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Lessons Learned Developing Client Navigation for People who are Trans and Gender Diverse

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Note: One of our co-authors, Lori Ebbesen, passed away during the development of this article. She was a foundational member of the team, who helped build the team and lead early discussions of the project's direction, including setting up the team's collaboration style. The initial idea for this paper was hers. We are ever grateful for her tremendous contributions to this work, and thank her, and her family for supporting this project. She is dearly missed.

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ABSTRACT

Background: People who are trans and gender diverse (PTGD) are underserved regarding healthcare in Canada, including the province of Saskatchewan.

Objectives: Design and conduct a research project that will address immediate and pressing community-identified needs related to improving access to healthcare for PTGD in Saskatchewan.

Methods: A multidisciplinary, community-based collaboration was established to address the self-identified obstacles to accessing healthcare of PTGD in Saskatchewan. This resulted in a pilot study creating and evaluating a healthcare navigation program.

Lessons Learned: The project led to four key lessons: 1) prioritizing team building and the well-being of team members; 2) committing to community-based participatory approaches from the outset; 3) taking language seriously and; 4) acknowledging and addressing power imbalances in our team.

Conclusions: The lessons learned have enabled us to sustain a large, diverse, research team that centers the experience of PTGD in Saskatchewan and is responsive to community need.

KEYWORDS

Community health partnerships, Community-Based Participatory Research, Community health research, Community Engagement, Gender Diversity, Transgender, Client Navigation, Patient Navigation, Canada

Introduction

People who are trans and gender diverse (PTGD) are underserved regarding primary healthcare in Canada. A 2019 survey of PTGD across Canada reported that 45% of respondents had unmet health needs in the previous year compared to 4% of the general population, with those experiencing intersecting forms of oppression even more likely to encounter barriers to care.[1] In Ontario, Canada, researchers have found that PTGD are less likely than others to have a primary care physician, and "more likely to live in lower-income neighborhoods, experience chronic health conditions," and "have higher health service use than the general population".[2]

In Saskatchewan—a province in central Canada with just over one million people—healthcare for PTGD in Saskatchewan lags behind much of the country. For example, Saskatchewan is one of the few provinces that requires referrals from two physicians (including one psychiatrist) to access transition-related surgeries. This approach requires that PTGD prove their mental integrity to a psychiatrist, often one with whom they do not have an existing rapport. Further, young PTGD in Saskatchewan (and the neighboring province of Manitoba) are more likely than those elsewhere to report a chronic health condition, and less likely to have a primary healthcare provider.[3] Further, while 95.8% (n=180) of primary care providers surveyed in Saskatchewan indicated that they were comfortable providing non-transition-related care to PTGD, only 30.3% (n=57) were comfortable providing transition-related care,[4] suggesting family medicine providers may need additional training to support the transition-related needs of PTGD.

In January 2018, community members established the Saskatchewan Trans Health Coalition (STHC),[5] to address the need for need for evidence-based information about the health of PTGD. The Trans Research and Navigation Saskatchewan Project (the TRANS Project) was subsequently established as a collaboration between the STHC, healthcare providers, community members, representatives of Two-Spirit, lesbian, gay, bisexual, trans and queer (2SLGBTQ+) service organizations, specialists from government, and university researchers.

This paper examines how the TRANS team created a research project that responds to the pressing, material, community-identified need for research to improve access to health care for people who are TGD in Saskatchewan. More specifically, it details how we have established and maintained a large and diverse research team, how we began piloting and evaluating a client navigation for people who are TGD in Saskatchewan, and the lessons we have learned in the process. In doing so, we identify what we learned about conducting responsive community-engaged research with a large, diverse, community-driven team, and provide recommendations for others seeking to do the same.

Background

Research on the health of PTGD has a long and fraught history. Relevant scholarship—what little existed in the mid-twentieth century—is marred by studies that were traumatic, voyeuristic, and pathologizing for participants, and ignored their lived experiences.[6,7] Research was historically conducted by "outside researchers coming into the community to act on a specific agenda with little, if any community involvement," and resulted in work that had little direct impact on the lives of PTGD.[6]

Since the mid-1990s, communities have been organizing to fill these gaps in research. One of the earliest was Transgender Community Health Project, a participatory action study that responded to a community-identified need to study HIV prevalence and risk behaviours among self-identified transgender people in San Francisco.[8,9] The TransPULSE project later emerged in the Canadian context from the recognition that to advocate for changes in public policy and service provision, community-led research was sorely needed.[10]

The centrality of PTGD in relevant studies is critical not only because of the history of exclusion and pathologization, but also because PTGD are experts in their own lives. Leadership and engagement in study design and execution means not only is a study more likely to respond to community need, but it is also likely to reach relevant participants, to collect data in ways that are culturally sensitive, and to disseminate results where they can have an impact.[11] Further, insofar as PTGD are a relatively small population, centering communities in conversations about what research is needed, useful, and most appropriate can prevent research fatigue.[12]

This approach—building research with those most affected by a community need—is part of a growing commitment to community-based participatory approaches to research in health.[13] This approach presumes that research about marginalized communities must involve relevant community members "in all aspects of the process, enabling all partners to contribute their expertise and share responsibility and ownership".[13] In community-based research with, by, and for PTGD, there are particular ethical considerations for the conduct of research, namely: "attentiveness to issues of legitimacy and impacts on communities; engagement with communities, consent and confidentiality; consideration of diversity, power, marginalization, and representation; accountability to participants and trans communities; and reflexivity on the part of researchers and research teams."[14] For the TRANS Project team, an ethical, community-based participatory approach, building on decades of community-led research has been a critical starting point.

Methods

Developing the partnership

In January 2018, the STHC was established and identified that an ongoing, comprehensive research program was essential to meeting its mandate of advancing the health of PTGD in Saskatchewan. Both co-principal investigators of what would become the TRANS Project attended the STHC’s first meeting and were asked to lead the research because of their academic positions and demonstrated commitment to the health of PTGD. Although we were not sure about what form the research would take, we knew it would centre the STHC'S mandate.

The project team quickly grew and it now numbers nearly thirty people—including healthcare providers, representatives of 2SLGBTQ+ community organisations, specialists from the Saskatchewan Health Authority and the Ministry of Health, and academics in medicine, physiotherapy, nursing, policy studies, education, and philosophy, with many people occupying more than one role (see Table 1). We started by assembling interested folks through the co-principal investigators’ networks with the support of a research facilitator, but as people joined, they identified others who might be interested in joining the team.

From the outset, we have worked to create rapport: holding meetings on a regular basis (at least quarterly) and exchanging updates, questions, and resources, via email. The meetings are facilitated by the co-principal investigators, and the tone is friendly and supportive. They are opened by icebreakers and follow an agenda with time allocated to sharing concerns, ideas, and experiences. Emphasizing what we are doing in our lives—rather than our expertise or our educational backgrounds—helps us engage as individuals committed to the project, rather than as “experts” or “those with lived experience” (or both at once). Our team decided early on that we would take a “nothing about us, without us,” approach to all aspects of the project, including at least one team member who identifies as TGD in all project activities (e.g., data collection, data analysis, manuscript drafting, presentations).

Building the team has not always been straightforward. Members of community organizations have dedicated significant time and resources to the project, but often in a context where their organization is under-resourced, requiring them to contribute "off the side of their desks." Others participate in meaningful ways but are doing so in addition to already-busy personal and professional lives. An important challenge for our team has been at once recognizing that academics and healthcare providers often have more resources, time, and capacity to engage, but that community members can and should be leading our work.

Creating the client navigation program

Although we established a research team without a specific project in mind, early on, members of the team who are TGD emphasized that the work should prioritize the *immediate* and *material* wellbeing of PTGD in Saskatchewan. An approach strongly endorsed by the team was the use of client navigators in order to improve access to healthcare. Navigation programs were first established in Harlem, New York in the context of breast cancer care, to increase screening and diagnosis among low-income Black women,[15] and studies have since demonstrated their effectiveness in other populations,[16,17] indicating that navigator programs can improve both access to care and feelings of support. An environmental scan of relevant programs in Canada[18]—together with TRANS team members' experiences of "falling through the cracks" of existing healthcare services—suggested that a healthcare navigator program could have an immediate impact. Working backwards from a potential intervention to more specific research questions also kept our team focused on making tangible improvements to the lives of PTGD.

We received funding to pilot a client navigation program and received ethical approval from the University of Saskatchewan (BEH-1897).

At the time of writing, the year-long client navigation pilot program is complete (although there is funding to continue some services). Because Saskatchewan is geographically large (651,900 km^2/251,700 mi^2) with two small cities, at least two navigators, one each for the Northern and Southern regions—were needed to serve the province. The two navigators have been working directly with clients who are TGD, providing information, developing pathways to care, helping people have discussions with health care providers, and assisting people through the difficult process of accessing trans-related surgeries. The navigators also communicate and collaborate with 2SLGBTQ+ organizations to coordinate care, provide education to healthcare providers, and lead community projects (e.g., an ongoing support group for youth ages 11-16). On the suggestion of a team member with legal expertise, the navigators completed notary public training, subsequently holding a legal name and gender marker change clinic. As their pandemic-related needs for clients emerged during the COVID-19 pandemic, the navigators also organized a trans-friendly vaccine clinic. Their work evolved to address community need as it arises.

We have been collecting data to evaluate the program throughout via navigators' anonymized journals, use statistics, and post-service satisfaction surveys. We conducted baseline focus groups with PTGD about healthcare access as well as interviews with clients and healthcare providers who used the service. The initial analysis shows that, during the year of the pilot project, the navigators provided support to 259 individual clients with over 90% contacting the navigators more than once. The satisfaction surveys found that 86.7% of respondents were satisfied with the navigator service and 83.6% reported increased confidence accessing healthcare. The navigators also provided support to 66 healthcare providers, including family physicians, nurse practitioners, mental health providers, and specialist physicians, with more than 50% contacting the navigators more than once. The navigators provided them with information, education, and connections to more experienced providers, and on the satisfaction survey 80.9% of respondents reported increased confidence providing healthcare to PTGD.

Lessons Learned

One principle for the ethical conduct of research with trans communities is "reflexivity on the part of researchers and research teams,"[14] and as we have proceeded through the project, we have been reflecting on what we have learned thus far. We speak often about how the project going, and what we are doing to ensure that our work together goes well. For this article, a subcommittee of our team developed a list of ten things we learned about working as a large and diverse team to create a project designed to improve access to care and addressing an immediate and pressing need. The authors then revised the long list into four "lessons learned."

Take time to build a team and prioritize their well-being. Perhaps the most important lesson of this project has been the need to build a team with a range of experience and expertise. This is particularly important insofar as the project started with the STHC approaching two researchers with a broad purpose but without specific research questions in mind. Embracing those interested in working with us has at once strengthened our work, while building future capacity among our team members and community. It is part of our reflective practice to continually reconsider if our team has the representation, experiences, and expertise we need, and how to best incorporate new members. This has also been a good strategy for increasing research capacity among PTGD in Saskatchewan, while ensuring that the research produces meaningful change.

As a team comprised of people with a wide range of experiences and social power, we emphasize the well-being of our team members over productivity. This has been important for team members whose job do not include research activities and people who have limited capacity due to disability, shifts in personal and professional responsibilities, and has ensured that people can be more or less active in the research when it fits their lives.

Commit to community-centered, participatory approaches, listening to community first. To ensure that the project is responsive to people who will use it, PTGD have been central to all stages of this project from conception to knowledge dissemination. This means not only ensuring that every aspect of the work includes at least one PTGD, but also continuously finding strategies to address voices not being amplified. We have learned, however, that it is harder than we expected to keep PTGD central to all stages of the project. It was relatively easy at the beginning when people initially committed their time and capacity but other demands in members' lives consumed their research time, we were required to find new strategies to ensure that the voices of PTGD were continuously being amplified. This included switching to more email communication and welcoming new team members throughout the project.

Language Matters. Engaging in our projects that involve a large team and people with a range of experiences has meant we have had to find a common language for our conversations. We have learned to come to meetings ready to speak with one another in plain language, to decide on contentious language issues early through conversation and consensus, and to ask frequently if we need to clarify ideas or explain terms. This has created a welcoming atmosphere. One team member has noted that: "What I feel during meetings is that I don't have to cover or code-shift. I mean this both as not having to hide or tone down my queerness or disability and in not having to shift completely into the role of an academic, and cease being a person."

When our team first started working together, we developed common approaches to the use of language, deciding in consensus that we would reflect "person first language" by using the term "people who are TGD" rather than TGD people. There have also been instances where members of the team were not comfortable with certain language. In one example (for an early draft of this paper), we initially wrote "all team members are equal" which some felt did not reflect the differences in power, privilege, and resources among team members. Engaging in this way requires an honest and compassionate approach that assumes everyone is participating with good intentions. It also requires that we address conflicting points of view directly when they arise, always acknowledging the value of diverse viewpoints, and working through challenges together.

Acknowledge and address power imbalances. Facilitating a culture of openness in a large team—with our broad range of experiences and expertise—is an ongoing challenge. Unfortunately, due to the small size of the community in Saskatchewan, there is little overlap on the team between PTGD (primarily recruited through their involvement in activism, and/or 2SLGBTQ+ service organizations) and academics and healthcare providers. This has meant that those able to participate in a professional capacity on the project are, for the most part, not team members who are TGD. We have taken a range of approaches to address this disparity from hiring PTGD as research assistants wherever possible, to ensuring that PTGD are in meaningful positions to make decisions and providing space in our regular meetings to prioritize the voices and perspectives of PTGD, but the challenge persists. This still means that the work of identifying problems and creating safe(r) spaces often falls to team members who are TGD, but it is something that our team both acknowledges and works to address.

Conclusion

The lessons we learned in the development of the TRANS Project lend themselves to a number of recommendations for other teams engaged in large community-engaged projects. Allotting sufficient time for team-building prior to the initiation of research activities and in every meeting can ensure that the responsibility of carrying out the research does not lie with any one individual, and there is "buy in" to the project from the start. Others too could build on our commitment to prioritizing community voices and experiences. Our project came from the community—a request by the STHC for research project could improve access to healthcare for PTGD in Saskatchewan, and we have worked to prioritize PTGD voices throughout the project. This prioritization of community voices is, to be clear, a lesson we take from decades of similar community-engaged participatory research, but this approach also recognizes that if a project can fill a need identified by community members, it should be flexible enough to do so. In this case, we recommend building flexibility into the timeline and budgets of community-engaged projects to respond to at least some needs as they emerge. Regarding both language and power imbalances, the way we speak to one another matters, and it is a constant reminder of how we are engaging in the project as people using our respective skills, resources, and capacity to work towards a common goal. Speaking without jargon is one way that we address and acknowledge power imbalances and our diversity of experiences, and we recommend to other teams of this kind to think carefully about language, to pay attention to who speaks in meetings, and to otherwise consider who may feel included and excluded from the project.

For PTGD in Saskatchewan, however, the need for research, but also access to healthcare, is acute, and we have been responding to both needs while taking action. The TRANS Project intervenes through a navigator program to improve access to healthcare for PTGD in the province. We have learned the importance of building and sustaining a large, diverse research team that includes PTGD, healthcare providers, 2SLGBTQ+ organisations and researchers. We strive to reduce power barriers among team members, and we are continuously evaluating and adapting the intervention to ensure that it is addressing community needs.

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Table 1

Role	Number of members	Representing
People with lived experience	28 (20)	People who are trans and gender diverse, as well as those with other lesbian, gay and queer identities. The group includes 2SLGBTQ+ organisation representatives, independent community members, as well as members in the other groups.
Researchers	8 (6) *6 (4)	Medicine, physiotherapy, nursing, policy studies, education, women's and gender studies, and philosophy
Healthcare providers	8 (7) *4 (3)	Medicine (family medicine and psychiatry), social work, occupational therapy
Other stakeholders	2 (1) *both with lived experience	Ministry of Health and Psychiatry
Research facilitators	2 (0) *neither with lived experience	Rehabilitation Science and Policy Studies
Research assistants	7 (5) *6 (4)	Navigators, research assistants at the undergraduate and graduate levels

Total number of team members from the inception of the project is 36, which includes 9 previous members. Seven have moved on because of changing professional and personal needs, and two have died. The number of members on the table exceeds the total number of team members because there are people with lived experience in most of the other categories and some of the healthcare providers are also researchers or decision makers. Currently, there are 27 team members. The number of current team members in each category is indicated in brackets.

* Indicates the number of team members with lived experience in each category. The only research assistant without lived experience is a volunteer.