EDI-related research, then this may give the impression that anyone is qualified to undertake it, increasing the potential for harm. The question is who qualifies as an expert and who gets to decide?

For students and early-career researchers, the hesitancy to label their work as EDI-related or even engage in conversations about it reflects not only an awareness of the inherent complexity but the fear and discomfort associated with it. Pursuing EDI-related

research poses potential career risks, as institutional bureaucracies often resist or oppose research that may identify deeply entrenched inequities. Since institutional approval is needed to conduct any research in either an academic or healthcare setting, addressing inequities within these systems is particularly challenging.

### **4.3 Psychological Implications for Conducting EDI-Related Research**

Shahram (2023) described the cognitive dissonance in studying health inequities within academia, as researchers work in systems that are oppressive and create inequities themselves. This contradiction is apparent when researchers engage with equity-deserving populations, often failing to ensure their research equitably benefits the communities involved. In a system where success is measured by productivity and EDI is becoming a requirement, this presents a challenge and tension between the institution's requirements and the responsibility to the communities studied. For example, the time required to build meaningful relationships with communities often exceeds that of most grants that would support EDI-related work. The integration of EDI principles in research is complex due to the lack of straightforward solutions often at odds with the traditional, linear approaches that dominate health research. When you become part of an institution you are inherently complicit in an environment that perpetuates inequities. This raises questions about the ethical responsibilities of researchers and the suitability of academic institutions as settings for conducting this work (Shahram, 2023).

As institutions continue to incentivize EDI-related research, this work is often offloaded onto less experienced researchers due to capacity issues. While students and early-career researchers feel they have been educated in a system that more readily

addresses equity issues, they often lack the research expertise or experience to lead these projects. Despite this, many students and early-career researchers, because of their lack of agency, find themselves continuously allocated this work. Participants described the emotional burden associated with this, including feelings of fear and discomfort when supervisors assumed that, due to their lived experiences with inequities or given their marginalized identities, they were naturally interested in contributing to EDI-related research studies. Many participants recounted feeling tokenized and pressured into triggering research projects, as declining these opportunities could be damaging to their careers. They also felt a sense of responsibility to ensure the safety of their communities and were asked to continuously make decisions on their behalf. These emotional burdens cause many early-career researchers, who are ethically dedicated to this work and recognize its importance, to ultimately decide against continuing with EDI-related research or to leave academia for their well-being. Meanwhile, researchers who do not feel an ethical imperative to ‘do no harm’ and who do not invest the necessary time and effort into continuous learning, often secure funding (McFarling, 2023). This trend continues to decrease the quality of research in the field.

This emotional burden is intensified, specifically feelings of loneliness and isolation, when early-career researchers and students find themselves in the position of having to educate their supervisors or the lead researcher on a project, adding to their academic responsibilities. Guidelines for graduate supervisors, supervisory committees, and programs outline the general responsibilities of a supervisor, such as providing feedback and creating a safe space for students to engage in their work (“Graduate



Studies”, n.d.). However, these guidelines do not address the complexities associated with EDI-related research and supervisors are not provided with support on how to implement the current guidelines. The current guidelines do not protect students from making decisions on behalf of a community, determining appropriate questions to ask others, or outline steps for students to protect their wellbeing when personally connected to a project. The current guidelines also do not provide direction for supervisors for the types of studies they are qualified to supervise. Participants in this study faced challenges in deciding whether it was appropriate to supervise students researching communities to which the supervisors did not belong. Currently, each supervisor makes this decision individually, whereas it should be established by institutional guidelines. Certain projects may not be appropriate for students (or anyone, for that matter) if the right support and resources are not available.

Institutions have a responsibility to create and enforce policies and offer training that supports researchers supervising students interested in conducting EDI-related research. They need to be advised on how to handle sensitive data and navigate complex power dynamics. They must critically assess and challenge power imbalances. When engaging participants on sensitive topics related to EDI, researchers must be highly intentional about their methodological choices. If the research involves asking participants to reveal personal and potentially traumatic experiences, it is the researcher’s duty to ensure these disclosures can be acted upon constructively. If not, such questions should be reconsidered to avoid unnecessary harm.

#### **4.4 Embedding EDI-Considerations into Education**

It is unclear what makes people think they are qualified to engage in EDI-related research without any prior research training or experience. One reason might be that lived experiences can provide a foundation for this type of work (Ibáñez-Carrasco et al., 2019). However, it is essential to support researchers or collaborators who have lived experience with the “emotional, instrumental, educational, and cultural/spiritual support” (Ibáñez-Carrasco et al., 2019, p. 4). It is also important to recognize that it is impossible to have the lived experience of every identity, and one person’s experience within a community is not the same as another’s. In EDI-related research, diverse lived experiences and research expertise are both needed, creating a challenge for those starting this research who may not have the vast network required to build an appropriately diverse research team (Hattery et al., 2022). There is also a lack of diversity in academia, especially higher within institutions where most of the funding and research opportunities are held, furthering this challenge (Hattery et al., 2022).

Regardless of their primary research focus, the shift towards embedding principles of EDI requires researchers to reflect on their motivations, ensuring their methods and teams are suitable for high-quality research. Researchers should incorporate critical reflexivity, a practice from the social sciences and that has yet to be widely adopted within the health sciences, to examine their roles within institutions and broader society, fostering greater social responsibility (Ng et al., 2019). Ng and colleagues (2019) define critical reflexivity as “recognizing one’s own position in the world both to better understand the limitations of one’s own knowing and to better appreciate the social realities of others” (p. 1124). A researcher engages in critical reflexivity by continuously

challenging their “epistemological assumptions (how we know what we know) and the social and discursive factors that influence conceptions of legitimate knowledge, social norms, and values” (Ng et al., 2019, p. 1124). Researchers must critically reflect on how their personal experiences and identity characteristics impact their work to help foster and maintain ethical relationships with participants and avoid misrepresenting their experiences.

Researchers can consider integrating positionality statements into their work, articulating their stance on their research both at the study’s outset and as part of result dissemination. Positionality statements, as defined by Yip (2023), detail how researchers perceive themselves and are perceived by others (p. 223). These statements encompass identity characteristics, personal experiences, beliefs, values, assumptions, worldview, and sociopolitical contexts—all factors influencing researchers’ interactions with participants, their research questions, and data interpretation (Yip, 2023, p. 223). Recognizing researchers’ perspectives and their associated limitations can identify crucial missing viewpoints to include in research teams. Institutions can foster reflexive practices by embedding education on critical reflexivity and positionality in research courses at both undergraduate and graduate levels. Normalizing positionality statements in ethics, grant applications, and journal articles can further support these efforts. However, it is important to recognize that uncritically mandating positionality statements could lead to performative compliance, where researchers strategically position themselves to secure approval or funding, without genuinely addressing gaps in perspectives. Such an

approach risks failing to foster meaningful improvements in team representation or researchers' community interactions, ultimately hindering real change.

A critical aspect of EDI-related research often compromised by perverse incentives within academia is knowledge translation. Future EDI-related research needs to better integrate knowledge translation throughout the entire research process to foster more equitable engagement and beneficial outcomes for equity-deserving communities. Integrative knowledge translation emphasizes engagement with communities throughout the entire research process, including the initial identification of research topics. This approach contrasts with the current standard of knowledge translation, which often results in journal articles written by academics for other academics, offering little benefit to the communities studied. Both researchers and institutions are responsible for ensuring knowledge translation is prioritized.

Despite good intentions, researchers are often constrained by institutional processes, limiting time for dissemination and knowledge translation. This reduces the potential benefit to communities. Researchers, especially students and early-career researchers, need to be taught innovative dissemination strategies to accessibly communicate their findings. Establishing effective and long-term partnerships with communities and organizations is crucial for developing appropriate dissemination methods through collaboration. Iterative feedback mechanisms within communities will help researchers focus on what is most relevant and tailor their dissemination strategies accordingly. By embracing varied approaches to dissemination and learning from the successes of other disciplines, researchers can enhance the impact and relevance of their

work. Institutions should ensure that knowledge translation plans are included in studies, aiming for tangible benefits for the community, not just academic publications.

#### **4.5 The Role of Scientific Gatekeepers in Promoting EDI**

Review processes within academia, including ethics approval, peer review, and grant review, often present additional obstacles for EDI-related studies. Researchers discussed frequently educating review boards on the necessity and methodology of their proposals. The lack of education among reviewers can compromise critical aspects of EDI research, such as time and resources for recruitment, collaboration, and knowledge translation allocated for a grant. Participants commonly noted how surprised they were by the low-quality studies conducted by researchers lacking experience and expertise that would get approved faster than experienced researchers using non-traditional methods, appropriate terminology, and equitably involving participants in the work. For example, participants described studies that used the term “anti-racism” or “colonialism” as taking longer to pass through ethics versus studies that did not recognize historical inequities impacting their research question or collaborate with the communities they wanted to study. Recognizing that this research falls disproportionately on equity-deserving researchers, the psychological implications of continually convincing institutional bodies that you are best suited to study your own community or being told that you are not representative enough furthers inequities. This may speak to the lack of representation and expertise in EDI among those review boards that seem uncomfortable with studies pointing to a truth about themselves and their environment that they may not want to face.

To a large extent, funding bodies and ethics boards control the quality of scientific research and motivate the topics researchers pursue. These bodies need to incentivize researchers to think beyond sex and gender in their studies. While these are important identity characteristics, many other aspects of people’s identities impact their experiences with the healthcare system and are not given equal opportunities and resources for study. Since only sex and gender considerations are mandated in Tri-Council grant applications, these identity characteristics are being prioritized over others. Embedding this one identity consideration for researchers incentivizes the inclusion of these identities when they may not be the most appropriate or the researcher might not be educated on how to include them appropriately. Participants in this study emphasized the need for improved education on how to effectively study experiences of intersectionality within research. With many identity characteristics to consider, researchers face challenges in deciding which variables are most relevant to their research questions and in selecting methods that align with the topic. Funding applications should require researchers to consider all relevant identity characteristics.

#### **4.6 An Interdisciplinary Approach to EDI**

A vast array of resources exists to guide the conduct of equitable research, reflecting the extensive scope of “EDI,” covering diverse topics and methodologies tailored to various communities. However, effective practices in one context may not necessarily translate to another, necessitating researchers to commit to lifelong learning and seek knowledge across different disciplines. This interdisciplinary approach is crucial because, as discussed by participants, there is often a tendency to “reinvent the wheel.”

This leads to burnout, capacity issues, and duplicative work that fails to recognize or credit existing research, which can be disheartening for researchers, especially those from equity-deserving communities that have been silenced and ignored (McFarling, 2023).

Improved collaboration across disciplines will enhance research quality and impact. For example, Indigenous research approaches offer valuable insights and methodologies based on principles of equitable partnerships and authentic participant engagement (Rankin et al., 2023), holding researchers accountable for the impact of their decisions on both people and the environment (Drawson et al., 2017). The sentiment “nothing about us without us” echoes participants’ suggestion for more guidance on participatory, community-based research designs. Integrating these approaches into undergraduate and graduate-level education is important, as they should be standard skills for all researchers in the health sciences (Drawson et al., 2017).

The future of EDI-related research lies in embedding these considerations into all educational levels within the institution. This includes incorporating EDI principles into promotion and hiring processes, evaluating how researchers integrate EDI into their research and teaching, and rewarding those who contribute to equitable research and institutional environments. By fostering an environment that prioritizes these values, institutions can support the development of high-quality, impactful EDI-related research that truly advances EDI in the health sciences.

#### **4.7 Limitations**

In our efforts to ensure appropriate diversity without our sample, we recruited researchers with a range of lived experiences, identities, research types, and career stages.

Despite these efforts, our sample many not have reflected all possible researcher identities. For example, our sample predominantly mirrored broader patterns around engagement in EDI-related work, where women were more likely to participate in the study than men.

We relied on researchers' self-identification as conducting EDI-related research, which introduced inherent limitations related to self-reporting. Participants may have chosen to present certain experiences over others that may be seen as less favorable. Despite many participants courageously discussing past mistakes, sensitive question may have inhibited the full expression of experiences for some participants.

Some challenges also arose from the position and identity of the lead researcher. As someone benefiting from certain identity privileges, interactions with participants holding different characteristics were not always conducive to open dialogue. This seemed to mainly be the case with researchers who chose not to participate in the study, not those who did. However, concerns about “cancel culture” and repercussions for discussing sensitive topics may have led some participants to withhold views or experiences, potentially limiting our understanding of researchers' challenges. The researcher's student status further shaped the scope of questions and practical implications of findings.

Recruitment proved challenging, especially among students wary of political implications and career risks associated with the topic. Many expressed negative emotions such as discomfort and fear, exacerbated by interview timing—conducted at the end of the semester, likely impacting engagement in sensitive discussions. Others



explicitly chose not to participate or simply did not respond to the study invitation.

Lastly, the findings from this study are from a single academic institution. While we believe that most of the findings are likely transferable to other contexts, it is possible that there are specific findings that would differ across institutions.

#### **4.8 Key Take-Aways**

Participants in this study strongly advocated for the creation of more “brave spaces” conducive to discussing EDI issues (Arao & Clemens, 2013). These spaces could be structured as communities of practice involving students, staff, and faculty researchers across disciplines and positions within institutions. Without such spaces, researchers often face the challenge of independently educating themselves and seeking out experienced mentors, undermining the essential community and emotional support needed for this work (Arao & Clemens, 2013).

To support new researchers navigating complex EDI issues, participants suggested establishing formal mentorship programs. Pairing less experienced researchers with seasoned mentors well-versed in EDI principles can build a supportive network and provide crucial guidance. Matching researchers who share similar identities and experiences can be particularly beneficial, as studies indicate the difficulty equity-deserving community members face in finding mentorship within institutions (Cabrera-Muffly, 2021). Recognizing mentorship as service work within research or simply part of good research, can help address capacity challenges and incentivize institutions to support improved EDI-related research initiatives. If insufficient mentors are available for pairing, institutions should urgently reassess their hiring practices to ensure representation.

Implementing robust evaluation mechanisms is essential to assess the impact of EDI-related research. This includes setting clear guidelines for community involvement, ensuring diverse expertise and lived experiences within research teams, and making research and educational materials accessible to everyone. Grant and ethics review boards are crucial in upholding these guidelines and ensuring ethical standards.

Researchers must make deliberate methodological choices when engaging participants on sensitive EDI topics to minimize harm and ensure a respectful research process. Ethical considerations, such as obtaining informed consent, maintaining confidentiality, and addressing potential emotional impacts, are paramount. Review processes should support rather than hinder EDI-related studies, with reviewers trained to understand the necessity and methodologies involved. Genuine commitment to EDI requires more than performative gestures; it necessitates meaningful support and understanding across all levels of research and education.

## **CHAPTER 5: CONCLUSION**

There is a diverse range of approaches to integrating EDI into health research, yet the lack of consensus among researchers on the requirements and attainment of expertise suggests that EDI is not yet recognized as a distinct field, at least not within the context of research. When conducting research that explores participants' experiences with EDI, particularly from a position of privilege, researchers must be acutely aware of the potential for harm. Careful consideration is essential in selecting research methods for such sensitive topics, acknowledging the responsibilities inherent in inviting participants to share experiences of inequities.

Researchers must also commit to acting meaningfully on the information shared by participants. It is unethical to request such disclosures without mechanisms in place to address the issues raised. While research frequently documents health inequities, there remains a considerable gap in developing and testing actionable solutions. Researchers should not only identify problems but also contribute to the creation and evaluation of potential solutions that directly address these inequities.

EDI should not be an afterthought or a mere checkbox during funding applications or ethics reviews. It must be the standard practice for all health sciences researchers, driven by the goal of improving people's lives through rigorous and inclusive health research. Ultimately, the term "EDI researcher" would become obsolete if all researchers inherently considered the impact of their work, guided by EDI principles.

The insights in this thesis, drawn from diverse experiences in health research, serve as a cautionary reminder: only engage in research with equity-deserving

communities if you are committed to and willing to be held accountable for ethical research practices. The current state of health research necessitates a fundamental re-evaluation of how EDI research is conceptualized, conducted, and valued. Moving forward, EDI research should aim for a paradigm shift where EDI considerations are more clearly integrated into education and institutional practices, ensuring that every researcher is equipped to address EDI as an essential element of their work. This transformation would foster an environment where diverse perspectives not only contribute but also drive research agendas. We envision a future where the term “EDI researcher” is redundant because every researcher inherently considers the broader impacts of their choices and research endeavors.

## References

- About DORA*. DORA. (2024, January 10). <https://sfdora.org/about-dora/>
- About - Faculty of Health Sciences*. (n.d.). <https://healthsci.mcmaster.ca/about-fhs/>
- Adams, T. E. (2017). Critical autoethnography, education, and a call for forgiveness. *International Journal of Multicultural Education*, 19(1), 79. <https://doi.org/10.18251/ijme.v19i1.1387>
- Anderson, L. (2006). Analytic autoethnography. *Journal of Contemporary Ethnography*, 35(4), 373–395. <https://doi.org/10.1177/0891241605280449>
- Arao, B., & Clemens, K. (2013). From safe spaces to brave spaces: A new way to frame dialogue around diversity and social justice. In *The Art of Effective Facilitation: Reflections from Social Justice Educators* (1st ed., pp. 135–150). Routledge.
- Ashlee, A. A., Zamora, B., & Karikari, S. N. (2017). We are woke: A collaborative critical autoethnography of three “womxn” of color graduate students in Higher Education. *International Journal of Multicultural Education*, 19(1), 89. <https://doi.org/10.18251/ijme.v19i1.1259>
- Atkins, S., Banerjee, A. T., Bachynski, K., Daftary, A., Desai, G., Gross, A., Hedt-Gauthier, B., Mendenhall, E., Meier, B. M., Nixon, S. A., Nolan, A., Palermo, T. M., Phelan, A., Pyzik, O., Roach, P., Sangaramoorthy, T., Standley, C. J., Yamey, G., Abimbola, S., & Pai, M. (2021). Using the COVID-19 pandemic to reimagine global health teaching in high-income countries. *BMJ Global Health*, 6(4). <https://doi.org/10.1136/bmjgh-2021-005649>

- Bajos, N., Spire, A., Silberzan, L., Sireyjol, A., Jusot, F., Meyer, L., Franck, J.-E., & Warszawski, J. (2022). When lack of trust in the government and in scientists reinforces social inequalities in vaccination against COVID-19. *Frontiers in Public Health*, 10. <https://doi.org/10.3389/fpubh.2022.908152>
- Banerjee, A. T., Bandara, S., Senga, J., González-Domínguez, N., & Pai, M. (2023). Are we training our students to be White Saviours in global health? *The Lancet*, 402(10401), 520–521. [https://doi.org/10.1016/s0140-6736\(23\)01629-x](https://doi.org/10.1016/s0140-6736(23)01629-x)
- Bauer, G. R. (2014). Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine*, 110, 10–17. <https://doi.org/10.1016/j.socscimed.2014.03.022>
- Benach, J., Cash-Gibson, L., Rojas-Gualdrón, D. F., Padilla-Pozo, Á., Fernández-Gracia, J., & Eguíluz, V. M. (2022). Inequalities in COVID-19 inequalities research: Who had the capacity to respond? *PLOS ONE*, 17(5), 1–13. <https://doi.org/10.1371/journal.pone.0266132>
- Binagwaho, A., Ngarambe, B., & Mathewos, K. (2022). Eliminating the white supremacy mindset from global health education. *Annals of Global Health*, 88(1). <https://doi.org/10.5334/aogh.3578>
- Boulware, L. E., Corbie, G., Aguilar-Gaxiola, S., Wilkins, C. H., Ruiz, R., Vitale, A., & Egede, L. E. (2022). Combating structural inequities—diversity, equity, and inclusion in clinical and translational research. *New England Journal of Medicine*, 386(3), 201–203. <https://doi.org/10.1056/nejmp2112233>

- Bourke, B. (2014). Positionality: Reflecting on the research process. *The Qualitative Report*. <https://doi.org/10.46743/2160-3715/2014.1026>
- Bouter, L. M. (2015). Commentary: Perverse incentives or rotten apples? *Accountability in Research*, 22(3), 148–161. <https://doi.org/10.1080/08989621.2014.950253>
- Brock, C. H., Borti, A., Frahm, T., Howe, L., Khasilova, D., & Ventura-Kalen, K. (2017). Employing autoethnography to examine our diverse identities: Striving towards equitable and socially just stances in literacy teaching and research. *International Journal of Multicultural Education*, 19(1), 105. <https://doi.org/10.18251/ijme.v19i1.1258>
- Büyüm, A. M., Kenney, C., Koris, A., Mkumba, L., & Raveendran, Y. (2020). Decolonising global health: If not now, when? *BMJ Global Health*, 5(8), 1–4. <https://doi.org/10.1136/bmjgh-2020-003394>
- Cabrera-Muffly, C. (2021). Mentorship and sponsorship in a diverse population. *Otolaryngologic Clinics of North America*, 54(2), 449–456. <https://doi.org/10.1016/j.otc.2020.11.016>
- Carney, N. (2016). All lives matter, but so does race. *Humanity & Society*, 40(2), 180–199. <https://doi.org/10.1177/01605976166643868>
- Chang, H. (2016). *Autoethnography as method*. Routledge.
- Chang, H. (2016). Autoethnography in Health Research. *Qualitative Health Research*, 26(4), 443–451. <https://doi.org/10.1177/1049732315627432>

- Cooper, L. A., & Crews, D. C. (2020). COVID-19, racism, and the pursuit of health care and research worthy of trust. *Journal of Clinical Investigation*, 130(10), 5033–5035. <https://doi.org/10.1172/jci141562>
- Duarte, F. P. (2007). Using autoethnography in the scholarship of teaching and learning: Reflective practice from ‘The other side of the mirror’. *International Journal for the Scholarship of Teaching and Learning*, 1(2), 1–11. <https://doi.org/10.20429/ijstl.2007.010221>
- Edwards, M. A., & Roy, S. (2017). Academic research in the 21st century: Maintaining scientific Integrity in a climate of perverse incentives and hypercompetition. *Environmental Engineering Science*, 34(1), 51–61. <https://doi.org/10.1089/ees.2016.0223>
- Fuentes, M. A., Zelaya, D. G., & Madsen, J. W. (2020). Rethinking the course syllabus: Considerations for promoting equity, diversity, and inclusion. *Teaching of Psychology*, 48(1), 69–79. <https://doi.org/10.1177/0098628320959979>
- Garson, K., Lindstrom, G., & McLean, A. (2021). Learning at intercultural intersections: Towards equity, inclusion and reconciliation. *Journal of Intercultural Studies*, 42(3), 273–280. <https://doi.org/10.1080/07256868.2021.1930728>
- Gaventa, J., & Cornwall, A. (2015). *Power and knowledge*. In H. Bradbury (Ed.), *The Sage handbook of action research: Participative inquiry and practice* (3rd ed.). Thousand Oaks, CA: Sage.



*Graduate studies*. School of Graduate Studies - McMaster University. (n.d.).

<https://gs.mcmaster.ca/current-students/resources/graduate-supervision/#tab-content-supervisors>

Graham, L., Brown-Jeffy, S., Aronson, R., & Stephens, C. (2011). Critical race theory as theoretical framework and analysis tool for population health research. *Critical Public Health*, 21(1), 81–93. <https://doi.org/10.1080/09581596.2010.493173>

Government of Canada, C. I. of H. R. (2024, January 29). *Canadian Institutes of Health Research*. CIHR. <https://cihr-irsc.gc.ca/e/193.html>

Government of Canada, C. I. of H. R. (2023, November 24). *What is health research?*. CIHR. <https://cihr-irsc.gc.ca/e/53146.html>

Hattery, A. J., Smith, E., Magnuson, S., Monterrosa, A., Kafonek, K., Shaw, C., Mhonde, R. D., & Kanewske, L. C. (2022). Diversity, equity, and inclusion in research teams: The good, the bad, and the ugly. *Race and Justice*, 12(3), 505–530. <https://doi.org/10.1177/21533687221087373>

Heidari, S., Babor, T. F., De Castro, P., Tort, S., & Curno, M. (2016). Sex and gender equity in research: Rationale for the sager guidelines and recommended use. *Research Integrity and Peer Review*, 1(1), 1–9. <https://doi.org/10.1186/s41073-016-0007-6>

*Home | Black Health Equity Working Group*. Black Health Equity Working Group. (2021, May 31). <https://blackhealthequity.ca/>

*Home-The Declaration on Research Assessment*. DORA. (2024, February 2). <https://sfdora.org/>

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis.

*Qualitative Health Research*, 15(9), 1277–1288.

<https://doi.org/10.1177/1049732305276687>

Ibáñez-Carrasco, F., Watson, J. R., & Tavares, J. (2019). Supporting peer researchers:

Recommendations from our lived experience/expertise in community-based research in Canada. *Harm Reduction Journal*, 16(1), 1–5.

<https://doi.org/10.1186/s12954-019-0322-6>

Johnson, J. L., Greaves, L., & Repta, R. (2009). Better science with sex and gender:

Facilitating the use of a sex and gender-based analysis in health research.

*International Journal for Equity in Health*, 8(1). [https://doi.org/10.1186/1475-](https://doi.org/10.1186/1475-9276-8-14)

[9276-8-14](https://doi.org/10.1186/1475-9276-8-14)

Kohl, K., Hipple, K., Huang, D. F., Mesrobian, G., & White, E. (2022). *Driving justice, equity, diversity, and inclusion*. Auerbach Publishers, Incorporated.

Lett, E., Adekunle, D., McMurray, P., Asabor, E. N., Irie, W., Simon, M. A., Hardeman,

R., & McLemore, M. R. (2022). Health equity tourism: Ravaging the justice landscape. *Journal of Medical Systems*, 46(3), 1–6.

<https://doi.org/10.1007/s10916-022-01803-5>

Levine, R. B., Ayyala, M. S., Skarupski, K. A., Bodurtha, J. N., Fernández, M. G., Ishii,

L. E., & Fivush, B. (2020). “It’s a little different for men”—sponsorship and gender in academic medicine: A qualitative study. *Journal of General Internal Medicine*,

36(1), 1–8. <https://doi.org/10.1007/s11606-020-05956-2>

- Lofters, A., Prakash, V., Devotta, K., & Vahabi, M. (2023). The potential benefits of “community champions” in the healthcare system. *Healthcare Management Forum*, 36(6), 382–387. <https://doi.org/10.1177/08404704231179911>
- Marx, S., Pennington, J. L., & Chang, H. (2017). Critical autoethnography in pursuit of educational equity: Introduction to the IJME special issue. *International Journal of Multicultural Education*, 19(1), 1–6. <https://doi.org/10.18251/ijme.v19i1.1393>
- Marx, S. (2017). Intercultural manifestations of racial, language, and class privilege in schooling: An autoethnographic tale. *International Journal of Multicultural Education*, 19(1), 24–40. <https://doi.org/10.18251/ijme.v19i1.1270>
- Merriam, S. B., Johnson-Bailey, J., Lee, M.-Y., Kee, Y., Ntseane, G., & Muhamad, M. (2001). Power and positionality: Negotiating insider/outsider status within and across cultures. *International Journal of Lifelong Education*, 20(5), 405–416. <https://doi.org/10.1080/02601370110059537>
- McFarling, U. L. (2023, July 31). “Health equity tourists”: How white scholars are colonizing research on Health Disparities. STAT. <https://www.statnews.com/2021/09/23/health-equity-tourists-white-scholars-colonizing-health-disparities-research/>
- McGrail, K., Morgan, J., & Siddiqi, A. (2022). Looking back and moving forward: Addressing health inequities after COVID-19. *The Lancet Regional Health - Americas*, 9, 1–7. <https://doi.org/10.1016/j.lana.2022.100232>
- Medford, K. (2006). Caught with a fake ID. *Qualitative Inquiry*, 12(5), 853–864. <https://doi.org/10.1177/1077800406288618>

- Morrison, C., & Dearden, A. (2013). Beyond tokenistic participation: Using representational artefacts to enable meaningful public participation in health service design. *Health Policy, 112*(3), 179–186.  
<https://doi.org/10.1016/j.healthpol.2013.05.008>
- Mugo, S., & Puplampu, K. P. (2022). Beyond tokenism and objectivity: Theoretical reflections on a transformative equity, diversity, and inclusion agenda for higher education in Canada. *SN Social Sciences, 2*(10), 1–17.  
<https://doi.org/10.1007/s43545-022-00509-2>
- Nana-Sinkam, P., Kraschnewski, J., Sacco, R., Chavez, J., Fouad, M., Gal, T., Auyoung, M., Namoos, A., Winn, R., Sheppard, V., Corbie-Smith, G., & Behar-Zusman, V. (2021). Health disparities and equity in the era of COVID-19. *Journal of Clinical and Translational Science, 5*(1), 1–31. <https://doi.org/10.1017/cts.2021.23>
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description – the poor cousin of health research? *BMC Medical Research Methodology, 9*(1). <https://doi.org/10.1186/1471-2288-9-52>
- Ng, S. L., Wright, S. R., & Kuper, A. (2019). The divergence and convergence of critical reflection and critical reflexivity: Implications for health professions education. *Academic Medicine, 94*(8), 1122–1128.  
<https://doi.org/10.1097/acm.0000000000002724>
- Nixon, S. A. (2019). The coin model of privilege and critical allyship: Implications for health. *BMC Public Health, 19*(1), 1–13. <https://doi.org/10.1186/s12889-019-7884-9>

Nweke, N., Isom, J., & Fashaw-Walters, S. (2022). Health equity tourism: Reckoning with medical mistrust. *Journal of Medical Systems*, 46(5), 1–3.

<https://doi.org/10.1007/s10916-022-01812-4>

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2022). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 45(3), 241–251. <https://doi.org/10.1080/0142159x.2022.2057287>

Perez, R. J., Robbins, C. K., Harris, L. W., Jr., & Montgomery, C. (2020). Exploring graduate students' socialization to equity, diversity, and inclusion. *Journal of Diversity in Higher Education*, 13(2), 133–145.

<https://doi.org/10.1037/dhe0000115>

Rankin, A., Baumann, A., Downey, B., Valaitis, R., Montour, A., Mandy, P., & Bourque Bearskin, D. (2023). Two-eyed seeing application in research analysis: An integrative review. *International Journal of Qualitative Methods*, 22, 1–27.

<https://doi.org/10.1177/16094069231197342>

Raphael, D. (2024). *Health and illness* (3rd ed.). Fernwood Publishing.

Reed-Danahay, D. (2017). Bourdieu and critical autoethnography: Implications for research, writing, and teaching. *International Journal of Multicultural Education*, 19(1), 144–154. <https://doi.org/10.18251/ijme.v19i1.1368>

Romsland, G. I., Milosavljevic, K. L., & Andreassen, T. A. (2019). Facilitating non-tokenistic user involvement in research. *Research Involvement and Engagement*, 5(1), 1–12. <https://doi.org/10.1186/s40900-019-0153-3>

- Ross, L. E., Pilling, M., Voronka, J., Pitt, K.-A., McLean, E., King, C., Shakya, Y., MacKinnon, K. R., Williams, C. C., Strike, C., & Guta, A. (2023). ‘I will play this tokenistic game, I just want something useful for my community’: Experiences of and resistance to harms of peer research. *Critical Public Health*, 33(5), 735–746. <https://doi.org/10.1080/09581596.2023.2268822>
- Ruzycki, S. M., & Ahmed, S. B. (2022). Equity, diversity and inclusion are foundational research skills. *Nature Human Behaviour*, 6(7), 910–912. <https://doi.org/10.1038/s41562-022-01406-7>
- Salas, R. G. (2017). Disrupting equilibrium: Working for equity and social justice in education for English learners. *International Journal of Multicultural Education*, 19(1), 7–23. <https://doi.org/10.18251/ijme.v19i1.1274>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340. [https://doi.org/10.1002/1098-240x\(200008\)23:4<334::aid-nur9>3.0.co;2-g](https://doi.org/10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g)
- Sandelowski, M. (2009). What’s in a name? qualitative description revisited. *Research in Nursing & Health*, 33(1), 77–84. <https://doi.org/10.1002/nur.20362>
- Shahram, S. Z. (2023). Five ways ‘health scholars’ are complicit in upholding health inequities, and how to stop. *International Journal for Equity in Health*, 22(1), 1–8. <https://doi.org/10.1186/s12939-022-01763-9>
- Stephan, P. (2012). Perverse incentives. *Nature*, 484(7392), 29–31. <https://doi.org/10.1038/484029a>

- Tajima, E. A. (2021). First, do no harm: From diversity and inclusion to equity and anti-racism in interpersonal violence research and scholarship. *Journal of Interpersonal Violence*, 36(11–12), 4953–4987. <https://doi.org/10.1177/08862605211012999>
- Tamtik, M., & Guenter, M. (2020). Policy analysis of equity, diversity and inclusion strategies in Canadian universities – how far have we come? *Canadian Journal of Higher Education*, 49(3), 41–56. <https://doi.org/10.7202/1066634ar>
- The First Nations Principles of OCAP®*. The First Nations Information Governance Centre. (2023, July 25). <https://fnigc.ca/ocap-training/>
- Thompson Burdine, J., Thorne, S., & Sandhu, G. (2020). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education*, 55(3), 336–343. <https://doi.org/10.1111/medu.14380>
- Tolich, M. (2010). A Critique of current practice: Ten foundational guidelines for autoethnographers. *Qualitative Health Research*, 20(12), 1599–1610. <https://doi.org/10.1177/1049732310376076>
- Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (2018). *Community-based participatory research for health: Advancing social and health equity* (3rd ed.). Jossey-Bass.
- Wood, C. A. (2017). My story of Sal: A critical self-reflective autoethnography revealing whiteness in the classroom. *International Journal of Multicultural Education*, 19(1), 41–59. <https://doi.org/10.18251/ijme.v19i1.1264>

Yearby, R. (2021). Reifying racism in the COVID-19 pandemic response. *The American Journal of Bioethics*, 21(3), 75–78.

<https://doi.org/10.1080/15265161.2020.1870773>

Yip, S. Y. (2023). Positionality and reflexivity: Negotiating insider-outsider positions within and across cultures. *International Journal of Research & Method in Education*, 47(3), 222–232. <https://doi.org/10.1080/1743727x.2023.2266375>



## **Appendix 1: Interview Guide**

1. Please tell me a little bit about your role (e.g., faculty, staff, student, etc.).
2. The Canadian Institutes of Health Research classify health research into four distinct categories: Clinical, biomedical, health services, and population health research.  
Could you specify which of these pillars aligns with your research focus?
3. How is EDI integrated into your research?
4. How would you describe your level of expertise in conducting EDI-related research?
5. When did you first begin integrating EDI into your research? What motivated you?
6. Has the way you approach your research changed over time? If so, how?
7. What have been the challenges?
8. What keeps you motivated to continue?

Please pick an EDI-related research project that stands out to you. The experience of conducting this research can be positive, negative, or neutral—it is up to you.

With this project in mind:

9. Can you please provide some context for this project.
10. How did you come up with your research question/s?
11. What was the community or communities you studied?
12. How did you engage with this / these community / communities? What was this experience like for you?
13. What were the biggest challenges in conducting this research?

14. If you are comfortable sharing, what are some of your identities that you feel are salient to your research topic, methodology, and experience conducting research?
15. What advice do you have for future researchers / other academics wanting to do EDI-related research?
16. What questions do you still have about doing EDI-related research?
17. If applicable, what advice and/or resources would have been helpful to have when you first started conducting EDI-related research?
18. What resources would be helpful to you now?

## **Appendix 2: AM’s Positionality Statement**

In any research but qualitative research especially, it is essential to acknowledge the positionality of the researchers involved in the study to ensure transparency and reflexivity in the research process (Olmos-Vega et al., 2022). In this context, AM's positionality is particularly relevant due to their involvement in the data analysis. AM’s positionality statement is as follows:

*"I identify as a white Hispanic Canadian and am a disabled transmasculine undergraduate student. I recognize that I am a relatively inexperienced student and still learning and will have to rely on and ask questions to my mentors throughout this process. Prior to starting this research, I have done a literature review on EDI integration in academia and research, best practices, the impacts of EDI research, and my institution’s listless policies. EDI research results and outcomes tend to affect me personally through institutional policies and attitudes, so I tend to be more critical of people who undertake this and if they’re doing it for the right reasons. I will mostly be partaking in transcript analysis on this project. My undergraduate degree is in psychology, so I have had a lot of formal education on biases and their cognitive origins, psychological and neurological syndromes experienced by some people influenced by EDI research, as well as many psychological theories relevant to EDI and motivation. I will have to be conscious in not jumping to conclusions and allowing interviewees to expand further without judgment, and I hope some of the interviews inspire more faith in me towards professors and researchers, especially since I hope to be a health science graduate student in the near future."*

## **Appendix 3: Overview of Categories and Concepts**

### **Category 1: How EDI is Taken up in Health Research**

Concepts:

1. Research Methods
2. Research Topics
3. Research Environment
4. Institutional Environment

### **Category 2: Perceived Expertise in EDI-Related Research**

Concepts:

- No Clear Standard
- Hesitance to Label Oneself
- The Role of Lived Experience

### **Category 3: Motivations to Conduct EDI-Related Research**

Concepts:

- Personal Experiences of Being Part of an Equity-Deserving Group
- Need for More Data
- Desire to Create Change
- Early-Career Researchers
- Broader Sociopolitical Landscape

- Mentorship
- Student-Driven
- Education
- Mandated
- Paying Privilege Forward
- Trending Topic

#### **4. Challenges Encountered in Conducting EDI-Related Research**

Concepts:

- Pressure to Produce
- Perverse Incentives
- Lack of Representation
- Capacity Issues
- Opposition
- Quickly Evolving Terminology and Landscape
- Supervisory Decisions
- Community Involvement
- Intersectionality
- Tokenism
- Emotional Burden
- Resistance

### **Category 5: Advice and Resources**

Concepts:

- Accountability
- Reflexivity and Criticality in Research
- Team-Based Approach to Research
- Identities Beyond Sex and Gender
- Enhancing Institutional Processes
- Guidelines for Supervisors
- Learning from Existing Knowledge
- Changing Reward/Incentive Structures
- Translational Work: Community-Driven Research
- Methodological Guidelines
- Integrating EDI into Education Systems
- Brave Spaces