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"We've Been Researched to Death": Exploring the Research Experiences of Urban Indigenous Peoples in Vancouver, Canada

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Abstract

The belief among many Indigenous Peoples of being over-researched, often through questionable research practices, has generated mistrust towards researchers. Despite growing critiques of conventional research practices, understanding of Indigenous Peoples' contemporary research experiences remains limited. The research this article describes was undertaken by a community organization led by Indigenous Peoples who use illicit substances. Community researchers facilitated talking circles to explore the research experiences of peers living in a highly-researched inner-city neighbourhood in Vancouver, Canada. While participants reported distrust towards researchers, this wariness did not preclude participation in research given a context of extreme poverty. Participants noted lack of transparency in research and perceived research as having little benefit to their community. We argue for increased support for Indigenous-led approaches to research that emphasize community concerns and meaningful community participation.

Keywords

community-based participatory research (CBPR), Indigenous methodologies, Indigenous Peoples, research, substance use, Canada

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"We've been researched to death here on the Downtown Eastside."

Globally, Indigenous Peoples have a long-standing history as research subjects. Their involvement dates back to the time of imperialism when early European travelers, pioneers, and missionaries began observing and recording Indigenous Peoples under doctrines of discovery and conquest (Martin, 2003). Led by European colonists and scientists, this "research" was founded in an assumed superiority over Indigenous Peoples (Wolfe, 2006), a concept deeply engrained in the tactics of colonization. This allowed for the body parts and cultural objects of Indigenous Peoples to be taken in the name of scientific interest, and such specimens and remains can still be found in museums and laboratories (Prior, 2007). In the service of the "advancement of knowledge," Indigenous Peoples and their lands were systematically named and claimed by colonizers, taken as their own, and subsumed into its cultural archive (Smith, 1999). Indeed, these efforts were part and parcel of wider colonial processes involving the subjugation and exploitation of Indigenous Peoples, and served to facilitate their dispossession from their lands and social, economic, political, educational, and cultural systems (Smith, 1999).

These early epistemologies contributed to the detrimental effects of colonization that continue to manifest among generations of Indigenous Peoples (Adelson, 2005; Kovach, 2015). Ironically, the resulting social, economic, and health disparities between Indigenous and non-Indigenous groups have served as an impetus for their ongoing research. Unsurprisingly, Indigenous Peoples have grown wary and mistrusting of researchers (Humphery, 2001; Hunter, 2001; Smith, 1999). This suspicion has caused some to resist research altogether, while others have responded by reclaiming their involvement in research and, as Māori writer Linda Tuhiwai Smith (1999) argued, they have begun to "research back" (p. 7; see also Humphery, 2001).

Despite ongoing research efforts dedicated to Indigenous health, little progress has been made towards bridging the health gap between Indigenous populations and Western societies. Much like other Indigenous groups, Canada's Indigenous population experience significant disparities in health status, including morbidity and mortality rates, compared to the non-Indigenous population (Adelson, 2005; Allan & Smylie, 2015; Allard, Wilkins, & Berthelot, 2004; Bourassa, McKay-McNabb, & Hampton, 2009; Frohlich, Ross, & Richmond, 2006; MacMillan, MacMillan, Offord, & Dingle, 1996; Reading & Wien, 2009). Premature mortality has a number of causes, including high rates of suicide, tuberculosis, HIV/AIDS, and diabetes, and an increased risk of problematic substance use (Public Health Agency of Canada, 2014, 2015). Likewise, the Indigenous population does not experience these inequities equally (Estey, Kmetic, & Reading, 2007).

Health outcomes in Canada are framed by past and present colonial state practices, which continue to negatively shape the lives of Indigenous Peoples. First Nations people, for instance, are managed within the Indian Act, which regulates the lives of *Status Indians* (Million, 2013). Indigenous women in Canada are especially vulnerable to gendered violence (Harper, 2010; Million, 2013). State interventions, for which Indigenous people are particularly overrepresented, such as child apprehensions (Statistics Canada, 2015; Turpel-Lafond & Kendall, 2009) and prisons (Sapers, 2014), further reinforce and

reproduce racialized socioeconomic inequalities, including health outcomes (Allan & Smylie, 2015). The state of Indigenous health in Canada thus presents a compelling case to call for effective research.

Some have argued that the means by which research is carried out with Indigenous communities is just as pertinent in addressing health disparities as is the knowledge acquired about a particular health problem (Cochran et al., 2008). In the past, research was often led by non-Indigenous scholars and thus, often reinforced the western domination over research involving Indigenous Peoples. Calls for action have led to innovation in research methodologies, such as participatory and collaborative research frameworks, culturally appropriate methods, ethical considerations, and the development of guidelines specific to research with and by Indigenous Peoples (Anderson, 2010; Blodgett, Schinke, Smith, Peltier, & Pheasant, 2011; Castleden & Garvin, 2008; Denzin & Lincoln, 2008; Evans, Hole, Berg, Hutchinson, & Sookraj, 2009; Faculty of Human and Social Development, 2003; Kovach, 2010, 2015; Lavallée, 2009; Loppie, 2007; Louis, 2007; Smith, 1999). Early on, the principles of Ownership, Control, Access, and Possession (OCAP®), developed by the National Steering Committee of the First Nations Regional Longitudinal Health Survey, represented the desire for self-determination in research among Indigenous Peoples in Canada (Schnarch, 2004). However, Humphery (2001) argued that efforts to challenge conventional research practice often have "too great a reliance on written guidelines and positive rhetoric" (p. 201). In her historical review of the "reform" of Indigenous health research, Humphery (2001) further argued that this work rarely materializes in practice. Recently, health research conducted by Indigenous scholars explores culture-based approaches and reciprocity (Anderson, 2010), and the meaning of healing and self-determination in the neoliberal Canadian state (Million, 2013).

Feminist and critical Indigenous researchers, attentive to the ways that conventional research is implicated in the colonial process and marked by unequal power relations, have proposed decolonizing methodological approaches (Chilisa, 2012; Olsen, 2017; Smith 1999). As dominant methodologies are constitutive of a Western worldview, some Indigenous scholars have advocated for the recognition of and support for Indigenous methodologies, such as conversational methods developed from oral traditions of knowledge sharing grounded in Indigenous perspectives and epistemologies, or ways of knowing (Kovach, 2010; Wilson, 2001). Nevertheless, St. Denis (2007) has noted that there is value in tracing the canonical practices of Western knowledge in order to demarcate the ways in which it (re)produces difference by constructing Indigenousness, for example, through racializing discourses.

Aside from Indigenous Peoples' participation in knowledge production and the development of research guidelines, there is still more room in academia for Indigenous Peoples to speak more candidly about their experiences of being research subjects. Within the context of our research, this limited knowledge further intersects with the dearth of literature on participants' experiences and perceptions of research among economically disadvantaged and/or marginalized populations, including Indigenous people who use drugs. Research in this area has largely focused on the role of financial payment for research participation and is often discussed within the framework of research ethics (Fry & Dwyer, 2001; Hughes, 1999; Singer & Bossarte, 2006; Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007). In light of ongoing research reform and research efforts involving Indigenous Peoples, we propose that additional work is needed to document their contemporary research experiences. We further argue that this knowledge should be produced by unconventional means that overturn the very structures that have been problematized (i.e., Western, non-Indigenous-led research). Led by a community organization comprised of Indigenous Peoples who are current or former users of illicit drugs and/or alcohol residing

in an impoverished, and arguably over-researched, inner-city neighbourhood, this research provides insight into the unique urban research experiences of a group of marginalized Indigenous Peoples.

Current Project

The Setting and Community

This research was undertaken in Vancouver, British Columbia, Canada. In 2011, federal census statistics estimated Vancouver as being home to approximately 12,000 Indigenous people, who accounted for 2% of the city's total population (Statistics Canada, 2015). Community members involved in this research consisted of individuals who identify as Indigenous, use illicit drugs and/or alcohol, and live in an inner-city neighbourhood—the Downtown Eastside (DTES). The DTES is located on unceded Coast Salish territory and is a neighbourhood marked by high rates of poverty, homelessness, substance use, mental health issues, and violence, as well as immense social and economic marginalization (Kazempiur & Halli, 2000; Miller et al., 2002; Shannon et al., 2008; Spittal et al., 2002; Werb et al., 2010; Wood & Kerr, 2006). The DTES is also unique in that at least one-third of the city's total Indigenous population lives in or near the area (Cardinal & Adin, 2005), making up approximately 10% of the population (City of Vancouver, 2012), and is known for its "open" drug scene (Fast, Shoveller, Shannon, & Kerr, 2010). The unique challenges experienced by this community have made it a hub for activism, health services, and research.

The Research Team

The research team comprised of a partnership between a community organization, the Western Aboriginal Harm Reduction Society (WAHRS), and academic researchers from the British Columbia Centre on Substance Use (BCCSU). WAHRS is an Indigenous-led organization that represents current or previous users of illicit drugs and/or illicit alcohol. They are dedicated to harm reduction and the improvement in the quality of life of Indigenous people who use illicit drugs or alcohol by encouraging the development of support, education, and training programs that reflect the values of Indigenous Peoples. WAHRS board members undertook dual roles as both community researchers and participants. As a community research team, WAHRS developed both the research topic of interest to be investigated and the research methodology, and they were responsible for data collection and analysis. Academic and research support was provided by the BCCSU, which included a designated research coordinator for the project.

Project Background

This community research collaboration was a result of a longstanding research relationship between the BCCSU and the DTES community. In recognition of the significant research presence in the community and critiques of the effectiveness of traditional research methods, the BCCSU partnered with WAHRS to conduct community-based research to explore Indigenous experiences as research subjects. To address power imbalances between research institutions and community partners, WAHRS board members adopted active roles as community researchers and employed Indigenous ways of knowing and sharing to carry out this research.

The Project

With significant research activity in the community, the research team sought to collectively explore and share their personal research experiences amongst their peers through the use of talking circles. Health-based research related to Indigenous Peoples' contemporary experiences as research subjects is scarce. More significantly, there is a shortage of Indigenous-led health research with peer-run drug user groups. This article seeks to contribute to the literature in this area, shedding light on marginalized Indigenous Peoples' participation in research—specifically, their perceptions of research processes and outcomes, and motivation to participate. This article is designed to illuminate how Indigenous people who are faced with multiple disparities, arguably those populations of most interest to scientists, experience research.

Method

The methods used in this study have been described in detail elsewhere (Goodman et al., 2017). Indigenous knowledge is premised upon oral traditions so the community research team selected talking circles as a culturally appropriate conversational research method (Kovach, 2010). Two WAHRS board members (i.e., community researchers) facilitated talking circles to explore their peers' (i.e., community participants) experiences as research subjects. Participation in the talking circles was open to WARHS members, and both facilitators and community participants were limited to participating in one talking circle. Community researchers served as facilitators to the talking circles, while also contributing their own lived experiences. During the WAHRS weekly membership meetings, convenience sampling was used to recruit participants. The names of those members interested in participating were submitted into a draw to be selected for the talking circles, which were limited to 10 participants. This selection process is regularly adopted by WAHRS to facilitate their memberships' participation in research and various other activities that involve compensation (i.e., stipends) to provide equal opportunity to members and avoid intragroup conflict. A total of three talking circles were completed, each averaging one hour in length, with 10 participants. Each speaker was given approximately 5 minutes to share, but could pass on speaking if they preferred. An eagle feather was held by the person speaking, signifying a space to speak without interruption. In respect of Indigenous oral traditions, participants provided informed consent verbally, which was completed prior to their participation. The research was undertaken with ethical approval granted by the University of British Columbia Providence Healthcare Research Ethics Board.

Each talking circle was led by two community researchers who introduced the research topic to the group and then initiated the talking circle by sharing their personal experiences with research as an Indigenous person who uses illicit drugs and/or alcohol, and who lives in the DTES. Discussion was not limited to specific types of research or research methodologies, but rather sharing of all research-related experiences were encouraged. Participants took turns speaking. In addition to the collection of field notes by the project coordinator, the talking circles were audio recorded and transcribed verbatim. Upon completion of each talking circle, the two community researchers and research coordinator reviewed the field notes for accuracy and preliminary themes.

With a few exceptions, WAHRS Board Members participated in the research as community researchers. Qualitative analysis of the data was undertaken individually and as a group, which involved detailed review of the transcripts. Community researchers identified emerging themes and illustrative quotes.

During the group analysis, the transcripts were read aloud and then coded line-by-line by hand to identify key themes. Following group consensus on key themes, the community research team compiled a series of recommendations. A meeting with the WAHRS general membership was held to present a preliminary summary of the analysis and findings for input and validation. A total of 36 individuals attended the group meeting. At the meeting, members were encouraged to provide additional insight on the research topic and findings, and to contribute to the recommendations.

Upon completion of data collection and analysis, an Indigenous researcher from the BCCSU extensively reviewed the research data for the purpose of drafting an academic peer-reviewed research article. The authors adopted an iterative writing approach to ensure this article represents WAHRS' analysis and interpretation of the data, and presents an accurate depiction of their research experiences. This circular process entailed several joint meetings with WAHRS Board Members to share, discuss, and revise the manuscript. Manuscript meetings were audio recorded and transcribed verbatim by the first author. The transcriptions further allowed the first author to maintain the integrity of the community researchers' voices in the development and writing of this manuscript.

Findings

The talking circles revealed high rates of research activity and subsequent participation among community members. Participants' primary interest in being a research subject was associated with financial compensation. While research opportunities represented a welcomed resource to earn wages for many, a few reported dissatisfactions with research participation that stemmed from a lack of knowledge translation and transparency in the research process.

"We've Been Researched to Death": Research Activity in the Downtown Eastside

Participation as a research subject appeared to coincide with living in the DTES. While the need for local research seemed warranted by participants, much research activity was described as excessive. However, many described countless and seemingly endless participation in studies:

> I've been in a lot of surveys. Lots. Like lots […] I've been in so many different uh programs down here. Can't even count how many. (Female participant, Talking Circle #1)

Another likened the local research efforts to living under constant scrutiny and intrusion:

> Since I been living down here [i.e., Downtown Eastside] […] there's been so many research opportunities that you know, it gets to a point where you think—you feel like you're a lab rat, eh. […] When they're […] targeting a certain group of people. […] So you feel targeted. I feel targeted. […] As long as we're here, in the Downtown Eastside, we still gonna have people walking through and wondering what makes us tick. And it could be positive, it could be negative but you know, I still don't mind being researched. (Male participant, Talking Circle #1)

In recognition of the prevalent social and health issues in the community, most understood the motivation for the community-focused research. However, narratives often depicted the research as unnecessary scrutiny and irrelevant to the community's needs. In spite of regular participation in studies,

some appeared antipathetic to research and spoke of simply trying to tell researchers what they wanted to hear:

> We've been researched to death here on the Downtown Eastside […] Researchers come in and ask us who we are and about the "informal consent" about HIV [tests] and about all sorts of things—smoking crack, injections. We get researched so much by people coming in that we just tell them what they want to hear. (Female participant, Talking Circle #3)

Not only was the number of research activities seemingly overwhelming, many questioned the practicality and appropriateness of research they had been involved in.

> Focus group didn't work. It was just what [researchers] wanted, I mean, they wanted to do this focus group and it was just too much information. Too many questions. Here at least we have one question [referring to the research presented here]. What's your experience? (Female participant, Talking Circle #3)

This participant continued on to tell of her experience with the community-based research presented in this article, and contrasted that with experiences in other non-Indigenous-led research projects:

> I've been part of actually peer-run research. Which is what this is. Where, people you know, not people in suits, you know or white jackets come and ask you questions. And for me when I do research in that sense, I tell the person what they wanna hear. […] So I find like the peer-run research is way better. Because you're actually talking to people who you know and who you are comfortable with. You know. […] I'm so, uh, I feel so blessed to be part of this Aboriginal research cause I've never really been in any Aboriginal research. (Female participant, Talking Circle #3)

For another, participating in *Aboriginal research* represented an act of reclaiming his Aboriginal identity in the city and, as was shared by others, the talking circles provided a safe space to speak candidly to personal experiences:

> We were holding a feather. Got us a chance to speak. And you know I kinda combine the two as in talking circle and healing circle. Cause it's confidential and we're pouring out stuff that we feel we're comfortable with other people allowing them to know. […] I like the setting of this circle. I mean it's like a thing that's been done for many generations of First Nations people. […] It's kinda really neat. I would never have thought I could see one in the Downtown Eastside. And here it is. There I am, part of it. I really like it. (Male participant, Talking Circle #2)

Despite the overrepresentation of Indigenous Peoples and abundance of research in the DTES, aside from this research project, not a single participant referenced any experience with Indigenous research (i.e., research in partnership with Indigenous Peoples, Indigenous-led research, or research employing Indigenous methodologies).

"I Love Being Researched. As Long as It Has That Money Tag Attached to It!" Implications of a "Research Economy"

Participation in research studies was largely motivated by compensation, with most relying on research stipends as a form of income. Consequently, participants' strong motivation for economic gain was at times associated with providing false information to meet study eligibility. Several participants described efforts to fit the research criteria:

> I'd tell 'em that I was homeless because I wanted a cigarette and candy that they gave you. Right. So, in a lot of things when you, try and reach the criteria, you just tell 'em what you wanna, what they wanna hear. So it's not really, truthful. (Female participant, Talking Circle #3)

Pretending to meet the research criteria in exchange for stipends as meagre as a candy speaks to the state of deprivation in the DTES. Furthermore, her comment alludes to the power and persuasion that researchers can exude over economically disadvantaged groups through the lure of research incentives. Participants conceded to actively seeking out surveys for the financial reward:

> I'm an addict too right. You know and, and I do surveys. […] I actually look around for them. […] Cuz it helps feed my addiction. (Male participant, Talking Circle #2)

Another noted how community members had little choice, but to participate in studies in light of their economic deprivation.

> There's quite a few different [surveys], but it's like he said over there, [people] go, you always gotta go cause of the money. Cause we get so little money down here right. (Female participant, Talking Circle #1)

While a few described using research stipends to purchase drugs, it was evident that for most personal reliance on research compensation was significant for survival. As one woman explained, research earnings provided her with the stability to transition out of sex work:

> I was switching off actually from being a working girl in the bar […] my gig was the bars. That's how I got my, you know my clients. To get outta that, a friend told me about these surveys. So that was kind of like my, you know, extracurricular activities during the day and at night and then I'd pass these uh numbers out to everybody if they wanted to [participate] and give 'em the criteria they need to get in [the surveys]. (Female participant, Talking Circle #3)

With limited opportunities to earn wages, research was recognized as an important component of the local economy, as one labeled it the "research economy." The associated incentives prompted impoverished individuals to agree to partake in research.

For most, the value of research was tied to financial gain, but a few noted alternative profits of study participation. One participant shared his experience with participatory research and explained how community members were involved in the development of research questions and priorities.

> I was with the study from the day one and […] we were part of [developing] that survey. […] They [researchers] were using us to put the questionnaire together […] But it [the research] is really what we want to know.

Subsequently, the research resulted in evidence in support of the opening of North America's first supervised injection site:

> They opened the safe injection site (SIS). Before people were doing it in the [SIS], [they were injecting] in the alleys, in the park […] No wonder they got all the hepatitis and all the disease and everything. [Researchers] had to find out what the hell was going on here. (Male participant, Talking Circle #2)

Unlike most others who only alluded to the good intentions of community research, yet rarely saw any tangible benefits materialize, this participant was one of the few to have witnessed firsthand positive research outcomes and to have been directly involved in research design. While only two shared such research experiences, it is telling of both the perceived and actual potential of community-based participatory research.

"Where Does All This Information Go?" The Practice of (Un)informed Consent in Research

Most raised concerns about transparency in the research process. As participants recounted their involvement with various studies, individuals reported little understanding of their and others' access to research data, as well as the dissemination and use of findings. One individual shared a disturbing experience:

> I was working with linguists from the States. He was paying maybe 25 dollars an hour for my own language while he recorded it. Wrote it down. And when he was through with me, I was disappointed. I could not get a hold of him again. No email. No Facebook. No cellphone number anymore. After he got all the information from me, it was on, recorded on tape recorder. And I would say in my language then he would say it back to me then I'd define it for him. So to this day he's never to be found. Maybe he's got a book out somewhere. (Male participant, Talking Circle #2)

Most reported research objectives were not understood. Some attributed this to a lack of transparency in the research process, while others accredited this to participants' fixation on the economic gain:

> I've asked them before, eh. After they did that, why can't I look at the results of my brain. Right? What's, what's going on with my brain? Why are you guys so interested once a year to look at what's happening in my brain? And uh, they didn't answer that question. (Male participant, Talking Circle #1)

> I mean on our end a lot of times for a survey, they'll offer us, um, a stipend so we're thinking of just money […] Where it goes no one's really thinking about it. (Male participant, Talking Circle #2)

Ironically, often the informed consent process was rather ambiguous and left most uninformed. For one, providing consent was described as relinquishing one's rights and knowledge:

> Where does all this information go? Like once you sign the consent form basically all we're saying is that it doesn't really matter where it's going, eh, because we're giving you our consent. Right? (Male participant, Talking Circle #1)

As participants shared common feelings that information was taken and never returned to study participants, the dearth of knowledge translation undertaken by community researchers was highlighted. Many perceived the lack of follow up by researchers as a missed opportunity for public health education, which was seen as particularly important given the numerous social and health issues experienced in the community.

> It's good to have these surveys, but it's good to have the feedback. […] That means public awareness nowadays. You gotta be educated nowadays with all these diseases so. But it's good […] to have the feedback too. Like just not give it out and take the information and go elsewhere with it. (Female participant, Talking Circle #2)

Many felt the valuable information acquired through research was produced for the consumption and benefit of audiences outside of the community (i.e., academics, government).

> I kinda wonder myself a lot of times, where particularly does this information go. You know cause, I'm gonna surmise per se that it gets broken down, disseminated, hopefully it gets into a peer-review paper, if it's at the uh, university level. And then possibly published or, possibly online, if I can access it. (Male participant, Talking Circle #2)

Additionally, revealing personal information to strangers was a cause for anxiety for some, especially when the research appeared obscure, and the questions were sensitive and possibly incriminating (i.e., illegal activities) in the event confidentiality was compromised. With the exception of compensation, research participation could be perceived as a wasted effort without knowledge of research outcomes or implications:

> I've always wondered what they do with those, uh, surveys [name of longitudinal survey], like they do it every 3, 6 months or something. And they're asking all these questions of [what do] you use and where do you get it and all this like, they get really personal sometimes. And oh do the cops stop you and all that and why are they even asking these questions if they're not gonna do nothing about it? Like that's crazy, but I don't know how they're researching that, uh, drug users or something. It's supposed to be for [name of university] or something. […] I dunno what they're doing with that information. (Female participant, Talking Circle #2)

Discussion

> I think personally why this research works is because it was done in the community, for the community and for a specific reason because we have been researched to death and we want it in a good way. We want change. We are sick and tired of not even being classified as human beings, especially with doctors and academics, that's how I feel. (WAHRS, Community Researcher)

This project was born from the desire for WAHRS and the BCCSU to work together on research that meaningfully explores and addresses community issues, but with the recognition that the research methods traditionally relied upon by our local academic community were not serving researchers or the community. This realization was exemplified by a case where lab tests completed as part of another research study were collected for a purpose that was incongruent with what Indigenous participants in the area were reporting. Naturally, without an in-depth or accurate understanding of community issues, research will have little to no effect in producing change for the betterment of those it intends to serve. As Leung, Marshall, and Wilson (2007) have noted, researchers must continually evaluate their research methodologies and data interpretations, a process that must involve the participation of colleagues, community partners, and participants. Fittingly, this discussion section presents research recommendations and implications as put forth by our Indigenous co-researchers. It has been written to preserve WAHRS' voices (represented by verbatim quotes in the Results section) and their understandings of the findings based on their lived experiences.

Skepticism and distrust towards researchers are common sentiments held by many Indigenous Peoples (Humphery, 2001; Hunter, 2001; Smith, 1999); yet, the wariness shared by talking circle participants did not preclude high participation in local research activities. In fact, the profusion of research among the impoverished neighbourhood was found to be seemingly welcomed, as it represented an important income source. Similarly, others have found incentivized research to be favourable among those who are economically disadvantaged as it contributes to an "informal economy" (Bell & Salmon, 2011; Slomka et al., 2007), albeit only temporarily and superficially (Salmon, Browne, & Pederson, 2010). Interestingly, to the best of our knowledge, this research is the first of its kind to report such willingness among Indigenous Peoples to participate in research. While some participants' hesitation towards research were attributed to perceptions that there were little associated tangible benefits, the financial gains were seen by most to outweigh these shortcomings. We argue that research participants should be paid for their expertise, while also acknowledging that the reported reliance on and interest in research wages among participants raises some important ethical questions in relation to the economic and social structural conditions of their lives.

Ethical considerations regarding incentivized research practices are particularly heightened when research concerns the involvement of vulnerable populations like those economically marginalized (Fry, Hall, Ritter, & Jenkinson, 2006; Head, 2009; Macklin, 1981; McNeill, 1997; Salmon et al., 2010). Arguments surrounding the ethical debate on the use of incentives in research with human subjects typically postulate whether incentives cause undue influence or serve as coercion to participate and compromise the dignity of the subject (Grant & Sugarman, 2004). For those populations who use drugs, there are additional concerns that financial payment may facilitate substance use and enable "addictive" behaviours (Buchanan et al., 2002; Hughes, 1999). However, such concerns are grounded in moralizing discourses. While some participants noted that they used research payments to purchase drugs, they also

illustrated that research compensation provided a means to earn income that, for some, would otherwise be earned by activities that carry significant risk (e.g., sex work). Our research demonstrated that incentives could induce participation among this population, with even the scantest of honorariums serving as a forceful motivator. As other community research has found, incentives can serve as leverage with those living in poverty in the DTES, making it difficult for individuals to refuse to participate in research even where ethical concerns exist (Damon et al., 2017). This type of inducement runs counter to conventional research ethics guidelines (Dunn & Gordon, 2005; Medical Research Council of Canada, 1987; Ripley, 2006), which assert that financial gain should not be a primary motivation for participation in research. These findings speak to the need to address economic deprivation among this population, alongside ensuring research results in material improvements for marginalized communities.

Incentivized research may also negatively impact the research(er) through the loss of data integrity and rigour due to the provision of misleading research criteria information. Providing misleading research criteria information to secure research income was common practice amongst participants; yet, it must be considered alongside participants' extreme social and economic marginality (Salmon et al., 2010). Researchers who inadvertently exposed pertinent study criteria, often during the research script or consent process, enabled the provision of misinformation related to participant eligibility. While participants could feel disempowered by their research participation, mainly as a result of stigmatizing research methods and/or inadequate knowledge translation or transparency in research, arguably many claimed a minute level of control over their narrative as a means to economic survival.

Indeed, for many, this tactic of "telling [researchers] what they want to hear" was perceived as an exchange for much needed income facilitated by the over-researching of people in our setting. Yet, for others, it was associated with mistrust of and discomfort with the researcher, due to experience with questionable research practices. Also, we cannot ignore the persisting power imbalances that exist between the "native" and the "academic," or as one participant described, those in "white jackets" and "suits," and the ongoing colonial undertones of traditional academic research captured by participants' feelings of exploitation and marginalization (Smith, 1999). One co-researcher explained misrepresentation was not always calculated with malice; an unwillingness to answer truthfully could be attributed to "shyness, sometimes because of stigma, sometimes because of lack of not knowing what one can say to somebody and trust how it is going to be perceived" or how their information will be used. Overall, participants may simply not feel comfortable disclosing personal information to a person in a position of power or to those in suits.

As Indigenous participants previously noted, distrust resulted in the underreporting of HIV risk behaviours to local academic teams. This wariness and that described by participants here may be explained in part as a result of experiences of misrepresentation and subsequent stigmatization of Indigenous Peoples. Without an in-depth understanding or analysis, research can result in the stigmatization of a population or community. For instance, reporting data demonstrating a higher incidence of substance use based on the single determinant of ancestry (i.e., Indigenous versus non-Indigenous) without contextualizing or explaining the underlying causes of such disparities not only intensifies negative stereotypes (Elliott & de Leeuw, 2009), it also prevents the development of meaningful solutions to address health inequalities (Marshall, 2015). Unfortunately, the immense disparities and social challenges affecting both Indigenous Peoples and the DTES have made this population vulnerable to stigmatizing research practices (Culhane, 2011).

In attempt to address the historical and ongoing tumultuous research relations with Indigenous populations (Humphery, 2001; Hunter, 2001; Martin, 2003; Smith, 1999), community-based participatory research is increasingly being adopted by Canadian researchers to facilitate research *with* Indigenous Peoples versus *on* Indigenous Peoples (Anderson, 2010; Castleden & Garvin, 2008; Canadian Institutes of Health Research [CIHR], 2007; Kovach, 2010, 2015). Such participatory paradigms may facilitate transparency in the research process as these frameworks serve local needs and interest by adopting principles of co-learning and mutual benefit (Blodgett, Schinke, Peltier, et al., 2011; Frisby, Reid, Millar, & Hoeber, 2005; Wallerstein & Duran, 2006). Certainly, research efforts in the DTES have resulted in positive changes for the greater community (Boyd, Murray, & NAOMI Patients Association, 2017; Culhane, 2011; Salmon et al., 2010; Small, Palepu, & Tyndall, 2006; Wood et al., 2001). Yet, most participants reported being uninformed of research outcomes, which may explain why many perceived research as having little benefit to the community and participants' reticence towards researchers.

Our findings suggest establishing trust and rapport with participants are important elements to conducting respectful and robust research: "you gotta have a connection with those people and at least have an understanding of the people you are researching." Peer ethnographic research holds trust and rapport as prerequisites to social research and is "based on the premise that what people say about social life and behaviour changes according to the level of familiarity and trust established between the researcher and researched" (Price & Hawkins, 2002, p. 1328). As one co-researcher explained, when being interviewed by a peer, participants can respond more accurately "without feeling the stigma and without being judged," which would allow researchers to "actually get to the core truth and get to the actual reasons of the issue" under investigation. Others have shared these feelings in the community. For example, Damon et. al (2017) found that participants are more willing to provide accurate and detailed responses to peer researchers. Therefore, the mediating effects of peer researchers in the research process and their importance in mitigating against misperceptions about marginalized populations often held by researchers is significant (Coser, 2010; Damon et al., 2017; Israel, Schulz, Parker, & Becker, 1998).

With the immense health disparities Indigenous Peoples face, it is critical that research does not contribute to negative stereotypes and assumptions. One co-researcher referred to this as "getting to know a little bit about them [Indigenous Peoples] besides the diseases." Peers may also support the credibility of research findings by verifying researchers' data interpretations and coding processes (Graneheim & Lundman, 2004; Ryan-Nicholls & Will, 2009). Certainly, the use of peer researchers in community-driven academic-based research is not without its challenges. For instance, those peer researchers who were deeply committed to the process had to balance their participation with other limitations, such as health concerns, given their extreme marginalization, while working to minimize the reproduction of unequal power relations through attention to "responsibility, reciprocity and respect" (Olsen, 2016, p. 29; see also Olsen, 2017). This process and dialogue was ongoing throughout the study. Peer researchers must be thoughtfully selected with consideration of community dynamics and politics, and to ensure stringent practices of participant confidentiality are upheld. Similarly, community-based participatory research must be adopted with careful consideration and execution of its core principles as to not risk reproducing stigma and reinforcing power structures between researchers and community-based peer researchers (Damon et al., 2017; Travers et al., 2008), which can result when co-researchers exist as tokenistic to the research process.

Supporting Indigenous-community led research is one way to avoid such tokenism in research. While a methodological evaluation was not the aim of this article, several participants and community researchers attributed the success of this research (i.e., fulfilling the credentials of what was perceived as "good research") to the method used. Beyond the benefits of being peer-led, using Indigenous methodologies was perceived as "groundbreaking" amid local research experiences, which are consistently dominated by non-Indigenous practices. This research allowed community members to take control and ownership over the research, thus adhering to the principles of OCAP® described previously. In contrast to experiences in which participants often perceived control or oversight over personal information was relinquished through non-Indigenous research practices, Indigenous approaches to research can provide participants with a sense of maintaining control over their knowledge and community information.

Before concluding, we must note that this research is limited to the experiences of a group of participants who have a longstanding partnership with a research institution and reside in a hyper-researched inner-city neighbourhood, and therefore our findings cannot be generalizable to other Indigenous Peoples and neighbourhoods. Although participants did comment on the methodology of this particular Indigenous-led research project, this was not the intended topic of investigation. As such, future work exploring the significance of Indigenous-led research projects and an evaluation of the application of Indigenous research methodologies would be of great value and could further contribute to a movement away from non-Indigenous research.

As a few participants noted, and we can appreciate, research does have the potential to provide much benefit to the communities and populations it intends to serve, and there have been some material improvements in the DTES as a result of research. However, with the exception of the research presented here, the fact that participants rarely perceived such benefits and instead felt research was for the obscure benefit of "others" emphasizes the need for research to be done in a "good way"; this means embracing Indigenous approaches to research to ensure individuals and communities are both informed of and touched by research outcomes in ways that foster the empowerment of Indigenous Peoples in research. To move beyond superficial benefits and to work towards structural and policy change, we must call for a shift in research practices towards methods that emphasize meaningful community participation, are action-oriented, and address Indigenous community concerns —"Nothing about us, without us!"

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