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“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

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Abstract

Background—Compensation for participating in research has been a fundamental element of the research apparatus despite concerns about its impact on incentivizing participation. Researchers and research ethics boards acknowledge that compensation may prompt structurally vulnerable populations, such as people who use drugs (PWUD), to engage in research primarily out of financial need. Thus, institutional restrictions around compensation have been implemented. This study explores the ethical implications of compensation practices aimed at ‘protecting’ structurally vulnerable people living with HIV (PLHIV) who use drugs within the context of individuals’ lived realities.

Methods—We draw on five focus groups conducted in 2011 with 25 PLHIV who use drugs and access a community-based HIV care facility in Vancouver, Canada. This analysis focused on participants’ perceptions of research compensation, which became the central point of discussion in each group.

Findings—Participants viewed research as a transactional process through which they could challenge the underpinnings of bioethics and bargain for compensation. Research compensation was thus critical to attracting participants and positioned as a ‘legitimate’ form of income. Participants’ medicalized identities, specifically living with HIV, were fundamental to justifying

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Conflict of Interest Statement

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compensation. The type of compensation (e.g. gift card, cash) also significantly impacted whether participants' were fully compensated and, at times, served to exacerbate their structural vulnerability.

Conclusion—Research compensation is critical in shaping structurally vulnerable populations' participation and experiences with research and can further marginalize individuals. Practices surrounding research compensation, particularly for drug-using and HIV-positive populations, need to be evaluated to ensure participants are equitably compensated for the expertise they provide.

Keywords

HIV/AIDS; drug use; research compensation; research ethics; Canada

Introduction

Research compensation has been a fundamental, albeit controversial, element of the health research apparatus for decades (Dickert & Grady, 1999). For structurally vulnerable populations, compensation remains highly contentious despite a wealth of literature exploring its tenuous impact on research (Festinger et al., 2005; Fry & Dwyer, 2001; McKeganey, 2001; Pandya & Desai, 2013; Permuth-Wey & Borenstein, 2009; Ripley, Macrina, Markowitz, & Gennings, 2010). Structurally vulnerable populations, such as people who use drugs (PWUD) and people living with HIV (PLHIV), occupy marginalized positions within larger social hierarchies based on socio-structural inequities (e.g. drug criminalization, racism, poverty, sexism), as well as institutional structures (e.g. policies, regulations) (McNeil et al., 2015; Quesada, Hart, & Bourgois, 2011). Researchers and research ethics boards recognize that compensation incentivizes participation (Ripley et al., 2010) and may prompt PWUD and other structurally vulnerable populations to engage in low or high-risk research primarily out of financial need (Dickert & Grady, 1999).

As a consequence, there are persistent concerns that research compensation for the broader research enterprise, including socio-behavioural and biomedical research, might increase vulnerability among structurally vulnerable populations (e.g. undue risk-taking to access compensation) (Dickert & Grady, 1999; Macklin, 1981; Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007) or, in the case of PWUD, lead to increased drug use following participation (Davidson & Page, 2012; Ritter, Fry, & Swan, 2003; Seddon, 2005). This dynamic has also led to concerns about the capacity of these populations to provide voluntary informed consent (Beauchamp & Childress, 2009; Grady, 2001), thus endangering participants' voluntary involvement. Individuals who choose to participate in research largely due to compensation may not be able to refuse or withdraw from the study, even when confronted with potential risks (Faden & Beauchamp, 1986; Grady, 2001). These concerns have prompted institutional restrictions by ethics boards around compensation (i.e. limiting compensation to reimbursement of incidentals, degree of risk) (Ackerman, 1989) or low monetary value of research compensation. Such limitations have subsequently led some researchers to provide little or no compensation for research participation, despite a range of possible approaches (e.g. monetary, gift cards) (McNeill, 1997; Permuth-Wey & Borenstein, 2009; Reiser, 2005). While there is important scholarship supporting concerns about

research compensation, there is a need to explore the impact of different types of compensation on structurally vulnerable populations' voluntary consent and how it shapes research-related interactions in order to better inform the ethical framework around compensation.

Understanding how research compensation practices shape individuals' participation is particularly relevant in the context of PLHIV who use drugs, as such constraints can deter their participation in research that may be of benefit to them or their communities (Bell & Salmon, 2011; Permuth-Wey & Borenstein, 2009). Moreover, concerns regarding the impact of compensation on structurally vulnerable populations (e.g. exploitation, undue inducement), particularly PWUD, have not been fully accounted for in the literature. Although limited, previous work has documented the impact of research participation and compensation on the lives of PLHIV and PWUD to address the ethical concerns of respect, beneficence, and justice (Fisher, 2004; Russell, Moralejo, & Burgess, 2000; Semaan, Santibanez, Garfein, Heckathorn, & des Jarlais, 2009), as well as concerns of undue inducement or increased vulnerability (Festinger et al., 2005; Slomka et al., 2007). For example, Russell and colleagues (2000) highlight the need for an expanded interpretation of ethical principles in relation to structurally vulnerable research participants, while Seeman and colleagues (2009) underscore the need to uphold ethical principles in research with people who inject drugs. Additionally, Festinger and colleagues (2005) demonstrated how neither amount nor type of compensation significantly impacted drug use or perceptions of coercion for PWUD participants. Similarly, Slomka and colleagues (2007) found that structurally vulnerable PWUD dismissed concerns that compensation impacted their drug use or risk-taking. Additional studies have sought the perceptions of research participation and compensation of PWUD's (Barratt, Norman, & Fry, 2007; Davidson & Page, 2012; Fry & Dwyer, 2001). One study found differences between research ethics board regulations and how people who inject drugs (PWID) understand their participation (Davidson & Page, 2012). While ethics boards framed participation as a voluntary act, participants viewed their research involvement as an income-generating opportunity (Davidson & Page, 2012). Another study identified a range of motives for participation among PWID (Fry & Dwyer, 2001). While economic gain was included, findings highlighted how participation was motivated by more than personal benefit.

Whereas these studies have highlighted the role research participation and compensation play in the lives of PWUD, there remains a need to explore how participants rationalize their involvement in research, particularly around their intersecting identities (e.g. HIV status, drug use). Identities are comprised of various characteristics, such as class and race, which intersect at the micro-level and often reveal larger socio-structural inequities (Bowleg, 2012; Kelly, 2011). For structurally vulnerable populations, HIV status and drug use can be additional social identities of particular relevance. As such, it is necessary to interrogate the rationale and theory that forms the basis of bioethics – ethics applied to health-related fields and medicine, including research – by examining the broader macro- and micro-contexts (e.g. power structures) in which it is practiced (Benatar, 2006; Hedgecoe, 2004; Murray & Holmes, 2009). It is especially important to explore the ethical implications of compensation aimed at 'protecting' structurally vulnerable PLHIV who use drugs in the context of individuals' lived realities.

We undertook this qualitative study to explore the perspectives of structurally vulnerable PLHIV who currently or formerly used drugs regarding research participation and compensation. We sought to generate insight into the ethics of research compensation and how current approaches impact participants, particularly within the context of structural vulnerability. Ultimately, we aimed to better understand what constitutes ‘equitable’ research compensation for drug-using populations, including those living with HIV.

Methods

We draw upon data collected during five focus groups conducted with PLHIV who use drugs recruited from the Dr. Peter Centre (DPC), a community-based HIV care service in Vancouver, British Columbia (BC). The service includes a 24-hour specialized nursing care residence and low-barrier integrated day health program operating under a harm reduction approach. Focus group discussions were conducted to understand the perspectives of DPC clients on research participation in order to inform future research activities at the centre.

Eligibility and participant recruitment

All DPC residents and clients were eligible to participate in this study, and there were no other inclusion criteria. Posters containing information about the focus groups were posted at the DPC, and instructed interested individuals to sign up for focus groups at the front desk. Prospective participants were provided with an appointment card stating the date and time of the focus group for which they had signed up. Enrolment remained open until the final focus group session, after which it was determined that saturation had occurred. A total of 25 DPC clients and residents signed up for, and participated in, the focus group discussions (see demographics in Table 1).

Data collection

Focus groups were conducted in a meeting room at the DPC over the course of two days in July 2011, and were facilitated by an experienced qualitative researcher (RM). Prior to commencing each group, the facilitator used a research information sheet to explain the purpose of the study, highlighting the need for participant input to develop research relevant to, and respectful of, the experiences of residents and clients of the DPC. The facilitator then answered any questions, and obtained verbal and written informed consent. Participants were asked not to disclose what was said during the discussion, and were informed of the limited confidentiality afforded by focus groups. An interview guide was used to facilitate discussion. Each focus group lasted approximately 60 minutes and was audio recorded. As outlined in the consent form, each participant received a \$10 CAD gift card for a pharmacy chain store – the closest store was two blocks from DPC – as compensation for their time and participation. These research compensation practices were in accordance with the DPC’s research guidelines at the time of the study. One participant withdrew prior to the start of one of the focus groups and received a gift card. A professional transcription service was used and transcripts were later reviewed for accuracy by the facilitator. Ethical approval for the study was obtained from the University of Toronto research ethics board.

Data analysis

Interview transcripts were imported into NVivo qualitative analysis software to facilitate coding and thematic extraction. The research team met regularly to discuss emerging themes in the data and developed a coding structure that was used to code data. An intersectionality framework (Bowleg, 2012; Crenshaw, 1991; Viruell-Fuentes, Miranda, & Abdulrahim, 2012) was utilized in this analysis to better understand the various, interconnecting elements that impacted participants' previous experiences with, and understanding of, biomedical and socio-behavioural research procedures. Based on emerging findings relating to experiences of socio-structural inequities within research settings and elsewhere, we drew upon the concept of structural vulnerability to better understand the larger socio-structural factors shaping participants' experiences with, and access to, research (Quesada, Hart, & Bourgois, 2011). This theoretical 'lens' has been previously employed to facilitate analyses of how specific groups interface with social and structural environments on the basis of their positions within social hierarchies and the resulting outcomes (McNeil et al., 2015; Parker, Easton, & Klein, 2000; Quesada, Hart, & Bourgois, 2011). This analytical approach was deemed to be relevant to our focus on interactions between PLHIV who use drugs and the broader research apparatus in the context of research compensation practices. Preliminary findings were shared in a debriefing session held with focus group participants at the DPC in August 2011. Of particular interest was research compensation, which became an important discussion point in each of the five focus groups, highlighting key issues related to standard research compensation. Participants provided feedback during the debriefing session, which confirmed that our themes reflected their experience and mitigated personal biases in this interpretation.

Findings

Breaking power dynamics in search of "fairness"

All participants had previously participated in at least one biomedical or socio-behavioural research study, ranging from clinical HIV-related studies to focus groups discussing nutrition. In Vancouver, research opportunities for PWUD are numerous and include prospective cohort studies, randomized control trials, and socio-behavioural research. As such, participants often had experience of participating in multiple studies. Participants' discussions of past research experiences highlighted knowledge and power dynamics between participants and researchers, particularly in relation to the perception that researchers were 'taking' their expertise and personal information. Many participants expressed the view that researchers often "*just take the surveys and leave*" without "*com[ing] back...with their [findings].*" Such perceptions shaped participant views of research-related interactions, which they characterized as "*impersonal.*" Other participants explained that they were "*living on one meal a day...[and] smoking [cigarette] butts off the ground,*" and the lack of acknowledgement and respect from researchers made them feel unimportant, despite sharing intimate parts of their lives.

While participants reported that they would like to learn about research findings, it was evident that interest in research did not drive participation. Instead, participants viewed research as a transactional process. One participant noted, "*We're giving you something,*

right, so we just feel it's [compensation] fair" (Group 3 participant). Another participant followed with, "[It is fair] *we get something in return*" (Group 3 participant). Viewing research as transactional allowed participants to assert some power over the research process by compelling researchers to provide compensation for what they perceived as a service performed. This response to their structural vulnerability provided participants with a way to reposition themselves by leveraging power within the expected researcher-participant relationship toward meeting material and monetary needs. Through participant accounts, it was evident they felt that researchers needed access to their experiences and perspectives in order to undertake research activities. One participant explained:

You know, we're in the process [of what is being studied], and that is what it is, so you know, we're not gonna be coming to [the] thing like this for our own good... We're gonna be coming because there's something to be had... The onus is all on you guys, cause we don't feel any compulsion to do any of this for nothing. [Group 4 participant]

Other participants echoed this view, with one reporting: "*Without us, [researchers] wouldn't know what the heck is going on.*" Some expressed the view that it was up to the researcher "*to make [them] care*" about the topic studied or else they will only "*give [researchers] so much for so much money.*"

The aforementioned dynamic illustrates how participants challenged expected power relations by seeking to advocate for compensation, reflecting experience stemming from their multiple and overlapping identities, which included their status as PLHIV who use drugs or being street-involved. Participants' experiences in relation to their medical identities, previous research experience, and structural vulnerability were positioned as 'expertise' that allowed them to make unique contributions to research. Moreover, it was within this context that participants could claim a greater degree of agency within the research apparatus. For example, one participant stated:

I think it's important to make sure that, you know, you have people there [participating in research] who have some experience of the street. Some experience of, you know, the reality of peoples' lives... A lot of us are living on one meal a day. [...] A lot of what's obvious to us isn't to people who haven't lived that life. [Group 4 participant]

Due to this unique knowledge and positionality, participants felt they should be equitably compensated. However, participants' accounts also highlighted tensions arising between altruistic expectations of research participation and their real material needs. For example, a minority of participants stated how either they or others "*are willing to do it [participate] even for free*" to help other PLHIV. Such positioning was at odds with participants' simultaneous aim at bargaining for compensation to temporarily lessen the effects of extreme poverty.

"If you never were marginal..."—structural vulnerability and research participation

Participants articulated that factors associated with their structural vulnerability (e.g. poverty, unemployment) meant that research participation often hinged on compensation.

Among participants, research compensation offered a legal or ‘legitimized’ form of income to supplement modest social assistance payments and other forms of informal income-generation (e.g. recycling, sex work). As such, research participation offered structurally vulnerable individuals a safer, albeit variable, form of income generation. One participant explained:

I think any of the research you’re going to talk about, if there’s cash involved, we’ll do it. And it’s a horrible thing, but again... we’re all probably close to the bottom end of the poverty area, so if the cash level is good... [Group 2 participant]

Another participant noted:

[For research participation] getting compensation would help [...] One thing for sure is a little money is always therapeutic for people who live without enough money. You know what I mean? [Group 4 participant]

Other participants stressed that research recruitment efforts should be “*later in the month*” when individuals “*have nothing to do*” and need additional monetary support, rather than “*just after cheque day* [i.e. the day at the end of months when monthly social assistance payments are disbursed].” For many participants, research participation was based on whatever studies were recruiting rather than the research topic. As such, participants frequently viewed research as another source of income support - a type of ‘work’ or service for which they should be equitably compensated - rather than as meaningful participation or a collaborative partnership.

Notions of research participation as a transactional process were further solidified as participants expressed that, without compensation, they “*would feel used*” by researchers because “*time...costs money*.” For many participants, research participation competed with their ability to engage in other forms of income generation necessary to negotiate survival within the context of their structural vulnerability. Compensation thus made research participation worthwhile, particularly as participants were not receiving reimbursement from an employer or other sources for their time spent.

Moreover, participants mobilized their medicalized identities (e.g. living with HIV, mental health issues) to justify research compensation. Often, participants compared their identity living with HIV with non-positive persons to imply how their “*real life perspectives*” and experiences were valuable, particularly for research. For participants, most socio-behavioural, HIV-related research focused on structurally vulnerable populations, suggesting the perceived importance of their particular identities and experiences. Participants in one focus group explained:

Participant 1: Our blood, our blood is valuable. We have special blood... We have very special blood.

[...]

Participant 2: And we’re speaking from a unique experience—from our perspective, which is actually unusual compared to your average citizen.

Participant 3: Knocks them off the wall.

Participant 2: *We've all faced life threatening diseases and death, and we choose to live as healthy as possible in most cases.* [Group 1 participants]

As such, participants rendered their often-stigmatized identities as appealing for research and simultaneously deserving of compensation. Specifically, participants drew on HIV-related medical experiences and challenges (e.g. experimental HIV treatment) to further justify research compensation:

We are an experimental life-giving group. I mean we are dealing with experimental drugs. We're living off, you know, subsidies and things like that that people are giving us. [...] The research is very important to find out that our needs are being met. [Group 4 participant]

This leveraging of HIV status, along with other comorbidities and socio-economic characteristics, highlights participants' internalization of otherwise stigmatized identities to defend compensation for research participation and push back against their structurally vulnerable positionality.

'Ethical' compensation and institutional limitations

While participant accounts elucidated the significance of research compensation, types of compensation (e.g. gift cards, cash) had deeply entrenched meanings for participants. For many, cash compensation were considered a type of "*freedom*" that was otherwise restricted by their structural vulnerability and 'protective' actions of others. For example:

Participant 1: Freedom to do what you want to do with your money.

Participant 2: *And we never get cash. We always get [a] cheque or automatic deposit. We rarely see cash given, handed to us in our lives.*

Participant 1: It's like you're saying to us 'Because you're HIV and you're at the Dr. Peter Centre, you can't have cash cause we know what you'll do with it'.

Participant 2: *Exactly. And it's nice to be given cash.* [Group 1 participants]

In addition to being easier to use, cash allowed participants to challenge the stigmatized medicalized identities that often influenced how they were compensated or supported through research. For example, participants expressed how their association with past or current drug use and low socio-economic status greatly shaped how others (e.g. researchers, service providers) viewed them and their decision-making abilities. Thus, the type of compensation represented not only compensation for work done, but also an opportunity to be seen as a trusted and equal individual. As such, cash compensation afforded participants agency that was otherwise not available to them within the traditional bioethics framework.

However, the ethical concerns from which institutional constraints stem (e.g. participant could purchase and consume illicit drugs) were alluded to by participants in the focus group discussions: "[With gift cards] *it's like they're saying, 'Well you can't handle cash because*

we're under the understanding that you may have an addiction problem'..." (Group 1 participant). Participants frequently alluded to their disappointment about receiving a \$10 CAD gift card honorarium for participation in the focus groups: "*Yeah, [compensation should be] 30 bucks. Like \$10 [for this focus group], I'm surprised by that*" (Group 4 participant). For many, gifts cards were deemed "*kind of juvenile*" because they were seen as patronizing and as a form of control over participants. One participant expressed the view that gift cards "[are] *not giving us the freedom... We came here on our own time...and we're getting honest with you, so why not give us a break and give us cash.*"

As participants echoed the relationship between compensation-type and current or past drug use, their narratives highlighted how gift cards exacerbated their structural vulnerability by creating additional barriers to accessing resources, monetary support, and equitable compensation. The restrictiveness of gift cards often made participants more vulnerable. One participant explained:

Many marginal people—and the people who come here...are by and large marginal—they're barred from the drug store. They're barred from every fucking drug store from here to New West [i.e. a municipality within the greater-Vancouver area]. [...] If they took that [gift] card and walked over to a [pharmacy chain store], they'd be ejected from the building the moment they walked in. [Group 4 participant]

Others expressed recurring discontent about the restricting effects of gift cards, and specifically how it constrained their agency in benefitting from the anticipated 'rewards' of research participation. For example, one participant noted:

I said okay, [pharmacy chain store] card, I'll go get a gallon of milk... But believe it or not, a gallon of milk at [a grocery store] is \$4.50. A gallon of milk there [pharmacy chain store] is \$6.70... I could have two gallons of milk or gotten other stuff. [Group 4 participant]

Due to such constraints and barriers posed by non-monetary compensation, selling or trading gift cards for cash or other goods were ways for participants to gain some degree of agency over their compensation. For example, one participant explained, "*as long as I can turn that gift certificate into a pack of cigarettes...I'll be happy*" (Group 4 participant). These examples underscore how gift cards can often result in less (or no) compensation for participation. When exchanged for cash or other goods, participants often receive less than the full compensation value: "*That gift card is going to be changing hands as soon as this person leaves, probably for half of what the face value is...you know what I mean?*" (Group 4 participant). These examples highlight how larger socio-structural forces and vulnerabilities shape participants' experiences. As a result, typical compensation methods (i.e. non-monetary) were not aligned with the lived realities of structurally vulnerable participants, influencing whether individuals actually receive compensation.

"Getting virtually nothing": perceived fairness of compensation amounts

Perspectives regarding what constituted equitable research compensation were commonly articulated by participants. Participants expressed the view that compensation and incentives were often "*way too low*," stating compensation should reflect the psychological

“*intens[ity]*” of the research approach (i.e. focus group, survey, interview) and time committed. One participant explained: “[The] *incentive is usually either donated...it’s kind of low, it’s whatever they scraped together sometimes*” (Group 2 participant), and thus not an equitable reimbursement for work done. The majority of participants deemed \$20 to \$30 compensation per hour to be fair. Participants further contrasted previously received monetary compensation with what they viewed as minimal compensation for focus group participation (i.e. \$10 gift card):

Participant 1: *You should just start at 20 [dollars]. Everybody else does. That’s just my opinion.*

Participant 2: *I think 10 bucks an hour is- \$10 to \$15 an hour is a fair deal. [...] I’ve done the ones that have been an hour and a half and gotten 20 bucks...I think it’s based on the time it takes. I’ve been to one whole four [hour] session, they gave me 50 bucks. [Group 2 participants]*

Although some participants acknowledged that research works within the confines of a budget, ‘fair’ compensation was considered imperative to participation. For example, when asked about \$10 per hour as compensation, one participant noted:

What is \$10 worth anyway? Nothing. It should be a minimum of \$20 and there shouldn’t be any strings attached to it...give you just a \$20 bill in an envelope and thank you very much. [Group 4 participant]

However, several participants explained that \$10 compensation was fair if an additional incentive, such as a meal or written thank you note was also included. Despite being non-monetary, the proposed incentives provided additional rewards and benefits (e.g. validation, meeting subsistence needs). Other participants reflected on previous experiences of not being equitably compensated in comparison to researchers for their research involvement. For example:

I’ve been involved in projects...in the past where they bring in one or two people from the outside, and then it’s sort of dependent upon local populations for their data or whatever. But at the end of the day, they’re [researchers] getting a paycheck; you’re getting virtually nothing. [Group 4 participant]

These accounts in which participants felt taken advantage of due to little or no compensation, despite making the research possible, underscores how inequitable compensation can exacerbate participants’ structural vulnerability.

Discussion

In summary, our findings demonstrate that research participation for PLHIV who use drugs was seen as a transactional process through which structurally vulnerable participants could challenge the underpinnings of bioethics practice. Our findings also underscored how research compensation was crucial to attracting research participants and positioned as a ‘legitimate’ form of support. In addition, participants’ medicalized identities, specifically living with HIV, were fundamental to justifying research compensation. The type of

compensation offered to participants was materially and symbolically important and, if not done equitably, could exacerbate their structural vulnerability.

Consistent with previous work (Davidson & Page, 2012; Fry, Hall, Ritter, & Jenkinson, 2006; Slomka et al., 2007), our findings elucidate that participants viewed research as another source of ‘legitimized’ income. Whereas previous research has shown that research participation is often influenced by compensation (Davidson & Page, 2012; Farre, Lamas, & Cami, 1995; Fry & Dwyer, 2001; Rudy, Estok, Kerr, & Menzel, 1994; Slomka et al., 2007), our findings highlight how structural vulnerability intersects with medicalized identities to shape participants’ willingness to engage in research. Participants positioned their perspectives and experiences living with HIV as a valuable resource or marketable skill to researchers. Leveraging their multiple identities and lived realities enabled participants to resist the traditional binary basis of research ethics that positions ‘actually existing’ research practices in opposition to ethical constraints placed on them by research ethics boards or bioethics theory (Hedgecoe, 2004; Murray & Holmes, 2009). By shifting the conventional researcher-participant power dynamic, socio-structurally marginalized participants can manage stigmatized identities by assuming the role of expert for which compensation is seen as equitable. For vulnerable individuals, this shift of power can be an avenue through which survival within the context of their structural vulnerability can be mediated.

Although compensation remains a contentious issue within the literature (Festinger et al., 2005; Fry & Dwyer, 2001; McKeganey, 2001; Pandya & Desai, 2013; Permeth-Wey & Borenstein, 2009; Ripley et al., 2010), our findings have important implications for how research compensation is approached. Specifically, our findings highlight the need to determine what constitutes equitable compensation for research participation, particularly when recruiting structurally vulnerable populations (e.g. PLHIV who use drugs). Research compensation can have pronounced ramifications on participants’ experiences of the research process (e.g. feeling valued versus exploited) and can exacerbate participants’ socio-structural marginalization and ability to provide voluntary consent. Consistent with Seddon (2005), participants shared how gift cards can create additional barriers (e.g. cannot access specific store, unable to purchase needed goods). As a result, they are often traded or sold for less than the original value, which can lead to inequities in compensation between those who likely have to trade the gift cards (e.g. structurally vulnerable populations) and those who do not. This further impacts on whether participants are fully compensated for their work. As a direct result of this, the DPC revised its approach in relation to research partnerships to promote more meaningful involvement of the organization’s clients in the research process, which included ensuring that compensation practices were responsive to clients’ structural vulnerabilities. Studies currently underway at the DPC (e.g. community-based participatory research studies, mixed-method evaluation) are providing cash honoraria to research participants in accordance with organizational policies and local practices.

Additionally, while some ethics boards, institutions, organizations, and researchers prefer non-monetary compensation or honoraria (e.g. gift cards) for PWUD (Davidson & Page, 2012; Ritter et al., 2003), the University of Toronto (2011) has established progressive guidelines for research compensation, which could be used as a model to inform research design and approaches to compensation. These highlight the need for compensation to be set

at a level that reflects participants' value while not influencing their participation. The university's guidelines also underscore that compensation restrictions for vulnerable populations should not differ from those set for non-vulnerable populations, as participants are autonomous. Similarly, the Canadian HIV/AIDS Legal Network (2006) offers peer and participant-influenced guidelines for research that highlight the critical need for ethical participation and compensation. Similarly, our data highlights how offering non-monetary compensation is a paternalistic approach that constrains the agency of structurally vulnerable populations (Slomka et al., 2007), and should thus be avoided within research design.

Despite concerns around compensation type for individuals who use drugs (Davidson & Page, 2012; Festinger et al., 2005; Flicker, Savan, McGrath, Kolenda, & Mildenerger, 2008; Fry & Dwyer, 2001; McKeganey, 2001), there is a need to rethink the ethical framework guiding research compensation and how marginalized participants are perceived within the biomedical system. Rather than volunteers motivated by altruism, participants reminded us that they should be seen as experts whose insights deserve equitable compensation. To this end, we suggest that research compensation be provided in cash form, as participants are partaking in what they view as a transactional process that necessitates compensation in exchange to meet their own material needs. As suggested by Bell and Salmon (2011), researchers should consider compensation that is comparable with additional opportunities of income, thus mitigating potential threats to voluntary consent. In addition, our findings highlight the need for transparency around compensation amount, method, and rationale, which should be conveyed to the various members of the research apparatus (e.g. ethics boards, institutions, comptrollers), including participants (Fry et al., 2006; Seddon, 2005). Furthermore, we suggest that those involved in the research apparatus consider how participants perceive their involvement in research and design research compensation guidelines accordingly. Specifically, ethics boards' and institutions' compensation guidelines should ensure that structurally vulnerable participants are respectfully compensated and that their agency is not restricted through paternalistic compensation methods as a form of 'protection.' There are examples of research ethics boards working with researchers to develop a mutually supportive review cultures and processes (Guta, Nixon, Gahagna, & Fielden, 2012). This is particularly significant, as concerns regarding the potential harms of compensation for structurally vulnerable populations have not been substantiated.

Researchers have an ethical responsibility to remain informed of developments in research ethics and compensation practices, as well as to ensure that participants are protected and adequately remunerated. We, therefore, encourage researchers to advocate to their respective research ethics boards and institutions for compensation protocols attuned to participants' lived realities, if these are not already in place. Notably, researchers would be wise to highlight the increased harm specific types of compensation can produce. Moreover, our findings also underscore the critical need to maintain an open dialogue with community members and participants to reassess compensation protocols and readjust as necessary.

This study has several limitations. First, the DPC clients who participated in the focus groups represent a small subset of a group of structurally vulnerable PLHIV who use drugs within the local context. Their experiences might not be transferable to all drug-using or HIV-positive populations, particularly those not faced with the same degree of structural

vulnerability. Second, all of our participants had previously been engaged in research. As such, previous experiences might have shaped their opinion of the research apparatus and research compensation. Further research on this issue with research-naïve participants may provide an alternative perspective to structurally vulnerable populations' research engagement and compensation. Third, we also conducted focus groups, rather than one-on-one interviews, which might have led to under- or over-reporting of particular views and experiences. Fourth, women and transgender persons were underrepresented in our study, and additional research is needed to better understand how research compensation impacts their participation.

In conclusion, our findings highlight the importance of research compensation in shaping structurally vulnerable PLHIV's participation and experiences with research. Our data also demonstrate how particular methods of research compensation (e.g. gift cards) can further marginalize populations. These findings underscore the need to rethink the ethics and ideologies shaping research compensation, particularly for PLHIV and PWUD populations. Individuals' multiple and intersecting identities need to be considered when selecting compensation type for research, so as to ensure participants are equitably compensated for the expertise they provide.

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Table 1

Participant characteristics

Participant characteristic	n (%) N=25
Age	
30–39 years	2
40–49 years	12
50–59 years	9
60+ years	2
Gender	
Men	18 (72.0%)
Women	5 (20.0%)
Transgender	1 (4.0%)
No response	1 (4.0%)
Race	
White	14 (56.0%)
Indigenous ancestry	5 (20.0%)
Other	5 (20.0%)
No response	1 (4.0%)