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FULL-LENGTH ARTICLES

Our Journey of Co-Designing a Suicide Stigma Reduction Program for Postsecondary Students: Highlighting the Value of Lived Expert Collaboration in Program Development

Brittany L. Lindsay[1], Emily Bernier[1], Arianna M. Gibson[2], Monique Chen[1], Gemma Reynolds[1], Alexis Berends[1], Faith Belarmino[1], Caden Nelson[1], Rigel Tormon[1], Andrew C.H Szeto[1]

[1] University of Calgary, [2] University of Saskatchewan

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The stigma towards suicide is still very prevalent in our communities. With the increase in reported suicide thoughts and behaviours in postsecondary students, stigma reduction interventions are an important area of mental health promotion. When creating any type of mental health program, people with lived experience (PWLE) should be included in the process. In this article, we share our approach to co-designing a suicide stigma reduction program for postsecondary students, highlighting the advisory group experience within this methodology. The relational approach to recruitment is described, as well as an introduction to each advisory group member and their motivations and experiences with participating in research. We discuss how the advisory group functions, including an outline of our group norms and values, decision-making processes, challenges we experienced, and lessons learned. We end with five recommendations for researchers interested in co-designing programs with PWLE: 1) Be Informed, but Act with Humility; 2) Make Meaningful Connections Early and Often; 3) Strive for Diversity and Representation; 4) Value ALL Forms of Knowledge; 5) Promote Self-Care and Self-Reflection. This article shares broad, personal stories of suicide stigma, but avoids specific details regarding suicide thoughts and behaviours.

A Note Before We Begin

The primary objective of this article is to highlight a methodology of program development that highlights the voices of postsecondary students with lived experience of suicide thoughts and behaviours and other mental health challenges in academia. As the lead researcher on the overarching research project, I (Brittany) intend to publish on the research findings of this project, but this article was a collaboration to celebrate my advisory group members (co-authors on this article) and our journey through the co-design process (i.e., not research outcome focused). I am so grateful for this opportunity to work with such a passionate, talented, and resilient group of people. We thank my supervisor Dr. Andrew Szeto, and the many others who have supported us. Lastly, we thank you, the reader. We hope that you find this article both impactful and helpful in your own journeys, whether that be personal or professional.

Throughout this article, we have been intentional about using stigma-free language, avoiding specific details regarding suicide behaviours, and focusing on positive messages, but this article does share personal stories of suicide thoughts and behaviours, as well as stigma experiences. We encourage you to embrace the emotions that may arise when engaging with this material, practice self-reflection, and take care of yourself. Please reach out if you need support—you are not alone. If you are in Canada or USA, you can dial 9-8-8 for direct suicide crisis support.

Introduction: Postsecondary Suicide Awareness and Prevention

As current or former members of postsecondary institutions ourselves, many of us still students, we have first-hand experiences with the mental health challenges that can come with pursuing higher education. We have witnessed this topic becoming a growing concern, and survey data has found a high prevalence of mental health challenges in student populations, including hopelessness, depression, anxiety, and suicide thoughts and behaviours (American College Health Association [ACHA], 2022). Specific to suicide, recent reports indicated that 27% of Canadian students have had suicide thoughts or ideations at least twice in a one-year timeframe, with almost 3% having reported at least one suicide attempt (ACHA, 2022). When asked whether they have ever thought about or attempted to kill themselves, less than half of students (44%) indicated "Never", and almost 5% of the students indicated that it was "Likely", "Rather likely", or "Very likely" that they will attempt suicide someday. Although there has been a shift towards increased open dialogue around mental health and mental illnesses more broadly in our postsecondary communities, the topic of suicide can still be extremely taboo, despite the high prevalence of suicide thoughts and behaviours in students. This reluctance to discuss suicide is likely a result of stigma, or the negative—and often unfair—thoughts, feelings, and actions towards those with suicide thoughts and behaviours, suicide survivors (i.e., those who have survived a suicide attempt), or those who have died by suicide (Corrigan et al., 2017; Link & Phelan, 2001).

Mental health promotion (MHP) may be one way to decrease this stigma. MHP aims to improve mental health and wellbeing in our communities by increasing its value in society; improving individuals' resilience, coping strategies, and capacity for wellbeing; increasing protective factors; and reducing health inequities through empowerment, collaboration, and participation (Barry, 2019; Singh et al., 2022; Youth Gov, 2022). MHP can occur anywhere—in the home, our schools, our communities, our workplaces, and even online—but having MHP embedded within structural frameworks can be very impactful (Sharma et al., 2017). Many postsecondary institutions have been progressive in implementing MHP initiatives on their campuses, such as signing the Okanagan Charter (International Conference on Health Promoting Universities & Colleges, 2015), implementing The National Standard for Mental Health and Well-being for Post-Secondary Students (Canadian Standards Association, 2020), and developing their own

institutional mental health frameworks; however, not as many institutions have made large-scale efforts for suicide prevention specifically. One initiative that has recently gained traction over the last few years at postsecondary institutions is the *International Zero Suicid*e initiative, a practical framework for suicide prevention developed originally for the healthcare context (https://zerosuicide.edc.org/). For example, the Georgia Institute for Technology (Georgia Tech) has implemented *Tech Ends Suicide Together*, which is a bold plan to end suicides in their campus community (Georgia Tech, n.d.). In Canada, the Centre for Innovation in Campus Mental Health (CICMH, n.d.) has also supported this initiative, and our institution, The University of Calgary (UCalgary), has also made this an institutional priority by implementing a suicide awareness and prevention framework strongly guided by *Zero Suicide* (UCalgary, 2024).

These suicide prevention and awareness initiatives often include campus-wide events, as well as training for faculty, staff, and students around providing help to someone with suicide thoughts or behaviours (e.g., ASIST: Applied Suicide Intervention Skills Training, Centre for Suicide Prevention [CSP], n.d.). In fact, most of us have at least one suicide intervention training. Although these types of events and workshops are critical for the community, and they can certainly help reduce the stigma towards suicide on campus, stigma reduction is not their primary focus. As stigma has a variety of negative consequences, often cited as one of the main barriers to help-seeking behaviours, decreasing the stigma around suicide can have a huge positive impact on those who need support most (Rastogi et al., 2024; Reynders et al., 2014; Sheehan, Corrigan, et al., 2017; Sheehan, Dubke, et al., 2017; Thornicroft et al., 2022).

Since stigma can be so impactful in the context of suicide and mental illnesses, postsecondary institutions should consider implementing stigma reduction programs that can provide insight and education regarding suicide to students, staff, and faculty. It is our opinion that when creating and implementing these types of programs, researchers must be intentional in their approach and value the knowledge of people with lived experience (PWLE). Our first exposure to this was a mental health promotion and mental illness stigma reduction program for postsecondary students known as *The Inquiring Mind*, created and used by the Mental Health Commission of Canada, where students were consulted in the development process of the program and shared their experiences with stigma, mental health concerns, and help-seeking behaviours for the program material itself (Szeto et al., 2023). This idea, more broadly, however, is not new. "Nothing about us without us" is a phrase used by various structurally marginalized groups to emphasize the importance of including communities in any research that intends to improve their lives or impact them in any way (e.g., Indigenous research; Funnell et al., 2019). This phrase was popularized by disability activists in the 1990s following an International Disability Rights Conference, with the recognition that "when others speak for you, you lose"

(Ed Roberts, quoted in Charlton, 1998; Driedger, 1989, p. 28). In Indigenous public health research, Came et al. (2019) advocated that an important step in achieving positive change is for Indigenous peoples to take control and direct the development of Indigenous solutions. These sentiments highlight the necessity of not only collaborating with the groups we seek to help but putting them at the forefront of these endeavours.

Another approach to including lived experience in mental health research is autoethnography, a methodology that draws upon a researcher's personal lived experiences to describe or critique societal norms or practices (Fourie, 2021). For example, Pryer et al. (2023), a team of lived expert researchers, utilized a collaborative approach to autoethnography, identifying their own resilience regarding their disabilities and mental illnesses in the face of unsupportive and problematic institutions. Similarly, Johnston (2020) explored their experiences with mental illness and recovery, and Campbell (2018) shared their academic identity process after a mental health absence from university. Fixsen (2023), another lived expert researcher, argues that autoethnography of mental illness, such as these examples, is a methodology that can contribute to broader societal debates that impact policy, promote awareness and understanding of mental illnesses, and in turn, reduce the public stigma towards mental illnesses.

Community-Based Research and the Co-Creation Approach

With this in mind, we came to focus on community-based (participatory) research (CBR) and co-creation methodology, which uphold the value of relationality – engaging in meaningful collaboration and consultations within communities. CBR integrates community and academic expertise, emphasizing collaboration and partnership with the community itself (Roche, 2008). Actively including communities in the research breaks down traditional power dynamics, shifting power to those in the community who are often excluded (e.g., PWLE; Faulkner, 2017; Jones et al., 2014). Often in mental illness and suicide research, lived experts (i.e., PWLE) and their insights can be dismissed or ignored, as they may be seen as unreliable, fragile, incapable, or a variety of other negative stereotypes (Sheehan, Corrigan, et al., 2017; Sheehan, Dubke, et al., 2017). For this reason, including PWLE in the research process *is* stigma reduction in and of itself.

In the area of suicide prevention specifically, various CBR methodologies have been implemented by many researchers, which typically involve collaboration with various stakeholders to improve clinical outcomes for those with suicide thoughts and behaviours. For example, Dumon & Portzky (2020, 2023) discuss a Suicide Prevention Strategy in Belgium, which aims to decrease suicide rates and support those affected by suicide. They emphasize cooperation with various communities, including researchers, policymakers, healthcare workers, and PWLE. Denton (2021) used a community relevant-research partnership to explore correlates with recurrent suicide attempts in high-risk youth. McKay et al. (2024) used a co-consultation process with international students in Australia to adapt the LivingWorks safeTALK

suicide prevention program. Their participants found this process empowering and engaging, with results supporting a mutual understanding of mental health and suicide. In Canada, Thompson et al. (2020) used participatory model building with healthcare providers to explore their implicit models of risk and prevention factors for suicide, resulting in upstream factors that can better support suicide prevention efforts in the country. Langdon et al. (2016) and the Lumbee Rite of Passage Study (LROP) utilized CPR to create a culturally tailored suicide prevention program to support Lumbee Indigenous youth in North Carolina (USA) directly involving youth, cultural leaders, and other community members in their process.

Co-Creation Approach to Program Development

In a co-creation design to program development, researchers should engage in frequent collaboration and engagement with relevant communities throughout the entire research process (Greenhalgh et al., 2016; Lyon & Koerner, 2016; Norris et al., 2017; Vargas et al., 2022). For example, if research is being conducted to create an intervention to support a specific community, the best way to create a suitable, successful program is to actively include that community in developing materials (Greenhalgh et al., 2016). This co-design approach can lead to programs that are more effective and practical than other traditional approaches (e.g., using only academic literature; Jull et al., 2017).

Specific to programs aimed at educating the public on mental health topics, co-creation approaches can vary in what communities are included as partners or collaborators. For example, for a program designed to reduce the public stigma towards mental illnesses and suicide, researchers might collaborate with PWLE of suicide thoughts and behaviours, as the program is designed to reduce the stigma *towards* them. They may also collaborate with the population(s) whose stigma the program is trying to reduce (e.g., student population, faculty), as they are the group who needs to find the program useful and impactful. Ideally, all relevant populations should be involved whenever possible. One common way to collaborate and co-design with communities in CBR is to form advisory boards, councils, panels, or groups (Lewis et al., 2022; Newman et al., 2011; Portalupi et al., 2017). These advisors, or partners, can serve a variety of roles, including voicing issues from the community, providing insight or information from personal experiences, and actively helping to create materials for the project (Morin et al., 2003; Newman et al., 2011).

Our Co-Design Process to Suicide Stigma Reduction Program Development

In this article, written collaboratively by the research team, we describe the co-design process of developing a suicide stigma reduction program for Canadian postsecondary students. The overarching research project, which includes the creation and evaluation of this program, is inspired by similar

programs aimed at overall mental illness stigma reduction (e.g., Szeto et al., 2023). Drawing on our own experiences, we discuss why stigma reduction is important to us; the purpose of the advisory group; the recruitment process and considerations; the advisory group processes, norms, and outcomes; and the experiences, challenges, and lessons learned. Lastly, we provide recommendations to researchers who may be interested in taking a similar approach in their research. Since we found limited literature on these types of approaches in stigma reduction research specifically, we hope that our reflections provide a successful example for researchers in the field to consider, highlighting the importance of lived experience and co-creation methods in stigma reduction.

Brittany's Positionality Statement

When I began my PhD studies, I knew that I wanted to continue suicide stigma reduction research. I had focused on the impact of postsecondary institutions' responses to a suicide death for my master's research (see Lindsay & Szeto, 2022), and I wanted to explore possible suicide stigma reduction programming next. With a social psychological perspective in mind, I decided to create and evaluate a suicide stigma reduction program for postsecondary students. After familiarizing myself with other relevant literature during the research process (i.e., co-creation; implementation science), I realized that this was not a project I could—or should—do on my own. I had included some basic engagement with relevant experts in my previous research on suicide stigma (e.g., one suicide survivor, counsellors, media expert), but I did not have experience with more rigorous collaboration before. I have learned so much through this process, working hard to be intentional and reflexive in this research.

Regarding my overall social location as a white, English-speaking, cisgender Canadian woman, I acknowledge that I have been granted many unearned privileges in my life, and I reflect frequently on where I can use this power to push back against systems of oppression and support others who are impacted by them. For example, I have tried to avoid centring myself and my experiences in this work, leaving space to showcase the experiences of my collaborators. As a first-generation college student from a rural upbringing, I have also struggled at times to find my place in academic spaces, which has shaped how I perceive the academy. I often question the traditional processes and seek the most impactful solutions, which has led to my pragmatic approach to research (Kaushik & Walsh, 2019). Alongside this worldview, unexpected losses in my early adulthood created a sense of urgency for mental health prioritization and resiliency in my own life and increased my passion for mental health and stigma reduction research.

Although suicide had significantly impacted my life, I do not have personal lived experience with suicide behaviours; therefore, I do approach this research from a position of active allyship, humility, and profound compassion. I know the importance of practising reflexivity in this work, and I am deliberate in considering how my personal biases might impact

how I perceive this work, how I can learn and collaborate with others who have lived experience, how I can limit assumptions, and how I can check in honestly with myself and my team regarding the research process (Jacobson & Mustafa, 2019). I acknowledge the immense privilege I have in pursuing this research to earn a PhD, and I do not take the responsibility of leading this project lightly.

The Advisory Group

Purpose

When I first decided to begin the journey of program development, I reflected on the best practices for doing so. I engaged with mental illness stigma reduction program literature (e.g., Codjoe et al., 2021; Corrigan et al., 2012; Knaak et al., 2014; Martin et al., 2020; Szeto et al., 2023), which helped me understand what the core components of that type of programming might be (e.g., intergroup contact, myth-busting, focus on recovery, teaching skills, tailored approach). I also explored mixed methods, program development, and implementation science literature to better understand programming creation and evaluation techniques (e.g., Creswell & Plano Clark, 2018; Durlak & DuPre, 2008; Exner-Cortens, 2021; Gottfredson et al., 2015). This literature certainly helped me to narrow down the plan, create research questions and hypotheses, but in doing so, I realized that creating an *effective* and *meaningful* program to reduce suicide stigma in postsecondary could not be done alone. Stemming from reflection, and discussions with my supervisor (Andrew Szeto), we understood that collaborating with PWLE was critical and we began pursuing a co-design approach. We decided to form an advisory group for this purpose: *To advise on the creation and evaluation of a suicide stigma reduction program for postsecondary students being led by Brittany for her PhD dissertation and to provide valuable insight based on previous lived experiences and knowledge.* Specifically, members of this group provide ideas and feedback on materials and processes used in this research, aid with research tasks (e.g., material/literature search, data collection, recording content), and support knowledge dissemination on the project (e.g., attend conferences, write this article). From the beginning, it was agreed upon that this group would be *part of the research team* itself, not participants *of* the research. This research was originally unfunded, so the initial incentive to join the group was advocacy and representation, research experience, opportunities for presentation/publications, and helping their community. As the group members were all students at the beginning of this project, many of which were interested in pursuing further education, conference presentations and publications were important and valuable opportunities. Later pre-doctoral funding from the Killam Trust (https://killamlaureates.ca/) allowed for small honorariums for each advisory group member ($50 per semester; ongoing).

Recruitment Process and Considerations

To form effective advisory groups, research teams should consider the purpose or role of the group, as well as the diversity, expertise, and experiences that are relevant and beneficial to the project (Helms, 2022). For this research, several areas of expertise and lived experiences were relevant: past suicide thoughts and behaviours, recovery paths, mental health challenges, stigma experiences, student life (particularly at the institution the research is being conducted), advocacy/allyship, noticeable passion for helping others, research experience, and diverse personal and academic backgrounds. Aside from relevant lived expertise, passion (i.e., the willingness to invest time and energy; Vallerand & Houlfort, 2019) was an important criterion because it is crucial for intrinsic motivation and engagement towards research activities (J. Chen & Zhao, 2024).

I have been an active member of our institution for many years, involved in research and service work around mental health and suicide for students, and I knew it was important for my recruitment method to be *relational* in nature. Suicide awareness and prevention research, particularly for PWLE, is difficult work, and I felt that having pre-existing relationships with those involved in the project would be an asset to ensuring comfort and community within the advisory group environment. I had already established strong working relationships with many students (past/present) and researchers who had relevant expertise and lived experience, who I knew would bring a strong sense of motivation and expertise to this project. Previous researchers have emphasized the importance of building trust and good relationships, as well as strengthening pre-existing ones, as the first steps in CBR (Burhansstipano et al., 2005; Langdon et al., 2016).

Potential members who met some (or all) of the considerations listed above and expressed interest in participating in the advisory group, were encouraged to meet with me to discuss their potential involvement, and, organically, an eight-member advisory group was formed in Fall 2022. All interested members were encouraged to participate. Although this process was informal, with no exclusion criteria, we did consider whether the person was adequately supported in their own mental health journeys to safely participate (S.-P. Chen et al., 2016). Each member has important and unique perspectives, experiences, and reasons for their interest in this program and research.

Meet the Advisory Group: Motivations for Participating

Our advisory group consists of six women and two men representing a variety of different ethnicities, cultures, nationalities, languages spoken, upbringings, academic majors, and other important pieces of one's identity. We have representation from structurally marginalized groups, including the 2SLGBTQIA+ community (Two-Spirit, Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual +), the BIPOC (Black, Indigenous, People of Colour) community, and first-generation college students. Additionally, as the first version of the program was tailor-designed for a

specific postsecondary institution, all members of the advisory group had been students at this institution for at least one degree, varying from recent graduates to current students. To better understand our group's diverse perspectives, advisory group members have shared who they are, and their motivations for joining this project. The following excerpts were written in 2024.

Emily (she/her): I graduated with a Bachelor of Arts (Honours) in Psychology in 2020 and worked as a clinical research coordinator for over four years, with the goal of pursuing a PhD in Clinical Psychology. I am a first-generation university graduate and cisgender queer woman of rural upbringing in Quebec, and daughter to an immigrant mother and French-Canadian father with Indigenous heritage. My journey with suicidal thoughts and behaviours spans over two decades, beginning in early childhood. As an individual who has experienced firsthand stigmatizing, judgmental, and demeaning reactions from physicians and mental health care professionals, I vowed to pursue a career that would allow me to provide better experiences for other youth and young adults. As I began my degree in psychology, I often found myself questioning the relevance and effectiveness of research being conducted on certain populations if the researchers had no lived experience. Seeing how research had historically been carried out with little regard to the population of interest, my previous experiences with health care made sense. I wondered how researchers knew what questions or materials were appropriate and effective in enacting change without inquiring about peoples' experiences. It became clear to me that this was a key missing component in research. As time progressed, so did academia, and slowly, a shift toward CBR began. Having worked with Brittany and Andrew for many years prior, I was eager, honoured, and excited for my experience to be recognized and help contribute to change in the field. *This* is how research should be conducted.

Arianna (she/her): I completed my BA (Honours) in Psychology at the UCalgary in 2022 and began graduate school in Clinical Psychology at the University of Saskatchewan in 2023. I am a Métis-European woman and have lived experience with suicide thoughts and behaviours personally and within my family. Both prior to, and during my post-secondary education, I have often felt that the voices of people with lived experiences were left out of the conversation. In research and clinical settings, there is a palpable disconnect between those with an academic or theoretical understanding of a given experience and those who have personally lived through it. Unfortunately, it is not uncommon for those with the letters behind their name (e.g., PhD) to view themselves as the expert, sometimes at the expense of those with lived experience. It is my perception that PWLE have invaluable experience to share, which should be prioritized in our research efforts. My education has afforded me the opportunity to rectify this by placing more value on the voices of people with lived experience in the work that I do. As such, when

Brittany approached me about joining the advisory group, I was honoured to be part of a project that *sets a precedence of inclusivity and humility that we, as researchers and clinicians, should all be constantly striving for.*

Monique (she/her): Almost a decade ago, I left university due to mental health struggles, including suicide thoughts and behaviours. In 2024, I graduated from the UCalgary with a BSc in Psychology. My initial postsecondary experience inspired my interest in mental health and wellbeing. Due to my interest, I volunteered extensively in student wellbeing promotion and suicide intervention during my degree. But even with all those positive-mental-health-oriented experiences, I felt hesitant to disclose my lived experience with mental health and suicide. I was fearful that a vulnerable part of myself would be exposed to the public. When the opportunity to work with Brittany appeared, I took a momentous chance and joined. The advisory group highlighted the importance of lived experience in research, and I firmly believe that research cannot exist without the humanity behind the phenomenon investigated. This project has created a space in academia for me to honour loved ones that I have lost and my own battle with suicide.

Gemma (she/her): I have a BSc in Psychology with a minor in Sociology. I am also a MSc Counselling Psychology student at UCalgary. For two years following my undergraduate degree, I worked at a shelter for individuals fleeing domestic violence, and I often came across those exhibiting suicide thoughts/behaviours. Furthermore, I have lived experience with suicide thoughts. This research really interested me as it focused on stigma related to suicide specifically rather than stigma related to mental illness in a broader sense. This is especially important since many students seriously consider suicide at some point in their degree. I think it's also agreed that everyone feels rocked by a suicide on campus— whether you knew the person or not. Additionally, the fact that Brittany was wanting people with lived experience to contribute to the creation of the program also really spoke to me. It makes those of us with lived experience feel heard and valued.

When I learned that Brittany was writing a paper on forming and utilizing an advisory group, I was immediately interested. In my first year of my Master's, I aimed to research a structurally marginalized group of individuals with whom I did not share a core identity. An ethics committee member advised me that I could not proceed with the research unless I built strong relationships with the population of interest, which could take up to two years, and that I would also need to form an advisory group. As this concept was new to me, I struggled to find guidance in the academic literature on how to create and engage with such a group, ultimately changing my thesis topic due to this lack of direction. This paper addressed the gap in the academic literature by providing more guidance to researchers on the formation process, key considerations, and each stage involved.

Alexis. (she/her): I completed my Bachelor of Arts in Philosophy, minor in Psychology, and Embedded Certificate in Mental Wellbeing and Resilience at UCalgary. My time in university allowed me to further pursue my interests

in ethics, mental health, and building a caring community. This project appealed to me because of the focus on stigma reduction and acknowledging people with lived experiences. Although I was already motivated by this topic, I was greatly impacted by the number of students who were posting on forums about depression, suicide, and declining mental health. These posts were often regarded as humour, demonstrating existing stigma and creating barriers to help-seeking behaviors. I hope that as a community, we can become more vocal about mental health and instill courage and safety in reaching out for help. I believe this project will have an impact on the way that mental wellbeing and stigma are viewed and cared for.

Faith (she/her): I am a recent Bachelor of Social Work graduate and am the daughter of immigrant Filipino parents. Growing up in Canada, I found it difficult to manage cultural clashes and my mental health due to stigma. I came across this project after taking a class on mental health resilience and wellbeing and felt a sense of belonging knowing I was not alone in my experiences. I found this to be unique to other programs because it focused on suicide rather than mental health or mental illnesses more generally and highlights the urgency to normalize conversations around suicide and take it more seriously. It is something that especially impacts young adults and students, who are under immense stress due to various factors such as climate change, rising costs of living, academic competition, interlocking systems of oppression and so forth, but is not acknowledged as much as it should be. There is value in each and every story, our experiences are multidimensional and more than just numerical. Being more honest about my mental health and being surrounded by people who show up compassionately for me makes a whole world of a difference.

Caden (he/him): I am a political science major with a goal of a more equitable and inclusive future. I have a history of being involved with vulnerable youth and diverse groups, through community programs and youth programs right here at UCalgary. Being a transgender man, I struggled myself with thoughts of self-harm and suicide, but I felt that being open about those feelings was counterproductive to the male 'image' I was trying to establish for myself. That was, until I started to learn more about the widespread and diverse group of people who have those same challenges, for all different reasons. I realised stigma had a direct negative role in my life, and I was excited to be involved in looking more formally into the impacts of stigma, especially as it presents a barrier to reaching out and seeking help.

Rigel (he/him): I am a recent BSc graduate in Chemical Engineering, with a minor in Biomedical Engineering. My interest in this project stemmed from my prior collaboration with Brittany, where we examined predictors of academic performance among first-year engineering students. Our research highlighted the significance of stress on academic performance, which can also be a risk factor for suicide ideations. For me, stigma reduction is especially important as an immigrant from a country where mental health issues and help-seeking behaviours are heavily stigmatized. This project

represents a practical and crucial effort to reduce stigma in hopes of contributing to an environment that encourages help-seeking behaviour, demonstrating how straightforward and effective stigma reduction can be in real-life scenarios.

The Importance of Stigma Reduction: Advisory Group's Perspective

Research in mental illness and suicide stigma emphasizes the importance of stigma reduction initiatives in our communities (Thornicroft et al., 2022). As Arianna states, "Stigma is ingrained in our society, which means it is also embedded and enacted in our educational systems. The very programs that train the mental health professionals of the future have blind spots too. In the absence of concerted efforts to address this, we continue to perpetuate a landscape of stigma that has detrimental impacts on our most vulnerable populations." For this reason, stigma reduction is critical in our educational system, especially with those who intend to pursue careers which focus on wellbeing (e.g., psychologists).

As we all come into this work with different perspectives, we felt it was important to discuss why stigma reduction is important to each group member, and we have provided a summary of this conversation. It was agreed that stigma reduction is important because 1) "it encourages and normalizes open and honest conversations about suicide, mental health, and other important topics deemed taboo or inappropriate in society. This, in turn, aids in better action to address said issues, policy-making, increase and improve resources, and overall builds healthier and happier communities." (Faith); and 2) "it builds compassion and a safe space for people to reach out for help. It also brings us closer to mindful and more respectful conversations." (Alexis).

Related to the importance of stigma reduction, many of group members shared the negative impacts of suicide stigma personally, including witnessing stigmatizing experiences towards others and being stigmatized themselves. For example, Monique discussed how stigma around suicide hinders suicide prevention. She has witnessed people say incredibly hurtful things to people who are struggling and families grieving from recent losses, all because of myths around suicide. "Often, suicide becomes a topic so unspeakable that people stop mentioning it all together, and this makes reaching out for help so much more difficult" (Monique).

The impact that stigma has on help-seeking behaviours also emphasizes the importance of stigma reduction. As we know, when someone is experiencing suicide thoughts, it is vital that they can reach out for support. Disclosing suicide thoughts to another person is an extremely vulnerable experience, and if someone experiences stigma during their disclosure, it may make them shut down, disengage, and not reach out again. Gemma remembered a time in high school hearing a student in class say, "I think those who [die by] suicide are cowardly and selfish". She was a suicidal teen at that time, and this made her never want to reach out for help if that is what her peers thought. So, reducing stigma could mean saving a life. Emily shared that

she personally experienced stigmatizing reactions to her lived experience with suicide that ranged from smaller, inappropriate comments to more severe reactions, like the involuntary dissolution of friendships and relationships or the denial of jobs and opportunities. The stigma she experienced from individuals spanning all walks of life (family, friends, partners, physicians, therapists, and strangers) led her to internalize the thoughts and opinions of others (i.e., self-stigma; Corrigan & Watson, 2002) and consequently, shut down and hide from others, exacerbating her suicidality at the time.

For Arianna, "When I was going through my hardest times, I faced a lot of stigma. But the thing is, when you are in that place of feeling so negatively about yourself, you don't necessarily recognize that you are experiencing stigma. It just feels like another thing you're messing up, another reason you're not good enough. Similar to how Emily experienced self-stigma, I started to fully believe what people were saying to me and that I deserved the way I was being treated. That pain compounds itself. It wasn't until the work that I did with Brittany and Andrew that I realized that I *was* experiencing stigma. I would think back to those experiences, how confusing it was, and how much harder it made an already difficult situation - I knew that I needed to be part of addressing that."

Group Values, Norms, and Processes

Once an advisory group has been recruited, it is important to establish community values or principles that will help guide the collaborative research process and revisit them periodically throughout the process (Blumenthal, 2006; Ginzburg et al., 2022). Sharing insight and experiences regarding suicide can be emotionally, intellectually, and physically taxing for individuals, and I wanted to ensure that the advisory group space was an accessible, comfortable, and welcoming space to do so. To help ensure this, the first official advisory group meeting consisted of personal introductions and a discussion on group values and norms. To reduce burden and increase efficiency in the meeting, and after reflecting on the relevant literature, I created a draft document of seven overarching values and norms for the advisory group to discuss, adjust, and ultimately agree to uphold during the duration of the project (see Table 1). The aim of these guidelines was to provide a framework for discussions, mutual understanding, and accountability for all of us regarding the values we wanted to uphold as a group. Overarchingly, we wanted to ensure that our wellbeing was prioritized, boundary setting was emphasized, equity and diversity was valued, requested anonymity and confidentiality were respected, the space was one of respect (including respect for various experiences, disagreements, and each others' time), and that we all learned from the experience. As the advisory group was passionate about stigma reduction and sharing their experiences, and our group dynamic was supportive, anonymity was rarely requested. Group norms were discussed several times during group meetings, to ensure they aligned with our values.

Table 1. Advisory Group Values and Norms

Value/Norm	Details
1. Mental Health, Well-Being, and Self-Boundaries	• Everyone's mental health and safety is a main priority for this group • We will normalise conversations on mental health and express our feelings freely • We will practice self-care when we need • If a conversation is negatively impacting you, please take care of yourself by asking us to move on, taking a break, leaving the meeting if necessary. If you do need to leave, email Brittany to touch base on well-being • We will discuss leaving the group (or contributing in alternative ways) with Brittany if that is what is best for us
2. Equity, Diversity, and Inclusion	• We will value and learn from our differences • Whenever possible, we will use rounds for discussion to allow everyone space to speak if they would like • We will express our needs for this group, and as a group, we will include any accommodations that are necessary for folks
3. Options for Anonymity	• We all have our own experiences with mental health, and some may be more comfortable talking about these experiences than others • An anonymous option was made available whenever possible for folks to share comfortably (e.g., add to document anonymously, complete survey). • We will always discuss how information, including quotes, will be presented outside of our group (e.g., presentations, publications)
4. Choice of Confidentiality	• We will all learn from these meetings (and can take away what we learned), but we will not share other individuals' contributions with others • We will not name who is in this group to others unless they have given us permission • Folks can direct message Brittany during Zoom meetings or reach out anytime if they do not want to share directly with the full group (Share now or share later option)
5. Respect and Learning	• We all have lived experience of mental health concerns in our group, which may include suicide thoughts and behaviours. What we will learn and talk about might be very personal for us. We will show care and understanding to everyone • We will not all agree 100% of the time, and that is okay • We will have humility, recognizing that nobody knows everything, and everyone might have different bases of knowledge coming into this group • We will listen to understand, and not just to respond • We will ask for clarifications when we don't understand • We will make mistakes and we will apologise if necessary
6. Time Commitment	• We will try our best to start and end meetings on time and stay on track during them • We will respond to time-sensitive emails in a timely manner, including completing any polls if necessary • If we miss a meeting, we will connect with a fellow member and/or Brittany to catch up on anything we missed • We will recognize everyone is busy and tight deadlines for any deliverable should be avoided
7. Feedback	• We will express any concerns regarding the group as soon as possible • We will offer any advice or suggestions to Brittany on how to better facilitate this group

Group meetings and other interactions (e.g., emails, surveys) were always conducted with these values in mind. Online shared folders contained all relevant documents (i.e., all members had equal access to view and edit), meetings were planned with consideration of various schedules and time zones, and a general agenda for each meeting was shared in advance to allow for preparation and to keep meetings efficient. Meetings always began with a round of personal check-ins, with group members discussing their wellbeing, planned activities, challenges, and successes. When an important decision was being discussed, we always took an inclusive turn-taking approach, where every member of the group was given space and time to share their ideas before we moved into further discussion, as opposed to an exclusive turn-taking approach, where individuals can monopolize the speaking turns (Haan et al., 2021). This ensures that everyone has equitable space in the conversation and does not need to raise their hand or interrupt to have a turn speaking. When making any important consequential decisions, such as program content and presentation details, decisions were always made with full group consensus, after any concerns or disagreements were addressed. For

example, when deciding whether experiences and quotes would be attributed to a specific member or presented anonymously in presentations and publications, the group discussed the pros and cons and came to a general agreement to include their names when indicated (or specifically indicating the desire for anonymity for some quotes). The opportunity to connect with me individually was always an option as well, and one-on-one conversations about various topics were common.

Advisory Group Outcomes

Aligning with the overall purpose of the advisory group, the primary outcome of the project was to create materials for the program; however, further research support (e.g., participant facilitation) and knowledge dissemination (i.e., conference presentations) became important aspects of the group's purpose as well. This expansion stemmed from the groups' high engagement, passion, and motivation for the project. This group goes beyond traditional "advising" and fully contributes to the tasks involved in conducting this research, providing insight, guidance, accountability, and support throughout the research process.

After recruitment meetings, the advisory group and I had our first meeting together in October 2022, and communications (online/in-person), asynchronous work, and group meetings have been ongoing ever since, as needed. Consistent communication and meetings supported our CBP approach (Ginzburg et al., 2022). Related to the program content creation itself, the advisory group members participated in regular meetings, engaged in meaningful conversations with each other, agreed upon program goals, gathered and evaluated content for the program (e.g., relevant materials with PWLE), provided feedback and adjustment to numerous program drafts, and recorded segments of content for use in the program. For example, a core component of the program consists of debunking myths about suicide, and the advisory group went through a list of common myths collected from various sources for inclusion into the program. The group worked together to narrow the myths down to the eight most important ones. Together, we refined wording to be most appropriate, helped formalize the corrections to the myths in ways that were meaningful and accurate to their experiences, and recorded the audio for this section. This work, which spanned over six months, resulted in a 45–60-minute asynchronous online program *From Taboo to Talked About: Understanding Suicide on Campus and Fostering Community* with six modules, narrated by the nine of us (see Table 2). This program is now being evaluated for effectiveness in an experimental study (Lindsay & Szeto, in preparation).

Some advisory group members have also helped with finalizing research materials (e.g., piloting online surveys), facilitating research participants (and training others to do so), and creating an annotated bibliography with articles that focus on co-creation methods and valuing lived experts in research. Regarding knowledge dissemination and mobilization, whenever a presentation opportunity on our co-creation process arose, we discussed what

Table 2. Stigma Reduction Program Modules and Details

Module	Name	Summary	Advisory Group Contribution Highlights
0	Overview	• Program goals (and clarification of what it does not provide; i.e., direct support) • Supports and resources • Module overview	• Brainstormed and agreed upon program goals
1	Understanding Suicide on Campus	• Suicide terminology and statistics • Campus initiatives and their involvement in the community	• Definition selection and wording
2	Stigma: What is it? What are the impacts?	• Definition, complexity, and suicide stigma examples • Connection to help-seeking and help-giving behaviours	• Advocating for complexity and help-seeking/giving definitions • Creation of reflective exercise to help understand stigma
3	Suicide Myths: Correcting Misconceptions	• Eight myths, explanations of why they are incorrect, and their corrections • Interaction component (tallying how many myths they have believed/heard)	• Selecting and refining myths and corrections
4	Everyone's Roles: What can we do?	• Language Matters (replacing stigmatizing terms) • Reframing thoughts and changing behaviours, with practice exercise • How to interact with people being stigmatising, people in recovery, and people who need support	• Selection of information and exercises • Emphasize that we all make mistakes
5	Lived Experiences: Listening to Stories	• Videos or audio of PWLE of suicide thoughts and behaviours • Reflective moment	• Finding and reviewing all materials • Choosing final materials
6	Conclusion	• Call to action (i.e., made a pledge to reduce stigma) • Training specific to their postsecondary • Emphasize self-care and final thank-you	• Providing example pledges • Adding SMART goals to consider

information we wanted to include and who wanted to join as presenters. For example, the advisory group provided core content and/or participated in a panel discussion on the co-creation method for *Collaborations for Change 2023* (https://collaborationsforchange.ca/), a biannual conference around postsecondary student mental health, alongside several other formal and informal presentations. For any presentation about the research project more broadly (i.e., not focused on the program creation specifically), advisory group members are always credited as collaborators on the program development. Upon reflecting on our experience as an advisory group and deciding we wanted to publish together on the process, we collaborated on the content creation, writing, and editing of this current article. A meeting was held to choose the journal and agree on the general content and flow of the article. We then used a shared folder to collaboratively contribute to the manuscript and other relevant documents. Experiences and ideas were collected from the advisory group members throughout the research process (orally and in writing), which were used to begin many of the sections of the paper. From there, everyone contributed to various sections and approved the manuscript for submission. Authorship order was determined by relative contribution to the project.

Discussion

Our Experiences, Challenges, and Lessons Learned

This project would not have been possible without the guidance and support of this advisory group. The perspectives and expertise in the group were unmatched for the project, and I could not have asked for a more diligent and compassionate group to share this journey with. Their openness to discuss these difficult topics was inspiring, and I was constantly impressed by their contributions. I am so grateful for the ability to be involved in such a meaningful project and collaboration, and I know I have made lifelong connections with this group. Being reflexive in this work was incredibly important, and we acknowledge that much of our successes and challenges in our experiences, described next, were influenced by who we are and the connections we have made (Jacobson & Mustafa, 2019).

A common challenge that is discussed when working alongside an advisory group (or other co-design approaches) is the connection and collaboration with the group itself. It can be challenging for researchers to engage meaningfully and effectively with those who are from communities that are outside of academia, as connections are physically harder to make (i.e., the community members aren't in your campus community) and maintain (i.e., coordinating meetings around different schedules). Meaningful connections can contribute to positive relationship and reduce internal team conflict dynamics during the collaboration process (Ginzburg et al., 2022). Although experts on their own experience, many advisory group members in research may not have specific research experience draw upon. Two core strengths of this project were the natural connection that I already had to the community (i.e., involved with undergraduate mental health initiatives for years, part of the student community itself, although as a graduate student) and the connection that the community already had to research and mental health promotion. The ease of recruitment and collaboration can be attributed, at least in part, to this natural cohesiveness among all the members, myself included.

Although *our* overall experience in this process was a positive one, challenges can always arise with difficult work. Firstly, to do this work well requires the researchers to have profound empathy and understanding for PWLE. This means that this work can be **both intellectually and emotionally challenging** at times. Burnout (i.e., high levels of exhaustion and cynicism; Demerouti et al., 2010) and compassion fatigue (i.e., emotional, physical, or behavioural distress related to caring; Harrison, 2021) are real possibilities when working with PWLE. I learned to embrace my emotions during this experience and was constantly moved to tears by the advisory groups' words. Though I am generally comfortable with the topic of suicide, there were times when the emotionality of the materials or meetings weighed heavily on me. In those moments, I admittedly took a step back from the project, taking time to reflect on those emotions and prepare myself for

the next steps. This is not something I had incorporated into my timeline in advance, which also meant that this work took longer than originally planned. As anyone who has completed a dissertation knows, timelines can be stressful. I tried to be patient and compassionate with myself, knowing that this program development was being done in a good way—the right way. Rushing through tasks and emotions was not the answer.

As someone who naturally gravitates toward leadership, another challenge that I struggled with was "control". This is especially true when I have a strong sense of responsibility to something, such as this important project. As someone who began more traditionally trained in my academics (i.e., more quantitative, experimental research methods), I did have to reflect on what it **meant to "share control" with a community**. There were certainly times during this project when I could have made more intentional choices to include the advisory group earlier in the task at hand. For example, when creating our group norms, I created a list of norms on my own for us to discuss as a group and adjust as necessary, but I could have just come into that initial meeting without that list, getting initial ideas directly from the group. In my thought process, I wanted to avoid burdening the group members and be efficient with our limited time together, but reflecting now, this would have been a great opportunity to share control with the entire group.

Through working on this project, I learned that this type of work takes time and intentionality. Listening to the advisory group's stories, and the benefits they have felt supporting this work, is incredibly meaningful for me. What follows is their experiences, in their own words, when prompted to "share their experiences and any lessons learned."

Gemma: "Being part of this group has been incredibly **empowering**, marking a journey filled with hope and resilience. If you had told my teenage self, struggling with suicide thoughts, that I would have the chance to reclaim my narrative and use my struggles with suicide thoughts to advocate for mental health using my own struggles, I simply would not have believed it!"

Alexis: "Working on this project has been an amazing experience. I have gained knowledge on stigma reduction and training that will continue to positively impact my life and my capability of assisting others with suicidal ideations. I hope to **continue to learn** about stigma reduction and work in this field."

Rigel: "It was an honour being part of this project. As someone who has studied in the natural sciences, which perpetuates myths and misconceptions through its hidden curriculum, it is refreshing and empowering to be part of work that explicitly addresses stigma and actively involves the community it is intended for. Brittany's **compassion-first approach** to the co-design process ensures that our work is relevant, impactful, and achieves its goals with kindness and fairness."

Caden: "The process of bringing individuals and perspectives together is more than just neat, it's necessary to understand and overcome these big societal challenges, such as stigma. **At the heart of a more inclusive**

society is community, and that is what this project emulates—a diversity of perspectives to guide and inform the research. It was empowering to be consulted and heard throughout the process. Brittany showed that it is possible, through adaptable leadership, intentional design, and attention to people, to meaningfully integrate lived experience into the methods of research, not just the topic of it."

Faith: "Brittany and the rest of the team have really done an amazing job collaborating on this project. I constantly **felt heard and seen**, and I was learning a lot in the process as well. In my time in academia, I have not come across this type of approach in research and hope to see more of it in the future. As with any journey, there are ups and downs, but the intention to respect people's experiences and uphold the purpose of this project remained at the heart of every action we took. This has inspired me to continue to empower others and participate in stigma reduction as I come across more opportunities as a recent social work graduate.

Monique: "Brittany's unwavering intentionality throughout the co-design process has shown me that quality research can be full of warmth. This project will not only produce knowledge and materials that benefit people impacted by suicide stigma but also adds authenticity to research by involving individuals with lived experience like us. This experience is a crucial reminder to **always prioritize people**, as research should always remain a **human-centred endeavour**."

Arianna: "Bearing witness to how Brittany conducted herself in this research with such benevolence, compassion, and evident understanding for the importance it holds for PWLE was a constant reminder to me that it is possible to do research in this way, in a manner that goes leaps and bounds beyond tokenism or a simple check-box. With limited resources and funding, and working on a PhD student's schedule, she was always intentional in her work with the advisory group, never cut corners, or allowed her values to waver. **There are no excuses.** Brittany is an excellent example that when you have the resolve to do research which includes the population it aims to serve, it *will* have an impactful outcome."

Emily: "Having known and worked with Brittany for over seven years, she was privy to my suicide narrative. Little did I know that our working relationship would shed light on my own experiences with what I *now* know as stigma, instilling hope that research and mental health care can improve. Moreover, and importantly, it **emboldened me to combat stigma by speaking openly and publishing about my experiences**, a considerable risk while applying to graduate programs in Psychology. From the inception of her Masters research (Lindsay & Szeto, 2022), she demonstrated a steadfast intentionality for conducting research that was meaningful, relevant, and respectful of the populations it explored. She proactively undertook training to better understand the field and consistently sought out and implemented input and feedback from PWLE like myself, throughout the years, even *prior* to this project. Brittany exemplified doing rigorous and inclusive research,

including PWLE in her work well before it became a priority in the field. Undoubtedly, this process requires ongoing work, dedication, empathy, humility, and open-mindedness. People may, at times, get it wrong, but my experience with Brittany highlights that it *can* be done right, with integrity and respect. And for those fumbling through CBR, please don't give up when it gets difficult, after all, **research is about progress, not perfection.**"

Recommendations for Research Teams

Reflecting on our experiences and challenges, we have summarized some recommendations for research teams based on our experience with this project, which we hope will help other research teams successfully utilize co-creation through meaningful collaboration with an advisory group.

1. Be Informed (Do the Work), but Act with Humility

It is very important to value PWLE's expertise, but researchers need to be mindful of not overburdening PWLE or other structurally marginalized groups by asking for information that can be found themselves. It is critical that your research team has done the work to have prerequisite knowledge before engaging with the advisory group to avoid contributing to the burden that many groups face (i.e., do the work). However, when engaging in topics where you might not have personal lived experience, it is important to approach everything with humility and the willingness to learn and accept that - despite your years of education - you may never fully understand the experiences that you have not had. "It's okay that you won't always get it right but acknowledge that" (Arianna). "Researchers need to listen, ask questions, and if they don't have experience with the topic, be okay with getting it wrong but learn from it and apply what they learned moving forward" (Emily).

2. Make Meaningful Connections Early and Often

If you are focusing on research that would benefit from a CBR approach, your research team should be making connections with the relevant communities *before* they are ready to recruit an advisory group. This allows for the research team to build meaningful relationships with people. These fostered relationships can then help recruitment, either directly (i.e., they join the group) or indirectly (i.e., they know others in the community who may be interested). Relationality is key to collective co-creation (Ginzburg et al., 2022).

3. Strive for Diversity and Representation

When recruiting for an advisory group, research teams should always strive for diverse perspectives and experiences, including those from different academic disciplines, those with diverse personal identities (e.g., ethnicity, gender), and those from structurally marginalized communities (e.g., 2SLGBTQIA+, BIPOC; Helms, 2022). "Everyone has a unique story" (Alexis) and "You can never stop learning. Reach out to individuals and

groups with different experiences and backgrounds from you and see how they understand your topic and material. It is so important when doing this work to look outside of the faculty and [look to the] community who are also doing this work, to hear the voices of those who are less familiar or comfortable with the topics" (Caden). For example, different cultural perspectives are often overlooked. "Those in the field [mental health] should strive to make this vital topic more accessible and culturally sensitive. Often, mental health education initiatives are perceived as inaccessible or lacking cultural relevance, leading to the potential failure of reaching vulnerable populations as intended. It is essential to address this issue to ensure that everyone can benefit from these initiatives and receive the support they need" (Rigel).

4. Value ALL Forms of Knowledge

Historically, positivist roots of psychology and the denial of subjective experiences has meant that we have missed critical information in research. Engaging in this type of research requires the recognition that subjective lived experience is valuable, and that someone with lived experience is an expert. Lived expertise and empirical evidence must be seen as equally valuable. For PWLE, sharing their experiences in research can be taxing, or even risky; therefore, it is important for researchers to express how much their contributed are valued and appreciated. Make opportunities for the voices of people with lived experience to be heard. People with lived experience are not necessarily always in the position to make that happen on their own, so advocate for them and practice including them wherever possible. Another piece of advice was to ensure that everyone can contribute and learn from one another during the collaborative process, as that can be a connecting and rewarding experience as well.

It is also recommended to make sure that lived experts are compensated in a way that is feasible for the researchers, whether that be publications or opportunities, and/or monetary honorariums or wage if you have the means. Be open about this (from the beginning). "I don't think everyone expects this, but some do share their experiences for a living. Some will not want any compensation, but showing your gratitude for their time and expertise, is always important" (Emily). Expressing how much you value their time, and their experience, can go a long way.

5. Promote Self-Care and Self-Reflection

Self-care and self-reflection are both important for researchers and PWLE. "Brittany was great when it came to checking in on everyone and encouraging everyone to practice self-care; it goes without saying that speaking about sensitive topics like this impact lived experts and the person conducting the research" (Gemma). Regular check-ins at the beginning of meetings (e.g., sharing a *Brag and a Drag*), for example, is a great way to reflect, build connections, and normalize conversations about wellbeing.

Conclusion

Research that focuses on improving the lives of structurally marginalized groups, such as those with suicide thoughts and behaviours, cannot be done in isolation from those who will be impacted most. Advisory groups are one way to meaningfully collaborate with communities to properly engage in this type of research. Co-designing a stigma reduction program is one specific application of advisory groups, and our experiences have shown the effective and meaningful results that can arise from this approach. Though this methodology allows for more well-informed, effective research and social programs, it also requires significant consideration, time, and a particular skill set from the primary researcher. My advisory group has been a true inspiration and huge reason for why my passion for this project has flourished throughout this journey, and I highly recommend this approach for researchers who are considering it. Not only do you create a much better program doing so, but the journey is pretty amazing too!

Author Notes

Correspondence concerning this article should be directed to Brittany L. Lindsay. Email: bllindsa@ucalgary.ca, Department of Psychology, University of Calgary, 2500 University Drive NW, Calgary T2N 1N4, Canada.

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Positionality Statement

As a research team, it is important to recognize that our positionality influences our research. The authors include three men and seven women of various ethnicities/races (Chinese, Filipino, Metis-European, mixed/multiracial, white). We also have representation from the 2SLGBTQIAQ+ community, as well as various authors who are immigrants to Canada or first-generation Canadians. Further details regarding our identities are included in the article itself.

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