



# Community-based participatory research in a heavily researched inner city neighbourhood: Perspectives of people who use drugs on their experiences as peer researchers



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## ABSTRACT

Community-based participatory research (CBPR) has become an increasingly common approach to research involving people who use(d) drugs (PWUD), who are often employed as peer researchers on these projects. This paper seeks to understand the impact of CBPR on PWUD, particularly those living in heavily researched and stigmatized neighbourhoods where CBPR projects are often located. This study draws on 14 in-depth interviews with PWUD who had previous experience as both peer researchers and research participants in CBPR projects conducted between July 2010 and February 2011. The study employed a CBPR approach in its study design, recruitment, interviewing, and analysis. Our analysis indicates that participants were supportive of CBPR in principle and described the ways in which it helped contest stigmatizing assumptions and researcher bias. Participants also reported positive personal gains from participation in CBPR projects. However, many participants had negative experiences with CBPR projects, especially when CBPR principles were implemented in a superficial or incomplete manner. Participants emphasized the importance of inclusiveness and active deconstruction of hierarchy between researchers and community members to successful CBPR among drug using populations. CBPR has been widely adopted as a research approach within marginalized communities but has often been implemented inconsistently. Still, CBPR can empower communities to contest forms of social stigma that are often reproduced through academic research on marginalized communities. Our findings describe how the benefits of CBPR are maximized when CBPR principles are consistently applied and when community-based researchers are supported in ways that reduce power hierarchies. This suggests a need for capacity building within affected communities to develop independent support, training, and grievance processes for peer researchers.

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## 1. Introduction

Stigma is a ‘fundamental cause’ of health inequality (Hatzenbuehler et al., 2013) and has been shown to affect community health through multiple and inter-related pathways (Keene and Padilla, 2014). The stigma faced by people who use(d) drugs (PWUD) is particularly intense and multifaceted (Bourgois, 2009; Strathdee et al., 2012). It is driven by structural factors like the

criminalization of drug use, the stigma directed towards people living with HIV/AIDS (Parker and Aggleton, 2003), and the intersecting oppression many PWUD face based on their gender (El-Bassel et al., 2010; Van Olphen et al., 2009), sexuality (Ibañez et al., 2005), ethnicity (Williams and Mohammed, 2008), and class (Bourgois, 2009). The spatial concentration of stigmatized groups, and in particular PWUD, within stigmatized ‘neighborhood of relegation’ (Wacquant et al., 2014) has given rise to forms of stigma, often termed socio-spatial or territorial stigma, that shape understandings of these neighbourhoods and follow residents even when they seek to leave (Takahashi, 1997; Wacquant, 2016, p.1273). Research has shown that socio-spatial stigma is a social determinant of health (Keene and Padilla, 2014) that contributes to, and is

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reinforced by, the concentration of socially marginalized groups (e.g., PWUD) in these neighbourhoods (McNeil et al., 2015).

In many cities, such neighbourhoods are the site of significant health inequities (Roux, 2001; Keene and Padilla, 2014), including heightened rates of HIV/AIDS infection (Hixson et al., 2011) and elevated risk of pre-mature mortality (Cohen et al., 2003). These areas are also the subject of considerable academic research (Neal et al., 2016). The academic gaze cast on areas of concentrated inequality can intensify the socio-spatial stigma directed toward people living within these areas (Wacquant, 2009) while also leading to 'research fatigue' among community members (Clark, 2008; Neal et al., 2016). Over the past fifteen years, researchers have increasingly responded to these concerns through research integrating principles of community-based participatory research (CBPR), a shift in research praxis that has given rise to new forms of community engagement in research processes (Minkler, 2005; Minkler and Wallerstein, 2010; Guta et al., 2014). In particular, the participation of people from heavily researched communities, including PWUD, as 'peer researchers' working closely with academics within CBPR projects has created new opportunities within marginalized neighborhoods that carry with them potential benefits, risks, and ethical dilemmas.

CBPR emerged from grassroots organizing against unaccountable and stigmatizing research of marginalized groups (Minkler, 2005). PWUD organized along with other groups around the world (e.g., people living with HIV) under the banner of 'Nothing About Us Without Us' in a political movement that resulted in widespread changes to research praxis (Travers et al., 2008). This movement fought for the emancipatory involvement of marginalized and stigmatized people in the research process (Canadian HIV/AIDS Legal Network, 2006; UNAIDS, 1999). This movement demanded the creation of programming and supports, "in fighting the fear, shame and stigma that keep us from fully participating in our communities and from accessing health services" (Canadian HIV/AIDS Legal Network, 2006, p.22). CBPR methods have been increasingly adopted in research with diverse groups, including PWUD (Souleymanov et al., 2016), men who have sex with men (Rhodes et al., 2011), people living with HIV/AIDS (Guta et al., 2014), and survivors of domestic violence (Malpass et al., 2016).

In practice, CBPR projects reflect diverse interpretations about what meaningful community involvement looks like (Israel et al., 2012). Community involvement in CBPR projects can take on a number of forms including in community review panels, advisory groups, and as peer researchers. As CBPR methods have become increasingly common and better funded, a growing number of projects have adopted a peer research approach (Guta et al., 2013). The use of peer researchers is often positioned as highly participatory and typically involves employing community members directly in the research process as members of the research team (Greene et al., 2009). Past research on peer researchers' experience documented how this kind of involvement can sometimes be disempowering (Boyd, 2008; Guta et al., 2013), such as when peer researchers are underpaid, lack opportunities for advancement, or are disciplined for failing to meet program expectations. For example, Boyd (2008) has described how participants have felt excluded and fetishized by academic researchers, and cautioned that CBPR can make power differentials between peer and academic researchers more visible. Given the increasingly large footprint that CBPR projects have within areas of concentrated poverty, there is a need for research exploring how peer researchers experience their participation in CBPR projects in order to best navigate power differentials and secure the most benefit from CBPR methods for heavily researched communities. While CBPR methods are a promising, evidenced-based approach to research (Viswanathan et al., 2004), key concepts within CBPR, like

'meaningful involvement' and 'community participation' may be applied in varying ways and translate differently within urban areas facing intense socio-economic marginalization and territorial stigmatization.

As one of the most heavily researched communities in the world, Vancouver, Canada's Downtown Eastside neighbourhood affords a unique opportunity to document and understand how CBPR methods work within heavily researched communities (Boyd, 2008; Boyd and Kerr, 2016). The Downtown Eastside is a low-income neighbourhood that is the site of Canada's largest street-based drug scene. The neighbourhood is known for its pioneering harm reduction initiatives, cutting edge addictions research, as well as high rates of poverty, unemployment, and entrenched drug use (McNeil et al., 2015). The Downtown Eastside is frequently stigmatized in journalistic, governmental, and academic discourse (Liu and Blomley, 2013; Boyd and Kerr, 2016). Here, research studies are so commonplace that participation in research has been positioned as a viable income generation strategy for PWUD (Collins et al., 2017). Filling out questionnaires, providing blood samples, and participating in interviews and clinical trials figure in alongside street vending, panhandling, and binning as a supplemental income source to offset stagnating social assistance rates (DeBeck et al., 2011). Vancouver's Downtown Eastside, the site of some of the earliest and most effective advocacy around the "Nothing About Us Without Us" principles (Boyd et al., 2009), now offers a unique opportunity to study how peer researchers experience participation within CBPR projects and their perspective on the impact that CBPR methods have had on the intense stigma and socio-economic marginalization faced by their community (Boyd and Kerr, 2016; Collins et al., 2016).

Here, we seek to add to the research literature on CBPR by drawing on the expertise of community-based 'peer researchers' with CBPR experience who live in the Downtown Eastside. We explore how some projects have successfully navigated the complex power dynamics between PWUD and academic researchers in a research setting. We document how PWUD have experienced the proliferation of CBPR projects in the Downtown Eastside, as well as the promises and pitfalls of CBPR to upset the intense social stigma faced by PWUD living in areas of concentrated poverty. We seek to broaden understanding of how CBPR functions within a heavily researched and marginalized community.

## 2. Methods

This project took a qualitative, CBPR-informed approach. This was operationalized by meaningfully involving members of the affected community in the research process from the development of the study objectives through to the analysis, interpretation, and publication of research findings. The study emerged from our established research partnership with the Vancouver Area Network of Drug Users (VANDU), a democratically-governed and peer-driven drug user organization (Kerr et al., 2006), and was developed in consultation with the organization's Board of Directors. Fourteen in-depth qualitative interviews were conducted in collaboration with a peer researcher recruited from among the membership of VANDU. The peer researcher was selected through a low-threshold four week long hiring process in which the position was posted at VANDU and interested persons were invited to fill out a simplified application form. Three members of the VANDU Board of Directors then interviewed all applicants and selected the most suitable candidate. Only one peer researcher was hired because of the scope and targeted nature of data collection and analysis activities. The peer researcher collaborated with the research team throughout the research process, from study design to data collection, analysis, and the interpretation of findings. The

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