'Community control' in CBPR: Challenges experienced and questions raised from the Trans PULSE project

Robb Travers
Wilfrid Laurier University, Waterloo, Canada

Jake Pyne
Trans PULSE Project, Ontario, Canada

Greta Bauer
The University of Western Ontario, London, Canada

Lauren Munro
Wilfrid Laurier University, Waterloo, Canada

Brody Giambrone
Trans PULSE Project, Ontario, Canada

Rebecca Hammond
Trans PULSE Project, Ontario, Canada

Kyle Scanlon
519 Church St. Community Centre, Toronto, Canada

Abstract

Newer forms of community-based participatory research (CBPR) prioritize community control over community engagement, and articles that outline some of the challenges inherent in this approach to CBPR are imperative in terms of advancing knowledge and practice. This article outlines the community control strategy utilized by Trans PULSE, an Ontario-wide research initiative devoted to understanding the ways in which social exclusion, cisnormativity (the belief that transgender (trans) identities or bodies are less

Corresponding author:
Robb Travers, Department of Psychology, Wilfrid Laurier University, 75 University Ave. West, Waterloo, Ontario, N2L 3C5 Canada.
Email: rtravers@wlu.ca

authentic or 'normal'), and transphobia shape the provision of services and affect health outcomes for trans people in Ontario, Canada. While we have been successful in building and supporting a solid model of community control in research, challenges have emerged related to: power differentials between community and academic partners, unintentional disempowerment of community members through the research process, the impact of community-level trauma on team dynamics, and differing visions about the importance and place of anti-racism work. Challenges are detailed as 'lessons learned' and a series of key questions for CBPR teams to consider are offered.

Background and rationale

A growing literature addressing the value of community-based participatory research (CBPR) is showing promising evidence about its practical application and contribution to solving real world problems (Viswanathan et al., 2004). CBPR is a process for undertaking research that involves community and academic partners committing to identifying, researching, and offering solutions to the complex challenges facing communities (Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2003). CBPR also strives to use transparent and equitable decision-making structures, open writing and publishing processes, maximum attention to the marginalization that communities face, maximum respect for community knowledge, and a full commitment to community engagement and action outcomes (Flicker, Travers, Guta, Macdonald, & Meagher, 2007; Minkler, 2005; Travers et al., 2008).

Stoeker (2012) notes that CBPR is offering communities access to the 'knowledge-power' loop, thereby positioning them as *creators* of knowledge rather than passive recipients of so-called 'expert' knowledge, which can be inaccurate and oppressive. Yet, as CBPR gains credibility, new questions are emerging about the inherent challenges in operationalizing its principles (Stoeker, 2012; Travers et al., 2008). For example, while CBPR appears to address ethical considerations and questions, such as whether communities are consenting to, benefiting from, or being harmed by research (Guta et al., 2010), questions remain about who is really in control of the agenda in CBPR. For example, Jacobs (2010) speaks to the need to 'truly empower' community members by being open to them as 'co-thinkers' and 'co-organizers' at all stages of a research project, in order to be really successful.

Critical questions about real and meaningful community participation in CBPR have been raised through Stoeker's (2012) analysis of funding protocols to a US-based funder of action-oriented research. Community-based organizations or community members were rarely involved in helping to define research questions or

study methods, and few studies explicitly linked research goals to action-oriented outcomes. Indeed, the greatest involvement of community members was likely to occur during data collection, raising significant doubts about any meaningful power sharing between community and academic partners (Stoeker, 2012). Travers et al. (2008) found a similar set of challenges facing Ontario's HIV/AIDS sector, despite its reputation as being an international leader in CBPR. Community members tended to be more involved in knowledge dissemination stages of research, while academic researchers were in greatest control during study formulation and data collection stages (Travers et al., 2008).

'The right amount of community participation'?

For some time now, academics have attempted to theorize models of citizen participation that would move lay people from tokenistic roles in partnerships with academics into roles characterized by greater decision-making and power-sharing. Articulating a typology of citizen participation, Arnstein (1969) differentiates the amount and depth of citizen participation according to gradations of non-participation, tokenism, and citizen power. Pretty, Guijt, Thompson, and Scoones (1995) offer another model with 'no participation' on one end of the spectrum of involvement and 'self-mobilization' of community on the other. Ray (2007) distinguishes between 'traditional' (community members provide information), 'consumerist' (community members are there for researchers to achieve their end goals) and 'democratic' (a model of community involvement in research partnerships, where the latter attempts to redistribute power. Common to all CBPR models are the democratic and empowering characteristics of community engagement, and a genuine desire to challenge dominant power arrangements (Jacobs, 2010). However, at one end of the CBPR spectrum are more 'traditional' forms of research processes that value community input while academic researchers retain control, ownership and management. At the other end, are newer forms of CBPR that position community members as 'owners' (instead of 'partners') of projects. The 'Community Owned and Managed Research Model' (Heaney, Wilson, & Wilson, 2007) is just one example of such an approach in which communities retain control, ownership and management, while choosing academic partners and 'valuing' their input through collaborative memoranda of understanding. While 'community-owned' research is gaining in popularity as a new frontier in CBPR, reflections on some of its successes and challenges will be helpful in enhancing the work of future CBPR teams.

Method

This article describes the strategy and approach used by an Ontario, Canada, CBPR collaborative – Trans PULSE – to develop and implement a project that was firmly committed to prioritizing community needs and concerns, valuing lived experience, and attending to action outcomes. On the CBPR spectrum, Trans

PULSE has committed to (and operationalized) community control, while retaining funding and management within academic settings in order to work within established bureaucratic frameworks. In presenting this strategy, we attempt to provide a concrete example of one way of conceptualizing and operationalizing a CBPR project – one in which discourse was, from the beginning, less about 'community engagement' and much more about 'community control'. We describe the history of the project, as well as the development of its innovative community engagement and capacity-building strategies. Through a process of retrospective reflection, we offer some of the important lessons learned along the way about this approach, and some questions for other CBPR teams to consider in their own work. The authorship of this paper is made up of a mixture of academic researchers, community investigators and students from Trans PULSE.

Our individual and collective reflections, which incorporate learnings from conversations throughout the project are represented throughout. Given that we represent a subset of Trans PULSE, and that we as authors experienced the project as individuals within a larger group dynamic, it is important to note that differing interpretations of a similar issue or phenomenon may exist but we were able to arrive at consensus in this article. As such, we are reticent to make bold conclusions such as 'x caused y', and instead, we draw upon the wisdom provided by others in the literature to frame our understanding of phenomena that are actually, at times, quite complex.

Key aspects of community ownership in the Trans PULSE project

Trans PULSE is an innovative, mixed-methods, CBPR project that responds to problems and concerns identified within Ontario trans[1] communities regarding health and access to health and mental health services. The project is particularly centered around understanding the ways in which social exclusion, cisnormativity (the belief that trans identities or bodies are less authentic or 'normal'), and transphobia shape the health of, and provision of services for, trans people in Ontario. Some of Trans PULSE's focus areas include: employment and income, housing, health care, transition-related care, relationships and family, sexual health, HIV vulnerability, mental health, community connectedness, and access to social services. The team has a successful history of funding from foundations and provincial and federal granting bodies,[2] and of production of research results for multiple audiences.[3] Prior studies with trans people in other regions have found that trans people's health is profoundly affected by disproportionately high rates of violence and harassment (Lombardi, Wilchins, Priesing, & Malouf, 2001), employment discrimination and job loss (Minter & Daley, 2003), and discrimination in the provision of health and social services (Namaste, 2000). From the inception of Trans PULSE, a commitment was made to undertake research that respects this lived experience, the resilience and capacity of trans communities, and community knowledge and needs.

The Trans PULSE community engagement strategy includes both research and action stages, and builds on the theoretical model proposed by Paez-Victor (2002). The stages of this model include *input* (activities related to study initiation and design), *process* (activities related to data collection, analysis and interpretation) and *outcome* (activities related to dissemination and social action). In developing the model, particular attention was paid to the roles of community members in each stage of the research process, as well as issues related to community control, power-sharing, and social action; indeed, the project's tag line is 'Trans PULSE: Building Our Communities Through Research'. Three central principles have informed the community engagement strategy for Trans PULSE: 1) community initiation; 2) continual building of capacity; and 3) community control (versus community engagement) over each project stage. The third central principle, community own-ership, forms the core of the project and this article. It is evidenced in part by com-munity initiation, and informs the need for community capacity-building. However, the impacts of community ownership go far beyond these principles.

Community initiation of the research project

Unlike most CBPR initiatives, Trans PULSE was driven by community members since its nascent stages. Trans PULSE was initiated by a group of trans community members and a cisgender[4] ally, and was supported by a municipally funded LGBT community centre and a provincially funded community health centre with a man-date to provide primary health care to LGBT communities in Toronto. As a first step, the initial group sought additional community team members through an application process, and then following that added academic partners. Community members interviewed and selected research partners from academic institutions and non-governmental organizations based upon five distinct criteria: 1) their ability to be allies; 2) their ability to bring resources to the project; 3) their history of progressive forms of LGBT research; 4) their potential to let trans people be experts in their own issues; and 5) their ability to provide research-related expertise and skills for building a sound and rigorous study design for future phases of Trans PULSE. While not all of the initial Trans PULSE members saw themselves as investigators, the shift in thinking happened quickly as CBPR-friendly funders (who welcomed non-academic, community co-investigators) were identified, and successfully applied to. Over eight years, this community–academic partnership was built, and when some community investigators left others were recruited to replace them. Based on community feedback we received, priority was placed on recruiting new investigators who were trans members from racialized communities.

Building knowledge upon lived experience

Trans community members were instrumental in defining the research project's overall goals and objectives, as well as its theoretical framework. Most centrally,

community priorities directed us to move beyond individualistic explanations for, and accounts of, health; instead, we prioritized a 'social determinants of health' (Raphael, 2009) lens in our research. Two community investigators were hired as part-time research coordinators to manage the workload during this stage of the project; through this experience, these coordinators developed the skills and capacity required to undertake and organize complex CBPR projects. Through discussions among the Investigators' Committee (IC), we created research goals, objectives, and questions, and selected appropriate and sensitive methodologies for subsequent stages of the research. Taking direction from community soundings (focus groups) that we held in select Ontario cities, the IC felt strongly that research methods be used that allowed for the voices and concerns of trans people to be heard, in addition to dispelling the myth that trans people exist in negligible numbers. Consequently, a mixed methods approach was chosen for Trans PULSE. The IC collectively felt that the use of the most rigorous methods possible was important for ensuring that we could produce results that would be less likely to be dismissed. An approach was chosen which combined respondent-driven sampling (Heckathorn, 2002) with subsequent qualitative interviews. Once these decisions were made, a collaborative funding proposal was developed and submitted. It was successful and the survey phase of Trans PULSE commenced.

Survey design: Prioritizing 'community knowledge'

The process of developing the Trans PULSE survey tool offered further opportunity for community input, capacity development, and community control. Building upon the items that were identified as important research priorities during the community soundings, IC members spent a number of sessions together as a team in order to identify further priorities for research. Drawing upon their lived experiences, community IC members offered many directions for the content of the survey tool, and participated in bringing the survey to fruition. The resulting tool was comprehensive in its scope, and community IC members were able to see firsthand how 'lived experience' and other forms of community knowledge can be drawn upon to shape the content and design of a research tool.

Steering committee membership and decision-making

The Trans PULSE IC has had majority trans community representation and control from its beginning. Each IC member has been assigned an equal voice, irrespective of their academic or organizational affiliation, and each has been designated as an investigator on at least one project funding application. The fact that early stages were driven by non-academic trans community members has been pivotal in shaping a culture of community control that has continued into subsequent phases of Trans PULSE. In its earliest stages, the Trans PULSE team agreed to a Terms of Reference (TOR), a contract that guides the work of the project. Stressing community integration, community control and

capacity-building in all project phases, the TOR functions as a memorandum of understanding, stating guiding principles, decision-making processes, team member roles and responsibilities, and policies for accessing data. An element of note is that the TOR mandates that trans community investigators will always constitute a majority of the Investigators' Committee, and must be present in majority numbers (50% plus one) for major project decisions. This helps to ensure that we prioritize community ownership in Trans PULSE in ways that go beyond typical CBPR initiatives.

Broadening community input

Despite the fact that the majority of the Trans PULSE IC comprised trans community members, we recognized that the IC did not represent the diversity of trans people or 'trans experience' in a province as large and populous as Ontario. Wanting to ensure a representation of community experience beyond our IC, the team held 'community soundings' to hear priority issues and concerns from 85 trans people and four allies in three Ontario cities (Ottawa, Guelph and Toronto). Trans members of the IC also contributed their lived experience to the development of an online sounding for service providers, by determining the key topic areas to be covered. Professionals and providers who worked with trans community members were consulted through this survey to help us identify their knowledge and training needs in relation to working with trans clients.

To ensure even broader community input into Trans PULSE, a Community Engagement Team (CET) was established, to provide many things, including: guidance into the development of the project's survey tools and interview guides, access to relevant geographically dispersed trans networks, strategic advice on project outreach and promotion, and direction and guidance on a 'knowledge to action' strategy for social change. The CET was comprised of 16 well-connected trans people, who were selected through a province-wide application process. They reflected (as best as possible) Ontario's geographic, ethno-racial, newcomer status, and age diversity, as well as a diversity of trans identities. The CET served as an alternative set of eyes and voices from the community, and functioned as 'seeds' (that is, as the first people to complete the survey) in the respondent-driven sampling data collection strategy. Overall, having the CET as the public face and voice of the project during the data collection part of the survey stage, helped to communicate the importance of community involvement and control in Trans PULSE to the broader trans community. The CET was a crucial component of Trans PULSE. It balanced our intention to engage a diverse array of trans communities in Ontario with the pragmatic limitations of doing research. Bringing people from across a province as large as Ontario together for regular meetings and ongoing time-consuming work was difficult and expensive; the limited commitment expected of CET members allowed for important contributions from people who may not be able to make the commitment to the more intensive involvement required of IC membership.

Survey promotion

The project's Community Development Coordinator, as well as trans IC and CET members, led the promotion of the survey. Given that respondent-driven sampling (RDS) had not been previously used in trans communities, IC members developed recruitment strategies both prior to initiation of the survey, and during recruitment when strategy adaptation appeared to be necessary. In fact, the creation of the CET itself was a strategy to attempt to engender greater trust and community 'buy-in' so that participants would both complete the lengthy survey and feel motivated to recruit other participants, as was necessary given the methodology we selected. CET members independently held information sessions in their communities, and developed a promotional video (available at http://www.youtube.com/watch?v=bqbVw4Vzpi4). A Facebook group further aided project promotion and recruitment. In-person and teleconference meetings were held with community leaders from communities throughout Ontario. A toll-free phone line allowed any community member to reach us with questions or comments. The success of our survey recruitment strategy – especially given the length of the survey – was due to continued contact with community members, and promotion by community members.

Knowledge transfer and community accountability

Trans PULSE team members see ourselves, first and foremost, as being accountable to trans people in Ontario. We regard ourselves as 'stewards of lived experience', who have an ethical obligation to return research findings to trans community and to decision-makers who are able to implement change. As such, we have presented at numerous conferences, released a number of e-bulletins and targeted reports highlighting key data (e.g. statistics on suicide and violence rates, key demographics, and rates of employment and discrimination), used data in numerous workshop presentations, and published papers in peer-reviewed journals.

Data collection using the Trans PULSE survey tool took place between May 2009 and May 2010. During this time 433 participants completed an 87-page survey addressing the most comprehensive list of health, mental health, and quality of life issues measured with trans people to date in Canada. Analysis and knowledge translation and exchange are underway, and will continue for several years. We consider these remarkable accomplishments that can be directly attributed to the principles we have implemented and upheld since the project's inception.

Building community capacity

Community capacity-building has been prioritized in Trans PULSE as a means to make positive change for trans communities. Capacity-building was prioritized based on two factors: a desire for community members to have the opportunity to learn to use more formal forms of knowledge production in their social action research, and to ensure that when the project ended, tangible skills would be left behind in the community to be put toward further research and social change.

Capacity-building has been integrated through ongoing activities designed to enhance the capacities of the trans community to undertake research, including qualitative data analysis training, survey development, and group writing. Team members are also committed to more informal means of capacity-building on an ongoing basis. Using the project's 'knowledge to action' framework, formal capacity-building initiatives have included an early research-to-policy think-tank, and in 2012, a trans health advocacy summit. Both were designed to bring together trans community leaders from throughout Ontario to develop our project in a policy-relevant way, and to strategize around use of project results to maximize impact.

While our initial shared goal was to increase trans community capacity to undertake research, and use research results to impact policy change, the project has also resulted in capacity-building for the academic researchers involved, both with regard to research methods and ability to work with trans communities. Moreover, to date, more than a dozen Masters and PhD students from a number of disciplines have contributed to Trans PULSE as part of formal graduate education requirements, including three trans community members undertaking graduate studies. Additional students, including trans graduate and undergraduate students, have contributed as investigators, staff, and/or Community Engagement Team members. Through these student mentorships, Trans PULSE has contributed to the development of a new generation of health and social science researchers who have skills and experience in CBPR, in addition to being knowledgeable about trans issues.

Reflections on Trans PULSE: Lessons learned

As a CBPR project, Trans PULSE is highly unique and innovative. Despite the considerable success Trans PULSE has had in implementing these guiding principles to date, in building capacities, and in creating a project that prioritizes 'community control', several challenges have emerged throughout the project. We believe that these are important to share, in terms of advancing CBPR theory and knowledge. These challenges and questions were first drafted by two of the project's investigators (one trans and one cisgender) and were refined and revised by the other authors on this article (who constitute a trans majority). We present these challenges first as issues and then as 'questions' for other CBPR stakeholders in the field to reflect upon in their own research projects.

Challenge 1: Power differences in academic/community partnerships

Knowledge and power are intertwined, and research projects are inextricably linked to the power relationships outside their immediate context (e.g. academic knowledge, in general, is held in higher regard than community knowledge). Despite safeguards for ensuring equity, sharing power in CBPR projects presents unique challenges, requiring significant anticipation and planning. Despite the fact that trans community members interviewed and chose their own academic partners for the study, inevitable challenges have emerged with two cisgender academics

serving as 'co-principal investigators' at the helm of Trans PULSE. The power of academics is enshrined in systems set up to support research, such as positions on grants, administration of funds, the complexities of research ethics boards, and the need to publish in academic journals. All of these require or promote academic leadership of projects and establish academics as experts in areas that are not typically their own lived experience. Thus, even if a project defines its power structure differently, on paper and in processes, academics must often be the formal project leaders. Though community members do have power in the research process (for example, the power to affect community support and give a project legitimacy), this power remains outside established systems. Moreover, funding bodies force inherent power imbalances in CBPR by forcing research teams to choose whether community members will be staff members or investigators: staff members are financially compensated for their time but tend to lack influence over project direction, while investigators have greater decision-making power, but are typically not financially compensated. Only two of our seven community investigators have paid work time allocated to the project by their employers. Consequently, they have had more time available while others have had to forgo potential paid time on other activities to contribute to the project.

Our attempt to mediate these power imbalances has been through our Terms of Reference, through trans people forming the majority of the investigators, and also through capacity-building, where numerous opportunities have been available to write and present, to receive training about technical research skills, to be able to engage in conversations about research, to design survey tools, to conduct focus groups, analyze results, and communicate those results effectively. Notwithstanding the Terms of Reference contract, and despite the fact that trans community investigators have had a high level of trust for the project's two academic researchers, there were no processes put in place for acknowledging and addressing the considerable power differences, were this to become a problem. Instead, power-related discussions sometimes emerged in forums where it was rushed, or where it was off topic (and would have usurped more immediate agenda items). We have tried to acknowledge differentials in paid allocated employment time to the grant with a small ($125/month) honorarium for investigators who do not have research included as part of their paid job descriptions, but this does not fully compensate for the work undertaken.

> *Question 1*: How do we better attend to, identify, and address issues of power in academic-community partnerships?

Challenge 2: Unintentional disempowerment during technical stages of research

Issues of power imbalance become particularly challenging during research stages that are necessarily driven by academic expertise (e.g. proposal development, ethics

review, data analysis). These phases sometimes take longer than expected, and during these periods of time, other community researchers may not feel that their contributions are as valuable (and especially if they are not able or willing to voice these concerns). As CBPR continues to advance in popularity and impact, it is important for teams to ensure that the development and implementation of 'technical' stages of a research project are meaningful for all team members. The RDS method used in this project required a high level of technical expertise at times, and during those times there was a noticeable withdrawal of some community investigators who found it hard to contribute to those discussions and hard to conceive of their roles. The vast majority of Trans PULSE community investigators were drawn to the project's social action model and came with backgrounds as activists and service providers. When team members did have research experience, it was often qualitative, rather than quantitative, and did not prepare them to understand the complex RDS method used in this project. During our lengthy survey development phase, project discourse shifted significantly in nature from 'social justice and community action and development' to 'question development, reliability, validity, standardized scales, and variables'. Unfortunately, as the work of the team became more 'scientifically sophisticated', some community investigators began to quietly question their roles and their ability to make meaningful contributions to this phase. The team, however, was facing considerable time pressures and did not always pick up on these cues. In our experience, the gap between existing community knowledge versus the technical needs of the research, can lessen the ability of community members to exercise control over the research process.

> *Question 2*: How can we design community roles where all people on a team can really contribute their strengths? How can we ensure community members have the expertise they need to lead?

Challenge 3: Unintentional disempowerment of community members

Another challenge experienced by Trans PULSE was the positioning of a trans community leader in a paid employment position where he did not have the equivalent voting power of investigators. On the one hand, a reasonable argument can be made about the necessity of avoiding potential conflicts of interest that may occur if a paid staff person has equal voice (and voting power) as an investigator. On the other hand, when a community member's ability to vote is not granted, the team and project may be unwisely (and unwittingly) suppressing 'voice' and wisdom. Traditional employment arrangements can put community members in positions where they are there to 'take orders and to execute them', diminishing the scope of skills and breadth of knowledge they can fully bring to the project. Ironically, CBPR teams often expect the investment of community members to be larger than their (usually) part-time roles. This standard way of viewing an

employer–employee relationship may serve to maintain the status quo by creating hierarchical arrangements in a CBPR project, where those who should have power according to CBPR principles (in this case, trans people), in reality have little.

Another issue related to unintentional disempowerment had to do with our Community Engagement Team. Despite our best intentions of pulling together a diverse Trans PULSE Community Engagement Team, like all CBPR teams, we were faced with significant budgetary limitations. This resulted in our CET meeting in person only once per year, for a total of two times, over the course of the initial three-year project (they also engaged in some teleconference activities with our Community Development Coordinator). Our intention in having a CET was to show the broader trans communities that we were 'serious' about community-engagement and input. Their ability to work effectively, however, was severely limited by infrequent meetings, making it difficult for the CET to have truly meaningful input into the project. Moreover, the CET largely comprised volunteers, receiving a small monthly honorarium, which led to some uncertainty about how much impact they could really have. We have found a potential contradiction in our expectation that the CET 'guides' the project from these under-resourced positions. Despite these good intentions, and despite the CET's success in shaping the survey, designing and producing a promotional video, and conducting workshops in their communities, this dynamic was quite disempowering for many of the CET members who felt that the real power in Trans PULSE resided in the project's Investigators Team.

Another issue emerged in relation to some community members feeling excluded from participating in the survey. The parameters of respondent-driven sampling meant that trans people had to wait to be invited by another trans person to fill out the survey (after a long period of advertising and promotion, accompanied by increasing community excitement and enthusiasm about the survey). This seems to have touched a sore spot for some people around 'popularity' or 'belonging' in the community. Some asked 'do I have to be part of the in-crowd to complete the survey'?

> *Question 3*: How do we find alternative ways of conceptualizing power and ensuring that community members who end up in staff roles in CBPR projects have power? How can we design, fund, and empower steering committees that are not symbolic but are able to truly steer? What are our responsibilities when it comes to the unintentional impacts of a CBPR project?

Challenge 4: Community trauma and team dynamics

'Horizontal hostility' can be a major factor within marginalized communities, where people who have been very damaged by trauma and exclusion enact similar patterns on one another. Some have described this tendency for power to be turned inwards in community organizations as 'eating our own' (Cain, 2002). There have been occasions in Trans PULSE where conflict has occurred between team

members, and where there has been disagreement about the cause or source of the conflict. Some team members have regarded the conflict as 'between individuals' (i.e. as interpersonal) whereas others have explained it vis-à-vis the framework of horizontal hostility. While our Terms of Reference addressed strategies and guidelines for making decisions, it did not originally state explicitly how we would deal with conflict, though it now identifies a series of steps to address this. Moreover, effective means of communicating about these conflicts were not always implemented, and instances where conflict was addressed were not always successful. When conflicts are left unmanaged, however, a team fails to address how they might be impacting the work of the team and the project in general. As such, unaddressed conflict has the potential to create rifts among and between team members, to demoralize them, and to even cause some people to leave a project. Our team came to realize that our deep and shared sense of the importance of the project was, in fact, part of what was causing us to be conflict-avoidant in order to avoid disrupting the project. We had to reconceptualize addressing conflict as something that was about ensuring the survival of the project, rather than threatening it.

> *Question 4*: What can CBPR teams put in place to minimize horizontal hostility among team members from marginalized communities? What can we put in place to address potential conflicts before they occur, or as soon as possible after?

Challenge 5: The reproduction of systemic inequities on CBPR teams

One of the key issues that Trans PULSE has struggled with is how to adequately address the range of experiences facing diverse groups within trans communities. At one point in the project, we started to get feedback from the trans community about the lack of representation of racialized trans people on this project; this feedback was entirely well-founded. Like other marginalized communities, those trans people who have access to forms of privilege derived from race, class, etc., often have increased access to leadership positions as 'community representatives'. When a number of investigators who were members of racialized communities left the team, overtime most of us accepted the individual reasons they provided for leaving, without asking ourselves 'is there a systemic problem here that is related to anti-racism'? At the prompting of community members, our team responded to these concerns by organizing an anti-racism training for project investigators and another later on in conjunction with the Community Engagement Team, adding anti-racism as a 'standing item' on each meeting agenda, creating three new co-investigator positions geared specifically towards trans members of racialized communities, and eventually developing an anti-oppression/anti-racism statement for the project. Despite taking these positive steps in action to community concerns, we failed to proactively plan a broad and systematic anti-racism strategy for Trans PULSE. Such a strategy might have included ongoing training, a well-articulated plan for addressing race and diversity issues in our promotion, in our survey and

knowledge translation phases, and implications for the composition of our team (for example, a policy stating that a certain percentage of investigators would be designated to trans members of racialized communities). What made this issue particularly challenging were the differing levels of awareness among investigators and Community Engagement Team members about the issues of oppression beyond transphobia.

> *Question 5*: What do we mean when we call our CBPR projects 'anti-racist'? How do we operationalize anti-racism?

Discussion

The imperative of values, voice and process

Trans PULSE strives to undertake high-quality research that fosters greater understanding about the health of trans people, and to make a real difference in trans Ontarians' quality of life. Moreover, to help to redress power inequities, and build the kind of trust between trans community members and researchers that would result in a truly community-driven research agenda, we undertook a model of research that centered community control and ownership. Stoeker (2012) maintains that we do not 'walk our talk' in CBPR and that 'we may not have an effective talk that can guide the walk of participatory and action-oriented research practice' (p. 386). We believe, that in Trans PULSE, we did our best to 'walk the talk' of CBPR by engaging in strategies to ensure that community were in control of all project phases. Moreover, in utilizing a Terms of Reference contract and regarding it as a living/breathing document, and by shifting the discourse from community engagement to control, we may actually have Arieli, Friedman, and Agbaria (2009) moved one step closer to developing what Stoeker (2012) calls for, 'talk that can guide the walk of CBPR'.

In light of our considerable successes, we struggled with issues related to power sharing between community and academic partners, unintentional disempowerment, horizontal hostility and differing ideas about how to approach anti-racism work. A significant challenge emerged at many points in the process that had to do with unintentional disempowerment of community members, including community investigators, community engagement team members and staff. It was particularly visible during the more technical stages of our research project, when some community voices were more noticeably absent in discussions. This flux in participation was never discussed openly by the full team. Gaventa and Cornwall (2001, p. 184) provide one explanation by arguing that the professional and technical nature of some conversations are fused with power relations, and '. . . may serve to silence the voices or ways of speaking of some groups while enabling those of others'.

Zakus and Lysack (1998) maintain that 'community participation is a complex and fragile process [and] there are many factors that operate to diminish its success' (p. 6). Building upon this, Arieli et al. (2009) assert the need to 'test the

assumptions' held by academic researchers, that community are willing and able to participate as partners in all stages of a research project. Despite our best intentions to create a model of community ownership, some community members may have preferred the planning and action-oriented stages of research over those more technical and academic in nature. Despite mutual respect between community and academic team members, the research team did not have open conversations about issues of power and voice on a regular basis. Ospina et al. (2004) maintains 'that a mutual inquiry space requires a very honest conversation about roles, tasks, boundaries, authority, and power in the context of each particular project and as relationships is being built' (p. 66). We are reminded that it is one thing to be aware of privilege and still quite another to proactively work toward minimizing its deleterious effects. As Minkler (2005) states '. . . even outsiders who pride ourselves on being trusted community friends and allies often fail to appreciate the extent of the power that is embedded in our own, often multiple sources of privilege, and how it can affect both process and outcomes in such research' (p. ii9).

CBPR has the potential to 'transform the culture of silence among oppressed groups' (Chavez, Duran, Baker, Avila, & Wallerstein, 2008, p. 97), however, that potential is easily compromised when we fail to adequately examine disparities in power and how they impact genuine participation. Over 40 years ago, Arnstein (1969) made a compelling point when she argued '. . . that participation without redistribution of power is an empty and frustrating process for the powerless' (p. 216). Maiter, Simich, Jacobson, and Wise (2008) speak to the importance of reciprocity in research – creating room for dialogue, openness and trust building, and the need to be explicit up front about the diverse needs of partners in a research project. Similarly, Nelson, Pancer, Hayward, and Kelly (2004) maintain that the values underlying partnerships are often neglected. They emphasize the importance of developing a shared vision and identifying the strengths of group members in the initial stages of partnership development. Trans PULSE has tried to address this by getting members to know each other and to declare their stakes and interests in the beginning and 'putting them on the table', so to speak. What we have not done as effectively is to create space for ongoing learning and reflection about the CBPR principles that guide our work, how well (or not) we are adhering to them, and how to resolve or unify the conflicts and contradictions that emerge in trying to reach our multiple goals.

Straddling two worlds: Research 'versus' community development

Despite operating under a model of 'community control' and being guided by a clear Terms of Reference contract, team members frequently experience a feeling of 'push-pull' on the ultimate goal of the project: data collection/knowledge production or social justice work? As such, we may approach how we do our work according to what we personally believe to be right based on a complicated mix of factors, including our training, our taken-for-granted assumptions about the world, our 'privilege', our cumulative 'lived experience', and our position in the world. Sometimes we have

different stakes in a project, are held up to quite different standards, and are account-able to different bodies. Community members are accountable to their communities (and in some cases employers); they must be trustworthy, humble, attentive to com-munity needs, and reflective of the diversity in that community. Academic research-ers are held to academic standards of excellence, must publish quickly, must present in academic contexts if seeking tenure, and must be first author on academic papers in some cases. These different standards are inextricably linked to what Minkler (2005) labeled as 'differential reward structures for partners in CBPR' (p. ii9) pro-jects, where academic researchers often stand to gain the most from such projects, even if the major goal is to benefit the community at hand.

As a CBPR project, the goal of Trans PULSE is to produce the highest quality data possible to inform longer-term health, mental health, systemic, and other community-level changes. As a community development initiative, its goal is rooted in social justice: Trans PULSE will mobilize knowledge and resources and will empower people to make changes in their lives. A community development framework and a research framework can potentially be viewed as competing lenses for approaching the goals and work of Trans PULSE. In some instances, they will complement one another, whereas in others, they may actively compete. Jacobs (2010) maintains that at times like this 'academic quality' may supersede the need or desire to pay strict attention to moral or ethical concerns in research and in CBPR. One very interesting dilemma that illustrates these two potentially contrast-ing lenses focused on the needs of 'isolated' trans people. Some of these individuals contacted us during the survey administration phase indicating that they did not know any other trans people and therefore would not be asked to complete our survey. This resulted directly from our usage of the RDS method whereby indi-viduals who complete the survey are given a set number of codes used to invite other trans people to complete the survey. Thus, one has to 1) wait to be invited to complete the survey, *but* 2) must know other trans people in order to be invited to participate. While our team recognized in advance that this would be a socially awkward methodology, we had engaged in extensive discussion and concluded that the advantages in terms of validity of information gained – and consequently both the increased protection of trans community from mis-information produced through biased research and the increased potential for policy impact – outweighed the awkwardness. However, in implementation, not only did the process involve awkward messaging and social dynamics, but some trans people felt excluded from the study. While we were able to ask some of those who contacted us to complete a survey and start a new chain of recruits, there is no way of knowing who else was missed as a result of the structure of this methodology.

Jacobs (2010) makes mention of such conundrums where anxieties about 'aca-demic quality' in research studies can risk potentially usurping moral and ethical concerns. Our discussions as a team, however, focused on upholding the integrity and rigor of the RDS method, while at the same time trying to figure out how to include isolated individuals as participants. Many of us did not see our role,

however, as one where the survey could be used as a means of community development or to connect people to others, as the method demanded that people recruit through existing connections. Thus, through a research lens, their dilemma (isolation) was usurped by concerns with the study methodology. Through a social justice lens, however, it could be seen as unacceptable to potentially contribute to the further isolation of those individuals – a reversion of sorts where isolated people are regarded as 'subjects' without an 'absolute right' to participate in research about 'their' communities. We thought that we might be excluding people from a study about 'social exclusion' and raised this as an ethical question – 'are we unintentionally hurting people here vis-à-vis our chosen method'? Could the production of what may be more 'ethical' knowledge (less biased, with greater potential impact) ever justify potential harm to community members through exclusion, or should the methods be compromised to preserve the aims of community development?

Conclusion

Historically, significant harm has been done by researchers who have pathologized trans communities, positioning themselves as 'experts' about transgender people, prioritizing their own career motives, and offering very little in return (Bauer et al., 2009; Namaste, 2000). In line with CBPR's aim to avoid errors made by more traditional approaches to research, Trans PULSE has been successful in implementing a model of 'community control' over time, though problems and challenges have occurred. We have learned as a team that there is a need to continually balance priorities and address privilege and inequities. In future phases, we are learning to set processes in place for conflict resolution in advance, and to set out roles for community members that are well conceived and actually engage their strengths. We will build in time for reflection and learning on an ongoing basis and will continue to evaluate how we live up to the CBPR principles we have chosen to guide our work.

Notes

1. Trans is an umbrella term that encompasses a diverse group of people whose gender identity or expression diverts from prevailing societal expectations for individuals of the sex they were assigned at birth. Trans includes transsexual, transitioned, transgender, and genderqueer people, as well as some two-spirit people. The corresponding terms cissexual and cisgender typically describe nontrans people.
2. Trans PULSE has received funding from The Wellesley Institute, The Ontario HIV Treatment Network and the Canadian Institutes of Health Research (Institute of Infection and Immunity, and Institute of Gender and Health).

3. To view research results and project resources, visit http://www.transpulseproject.ca
4. Cisgender refers to people who are not trans.

References

Arieli, D., Friedman, V., & Agbaria, K. (2009). The paradox of participation in action research. *Action Research*, 7, 263–290.

Arnstein, S. (1969). Ladder of citizen participation in the USA. *Journal of the American Institute of Planners*, 35, 216–224.

Bauer, G. R., Hammond, R., Travers, R., Kaay, M., Hohenadel, K. M., & Boyce, M. (2009). 'I don't think this is theoretical; this is our lives': How erasure impacts health care for transgender people. *Journal of the Association of Nurses in AIDS Care*, 20, 348–361.

Cain, R. (2002). Devoting ourselves, devouring each other: Tensions in community-based AIDS work. *Journal of Progressive Human Services*, 13, 93–113.

Chávez, V., Duran, B., Baker, Q., Avila, M. M., & Wallerstein, N. (2008). The dance of race and privilege in CBPR. In M. Minkler, & N. Wallerstein (Eds.), *Community based participatory research for health* (p. 97). San Francisco, CA: Jossey Bass.

Flicker, S., Travers, R., Guta, A., Macdonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478–493.

Gaventa, J., & Cornwall, A. (2001). Power and knowledge. In P. Reason, & H. Bradbury (Eds.), *Handbook of action research: Participative inquiry and practice* (pp. 70–80). London: SAGE.

Guta, A., Wilson, M. G., Flicker, S., Travers, R., Mason, C., Wenyeve, G., . . . O'Campo, P. (2010). Are we asking the right questions? A review of Canadian REB practices in relation to community-based participatory research. *Journal of Empirical Research on Human Research Ethics*, 5(2), 35–46.

Heaney, C., Wilson, S., & Wilson, O. (2007, December). Beyond the manuscript. Podcast interview transcript. *Progress in Community Health Partnerships: Research, Education & Action*, 3, 31–36. Retrieved from: http://muse.jhu.edu/journals/cpr/summary/v003/3.1.suminski01.html

Heckathorn, D. D. (2002). Respondent-driven sampling II: Deriving valid population estimates from chain-referral samples of hidden populations. *Social Problems*, 49, 11–34.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.

Jacobs, G. (2010). Conflicting demands and the power of defensive routines in participatory action research. *Action Research*, 8, 367–386.

Lombardi, E. L., Wilchins, R. A., Priesing, D., & Malouf, D. (2001). Gender violence: Transgender experiences with violence and discrimination. *Journal of Homosexuality*, 42, 89–101.

Maiter, S., Simich, L., Jacobson, N., & Wise, J. (2008). Reciprocity: An ethic for community-based participatory action research. *Action Research*, 6, 305–325.

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health*, 82, ii3–ii12.

Minkler, M., & Wallerstein, N. (2003). *Community-based participatory research for health*. San Francisco, CA: Jossey-Bass.

Minter, S., & Daley, C. (2003). *Trans realities: A legal needs assessment of San Francisco transgender communities*. National Centre for Lesbian Rights & The Transgender Law Centre. Retrieved from http://www.hawaii.edu/hivandaids/Trans_Realities__A_Legal_Needs_Assessment_of_SF_s_TG_Communities.pdf

Namaste, V. K. (2000). *Invisible lives: The erasure of transsexual and transgendered people*. Chicago, IL: University of Chicago Press.

Nelson, G., Pancer, S., Hayward, K., & Kelly, R. (2004). Partnerships and participation of community residents in health promotion and prevention: Experiences of the Highfield Community Enrichment Project (better beginnings, better futures). *Journal of Health Psychology*, 9, 213–227.

Ospina, S., Dodge, J., Godsoe, B., Minieri, M., Reza, J., & Schall, E. (2004). From consent to mutual inquiry: Balancing democracy and authority in action research. *Action Research*, 2, 47–70.

Paez-Victor, M. (2002). Input, process and outcome: Understanding the complexities of community based inner city health research. Paper presented at the First International Conference on Inner City Health, Toronto, Ontario.

Pretty, J., Guijt, I., Thompson, J., & Scoones, I. (1995). *Participatory learning and action. A trainers' guide*. London: Institute for Environment and Development.

Raphael, D. (2009). *Social determinants of health: Canadian perspectives*, 2nd Edition. Toronto: Canadian Scholars' Press Inc.

Ray, M. (2007). Redressing the balance? The participation of older people in research. In M. Bernard, & T. Scharf (Eds.), *Critical perspectives on ageing societies* (pp. 73–87). Bristol: Policy Press.

Stoeker, R. (2012). Are we talking the walk of community-based research? *Action Research*, 7, 385–404.

Travers, R., Wilson, M., Flicker, S., Guta, A., Bereket, T., McKay, C., . . . Rourke, S. B. (2008). The greater involvement of people living with AIDS principle: Theory vs. practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care*, 20, 615–624.

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., . . . Whitener, L. (2004). *Community-based participatory research: Assessing the evidence* (Evidence Report/Technology Assessment No. 99). Rockville, MD: Agency for Healthcare Research and Quality.

Zakus, J. D. L., & Lysack, C. L. (1998). Revisiting community participation. *Health Policy and Planning*, 13, 1–12.

Author biographies

Robb Travers works in the Department of Psychology, Wilfrid Laurier University, Waterloo, Canada, and the Trans PULSE Project.

Jake Pyne works on the Trans PULSE Project.

Greta Bauer works on Trans PULSE Project and at The University of Western Ontario, London, Canada.

Lauren Munro works in the Department of Psychology, Wilfrid Laurier University, Waterloo, Canada.

Brody Giambrone and **Rebecca Hammond** work on the Trans PULSE Project.

Kyle Scanlon worked on the Trans PULSE Project, and at The 519 Church St. Community Centre, Toronto, Canada.