

“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

What is this study about?

Historically, researchers and research ethics boards have acknowledged that compensation for research participants from particular populations, such as people who use drugs (PWUD), may prompt research engagement primarily out of financial need. This has led to institutional restrictions around compensation practices, often limiting compensation to reimbursement of incidentals or compensation of low monetary value. While there are concerns of increasing vulnerability and undue risk taking with compensation, there is a need to explore the impact of different types of compensation on vulnerable populations’ voluntary consent and how it shapes research-related interactions. By exploring the impact of compensation on study participants, the researchers hope to inform the ethical framework around compensation policy. This study draws on five focus groups conducted with 25 people living with HIV who use drugs and are clients at the Dr. Peter Centre, a community based HIV care facility in Vancouver, Canada. It explores the ethics surrounding perceptions of research compensation practices by research participants.

What are the key findings?

- Participants viewed research as a transactional process, seeing their lived experiences as providing unique and valuable contributions to research.
- Most participants thought that the type of compensation provided was materially and symbolically important, and could have negative impacts if not provided equitably.
- Social and structural factors (e.g. poverty and unemployment) often influenced research participation .
- For participants, research compensation offered a safer and legal form of income to supplement social assistance payments and other informal income-generation, such as recycling cans and bottles.
- Compensation was deemed necessary by participants in exchange for time and experience.
- Cash compensation was considered a type of “freedom” and was perceived as an opportunity to be seen as trusted.



What do these findings mean?

- Research participants view their experiences living with HIV as a valuable resource and marketable skill provided to researchers.
- Research compensation can have pronounced ramifications on experiences that are part of the research process, causing participants to feel either valued or exploited.
- There is a need to determine what constitutes equitable compensation for research participation, particularly when recruiting populations impacted by social and structural inequities.
- As a form of protection, guidelines for research compensation should ensure that all participants are respectfully compensated. Their agency should not be restricted through inequitable compensation methods.
- Research compensation protocols should be regularly assessed and readjusted as necessary, through open dialogue with community members and participants.

About the Dr. Peter Centre Study

The Dr. Peter Study is a joint initiative led by the BC Centre for Excellence in HIV/AIDS and the Dr. Peter AIDS Foundation, and brings together a team of academics, people living with HIV, policymakers, health care decision makers, and program managers from across Canada. This is a three-year mixed-methods evaluation funded by Canadian Institutes of Health Research Partnerships in Health System Improvement program and the Michael Smith Foundation for Health Research. The study will identify which aspects of the Dr. Peter Centre model of care contribute to enhanced treatment and health outcomes among persons living with HIV/AIDS.

Full paper available online: [http://www.ijdp.org/article/S0955-3959\(16\)30299-7/fulltext](http://www.ijdp.org/article/S0955-3959(16)30299-7/fulltext)

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