

A Seat at the Table: Designing an Activity-Based Community Advisory Committee With People Living With HIV Who Use Drugs

Qualitative Health Research
2019, Vol. 29(7) 1029–1042
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1049732318812773
journals.sagepub.com/home/qhr



Sarah Switzer¹ , Soo Chan Carusone^{2,3}, Adrian Guta⁴, and Carol Strike^{5,6}

Abstract

Recently, scholars have begun to critically interrogate the way community participation functions discursively within community-based participatory research (CBPR) and raise questions about its function and limits. Community advisory committees (CACs) are often used within CBPR as one way to involve community members in research from design to dissemination. However, CACs may not always be designed in ways that are accessible for communities experiencing the intersections of complex health issues and marginalization. This article draws on our experience designing and facilitating Research Rec'—a flexible, and activity-based CAC for a project about the acute-care hospital stays of people living with HIV who use drugs. Using Research Rec' as a case study, we reflect on ethical, methodological, and pedagogical considerations for designing and facilitating CACs for this community. We discuss how to critically reflect on the design and facilitation of advisory committees, and community engagement processes in CBPR more broadly.

Keywords

social participation; community and public health; research design; methodology; hospitals, substance use; HIV/AIDS; capacity and development; community and public health; qualitative research; popular education; case study; praxis research; Canada

Introduction

Within North American models of community-based participatory research (CBPR) (Brydon-Miller, Greenwood, & Maguire, 2003; Wallerstein & Duran, 2010), community advisory committees (CACs) are used as *one* way to engage community members in research from design to dissemination (Cox, Rouff, Svendsen, Markowitz, & Abrams, 1998; Newman et al., 2011; Quinn, 2004; Strauss et al., 2001). CACs are often comprised of community members who share an experience and come together to meet and discuss aspects of a research project such as developing research tools, or co-analyzing data (Flicker et al., 2010; Strauss et al., 2001). However, processes for designing and facilitating CACs may vary, and CACs may not always be accessible for community members experiencing the intersections of complex health issues and marginalization brought on by socio-structural issues (e.g., stigma, poverty, racism, criminalization). Without careful consideration to facilitation and design, our advisory committees may unintentionally exclude important community voices.

Recently, scholars have begun to critically interrogate the way community participation functions discursively

within CBPR and raise questions about its function and limits (Chiu, 2008; Guta, Flicker, & Roche, 2013; Guta et al., 2017). CBPR principles can be inconsistently translated into practice and may reproduce power inequities (Chavez, Duran, Baker, Avila, & Wallerstein, 2003; Damon et al., 2017) without careful attention to reflexive process and design (Snoeren, Niessen, & Abma, 2012). In addition, although there are individual and collective benefits of involving communities in research, for some, the stress and heavy demands of participation may cause unintended consequences for health and well-being (Attree et al., 2011).

¹York University, Toronto, Ontario, Canada

²Casey House Hospital, Toronto, Ontario, Canada

³McMaster University, Hamilton, Ontario, Canada

⁴University of Windsor, Windsor, Ontario, Canada

⁵University of Toronto, Toronto, Ontario, Canada

⁶Centre for Addiction and Mental Health, Toronto, Ontario, Canada

Corresponding Author:

Sarah Switzer, Faculty of Environmental Studies, York University, 137 Health Nursing & Environmental Studies Building, 4700 Keele Street, Toronto, Ontario, Canada M3J 1P3.

Email: switzers@yorku.ca

Despite the growing breadth of literature on CBPR, conditions behind participatory processes are often not named (Chiu, 2008). This has strong implications for practice. *How* we do this work together is as important as *what* we do. Although group facilitation has been identified as a key competency for CBPR practitioners (Grant, Nelson, & Mitchell, 2008; Nelson, Poland, Murray, & Maticka-Tyndale, 2004), literature and training opportunities on concrete practices for supporting affected communities to more actively participate in decision-making is rare. Research on CACs has also tended to focus on technocratic issues rather than relational ones (Newman et al., 2011).

In response, we reflect on our experience designing and facilitating Research Rec'—a flexible, and activity-based CAC to inform a program of research about the acute-care hospital stays of people living with HIV who use drugs. We were challenged by community members to design a CAC model that would suit their particular needs, and allow community members experiencing complex health issues and the impacts of sociostructural factors (e.g., stigma) to more fully contribute to our research projects (if they so desired). Community members wanted an engagement model that demanded less time and energy than the peer research assistant model that has proliferated with success across Canada (Logie, James, Tharao, & Loutfy, 2012; Roche, Flicker, & Guta, 2010). They also wanted opportunities to socialize and participate in what they perceived as 'fun' activities. This challenge raised a number of questions about how to engage communities ethically, and in meaningful ways without overburdening them (Guta et al., 2017; Switzer, Guta, de Prinse, Chan Carusone, & Strike, 2015), while also attending to our research objectives, and aims (i.e., co-producing knowledge).

In this article, we use our experience conducting Research Rec' as a case study to reflect on ethical, methodological, and pedagogical considerations for designing and facilitating CACs for people living with HIV who use drugs. We also draw on CAC members' experiences of Research Rec' to tease out our teams' reflections. Following the tradition of participatory researchers who see research as containing a cyclical process of learning and action (Grant et al., 2008; Wallerstein & Duran, 2008), we aim to move beyond a "lessons learned" approach (Chiu, 2006), and instead, use our findings to contribute a larger discussion within the field about *how* and *why* we design and facilitate CACs the way we do. We conclude by situating our findings within a discussion on community engagement in CBPR more broadly. While many of the processes described herein are not necessarily 'new,' by naming the specific conditions under which we designed and facilitated Research Rec,' our reflexive analysis seeks to make our processes explicit. In doing so,

we hope to encourage other community health researchers and practitioners to reflect on how they scaffold their own participatory approaches.

This article is written in collaboration between research team members and an external facilitator (Switzer)—who is the lead author of this article.¹

Methods

In this article, we use case study design (Yin, 2003) to glean insights about methodological, pedagogical, and ethical considerations for facilitating CACs with people living with HIV who use drugs. Because case studies are bounded, contextually specific entities, the study of the *context* which produced the phenomenon (i.e., Research Rec' in a hospital with people who use drugs) can yield implications for larger fields of work—in our case, the design of CACs for communities who experience marginalization and complex health issues. Case study research also warrants the use of multiple sources of data. Case study projects are often methodological hybrids (Compton-Lilly, 2012).

Our reflections are composed from detailed ethnographic observations of Research Rec' sessions, field notes, agendas, and team discussions, and are complemented with data from intro and exit interviews with CAC members, and evaluations. Multiple data sources triangulate researcher-generated data and analysis and provide insight into community member's participation. Research Rec' materials, interview data, and evaluations were analyzed thematically by the lead author, with attention to salient themes that emerged congruent with data, and her cumulative experience facilitating workshops at the hospital and in other harm reduction contexts. Co-authors (who led the study, and conducted interviews with participants) rounded out the lead author's analysis by offering suggestions and prompting questions and moments of challenge during the writing process. Combined with data from participant interviews, this multiperspectival approach to reflexive research incorporates first-, second-, and third-person accounts, thus deepening our reflexive account of the process (Chiu, 2006).

Our methodological approach draws on the rich history of reflexive analysis in participatory health research (Blanchard et al., 2017; Cartwright & Schow, 2016; Mayan & Daum, 2016; Montoya & Kent, 2011; Rutman, Hubberstey, Barlow, & Brown, 2005), as well as practitioner research in education (or "praxis research"). Here, practitioners "evaluate their own individual and collective praxis in the light of tradition and in response to current and emerging conditions and circumstances" (Kemmis, 2010, p. 20). Our "tradition" and "current and emerging conditions" are CBPR projects employing CACs—particularly in North American health research.

This form of inquiry—evaluating and changing practice *from within*—can translate learnings from beyond a single study to a broader practice within a field. There is also a strong theoretical congruence between this type of inquiry and Freirean (2000) ideas of praxis (reflection-action-reflection) and dialogical action as applied in community health (Wallerstein & Bernstein, 1988; Wiggins, 2012), and participatory research (Montoya & Kent, 2011; Wallerstein & Duran, 2008). This lens is also applied by the lead author (and facilitator), who employs Freirean principles in her facilitation practice.

Finally, although community members were not involved in the analysis of this particular article (in part because this article was written long after the study concluded), participants in the CAC consulted on preliminary findings for our larger program of research.

The Emergence of Research Rec'

Our past experiences as CBPR practitioners have led us to observe that it is often the same small group of community members who participate in advisory committees, which may limit the diversity of perspectives at the table. Over time, community members have suggested that we consider a more flexible, drop-in model as a way to encourage participation from individuals who might not be able to regularly attend meetings as a result of fluctuating physical/mental health and drug use needs. Many community members in our projects struggle with isolation, and requested that we embed 'fun' activities in meetings to encourage participation and create opportunities to socialize.

We received funding to design and evaluate our CAC with the goal of making our research process accessible to community members who might otherwise not be able to, or feel comfortable participating in research as a result of complex health issues and institutional stigma. Our flexible, activity-based model (Research Rec')² was designed with an open membership structure (i.e., drop-in format with ongoing recruitment) to accommodate people's fluctuating health needs (see table 1—Research Rec' model). The study underwent institutional review board (IRB) approval at the University of Toronto (protocol reference #29781).

Participants were recruited through a local AIDS Service Organization and Casey House, a small specialty HIV hospital. Participants (CAC members) provided written, informed consent to: (a) participate in a pre- and post-qualitative interview about their overall experience on the CAC; and (b) complete an evaluation form for each meeting. Fifteen participants attended our CAC over 13 months and attended one or more Research Rec' sessions. Most CAC members rated their physical health as fair or poor (64%) and had not worked in the past 12

Table 1. Research Rec' model.

Design Element	Description
Membership	<ul style="list-style-type: none"> • Drop-in and flexible attendance • Ongoing recruitment of members
Meeting structure	<ul style="list-style-type: none"> • Creative and participatory activities to meet meeting objectives • Agenda pre-set, with feedback solicited through or during activities
Decision-making	<ul style="list-style-type: none"> • Consensus
Location	<ul style="list-style-type: none"> • Common room at Casey House Hospital
Supports	<ul style="list-style-type: none"> • Food, honoraria, child care, and transportation costs reimbursed • Referrals to external supports available when needed

months (63%). The majority of CAC members self-identified as white (65%) and male (70%); 20% self-identified as Black (or of mixed ancestry); and 20% as Aboriginal. CAC members did not need to attend all meetings (although many CAC members attended semi-regularly). To orient new members, each meeting agenda included a project recap (e.g., the goals of the research) and what was discussed at previous meetings.

In comparison to a traditional CAC model which often resembles professional meetings (e.g., a researcher presents information or asks questions and a fixed group of stakeholders provide verbal feedback), community feedback was obtained through carefully designed and facilitated activities to guide and/or structure discussion. Activities were different each time, and included working with Lego, interactive brainstorming, tea tasting and making, collaborative writing, crafts, and visual arts. Before our first session, we held a meeting to consult community members on the new model. We provided a list of potential activities to vote on, and took suggestions for new activities.

Proposed activities were inspired from the lead author's experience working in arts-based research, popular education and youth participatory action research (Switzer, 2018; Switzer et al., 2016). Visual and collaborative poetry activities are common within creative, arts-based facilitation and evaluation practice (Charlton, n.d.; Taylor & Murphy, 2014) and LegoPlay (a formalized approach to working with Lego in group settings) has been used within the corporate sector, as well as within therapeutic and educational contexts (James, 2013). Other facilitated activities such as working with tea have roots in the local HIV movement (Whitbread, 2014).

CAC members received a \$20 honorarium for each meeting to thank them for their contributions. Providing compensation is considered a best practice in CBPR (Collins et al., 2017). Individuals also received transit






	Activity Description	Experiential Objective	Research Objective	Activity Type	Resources (\$)	Time	Facilitation Level ¹	Risk Level
	Collaborative poetry & guided free-form writing.	To foregrounded collective experiences and knowledge of CAC members & introduce the concept of working collaboratively in a low risk way	To introduce the project, and spark discussion of broad issues related to clinical care and substance use to help guide study development.	Integrated	Low	Low	Medium	Low
	Loose-leaf tea-tasting and making workshop.	To do something non-research related to build trust and community while discussing an otherwise sensitive topic	To discuss emerging themes to inform subsequent recruitment and data collection (e.g., participants identified pharmacists as important stakeholder we should talk to at this meeting).	Non-integrated	Med - High	High	Low - medium	Low
	Participants built Lego structures to respond to case scenarios highlighting themes from data	To help CAC members make connections between their lived experience and research findings and to encourage members to think structurally	To reflect on relevance and application of emerging themes – in particular, case scenarios developed from interview data	Integrated	Medium	Medium	High	Medium
	Decorating Clay Pots.	To break research discussions into multiple parts to help the group 'digest' the research & maintain focus.	To member-check findings and to refine of recommendations for future hospital care	Non-integrated	Medium	Med - High	Low	Low
	Rotating canvas activity (arts-based evaluation).	To share and make links between individual and collective experiences. To provide closure to the group, and celebrate our work together.	To reflected on and evaluate the impact of the CAC as a whole	Integrated	High	High	High	High

Figure 1. Description of Research Rec' activities.

Note. CAC = community advisory committees.

¹Here, facilitator level refers to suggested level of facilitation expertise required for an external facilitator (not that of the lead author).

fare, a meal, and reimbursement for child care costs where needed. Each meeting was 120 to 180 minutes long. Meetings included an informal period of eating and chatting at the beginning.

Considerations for Implementing an Activity-Based CAC With People Living With HIV Who Use Drugs

Below, we reflect on what we learned about designing and facilitating Research Rec.' We had initially hoped that by designing a more flexible model, individuals who might otherwise be reluctant to participate in a traditional CAC would be encouraged to join. Our initial instincts were confirmed. When surveyed, 57% of participants were advising on research for the first time. When compared with more traditional CACs we have facilitated with a similar community, this number is quite high (57% vs. 17%) (Robinson et al., 2015). Thus, the open nature of Research

Rec' led us to consult with *more* community members over the course of our project, and hear from a wider diversity of perspectives compared with other CACs we have run. As one Research Rec' member articulated in response to why we might want to try an alternate model, "More voices, more experiences, more information, more empowerment, more to see what we could do better."

Following this, we offer considerations for practice when designing and facilitating CACs in CBPR for people living with HIV who use drugs: adopting a participatory approach; identifying research and experiential objectives; incorporating a range of integrated and nonintegrated activities; attending to accessibility; accounting for stigma; and building community. Categories intersect pedagogically, methodologically, and ethically, and must be taken together as part of a larger engagement strategy. Figure 1 provides an overview of our meetings, selected activities, key objectives, and other issues. We refer to this figure and the enclosed information throughout.

“Doing a Little Activity Like This, Opens It Up”: Adopting a Participatory Approach

In planning our Research Rec’ sessions, we intentionally selected, designed, structured, and facilitated activities to engage CAC members in a collective discussion about our research, and to create an environment for open dialogue. By participatory, we mean that activities were designed to actively involve participants in the co-creation of knowledge and link to larger social change efforts—in our case, the continued stigmatization of people living with HIV who use drugs when accessing hospital care.

Activities were selected, developed, and modified by the external facilitator based on feedback from community members and the larger research team, as well as her past experience working with creative and participatory approaches. Inspired by Freirean (2000) tenants of popular education, these activities are part of an educational approach aimed to enhance dialogue, de-construct expertise, and encourage the active subjecthood of communities impacted by social injustice. Historically rooted in Latin America, popular education approaches have been used within community health—and other fields—both inside and outside institutionalized spaces (Mire & Kidane, 2015; Kane, 2001; Wallerstein & Bernstein, 1988; Wiggins, 2011). These approaches are also applied in many international, national, and local community development contexts to spark dialogue in participatory research projects (Chevalier & Buckles, 2013).

Participatory activities—when combined with other factors (i.e., structural supports)—helped to create an informal atmosphere that encouraged individuals to attend and contribute to our project. During exit interviews, CAC members referenced this informality by using words such as “organic,” “free-flowing,” “enjoyable,” or “holistic” to describe our meetings. Many of our CAC members experienced complex health and socio-structural issues, including social isolation and institutionalized stigma. They expressed that they wanted more opportunities to socialize and connect with others. The facilitation of activities helped with this pursuit. As one CAC member noted, “It’s a good lure, to encourage people, right? And the activity keeps you there.”

CAC members also spoke to the importance of working together on a common goal or purpose. While traditional CAC models are oriented around a shared goal, facilitated activities created an additional level of collaboration (i.e., making tea together; working collaboratively on a poem) and encouraged individuals to draw on a broader range of skills and knowledge than often required by a more traditional CAC. For example, facilitated activities—not often associated with research—introduced opportunities for CAC members to share details about their lives not directly

connected to the research topic (i.e., experience with a particular hobby or creative practice), thus allowing them to bring other sides of themselves to the project. Hence, the facilitation of activities enabled opportunities for *different types of participation*, which might otherwise not be possible with a traditional model.

Nonetheless, not all community members liked all activities evenly. Some activities we tried—such as spreading poster paper on tables during our collaborative writing activity to encourage free-thought doodling were not taken up. Thus, we learned that the diversity of participatory activities was more important than the success of any *one* activity. The integration of activities with clear objectives was equally important as discussed next.

Identifying Research and Experiential Objectives

We designed each Research Rec’ session around activities that met our research objectives (i.e., content objectives, or what we needed input on) and experiential objectives (i.e., what we wanted CAC members to experience). Thinking through meeting objectives allowed us to carefully select and tailor appropriate activities for each stage of our research and the conditions we sought to engender. Objectives also needed to be considered in relation to logistics, resources, access needs, time, and ‘risk’ level (figure 1). While risk is subjective and based on a number of factors, activities which required more in-depth participation levels or disclosure of personal information (i.e., where everyone shares) were considered higher risk than activities where individuals could participate without sharing feedback (i.e., making a craft). Here, risk must also be considered in tandem with issues of stigma—as discussed later.

For example, at our first meeting, the lead author designed and facilitated a collaborative writing activity to initiate a conversation on community perceptions of clinical care. She invited CAC members to contribute words in response to the word “clinical care” in a structured format that brought individual’s perspectives together into a collaborative poem. This facilitated activity allowed us to hear initial thoughts on a topic in a very short period of time, as well as introduce *the experience* of working collaboratively. Because words did not have to be linked directly to personal experience, and individuals only contributed if they wanted to, the activity did not require a high level of ‘risk’ and allowed us to ease into the idea of working collaboratively through activities.

In contrast, in our final session we used a rotating canvas activity (a modification on a mural activity often used in arts-based evaluation (Charlton, n.d.)) with the objective of hearing CAC members’ experiences of Research Rec,’ as well as to close the group in a way that honored

Table 2. Sample Agendas.

Nonintegrated Sample Agenda		Integrated Sample Agenda	
Setting the tone	<ul style="list-style-type: none"> • Welcome and food • Agenda on flip chart • Revisit group guidelines 	Setting the tone	<ul style="list-style-type: none"> • Welcome and food • Agenda on flip chart • Revisit group guidelines
Orientation	<ul style="list-style-type: none"> • Icebreaker activity • Overview of project and Research Rec' recap 	Orientation	<ul style="list-style-type: none"> • Icebreaker activity (often to introduce concept or approach to activity below) • Overview of project and Research Rec' recap
Activity/Input	<ul style="list-style-type: none"> • Presentation of data or info for feedback • Activity—Stage 1 (i.e., craft instruction) • Presentation and discussion of data or info for feedback • Activity—Stage 2 	Activity/Input	<ul style="list-style-type: none"> • Activity to work through meeting content • Debrief activity
Closing	<ul style="list-style-type: none"> • Evaluation and wrap-up 	Closing	<ul style="list-style-type: none"> • Evaluation and wrap-up

the spirit of collaboration we developed over the project. While CAC members were encouraged to only share what they felt comfortable with, this particular session required more vulnerability than the collaborative writing exercise in the first session, as we asked everyone to participate and speak openly about their CAC experience. However, this extra 'risk' was balanced by trust developed over the course of the project and supported by inviting participants who had attended at least one Research Rec' session in the past. This was also necessary as the purpose of this particular activity was to reflect on and evaluate CAC members' experience with past Research Rec' meetings. Considering our objectives upfront also helped to identify the right *type* of activity to meet our goals, as discussed next.

Incorporating a Range of Integrated and Nonintegrated Activities

We used two types of activities in our Research Rec' meetings: integrated or nonintegrated (figure 1). These activity types emerged when we began to analyze findings for this article, and share our work, publicly.

An integrated activity was an activity that was used as the *means* for soliciting input, such as inviting community members to create a collaborative poem about their impressions or perspectives on clinical care (as discussed above). For another integrated activity, we presented findings from our study about clinician perceptions of providing care to people living with HIV and who used drugs. We asked CAC members to build Lego structures that represented what they took away from what clinicians were saying in our research as a way to assess relevance. From there, we used small group facilitated discussions to talk through the Lego representations and open up conversation. We often used icebreakers to introduce core concepts

of an integrated activity (e.g., asking everyone to build something with Lego to represent what they did during the day) prior to discussing our topic.

A nonintegrated activity was an activity that was not used as a direct means of soliciting feedback, like a craft or tea-tasting, but was still tied to our objectives. Here, the activity functioned as a way to break the discussion of the research project into manageable parts, build relationships, and attract community members who might be new to talking about research. For example, while decorating clay pots, we sandwiched research discussions between craft stages. This allowed individuals time to digest the information; take lots of breaks; and have nonresearch-related discussions. At the end of the session, CAC members received a potted daffodil as a small thank you for "helping our project grow" (in addition to honoraria and transportation tokens).

Sample agendas for each activity type are presented below (Table 2). As will be discussed next, activity types had different implications for issues of accessibility and stigma.

"Sometimes I Just Got to Leave the Room": Attending to Accessibility

CBPR projects must carefully consider issues of accessibility—in other words, facilitators or barriers to participation—to meaningfully engage community members in study design (Minkler & Wallerstein, 2008). CAC members had a variety of accessibility needs related to: physical, cognitive, and mental health; diverse learning and information-processing needs; and drug use. Of course, the inclusion of activities does not make a meeting more accessible—per se—however, the careful facilitation and design of these activities may allow a *range* of opportunities for people to participate with different access needs.

We found that the facilitation of participatory activities allowed us to cater to a range of learning styles and ways of knowing, and offered CAC members opportunities to provide feedback in a way that did not rely on the reading of lengthy documents. The informal nature of meetings also made it easier for people to take breaks, to check in with members as needed, and provide modifications. Prior to meeting, we tailored activities for accessibility needs, and drafted clear instructions.

The drop-in membership structure of Research Rec' may have also assisted with creating an accessible environment. CAC members could attend and participate in a nonintegrated activity (e.g., a craft), without the expectation that they provide feedback on the research—a sensitive and highly stigmatized topic. Here, CAC members were able to make decisions about their involvement 'in the moment.' This may have allowed participants to trial their involvement before committing, build their confidence to contribute over time, or attend the CAC without worrying that health issues might inhibit *future* participation. Although CAC members could choose to attend only once, many participants attended consistently, suggesting that a CAC with an open membership structure might be less intimidating than a closed model. While community members participating in a more traditional CAC model can usually withdraw after one session (and in effect, trial their involvement), it is often expected that individuals commit to the entirety of a project. This might dissuade individuals with complex and fluctuating health issues from participating.

In addition, meetings were held at Casey House to make meetings more comfortable for clients and to support clients who were juggling hospital appointments. The location presents some unique ethical challenges around anonymity; however, having worked in partnership with the hospital since 2010, we have developed strategies to ensure community members are not put at increased risk (Strike, Guta, de Prinse, Switzer, & Chan Carusone, 2016). Members were not advising on care at this location, but on hospital care more broadly.

"We Haven't Harmed Anyone and That's Good Communication": Accounting for Stigma and Triggers

Stigma has been identified as an important determinant of social exclusion (Room, 2005) and is well documented as a key consideration when engaging people living with HIV and those who use drugs in research or programming (Belle-Isle, Benoit, & Pauly, 2014; Cain et al., 2014; Marshall, Dechman, Minichiello, Alcock, & Harris, 2015; Ti, Tzemis, & Buxton, 2012). As one CAC member told us, "in these walls, it [sharing information] could be more damaging." This is reflected in other research we

have conducted on the stigma drug users experience when sharing space in hospital (Strike, Guta, de Prinse, Switzer, & Chan Carusone, 2014). In our project, even though substance use was a condition of eligibility, discussing one's use still had potential consequences, such as breach of confidentiality by other CAC members or unexpected emotional distress. As discussed elsewhere (Switzer et al., 2015), researchers must account for issues of stigma—not just as one contextual factor of many—but as a constitutive feature of one's methodology, especially when working with creative or arts-based methods that may be unfamiliar to participants or introduce new ethical dilemmas.

Integrating activities into Research Rec' may have supported CAC members in discussing potentially difficult experiences. For example, facilitated activities allowed individuals to re-focus their attention away from particular topics when they found themselves at risk for being triggered. As one CAC member informed us, we're "talking about the drugs, but the emotion or the intensity . . . that might happen . . . isn't really [there], because we're focused, at the same time on something creative." Alternatively, for nonintegrated activities, a CAC member could attend the meeting and just participate in the activity without commenting on the research or their experiences. Some activities did ask that individuals share experiences and impressions; this was factored into the overall design and order of the sessions. This is in contrast to traditional CACs where the focus is solely on sharing feedback. The following section continues our discussion on stigma, as it relates to relationship-building and trust.

"We Got Closer Over This Little Meeting": Building Trust and Community

Developing a sense of trust and building community is considered an essential element of CBPR, especially in the context of research on sensitive or stigmatized topics in small communities (Labonte, 1997; Minkler & Wallerstein, 2008). While we recognize that no space can ever be completely safe, the facilitation of participatory activities—when combined with other elements—supported us in this pursuit. As one CAC member noted, "There [are] a lot of barriers that get put up because of different stigmas or, whether it's HIV or addictions or substance use. So, by taking those walls away you can get a lot more people's information." As mentioned above, CAC members often spoke to the "free-flowing" nature of Research Rec' which may have helped them "let their guard down" or feel more at ease when providing feedback that drew on past experiences. As the same individual continued—when speaking about an activity-based CAC model—"the more people that are at ease, the more

things that are going to go smoothly. [. . .] They're going to feel more open to talk." Of course, building trust is not a mere conduit for soliciting information but rather an important process in of itself.

While some CAC members knew each other prior to participating in Research Rec,' many individuals spoke about the impact of our meetings (and activities) on social cohesion. As one CAC member explained, "The activity's grounding us because we all did the activity. It was the same activity, but we all interpreted in our own ways . . . It gives us something to talk about, a bond, a common link." For example, one of our most successful sessions (according to participants) was when we facilitated a tea-tasting/making activity while also discussing emerging themes. We sampled, and learned about making dried teas, and made our own tea to consume during and after the workshop. As a nonintegrated activity, we structured research conversations between activity stages. Individuals received their own tea pot to brew their tea and take home.

With the support of careful facilitation, and an open-hearted approach by all team members, the tea-making activity assisted us in creating an atmosphere where individuals felt comfortable to share. This activity was conducted at our second meeting. While we did not realize it at the time, the open-ended format, the story-sharing element, and the fact that all team investigators participated built a strong foundation of trust for subsequent meetings. We were surprised by the number of times CAC members referenced this session throughout the project, including specific reference to the shared practice of tea-making at home, as well as their tea pot. This suggests that integrating shared activities that CAC members can continue after the meeting and small take-aways may have a big impact on group cohesion and community-building. This may be particularly important for communities who experience isolation, stigma, and poverty.

While CAC members did not speak directly to the issue of mistrust of researchers, as team members we reflected on what it might mean for community members to see us as researchers doing things that we might not be accustomed to in group settings. For example, at the tea-making workshop the facilitator joked that she was actually a coffee-drinker, and although she had done some research, she was also trying this for the first time. Similarly, some of our research team members were trained in more traditional health research methods and were less familiar with creative activities. As one CAC member noted, "[The activities] kind of brings everyone to a base level, cause no one's really comfortable with this . . . We're all trying something new."

Nonetheless, it is important to stress that activities in and of themselves may not build trust and must be considered as *one* element in a larger engagement strategy. Our Research Rec' model was embedded in a much larger

program of research that had been established since 2010. As echoed throughout, it is the facilitation of activities (not *what* you do but *how* you do it), alongside other factors (i.e., power dynamics, and participants' trust that you will take their input seriously), that impact group dynamics. Participatory activities alone cannot take the place of slowly built relationships. After all, "it is with people—and through relationships—that partnerships are built and sustained" (Mayan & Daum, 2016, p. 69). However, when taken together, we found that an activity-based CAC was a site to build and deepen these relationships. We have often been struck by moments when members from this initial Research Rec' CAC have vouched for us in front of other community members—on new projects—lending even more support to the importance of trust-building and the shared expertise of community members, who have counseled us on project design. This has allowed us to take risks and experiment with what participatory decision-making looks like in subsequent research projects (Switzer et al., 2017). In addition to influencing study operations, analysis, and knowledge translation (Robinson et al., 2018), feedback received during Research Rec' also influenced the design of new projects.

Discussion

In this article, we explore methodological, pedagogical, and ethical considerations for designing and facilitating an activity-based, informal CAC for people living with HIV who use drugs and who access hospital care. The goal of our larger program of research is to improve access to health care for those who experience significant barriers when accessing health systems (and who do not often participate in research because of these barriers). Adapting our CAC model met many of our study objectives by allowing individuals who otherwise would not feel comfortable participating in research to contribute. More importantly, it helped to deepen connections with communities *over time*. Once at the table, our CAC design allowed participants to trial their involvement, share experiences about hospital care (while also attending to potential triggers), and build their capacity to contribute to health systems research. Attending to issues of accessibility and stigma, and restructuring our CAC around community members' desires to connect, socialize, and have 'fun' allowed individuals who often do not participate in research to provide valuable feedback on our project and contribute on their own terms. The facilitation of activities also engaged participants and researchers alike in different ways of knowing and participating that extended beyond a traditional CAC model.

While we recognize that the primary goal of research is not necessarily to provide 'fun' activities (and that what

is ‘fun’ to one, may not be an enjoyable experience for another), restructuring and reflecting on our CAC allowed us to re-consider taken-for-granted assumptions about engagement processes, and about what ‘counts’ as meaningful participation. It also helped us reflect on the principles of reciprocity. As Maiter, Simich, Jacobson, and Wise (2008) argue, reciprocity in research can take multiple forms, including: creating opportunities for exchange and dialogue among community members who are *not at the table*; thinking of any project as part of a larger program of research and an on-going relationship; and devoting space for reflexive inquiry about CBPR processes. Without this, researchers may create engagement processes that unintentionally prioritize certain community voices over others.

In advocating for an applied communitarian ethics, Fry, Treloar, and Maher (2005) argue that harm reduction researchers, activists, and service providers ought to reflect on “what we actually do in harm reduction research as opposed to what we say we do” (p. 457). The same advice could be applied to participatory researchers more broadly: What are we actually *doing* when we talk about community participation and engagement? Why do we build and structure our projects the way we do? Are our CAC models structured to best meet the needs of diverse stakeholders, or are they merely modeled after the meeting structures of *past* projects? Whose voices do we exclude when we build our CAC structures to mirror those of professionalized spaces? There are methodological and pedagogical opportunities in making some of these decisions more explicit in our work. Engagement strategies are often informed by or designed to reflect the needs of individuals who are *already* participating in projects. For example, although patient engagement frameworks have begun to explore how health care systems might engage patients in larger decision-making processes, these frameworks often focus on individuals who *already* access the health care system with ease, and therefore may not be appropriate for individuals who experience multiple barriers when navigating health services (Hayward et al., 2004). We must be careful not to reproduce existing power structures by only consulting with or involving those individuals within a community who may be able to participate more readily or easily.

Of course, as with any reflexive process, we acknowledge that our reflections are partial. Not all community members appreciated our activity-based or informal approach. Some community members (who had participated in more traditional CAC formats) raised concerns that activities would take away from the seriousness of the task at hand. In this case, we found alternate ways for community members to provide feedback. While there are many different (and sometimes competing) reasons people participate in research (Fry, 2008; van der Velde,

Williamson, & Ogilvie, 2009), we must heed this community member’s warning. Asking community members to advise on stigmatizing and sensitive issues that are often bound up with larger systems of oppression and histories of trauma is a tall order. We must never forget what we are asking of people.

There may also be methodological costs (e.g., breadth vs. depth) in choosing a CAC model that follows a more flexible, drop-in structure. We have had to carefully reflect on what difference community members’ feedback can make within a *single* study. The resources and time required of academic projects (financial, but also human energy) present real material challenges for involving the community we work with in CBPR projects. Not all of our CAC members are with us today, with some individuals having passed away shortly after our sessions. As Belle-Isle (2016) warns, “While it is useful to examine such barriers and facilitators to participation, simply bringing representatives from marginalized communities to the table does not in itself imply [the] transformation of inequitable power relations, nor does it get to the core” of what shifting decision-making processes with communities really means (p. 6). For this reason, we choose to see Research Rec’ as one moment in time, in a long-standing partnership. While we continue to work with, and build relationships with community members in the hospital, the benefits of actively participating in CBPR are not always applied evenly (Flicker, 2008).

That being said, many considerations addressed throughout have relevance for the broader participatory or harm reduction research field. Table 3 synthesizes our findings for researchers and practitioners to encourage critical reflection on CAC design and facilitation. We are inspired by the principles of disability justice movements (Mingus, 2010) that encourage us to think beyond individual conceptions of access, to consider how we exist in relation to each other and larger power structures so that we can build spaces in which everyone can participate, if they so desire.

Strengths and Limitations

In her work on advisory committees with people who use drugs, Belle-Isle (2016) found that structural supports (i.e., compensation), solid relationships fostered on trust, relational and reflective dialogue, and well-facilitated meetings were critical elements in allowing community members to feel as if they could contribute to shared decision-making on advisory committees. As scholars have noted (Belle-Isle, 2016; Marshall et al., 2015), while work on facilitators and barriers to participation in CBPR is important (see Flicker, 2008; Travers et al., 2008; Wallerstein & Duran, 2010), we must also reflect on the relational and multidimensional aspects of how shared

Table 3. Designing Community Advisory Committees (CACs): Questions to Consider.

Consider your CAC within a larger sociopolitical context	• How do you envision your CAC as part of a larger engagement strategy?
Who's <i>not</i> participating?	• What sociopolitical factors may you want to consider when designing your CAC?
Consult with community	• Whose voices are missing in your project? Who is not participating and why?
	• How might consulting with community (in advance) help you structure your CAC differently, and reach underrepresented individuals?
Consider membership and overall CAC structure	• Do you have an open or closed membership structure?
	• If you use a drop-in model, how will you orient new members, and ensure group agreements are continued across sessions?
Reflect on objectives	• How might you think through research and experiential objectives for each agenda item and the CAC as a whole?
Consider integrating participatory activities	• How might the facilitation of activities bring new participants to your CAC, assist with team cohesion & encourage different forms of participation?
	• When integrating activities, have you considered time, resources, 'risk' level, facilitation expertise, and accessibility?
Plan for accessibility	• How might reformatting the structure make your CAC more accessible to people with complex health issues, drug use needs, and diverse learning styles?
	• How will you modify activities for accessibility, and be ready to adapt activities on the spot?
Think about how stigma impacts participation	• In our CAC, talking about drug use while in hospital was a sensitive topic, and had the potential to trigger participants. How might integrating activities allow participants to make 'in the moment' decisions about their type of participation vs. traditional CACs where the focus is solely on sharing feedback?
Build community and celebrate accomplishments	• CACs provide important feedback from diverse stakeholders. How might your CAC build community and relationships?
	• How might you use small take-aways, and closing activities to collectively reflect on process and celebrate collective accomplishments?

decision-making processes are actually enacted in research and practice. Our study builds on this work by elaborating on specific ethical and pedagogical considerations of how one might structure CAC meetings for people who use drugs and are also experiencing complex health issues, poverty, stigma, and isolation.

This article focuses on *one* element of a larger engagement strategy for including people who use drugs with complex care issues in research. Compensation, power dynamics, and participants' belief that researchers will take their input seriously are also important. Participation is not a panacea, and the integration of activities alone is not enough to enable participants an equal footing when contributing to research. Participatory activities cannot take the place of slowly built relationships, and/or CBPR processes that attend to structural inequities. Popular education has been critiqued for being overly focused on the facilitation of activities, at the expense of structural change (Kane, 2001; Wiggins, 2012). Participatory approaches can, and have been used to maintain, rather than dismantle, power structures (Dhillon, 2017; Leal, 2007). Researchers and practitioners committed to social justice must remain attentive to structural issues that not only impact (but also frame) participation—in our case, social determinants of health, drug policy, criminalization, institutionalized stigma, and governmental policies on harm reduction (Belle-Isle, 2016; Belle-Isle et al., 2014; Marshall et al., 2015), as well as the way in which

racism, sexism, homophobia, and transphobia impact (and prefigure) one's participation in research.

Our study—and this article—comes with limitations. First, our CAC sessions were explicitly designed for people who use drugs and who are also experiencing complex health issues, poverty, stigma, and social isolation. By focusing narrowly on these issues, we were not able to explore the impact of other intersecting social identities in our analysis. The intersecting identities (race, age, gender, etc.) of community members—and our own—likely influenced how individuals participated in our sessions and the power dynamics in the space. Our social locations and relationships with the site would have also impacted our reflective process. CBPR literature often emphasizes community participation, without considering the inter-subjective role of researchers shaping this process (Cartwright & Schow, 2016). Future studies might account for how social location, relationships, or larger sociostructural factors might affect the design and delivery of our CACs.

Second, we recognize that integrating activities in CACs may not be suitable for all community members, or in all contexts. Flyers advertising activities may have encouraged a more favored approach from some community members than others. Although many of our CAC members were new to CBPR, we had long-standing relationships with some of the members, which may have created an atmosphere of trust early on in the project.

Third, there is a degree of risk required in trialing activities or adopting a drop-in structure. There was always a risk that a CAC member might have a negative experience, and not return. Although participatory activities are often promoted as being “more engaging” or accessible, arts-based activities can bring new ethical concerns, especially for individuals who have experienced stigma or have trauma histories (Boydell et al., 2012). In our case, the external facilitator was experienced with using creative and participatory approaches in both research and community programming contexts and was able to modify or adapt activities as needed. However, because we were trying this model for the first time, there was a possibility that activities might not be successful at eliciting conversation on the research. Sometimes this created a degree of uncertainty for the facilitator and other research team members. Fortunately, ongoing dialogue between team members, a willingness (for all parties) to trust in the process, and continuous feedback from CAC members enabled us to try out our alternate model with relatively few bumps along the way.

Conclusion

Successfully working with community members to gain their trust and expertise in a way that is mutually beneficial often requires stepping back and adopting a more flexible design than in traditional research (Montoya & Kent, 2011). Adapting our CAC model allowed us to build trust and receive valuable input from many community members who otherwise would not have been able to join us “for a seat at the table.” Using Research Rec’ as a case study, this article outlines some of the methodological, pedagogical, and ethical considerations for designing and facilitating flexible, activity-based CACs when working with communities who experience complex health issues and other structural barriers. However, the integration of activities must not be only an add-on; activities must be carefully designed and facilitated with attention to a variety of factors so that both research and experiential objectives are met, and so meetings attend to issues of accessibility and stigma. The CAC must also be part of a larger engagement strategy. While we ground our project in the context of HIV CBPR, we hope that our considerations may shed insight on considerations for CACs in participatory and harm reduction research more broadly.

Acknowledgments

We are grateful to participants who trusted us with their feedback and to try a new approach to soliciting input on our studies. Thank you to members of the larger research team and to the staff at Casey House who treated us with a warm welcome. We also acknowledge participants of local research conferences with whom we shared and workshopped elements of this article.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Ontario HIV Treatment Network (CBR 926 [21977]) and the Canadian Institutes of Health Research (EPP 129926).

Notes

1. The lead author was hired to design and facilitate the CAC meetings with support from the larger research team. She is currently a PhD candidate with a focus on arts-based methods for HIV and harm reduction research and programs. She has worked with the team since 2010 to provide consultation on creative and arts-based approaches tailored for use in hospital settings with people living with HIV who use drugs (Switzer, Guta, de Prinse, Chan Carusone, & Strike, 2015).
2. Research Rec’ is named after a Rec’ Therapy program at the hospital.

ORCID iD

Sarah Switzer  <https://orcid.org/0000-0002-9320-3995>

References

- Attree, P., French, B., Milton, B., Povall, S., Whitehead, M., & Popay, J. (2011). The experience of community engagement for individuals: A rapid review of evidence. *Health and Social Care in the Community*, 19, 250–260. doi:10.1111/j.1365-2524.2010.00976.x
- Belle-Isle, L. (2016). *At the table with people who use drugs: Transforming power inequities* (Doctoral thesis, University of Victoria, BC, Canada). Retrieved from <http://hdl.handle.net/1828/7199>
- Belle-Isle, L., Benoit, C., & Pauly, B. (2014). Addressing health inequities through social inclusion: The role of community organizations. *Action Research*, 12, 177–193. doi:10.1177/1476750314527324
- Blanchard, A. K., Sangha, C. A. T. M., Nair, S. G., Thalinja, R., Srikantamurthy, H. S., Ramanaik, S., . . . Bruce, S. G. (2017). Pursuing authenticity from process to outcome in a community-based participatory research study of intimate partner violence and HIV vulnerability in North Karnataka, India. *Qualitative Health Research*, 27, 204–214. doi:10.1177/1049732316654871
- Boydell, K. M., Volpe, T., Cox, S., Katz, A., Dow, R., Brunger, F., . . . Wong, L. (2012). Ethical challenges in arts-based health research. *The International Journal of the Creative Arts in Interdisciplinary Practice*, 11, 1–17.
- Brydon-Miller, M., Greenwood, D., & Maguire, P. (2003). Why action research? *Action Research*, 1(1), 9–28.
- Cain, R., Collins, E., Bereket, T., George, C., Jackson, R., Li, A., . . . Travers, R. (2014). Challenges to the involvement

- of people living with HIV in community-based HIV/AIDS organizations in Ontario, Canada. *AIDS Care*, 26, 263–266. doi:10.1080/09540121.2013.803015
- Cartwright, E., & Schow, D. (2016). Anthropological perspectives on participation in CBPR: Insights from the water project, Maras, Peru. *Qualitative Health Research*, 26(1), 136–140.
- Charlton, M. (n.d.). *Arts-based evaluation toolkit*. Toronto. Retrieved from <https://artreach.org/toolkits/artbasedevaluation/>
- Chavez, V., Duran, B., Baker, Q. E., Avila, M. M., & Wallerstein, N. (2003). The dance of race and privilege in CBPR. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health: From process to outcomes* (pp. 81–97). San Francisco, CA: Jossey Bass.
- Chevalier, J. M., & Buckles, D. J. (2013). *Participatory action research: Theory and methods for engaged inquiry*. New York: Routledge.
- Chiu, L. F. (2006). Critical reflection: More than nuts and bolts. *Action Research*, 4, 183–203. doi:10.1177/1476750306063991
- Chiu, L. F. (2008). Health promotion and participatory action research: The significance of participatory praxis in developing participatory health intervention. In *The SAGE handbook of action research* (2nd ed.). Sage. Retrieved from <http://methods.sagepub.com/book/the-sage-handbook-of-action-research>. doi:10.4135/9781848607934
- Collins, A., Strike, C., Guta, A., Baltzer Turje, R., McDougall, P., Parashar, S., & McNeil, R. (2017). “We’re giving you something so we get something in return”: Perspectives on research participation and compensation among people living with HIV who use drugs. *The International Journal of Drug Policy*, 39, 92–98. doi:10.1016/j.drugpo.2016.09.004
- Compton-Lilly, C. (2012). Case study. In A. A. Trainor & E. Graue (Eds.), *Reviewing qualitative research in the social sciences: A guide for researchers and reviewers* (pp. 54–65). Florence, SC: Taylor and Francis.
- Cox, L. E., Rouff, J. R., Svendsen, K. H., Markowitz, M., & Abrams, D. I. (1998). Community advisory boards: Their role in AIDS clinical trials. *Health & Social Work*, 23, 290–297. doi:10.1093/hsw/23.4.290
- Damon, W., Callon, C., Wiebe, L., Small, W., Kerr, T., & McNeil, R. (2017). Community-based participatory research in a heavily researched inner city neighbourhood: Perspectives of people who use drugs on their experiences as peer researchers. *Social Science & Medicine*, 176, 85–92. doi:10.1016/j.socscimed.2017.01.027
- Dhillon, J. (2017). *Prairie rising: Indigenous youth, decolonization, and the politics of intervention*. Toronto: University of Toronto Press.
- Flicker, S. (2008). Who benefits from community-based participatory research? A case study of the positive youth project. *Health Education & Behavior*, 35(1), 70–86.
- Flicker, S., Guta, A., Larkin, J., Flynn, S., Fridkin, A., Travers, R., . . . Layne, C. (2010). Survey design from the ground up: Collaboratively creating the Toronto Teen Survey. *Health Promotion Practice*, 11(1), 112–122.
- Freire, P. (2000). *Pedagogy of the oppressed* (30th anniversary ed.). New York: Continuum.
- Fry, C. L. (2008). Research participation and internal normativity: Understanding why people participate. *The American Journal of Bioethics*, 8, 43–44. doi:10.1080/15265160802513184
- Fry, C. L., Treloar, C., & Maher, L. (2005). Ethical challenges and responses in harm reduction research: Promoting applied communitarian ethics. *Drug and Alcohol Review*, 24, 449–459. doi:10.1080/09595230500263905
- Grant, J., Nelson, G., & Mitchell, T. (2008). Negotiating the challenges of participatory action research: Relationships, power, participation, change and credibility. In *The SAGE handbook of action research* (2nd ed., pp. 588–601). Sage. Retrieved from <http://methods.sagepub.com/book/the-sage-handbook-of-action-research>. doi:10.4135/9781848607934
- Guta, A., Flicker, S., & Roche, B. (2013). Governing through community allegiance: A qualitative examination of peer research in community-based participatory research. *Critical Public Health*, 23, 432–451. doi:10.1080/09581596.2012.761675
- Guta, A., Murray, S. J., Strike, C., Flicker, S., Upshur, R., & Myers, T. (2016). Governing well in community-based research: Lessons from Canada’s HIV research sector on ethics, publics and the care of the self. *Public Health Ethics*, 10, 315–328.
- Hayward, C., Simpson, L., & Wood, L. (2004). Still Left out in the Cold: Problematising Participatory Research and Development. *Sociologia Ruralis*, 44(1), 95–108. doi:10.1111/j.1467-9523.2004.00264.x
- James, A. (2013). Lego serious play: A three-dimensional approach to learning development. *Journal of Learning Development in Higher Education*, 1–18.
- Kane, L. (2001). *Popular education and social change in Latin America*. London: Latin American Bureau.
- Kemmis, S. (2010). Research for praxis: Knowing doing. *Pedagogy, Culture & Society*, 18(1), 9–27. doi:10.1080/14681360903556756
- Labonte, R. (1997). Community, community development, and the forming of authentic partnerships: Some critical reflections. In M. Minkler (Ed.), *Community organizing and community building for health* (pp. 88–102). New Brunswick, N.J.: Rutgers University Press.
- Leal, A. P. (2007). Participation: The ascendancy of a buzzword in the neo-liberal era. *Development in Practice*, 17, 539–548.
- Logie, C., James, L., Tharao, W., & Loutfy, M. R. (2012). Opportunities, ethical challenges, and lessons learned from working with peer research assistants in a multi-method HIV community-based research study in Ontario, Canada. *Journal of Empirical Research on Human Research Ethics*, 7, 10–19.
- Maiter, S., Simich, L., Jacobson, N., & Wise, J. (2008). Reciprocity: An ethic for community-based participatory action research. *Action Research*, 6, 305–325. doi:10.1177/1476750307083720
- Marshall, Z., Dechman, M. K., Minichiello, A., Alcock, L., & Harris, G. E. (2015). Peering into the literature: A systematic review of the roles of people who inject drugs in harm reduction initiatives. *Drug and Alcohol Dependence*, 151, 1–14. doi:10.1016/j.drugalcdep.2015.03.002
- Mayan, M. J., & Daum, C. H. (2016). Worth the risk? Muddled relationships in community-based participatory research. *Qualitative Health Research*, 26(1), 69–76.
- Mingus, M. (2010). Changing the framework: Disability justice. *Resist Newsletter*. Retrieved from <https://leavingevidence>

- .wordpress.com/2011/02/12/changing-the-framework-disability-justice/
- Minkler, M., & Wallerstein, N. (2008). *Community-based participatory research for health: From process to outcomes*. San Francisco, CA: Jossey-Bass.
- Mire, H., & Kidane, L. (2015). *Constellations of black radical imagining: Black arts and popular education*. Ottawa: CCPA National Office.
- Montoya, M. J., & Kent, E. E. (2011). Dialogical action: Moving from community-based to community-driven participatory research. *Qualitative Health Research*, 21, 1000–1011.
- Nelson, G., Poland, B., Murray, M., & Maticka-Tyndale, E. (2004). Building capacity in community health action research. *Action Research*, 2, 389–408. doi:10.1177/1476750304047982
- Newman, S. D., Andrews, J. O., Magwood, G. S., Jenkins, C., Cox, M. J., & Williamson, D. C. (2011). Community advisory boards in community-based participatory research: A synthesis of best processes. *Prevention Chronic Disease*, 8, A70.
- Quinn, S. C. (2004). Ethics in public health research. *The American Journal of Public Health*, 94, 918–922. doi:10.2105/ajph.94.6.918
- Robinson, S., Chan Carusone, S., Guta, A., Switzer, S., de Prinse, K., Cooper, C., & Strike, C. (2015). One size fits all? Evaluation of an alternative approach to engage people living with HIV who use substances in HIV community-based research. *Canadian Journal of Infectious Diseases and Medical Microbiology*, 26(Suppl. B).
- Robinson, S., Chan Carusone, S., Guta, A., Tan, D. H. O., Leary, B., Upshur, R., & Strike, C. (2018). *You're not gonna stop using "cause you're in the hospital": Accounts from people living with HIV/HCV who use drugs and from providers about hospital substance use*. Paper presented at the 27th Annual Canadian Conference on HIV/AIDS Research, Vancouver.
- Roche, B., Flicker, S., & Guta, A. (2010). *Peer research in action I: Models of practice*. Wellesley Institute.
- Room, R. (2005). Stigma, social inequality and alcohol and drug use. *Drug and Alcohol Review*, 24, 143–155.
- Rutman, D., Hubberstey, C., Barlow, A., & Brown, E. (2005). Supporting young people's transitions from care: Reflections on doing participatory action research with youth from care. In L. Brown & S. Strega (Eds.), *Research as resistance: Critical, indigenous and anti-oppressive approaches* (pp. 153–179). Toronto: Canadian Scholars' Press.
- Snoeren, M. M., Niessen, T. J., & Abma, T. A. (2012). Engagement enacted: Essentials of initiating an action research project. *Action Research*, 10, 189–204. doi:10.1177/1476750311426620
- Strauss, R. P., Sengupta, S., Quinn, S. C., Goepfing, J., Spaulding, C., Kegeles, S. M., & Millett, G. (2001). The role of community advisory boards: Involving communities in the informed consent process. *The American Journal of Public Health*, 91, 1938–1943. doi:10.2105/ajph.91.12.1938
- Strike, C., Guta, A., de Prinse, K., Switzer, S., & Chan Carusone, S. (2014). Living with addiction: The perspectives of drug using and non-using individuals about sharing space in a hospital setting. *International Journal of Drug Policy*, 25, 640–649.
- Strike, C., Guta, A., de Prinse, K., Switzer, S., & Chan Carusone, S. (2016). Opportunities, challenges and ethical issues associated with conducting community-based participatory research in a hospital setting. *Research Ethics*, 12, 149–157.
- Switzer, S. (2018). What's in an image? Towards a critical and interdisciplinary reading of participatory visual methods. In M. Capous-Desyllas & K. Morgaine (Eds.), *Creating social change through creativity: Anti-oppressive arts-based research methodologies* (pp. 189–207). New York: Palgrave Macmillan.
- Switzer, S., Flicker, S., Carusone Chan, S., McClelland, A., Ferguson, T., Herelle, N., . . . Strike, C. (2017). *Picturing participation: Exploring engagement in HIV programming, service provision and care* [Community Report]. Toronto. Retrieved from: <https://pictureparticipation.wixsite.com/gallery>
- Switzer, S., Guta, A., de Prinse, K., Chan Carusone, S., & Strike, C. (2015). Visualizing harm reduction: Methodological and ethical considerations. *Social Science & Medicine*, 133, 77–84.
- Switzer, S., Lyrauu, T., Apong, K., Bell, O., Manuel-Smith, C., Hernandez, L., . . . Bykes, A. (2016). What's glitter got to do with it? Re-imagining harm reduction, decision-making and the politics of youth engagement. In C. Smith & Z. Marshall (Eds.), *Critical perspectives on harm reduction: Conflict, institutionalization, co-optation, depoliticization, and direct action* (pp. 113–133). New York: Nova Publishers.
- Taylor, P., & Murphy, C. (2014). *Catch the fire: An art-full guide to unleashing the creative power of youth, adults and communities*. Gabriola, B.C.: New Society Publishers.
- Ti, L., Tzemis, D., & Buxton, J. A. (2012). Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse Treatment, Prevention, and Policy*, 7, Article 47.
- Travers, R., Wilson, M. G., Flicker, S., Guta, A., Bereket, T., McKay, C., . . . Rourke, S. B. (2008). The greater involvement of people living with AIDS principle: Theory versus practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care*, 20, 615–624.
- van der Velde, J., Williamson, D. L., & Ogilvie, L. D. (2009). Participatory action research: Practical strategies for actively engaging and maintaining participation in immigrant and refugee communities. *Qualitative Health Research*, 19, 1293–1302.
- Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education & Behavior*, 15, 379–394.
- Wallerstein, N., & Duran, B. (2008). The theoretical, historical, and practice roots of CBPR. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health: From process to outcomes* (2nd ed., pp. 25–46). San Francisco: Jossey-Bass.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *The American Journal of Public Health*, 100(S1), S40–S46. doi:10.2105/AJPH.2009.184036
- Whitbread, J. (2014). *Tea time: Mapping informal networks of women living with HIV*. Toronto: Author.

- Wiggins, N. (2011). Critical pedagogy and popular education: Towards a unity of theory and practice. *Studies in the Education of Adults*, 43(1), 34–49. doi:10.1080/02660830.2011.11661602
- Wiggins, N. (2012). Popular education for health promotion and community empowerment: A review of the literature. *Health Promotion International*, 27, 356–371. doi:10.1093/heapro/dar046
- Yin, R. K. (2003). *Case study research: Design and methods* (3rd ed.). Thousand Oaks, CA: Sage.

Author Biographies

Sarah Switzer is a PhD candidate in the Faculty of Environmental Studies, York University. Her research explores participation and engagement in the HIV and Harm

Reduction sector, with a specialized focus on creative and visual methods.

Soo Chan Carusone is the director of research at Casey House, Canada's first and only stand-alone hospital for people with HIV/AIDS.

Adrian Guta is an assistant professor in the School of Social Work at the University of Windsor. His research explores health equity with a focus on HIV prevention, treatment, and care.

Carol Strike is a professor at the Dalla Lana School of Public Health, University of Toronto, and a Scientist at the Li Ka Shing Knowledge Institute, St. Michael's Hospital. Her research program aims to improve health services for people who use drugs and other marginalized populations.