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FULL-LENGTH ARTICLES

# Recruiting Under-Represented Racialized Young Adults to the Stem Cell Registry: How We Applied a Community-Engaged Research Approach and Lessons Learned

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Over the past two decades health researchers have increasingly applied principles from community-based or community-engaged research to address health disparities and improve healthcare access and outcomes for under-served communities. Many countries rely on a hematopoietic stem cell registry to help match unrelated donors to patients. Research indicates that people who are racialized wait longer for a match than those of White/European ancestry. As such, many countries, including Canada, make efforts to raise awareness of stem cell donation and recruit under-represented racialized young adults to the registry. This paper describes our efforts to apply community-engaged research principles to a qualitative stem cell recruitment project in Canada and lessons learned. We contribute to methodological scholarship that provides in-depth description of the methods used and steps taken in community-engaged research to offer transparency and detail that enables critical engagement. We offer suggestions to improve co-learning, equitable power-sharing, and building relationships over time.

Hematopoietic or blood stem cells (herein referred to as 'stem cells') are used to treat over 80 blood diseases and disorders, such as leukemia and lymphoma, (Canadian Blood Services, 2021).[1] An important factor in stem cell transplantation is a close match of human leukocyte antigens (HLA) between the donor and recipient (Mishra et al., 2018). Put simply, the closer the HLA match, the less likely for immunological complications and more likely for positive health outcomes for the recipient. Most people who need a blood stem cell transplant rely on an unrelated donor to find a match (Dehn et al., 2019; D'Souza et al., 2020; Fingrut, 2015). To support finding a match for an unrelated donor, over 80 countries participate in a global network of stem cell registries that provides patient access to over 41 million stem cell registrants and cord blood units (Canadian Blood Services, 2021; World

1 Hematopoietic stem cells are distinct from embryonic stem cells in several ways including their potency – pluripotent versus totipotent, respectively – and from where they are collected – adults or cord blood versus embryos, respectively. We deal exclusively with hematopoietic stem cells in this paper.

Marrow Donor Association, 2017). Stem cell registries aim to recruit younger (e.g., age 17-35 in Canada) and male registrants since these factors have been associated with better outcomes for recipients (Fingrut, 2015). Moreover, for registries in countries that have an ethnically diverse population, efforts are made to have an ethnically diverse donor pool since patients are more likely to find a close HLA match from someone who shares similar genetic ancestry. Recruitment efforts can include holding targeted in-person stem cell swabbing events whereby people who are not on the registry are invited to join (Fingrut et al., 2020). Stem cell swabbing events are one way in which people can join the stem cell registry (i.e., become a registrant). In Canada, at these events, people who are interested and eligible complete a screening questionnaire and consent form, swab their cheeks, and return the swabs in a pre-paid envelope to Canadian Blood Services to undergo typing.

Finding an unrelated stem cell match has been shown to be more difficult for some racialized people than others. For example, in the US the greatest disparity in finding a match has been shown to be between White patients (45% likely to find a match) and Black patients (27% likely to find a match) (Dehn et al., 2019). There are several reasons for this including under-representation and under-utilization of some racialized donors in stem cell registries (Fingrut, 2015; Landry, 2021), and greater genetic diversity in some groups than others making it more difficult to find a close match (Beatty et al., 1995; Mori et al., 1997). This latter point suggests that to find a match for people of an ancestry with greater genetic diversity, even if representation in the stem cell registry is proportional to their representation in the general population, they may still have to wait longer to find a match. One way to possibly reduce this extended wait would be to encourage increased representation from these groups in the stem cell registry. Several stem cell registries have been working to address some of these disparities by focusing recruitment efforts to increase registrants from under-represented racialized communities, including US NMDP (National Marrow Donor Program), Canadian Blood Services Stem Cell Program, the Australian stem cell registry (McErlean et al., 2023) and Anthony Nolan in the UK (National Health Service, 2023).

Addressing racial disparities in stem cell transplants from unrelated donors to recipients is complex and requires ongoing research including understanding barriers and enablers for racialized young adults to join the registry at the stage of recruitment. This area of research for stem cell donation is understudied, with no prior published research examining this topic in Canada at the time of our study. Research on barriers to stem cell donation for African Americans include lack of opportunities to donate (i.e., access), lack of awareness that transplantation can save lives, and the cost of donation (Laver et al., 2001). While research on the barriers to stem cell donation for underrepresented racialized communities is limited, evidence from other forms of donation, such as blood donation, highlight multiple barriers for racialized groups including systemic barriers such mistrust of

health organizations and experiences of racism in healthcare (e.g., Haw et al., 2023; Spratling & Lawrence 2019). Beyond donation, racialized communities are also less likely to participate in research studies and clinical trials given historical and current experiences with racism and marginalization (e.g., (Scharff et al., 2010). To address some of these barriers to equitable participation, researchers recommend the use of community-based research with under-represented groups (Lemke et al., 2022).

Community-based research is an approach to research that invites communities to take an active role in guiding or leading the project rather than limiting them to the 'objects' of study. This methodology is based on principles of co-learning, power-sharing, and prioritizing benefits to communities involved (Israel et al., 1998; Israel, Eng, et al., 2005; Minkler, 2005; Viswanathan et al., 2004). Referred to by many different names (e.g., community-based participatory research, action research, participatory research, community-engaged research, and others), this approach to research has been gaining attention in health and health-related areas over the past two decades (Key et al., 2019). Involving communities in research that affects them is recognized as an effective and, in many cases, preferred approach to research with under-represented and under-served communities and has even become a requirement by some funding agencies such as the National Institutes of Health, Clinical and Translational Science Awards program (Key et al., 2019). Studies that work closely with communities and position them as partners in the research process have been shown to produce more valid and accurate data, greater success in recruitment of study participants, and development of effective interventions (De las Nueces et al., 2012; Key et al., 2019; McFarlane et al., 2022). Researchers who have applied this approach recognize that a "one-size-fits-all" model does not exist and instead attention to which community or communities are involved and their needs, the goals of the study, and contextual factors, among other considerations, should guide the specific approach taken (Fontaine et al., 2024; Travers et al., 2013).

Given the different ways in which community-based research has been applied and the different terms used, it is worth clarifying which terms we use and how in this paper. We use the term community-engaged research (CEnR) as the broader umbrella term that includes the full spectrum of approaches that involve communities as more than research participants only (Key et al., 2019). We use community-based participatory research (CBPR) to refer to one end of the CEnR spectrum that ideally involves community members throughout the research process, beginning with identifying community needs and development of the research question. On the other end of the spectrum is community consultation whereby the study takes a more conventional researcher-led approach and invites community input on some aspects of the study (Key et al., 2019). Characterizing CEnR approaches, including CBPR, along a spectrum is one way to approach the range of research studies that aim to foreground the role and voice of communities. Viewing different approaches to community-engaged work this way offers

flexibility to researchers and community members to engage in research that works for the communities involved, the needs being addressed, and the resources available. We take the view that innovation and creativity in applying CEnR approaches is needed given the range in research and community settings; however, we maintain that it is important that CEnR studies and researchers be attentive to the principles of community-based work.

In this paper, we describe a CEnR study we conducted on increasing the number of stem cell registrants (i.e., people who register to be on the stem cell registry) from under-represented racialized communities to the Canadian stem cell registry. *Racialized* and *racialization* are contextual terms and used here as social concepts whereby some people are racialized while others are not, despite everyone having a race or ethnicity. In Western contexts, people who are racialized tend to be those who are considered 'non-White.' Power and privilege is associated with whiteness, and therefore at a systemic level, racialized groups have less access to power and privilege than those considered 'White' (Dalal, 2002). Our project makes a significant contribution to the CEnR and stem cell recruitment literatures in a least two ways. First, by applying a CEnR approach and working with Community Advocates on stem cell recruitment, we demonstrate how we applied this approach to studying barriers to stem cell donation for racialized communities. Second, by expanding how we worked with Community Advocates beyond their contribution to a research study, we demonstrate how CEnR can be applied flexibly and in novel ways. That is, while community members were involved in guiding the research component through their input on research materials and scenarios presented in focus groups; their main role was in holding events to increase awareness of stem cell donation. In and through this work with community members, project leads aimed to apply CEnR/CBPR principles. Our aims for this paper are as follows: first, we contribute to methodological scholarship that provides in-depth description of the methods used and steps taken in CEnR research to offer transparency and detail that enables critical engagement. In particular we focus on the work of community members, several of whom are co-authors on this paper, given the central role they played in our project and in CEnR studies more broadly (a note on voice: community members took the lead in writing the section on swabbing events and therefore this section is written in their voice). Second, we offer a critical assessment of what went well and what could have been improved, or lessons learned, through a process that has been referred to as "retrospective reflection" (Travers et al., 2013). In doing so, we aim to contribute to ongoing debate and discussion regarding the role and involvement of communities and community members in CEnR projects and how this can be done in ways that are meaningful and transformative for community members and researchers. Details of running the focus groups and empirical results from focus group data are outside the scope of this paper (see [anonymized for review] et al. [manuscript under review] for focus group results).

We begin with an overview of CBPR given its significance as a methodology grounded in political aims of emancipation, anti-oppression, and transformation. Next, we describe our study, what we did, the work of community members including how decisions were made and the exchange between community and research team members. Lastly, we discuss challenges and what we learned by working on this project.

## Community-based participatory research

Community-based participatory research (CBPR) methodology has a long and rich tradition in diverse fields of study including education (Friere, 1970; Wilson et al., 2023) and research from an Indigenous paradigm (Smith, 1999). Based on principles of shared power and decision-making between researchers and community members, justice and equity, reciprocity in transfer of expertise, and action orientation, a CBPR approach offers "a potential tool for social justice activism" (Wilson et al., 2023). By involving community members throughout the entire research process from conceptualizing the research question through data collection and analysis, and knowledge dissemination, CBPR aims to address the power imbalance between researchers and those being researched, and to guard against extractive modes of research whereby the researcher takes what they need from communities with only secondary consideration for whether the communities themselves benefit. In its more exemplary applications, community control of the project and ownership of data are explicitly built into the study design (Travers et al., 2013). While, in theory, CBPR promises to address many of the limitations of conventional research, in practice, there are many challenges to CBPR including institutional and funding structures that require power and authority be held by researchers, and limited resources that often circumscribe what can be done (Freeman et al., 2006; Holkup et al., 2004; Minkler, 2005; Travers et al., 2013).

Health researchers are increasingly applying CBPR methodologies to address health disparities, improve healthcare access and outcomes for under-served communities, and develop culturally relevant interventions (Key et al., 2019). While referred to by some as a methodology, CBPR is better understood as a research orientation guided by principles that prioritize relationships and societal transformation over specific methods and techniques (Wallerstein & Duran, 2006). One iteration of these inter-related principles as outlined by Israel and colleagues (Israel, Eng, et al., 2005; Israel et al., 1998; Israel, Parker, et al., 2005) include the following: 1) recognizing the community as a unit of identity; 2) building and utilizing the strengths and resources of a community; 3) facilitating collaborative partnerships in all phases of the research; 4) Integrating knowledge and action for the mutual benefits of all partners; 5) promoting a co-learning and empowering process that attends to social inequalities; 6) involving a cyclical and iterative process to develop and sustain community/research partnerships; 7) focusing on local relevance of public health problems and ecological perspectives; 8)

disseminating knowledge gained from the CBPR project to the community and involve partners in the dissemination process; and 9) involving long-term commitment from all partners (see Table 1 for details).

Table 1. Principles of community-based research (Israel, Eng, et al., 2005; Israel et al., 1998; Israel, Parker, et al., 2005)

| | |
|---|---|
| Recognizing the community as a unit of identity | Community is an aspect of individual and collective identity; CBPR aims to work with existing communities of identity and to strengthen a sense of community through engagement. |
| Building and utilizing the strengths and resources of a community | Recognizes that all communities have strengths and resources and aims to build on these. |
| Facilitates collaborative partnerships in all phases of the research | Views all groups involved as equal partners in the research process and aims to share control over all phases of the project with community partners. |
| Integrating knowledge and action for the mutual benefits for all partners | Aims to build knowledge base while also applying an action-orientation to benefit the communities involved. |
| Promoting a co-learning and empowering process that attends to social inequalities | Views all groups as being experts and knowledge holders; facilitates the reciprocal transfer of knowledge, skills, capacity and power. |
| Involving a cyclical and iterative process to develop and sustain community/ research partnerships | Research takes a cyclical and iterative process with community involvement throughout (e.g., partnership development and maintenance, community assessment, problem definition, development of research methodology, data collection and analysis, and dissemination). |
| Focusing on local relevance of public health problems and ecological perspectives | Focusing on a positive model of health emphasizing physical, mental, and social well-being, and paying attention to social and ecological determinants of health. |
| Disseminating knowledge gained to all community partners and involving them in knowledge dissemination | Disseminating knowledge to communities involved and affected is prioritized; community members are involved to provide insight on what is most useful and useable. |
| Involving a long-term commitment from all partners | Views research as a long-term commitment between all groups involved; necessary for relationship and trust building |

As an approach to research guided by principles rather than a prescribed set of steps, CBPR has inherent flexibility to be adapted for the specific communities involved and their strengths, priorities, and needs. Health researchers have applied CBPR principles using a range of research methods [e.g., qualitative (Valdez et al., 2021), quantitative (Shaw et al., 2015), mixed methods (Gwede et al., 2013), and randomized control trials (Watts et al., 2020)], and to different topic areas [e.g., public health intervention (Bharmal et al., 2016; Tiwari et al., 2014), development of training curriculum (Gwede et al., 2013), engaging vulnerable populations (Boucher et al., 2022; Shaw et al., 2015), and clinical care (Cunningham-Erves et al., 2020)]. While, ideally, communities would be involved from the very beginning of the research project including identifying community needs and study objectives, few studies have applied this level of community engagement. Many studies involve community members in the study design, recruitment, and data collection, with fewer engaging community members in developing research questions, analysis, and dissemination (Gwede et al., 2013; Kaida et al., 2019). A recent systematic review of CBPR in clinical trials research has shown an increase in the number of studies applying this approach over the past 10

years, with most community involvement occurring through participation in a community advisory committee, data collection, development of interventions, participant recruitment and delivery of intervention (McFarlane et al., 2022). The authors of this systematic review found a smaller number of studies included community partners in identifying research questions, disseminating results, and participating in interpretation of research findings (McFarlane et al., 2022). McFarlane et al. (2022) also found that the studies in their review offered limited details on the nature and quality of the community engagement including the number of meetings held with community members and how decisions were made. Without these details, it is difficult to assess the extent to which these projects had a transformative effect versus reproducing a 'top down' approach (McFarlane et al., 2022). We agree with McFarlane and colleagues that CEnR/CBPR scholarship would benefit from more details provided on the nature of community engagement in the studies and aim to contribute to addressing this limitation in this paper.

## Our project: Piloting and evaluating a community-engaged strategy to build a diverse stem cell registry

### A community-led approach to building a diverse stem cell registry

This project was a 1-year study (May 2022 – April 2023) that was national in scope with the goal of providing recommendations to the Canadian Blood Services' (CBS) stem cell team on how to increase registration of racialized young adults. We operationalized the age of participants as 17-35 years old to match the age range cutoffs to join Canada's Stem Cell Registry. As embedded social scientists at CBS, the organization that recruits and manages the stem cell registry in Canada, except for the province of Quebec, the two leads on this project met with staff from the CBS stem cell team to learn more about their needs. Based on these early meetings and given the limited research on barriers and enablers to stem cell registration for the population of racialized young adults, we designed an exploratory qualitative study that included all racialized young adults rather than focusing on any specific ethnicities. Aims of the study were to 1) explore racialized young adults' knowledge of stem cells and stem cell donation; 2) assess recruitment and educational materials provided by the CBS stem cell team; and 3) identify barriers and enablers to stem cell registration and donation. Because research suggests that the most common way for some racialized young adults to join a stem cell registry is at a school event (Hamed et al., 2022), and in this context may make a decision to register in conversation with their friends or peers, we decided to hold focus groups with young adults to create conditions where they could consider questions about stem cell donation in dialogue with one another.

Reflexive consideration of the positionality of the project leads in relation to the populations that the project hoped to reach (one is racialized and the other is not; neither are young adults) coupled with knowledge of

mistrust in health systems, including blood operators, for some communities (Charbonneau & Daigneault, 2016; Charbonneau & Tran, 2015; Ferguson et al., 2022; Haw et al., 2022, 2023; Renzaho & Polonsky, 2013) and personal and professional commitments to equity-informed research led to prioritizing community-based research principles in the study. At the same time, the project leads were working with a one-year timeline which they knew from prior experience would require some flexibility in applying these principles given the length of time required for research ethics board approval, the multiple communities they were hoping to engage for this project, and the time needed to build relationships and trust with community members.

Project leads began the project from the premise that young adults from racialized communities are experts on their community and would know best how to effectively reach other young adults in their community. One of the priorities was to ensure that community members were involved in the project from the beginning and throughout the year-long study to support co-learning between community members and members of the research team and build on their strengths. With these principles in mind, 6 young adults from under-represented racialized communities were hired to work with us as Community Advocates (CA) on the project.

**Building a team of Community Advocates**

CAs were tasked with designing and holding two swabbing events over the course of the study, providing feedback and input on focus group questions and materials, and assisting with focus group participant recruitment. CAs were hired on a contract and were paid for their work on the project. Hiring CAs made it possible to pay them for their work recognizing the value and contribution of their time and expertise. Following their paid work as a CA, all six were invited to participate in an interview to explore and evaluate their work on the project. Interviews were voluntary and conducted by a research assistant on the team and not one of the project leads. The research assistant had worked closely with CAs throughout the project to provide resources and support for their events facilitating trust building between CAs and the research assistant.

As outlined above, one of the central ways in which community members are involved in a CBPR project is through their involvement in a community advisory group (McFarlane et al., 2022), consistent with the principle of *recognizing the community as a unit of identity*. In conceptualizing this project, there was no clear singular *a priori* racialized community that we were aiming to engage with. Instead, our objective was to increase engagement with under-represented racialized communities, which to group under a single community (i.e., 'under-represented racialized communities') would be an abstract group category imposed by researchers and likely not a relevant identity for people in these communities. As such, from the start, the notion of a singular community as a partner on this project was complicated and unclear. Other CBPR researchers have noted the political nature of designating any group as a "community" (Israel et al., 1998). To facilitate

a more bottom-up approach to identifying communities, we placed a job advertisement (paid position) for young adults between the ages of 17-35 who identified as racialized or BIPOC, had connections with their communities of ethnic ancestry and wanted to make a difference in their communities. We included information about stem cell donation and the stem cell registry and that they would be tasked with developing and implementing a recruitment strategy so applicants would know what they would be asked to do. They were not, however, required to have any prior knowledge about stem cell donation to apply for a position. Our plan was for the CAs who were hired to guide which communities we engaged with on this project.

Referring to young adult community members as CAs was an intentional decision made by project leads in the early stages of the project. Recognizing the range in terms used for community members on CBPR projects (e.g., community advisory group, community advisory board, etc.), we wanted to frame the work that community members would be doing as advocacy work for several reasons. First, viewing race-based health disparities in stem cell transplants as a matter of health equity, we situated increasing stem cell registrants from under-represented communities as addressing health inequities. This is consistent with health researchers who argue that the under-representation of some racialized groups in clinical trials is a matter of equity and social justice (Michaels et al., 2015). As such, we viewed the work that community members would do on this project as a form of social and community advocacy. Second, the young adults who were hired for this role were asked to do more than advise the research team and instead were being asked to develop, plan, and execute what they felt would be an effective strategy to recruit members from their communities to join the stem cell registry. In building this into the design of the project, we aimed to *build on the strengths and expertise of the communities involved, foster collaboration,* and *encourage co-learning between community and research team members*. Lastly, by foregrounding the work of advocacy in the title of their role, we aimed to centre the social justice and advocacy origins of CBPR.

The job advertisement was circulated as widely as possible through personal and professional networks of members on the research team and through student groups and clubs at universities and colleges across the country. Discussions with experts in stem cell recruitment and donation, advised that universities and colleges were promising institutions to target since they offer a concentration of people who fall within the eligible age range and have been successful sites for recruitment. Moreover, some university campuses have stem cell clubs which would potentially increase awareness of the need for this work among students. Our team of CAs was diverse in terms of ethnic ancestry and gender. While all were enrolled students, they represented a range in educational stage with some undergraduate, graduate, and medical school students. CAs also had a range in knowledge of and experience with stem cell registration and donation.

## Training and preparing Community Advocates

CAs were responsible for developing, planning, and executing two swabbing events (one in the fall and one in the winter), and for assisting with participant recruitment for the focus group component of the study. Moreover, some of the swabbing events that they designed were incorporated into the focus group interview guide as "scenarios" that focus group participants were asked to reflect upon and discuss. To ensure that CAs had the information needed to be able to do their work, project leads developed materials and held three training meetings in July and August 2022 to prepare and support CAs as they planned their fall events. Prior to the first of these meetings, an introductory package was produced and distributed. The package included 1) Welcome Document outlining the project, their role on the project, anticipated schedule of meetings, anticipated contributions (e.g., developing a strategy and holding a swabbing event, notetaking and journal entries), where to find more information and resources, and bios for all the CAs and research team members; 2) a peer-reviewed article on stem cell donor recruitment in Canada (Kum et al., 2022) – because all the CAs were post-secondary students we felt this article was appropriate; 3) two online news articles featuring a person in need of a stem cell transplant; and 4) a recruitment toolkit produced by the stem cell team at Canadian Blood Services for family and community partners.

The aim of the first meeting was to introduce all the members of the team and for the CAs to get to know each other, to provide a more in-depth overview of the project, and to guide the CAs in starting to think about the needs of their communities and strategies for outreach. In the second meeting, stem cell recruitment resources and ideas were shared with CAs, a local community advocate gave a presentation on community mobilization including challenges and opportunities, and CAs were given an opportunity to share and discuss the ideas they had for their initial fall event. Lastly, the third meeting included a presentation by a transplant hematologist and director of a national non-profit organization on stem cell recruitment on the science of stem cell transplants and recruitment strategies, a presentation by a parent whose child needed a stem cell transplant to provide a patient perspective, a presentation by members of the CBS stem cell team about the stem cell program itself, and an opportunity for CAs to provide updates and ask questions. Information about community mobilization and advocacy were presented before information about the science of stem cell donation to foreground the advocacy nature and health equity focus of their work. From our discussions with people who had been working in stem cell recruitment, we understood that people would sign up to the registry not because they were convinced of the science but because they wanted to make a difference in their community. To facilitate community building and formation of a group identity, a project Facebook page and Instagram account were created for the team to post and share information with each other along with a file sharing system on an online platform.

### Supporting and co-learning

To support CAs and provide ongoing opportunities for co-learning, monthly 1.5-hour meetings were organized for the CAs and research team beginning in Sept. 2022 through to April 2023. These meetings were instrumental in facilitating communication between the CAs and the research team members, but also for communication and co-learning between the CAs. The aim in holding these meetings was to facilitate a collaborative and equitable partnership between the CAs and researchers throughout the project. The day and time of the meetings were determined based on availability of the CAs. In these meetings, the longest agenda item was provided to CAs to share their ideas and present their strategy and plan for, first, their fall, and second, their winter events. They were encouraged to share any challenges in organizing and executing their events with the aim of offering a supportive space for collective problem solving. In sharing successes and challenges, our intent was to offer opportunities for co-learning. At the same time, we as researchers were learning from the CAs about the very real complexities and challenges of not only recruiting stem cell registrants in their communities, but any challenges they were facing. Because as a research team, we felt that some CAs may feel more comfortable to share experiences and challenges with a single person rather than a group, a research assistant had two one-on-one meetings with each CA over the duration of the project. One meeting was held in the fall and the other in the winter.

CAs also offered support and learning opportunities to the research leads by providing input on recruitment strategies for the focus group component of the study. The study aimed to recruit racialized young adults and CAs supported this work by providing feedback on the study recruitment poster content and by sharing the recruitment poster amongst their social networks. As trusted and embedded members in their communities, CAs were able to reach young adults that research leads could not.

## Community Advocates' swabbing events

Together as CAs we hosted a total of 13 stem cell events, with one CA hosting three and the rest of us hosting two events each. These events spanned two provinces and five different cities. We collaborated with a range of community organizations such as faith-based organizations (e.g., Greek Community Church and Chinese Church) as well as university student groups (Black Medical Students' Association of Canada (BMSAC) and the Ismaili Student Association (ISA)). The locations of these events varied, including community centers of our ethnic ancestry as well as places frequented by racialized communities (e.g., local Asian supermarket and community YMCA). While the details of the different events varied, most were of two main types. The first type of event was a stem cell registration booth that was set up at either a community event or organization, or university location and was endorsed by the community or student association (e.g., Greek Church following mass or ISA fundraising event).

Here, volunteers would invite people to approach the booth, provide information on stem cell donation, and invite people to swab if interested. The second type of event focused on disseminating information with presentations given on stem cell donation and the need for under-represented racialized young adults to join (e.g., church youth group monthly meeting or BMSAC annual meeting). Attendees of these events were also offered an opportunity to swab.

To facilitate these events, many of us reached out to leaders in our community of ancestry and in some cases, went through family members to make introductions. Due to practical challenges with organizing events, for two of us our second event was not specific to our community of ancestry but instead focused on other racialized communities that we were connected with through campus initiatives and/or personal relationships (e.g., Tamil Community as well as Filipino and Caribbean student associations). Leading up to these events, we used several different strategies to advertise and let community members know about our event. These included formal community channels such as mailing lists, community newsletters, and faith leaders making a formal announcement about stem cell donation following service. We also used university clubs to promote the event through social media and traditional advertising methods such as posters. We took it upon ourselves to market our events personally and broadly by posting on social media and getting friends, family, and community members to share information as well (e.g., Instagram, WeChat, Facebook) in addition to using word of mouth within our community.

## Common themes: what we, the CAs, learned

### *Sharing personal stories and raising awareness of stem cell matching were effective*

Overall, all the events ran smoothly. We swabbed several people and informed many others on the importance of stem cell donation. Across our different events, we noted two themes that helped support our work. For both types of events, sharing stories was effective. During one of the information presentations, one CA shared a story about a patient who passed away waiting for a stem cell transplant as well as one about someone who received a transplant and was cured of their illness. These stories had a profound impact on the attendees and prompted several to swab as well as look into stem cell donation further. Another strategy that worked very well across events was emphasizing that people are more likely to match with someone of the same ethnic ancestry. This suggested to us that many people want to give back to the community that has helped them all their lives.

### *Timing, location and attendee make-up were challenges*

Across all our events we also noticed similar challenges. A large issue was the demographic makeup of the attendees present at the event. For a few events almost all attendees were above the age of 35 and thus were

ineligible to join the stem cell registry (e.g., Community Church or Asian supermarket). The events that did not have this issue were the ones hosted at universities and in conjunction with clubs organized around a specific ethnic or ancestral community (e.g., BMSAC and ISA events) as universities house an extremely diverse population, and the eligible age range. Another issue we ran into was the timing of the events themselves, both at the time of year and time of day. A few events were hosted around the exam period for schools and thus had a decreased turnout or interest of the targeted demographic. One event held during the winter had to pivot because of bad weather which also led to lower turnout. Other events took place around lunchtime and also had very little turnout during those hours. Along with the timing of the event, the location was crucial. Having a booth in visible, high traffic areas led to a dramatic increase in interest as people were much less willing to search for a booth rather than stop by one.

### *Community connections were invaluable*

Having a connection with the community we were working with was crucial in building trust with people. As we hosted events both in our ancestral community as well as outside of it, we found it much easier to plan the event as well as have engaging conversations with attendees when we already had a connection to the organization. Not only was trust built due to the event being hosted by a member of the community, but also because several of the events were endorsed and advertised by the leaders of the organization. Members have a great deal of trust placed in community leaders, and hearing about the event and its importance from them goes a long way in breaking down that initial barrier of mistrust. This extended to student groups at universities as well and since several of our booths "piggy-backed" off cultural events, people were much more likely to engage in conversation.

### *Building ongoing relationships is necessary*

A final important theme across all our events was the importance of longer-term and ongoing relationships with the communities we are a part of and working with. The first event was always the most difficult as many people had never heard of stem cell donation and were skeptical of it. As we only worked as CAs for one year, we were unable to fully create an ongoing relationship as a liaison between Canadian Blood Services and our community. However, we as CAs believe building relationships and working with communities over time while continuing to host information and swabbing events would be extremely beneficial in building trust and recruiting under-represented racialized people to the stem cell registry. Although we believe universities are a fantastic location for hosting stem cell drives, there are groups outside of universities that are eligible to register and using this longer-term approach with communities may be an effective way to engage these groups. As several ethnic communities host large outdoor festivals in the summer, we suggest investigating the use of stem cell booths at these events given the large turnouts and diverse demographics.

Unfortunately, we were unable to do this ourselves as the dates for these events did not align with the timeline of the project, a challenge that we discuss further below. Overall, we believe that this project was a success and that working as CAs offered a productive way to recruit under-represented groups to the stem cell registry.

## Challenges and lessons learned

### Fostering co-learning, equitable partnership, and power-sharing

A priority of this project from the beginning was fostering co-learning between research team members and CAs. Project leads developed the project with the view that racialized young adults are experts on their communities and know how best to reach them. Despite a commitment to co-learning, much of the knowledge sharing in the front end of the project during the training sessions was from the research team to the CAs with less opportunities built into the sessions for CAs to share knowledge with the research team. Because project leads felt there was a lot of information to share with the CAs at the start of the project and to ensure that they had the information needed to do their work, training sessions focused on providing knowledge to CAs. However, reflecting on the project, much could have been gained by offering CAs more opportunities to share their knowledge and expertise. While CAs were asked if they had any information to share during these training sessions, in retrospect, structuring time for CAs to lead and share knowledge about their communities and their prior experience would have been a better approach to facilitate co-learning.

Moreover, for studies such as ours where community members take on a role that is new for them, facilitating co-learning could be enhanced by providing CAs with specific questions or topics to guide the knowledge that they have to share. For example, asking CAs to share earlier on in the project about their communities, who makes up their communities, how they view their communities, how they are organized, the roles they play in their communities, and what they saw as potential challenges and opportunities to doing this work with their communities would have proven helpful. Instead, research team members learned later in the project about the many complexities of communities, the open and flexible boundaries of some of them, and the desire by many not to be limited to only their community of ethnic ancestry. Many people identify as belonging to many communities and we learned that this should be recognized and viewed as a strength at the outset of the project, rather than researchers reducing individuals to belonging to one particular community.

As other researchers have noted, equitable power sharing and addressing the power differential between research team members and community members on any CBPR project is a challenge for several reasons including funding and research structures that place greater responsibility and power in the hands of researchers (Travers et al., 2013). Despite these challenges, efforts should be made to minimize the power differential as much as possible. In

hindsight, there may have been opportunities for project leads to offer more decision-making power to CAs. For example, project leads drafted the agenda for all the meetings and chaired the meetings. Although the agenda was quite open with dedicated time for CAs to share how their work was progressing, asking CAs to lead some of the meetings may have been a more effective way to share power and decision making. Some of the CAs may have welcomed an opportunity to set the agenda and chair which would also have put them more in the 'driver's seat' so to speak and offer them the opportunity to organize a meeting around the items that they felt were most important or pressing. Because project leads set the agenda, it is possible that there were items that were missed or did not receive the attention needed. Secondly, as many of the CAs were in the earlier stages of their academic careers, providing them with an opportunity to lead or co-lead these meetings may have enhanced their professional skills and *increased capacity building*. Lastly, for those who may have chosen to co-lead a meeting, this may have facilitated collaboration and relationship-building between different CAs. Another idea that some CAs suggested was to hold more meetings with smaller groups in addition to the monthly meeting to allow for more discussion amongst CAs. This may have encouraged some CAs to take on more of a leadership role in the study.

**Building relationships and time constraints**

As noted above, CAs recognized the importance of building relationships with community members over time to continue to be effective in their efforts to raise awareness of the stem cell registry; however, timelines for the project did not make this possible. While noting this as a challenge to their work rather than a challenge within the team, it is relevant to this discussion in that what CAs recommended could not be built into the project given the timeline established at the outset. Beyond this, a principle of community-based research is *long-term commitment from all partners* involved to allow for, among other things, meaningful relationship- and trust-building; however, our work did not continue beyond the proposed project. This raises, for us, an important question regarding what *long-term commitment* means and looks like and what is possible for different community members and research teams. While, in theory, ongoing relationship building and collaborative work strikes us as an important and worthwhile aim, we also recognize that for many CAs, who are at different life and academic stages, it was not feasible to continue ongoing research work together. Having noted this, it is worth reflecting on what is meant by *long-term commitment* and if there are ways to practice this outside a formal research project. For example, we have continued to work together to produce outputs from our project, such as co-authoring this paper together. For CAs who are pursuing advanced degrees, co-authoring a peer-reviewed publication is a meaningful output. Further, the knowledge CAs gained through this experience could mean they become advocates for stem cell donation later in their training or in their lives. Other forms of long-term commitment may be

a commitment to maintain communication, share updates and outputs, and resources as they become available beyond completion of the project. This kind of commitment, we suggest, need not be bound by any formal timeline but can continue for as long as it is of benefit to the people involved.

CAs also recognized the importance of building relationships in their work with their communities and the challenges of time constraints including the one-year timeline of our project. This raises the importance of the principle of *long-term commitment* for relationships beyond those between researchers and community members for projects such as ours. One way to approach this challenge may be to consider how relationships might be maintained at an organizational level in addition to the interpersonal level. Young adults, such as CAs, and other community members may not themselves be able to maintain relationships over the long term, but they may be able to act as a bridge or liaison to build relationships for organizations involved. We did not do this in our project, however, would build this into future projects of this kind.

### Resource limitations and contextual considerations

Most projects must work within the resources available including the funding timeline which also impacts the scope of the project and what can be done. For our project, because of the 1-year timeline, CAs and the research team were required to act quickly from the start of the project. While CAs were successful in holding two events (three events for one CA) in several cities, if more time were available, they may have been able to hold additional events. Because swabbing events were held in person, events were held in the city or surrounding area where CAs lived at the time of the project. With more time and resources, this project could have had wider reach by hiring more CAs in additional provinces and cities. Lastly, while research leads did not intend at the outset to hire only CAs enrolled in university programs all CAs were university students. As university students this provided them with affiliations and contacts within their university as well as with their local ethnocultural communities. While some worked with university clubs, others hosted their events through faith-based, ethnocultural groups in their local community. Their social location as university students provided access to and familiarity with the cultural milieu of university settings. On the other hand, it is possible that for some CAs their "student status" may have unintentionally added to challenges in follow through from community leaders and greater reliance on family members or contacts to facilitate communication with community leaders.

## Conclusion

In this paper, we describe in-detail our approach to applying CBPR principles to a project aimed at understanding barriers and enablers to joining the stem cell registry for racialized young adults. Consistent with a broader view of community-based research (Key et al., 2019), we consider our work to be a CEnR project with our commitment to and engagement with

community members throughout the project. Community advocates engaged in the project learned that sharing personal stories, emphasizing the connection between stem cell donation and genetic ancestry, and connecting with leaders in the community were effective strategies to build the registry. They faced challenges with timing and location of the events and learned that having longer-term and ongoing relationships with communities involved is necessary for future work. Project leads also gained knowledge about the opportunities and challenges with using an CEnR approach. Project leads could have fostered shared decision-making power and autonomy among community advocates by creating space for CAs to share their knowledge and expertise, by asking them to discuss what community meant to them at the outset, and asking them to lead meetings. Our challenge with power-sharing and decision-making is not unique to us and we suggest that given the critical importance of this principle in CBPR/CEnR research, that research team and community members continue to have transparent discussions about how to do this better. Finally, as a project that included both an intervention or action aim (i.e., the events held by CAs) and an empirical aim (i.e., focus groups with young adults in the community) with CAs primarily being involved in the intervention, we suggest that our project offers an example of extending CBPR/CEnR principles in a novel way. We encourage researchers who have a commitment to equity-focused work to consider how CBPR/CEnR principles might be applied to their work, and to share creative ways of doing CEnR well.

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