

Considerations for Compensating Research Participants Fairly & Equitably

A Think Piece

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Wellesley Institute works in research and policy to improve health and health equity in the GTA through action on the social determinants of health.

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Think Piece

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Statement on Acknowledgement of Traditional Land

We would like to acknowledge this sacred land on which the Wellesley Institute operates. It has been a site of human activity for 15,000 years. This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. The territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

Today, the meeting place of Toronto is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work in the community, on this territory.

Revised by the Elders Circle (Council of Aboriginal Initiatives) on November 6, 2014

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TABLE OF CONTENTS

Introduction	1
Research for Health Equity	1
Debates about Payment.....	2
Ethical Considerations	3
Reducing Financial Barriers to Participation.....	5
Fair Recognition of Participant Contributions	6
Beyond Payment: Additional Considerations	6
Next Steps	7
References	8

Introduction

Researchers often ask people to contribute to our studies by sharing their experiences through interviews, focus groups, and surveys. In trying to advance health equity it is important to learn about the health and health-related experiences of participants from diverse social and economic backgrounds. While health and social science researchers often provide incentives or honoraria to participants debate remains about whether and how to compensate research participants.

Discussion about the ethical use of compensation has focused on questions about its use as a tool for recruitment and whether, unintentionally, compensation can unduly influence participants to disregard risks (Grady, 2005). Despite these tensions, research compensation has become conventional practice in health and social research taking distinctive forms (reimbursement, financial compensation akin to income, and symbolic of appreciation). Regardless of what form or approach is used there is a lack of consensus and guidelines on how participants' vital contributions to research should be recognized. The apparent widespread use of research compensation has in some respects shifted the debate from *whether* payment should be used to *how* it should be used to ensure that research compensation practices align with ethical standards and incorporate an equity lens (Collins et al., 2017).

This think piece draws on existing literature, a scan of existing online guidelines from research ethics boards (REB) across the Greater Toronto Area (GTA) as well as the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS) to highlight key considerations when making decisions about compensation for research participants in the GTA (TCPS, 2014; Ryerson, 2014; Sunnybrook, 2014; UofT, 2011). Based on this work, we propose that making decisions about what constitutes an equitable amount of payment or compensation requires a consideration of both reducing financial barriers to participants and fairly recognizing participants' contributions to research. Research payment practices that are fair and equitable contribute to more ethical and inclusive research, which is ultimately needed to improve health and health equity in the GTA.

Research for Health Equity

Reviews of the international literature on research compensation revealed a lack of uniformity in practices, with considerable variability in whether compensation is offered, and what form it takes (Fry et al., 2005; Ripley et al., 2010; Roche et al., 2013). The use of compensation in Canadian health and social research has highlighted nuances within ethical discussions and debates and raises the question of how we apply an equity lens to research.

Health disparities are systemic and unfair differences in health outcomes. Disparities are caused by unequal access to resources, opportunities, and services. Health equity “allows

people to reach their full health potential” (HQO, 2016) and requires that all Ontarians can access the resources, services and rights needed to be healthy and thrive.

Research can play an important role in advancing health equity. By adequately understanding the needs, experiences and health outcomes of diverse populations, research can inform better policies, programs, and treatment, and play an important role in advancing health equity. Historically equity-seeking populations have been both unfairly excluded from research and thus its benefits, as well as exploited and harmed by researchers. For example, the *Tri-Council Policy Statement (2014)* highlights that women have been inappropriately excluded from health research and then harmed by treatments and interventions that were informed by the generalized findings from male-only studies. Fair and inclusive research practices can improve the quality and generalizability of research, ensure diverse populations benefit both directly and indirectly from research, and prevent inequitable harms of research.

Debates about Payment

Debates in the literature on the ethics of compensation for research participants, have largely centered on whether financial incentives undermine the voluntary nature of participation; effectively creating undue influence. The counter argument has been that compensation functions as an acknowledgement of the contributions of the research participant.

For ethics boards these tensions have raised discussions around what is appropriate as compensation, and whether there should be limits. For many researchers, this may come down to which approach they take to understanding compensation and its role in research. In the literature there are, broadly, three approaches to how researchers frame compensation, and set limits accordingly (Resnik 2015; Ripley 2006; Permuth-way & Borenstein 2009; Grady, 2005).

1. **Appreciation:** The appreciation approach is focused on acknowledging the contributions of research participants to a research study. Often cast as an honorarium, the intent is to honour a participant’s involvement through a token gift, gift card or payment. It is not intended to be a form of paid labour.
2. **Compensation:** The wage payment approach identifies the participant’s contribution as a form of paid labour. In this sense, any payment is intended to be compensation for their time and contribution, akin to a wage.
3. **Reimbursement:** The reimbursement approach focuses on covering any out-of-pocket expenses associated with participation. This can mean that compensation covers travel expenses or childcare but can also be applied to the concept of lost wages.

In non-medical health and social research, where the risks of harm are minimal, there is widespread acceptance that compensation is unlikely to have a serious harmful impact for participants. Instead, it is often seen as a mechanism to enhance participation of some populations, who might otherwise be unable or reluctant to take part. However, this in turn

has surfaced ethical questions about the differential effect that financial compensation may have for some participants, notably those from marginalized or lower-income populations.

The tensions that have emerged here are two-fold. First, the question has been raised about whether incentives for marginalized populations might distort the voluntary nature of participation, reducing the question of involvement to one of economics and need. Second, concerns have been raised about whether incentives may exacerbate the potential for increased vulnerability for certain sub-groups. More concretely, the concern is that “structurally vulnerable” populations may participate in research out of financial need, and not fully assess potential risks (making them subject to undue influence, and compromising informed consent), and/or will buy and use more drugs as a result of payment (in the case of people who use drugs) (Permuth-Wey & Borsenstein, 2009).

Together these concerns have had a reverberating effect through research practices, with many researchers exercising caution on how much they compensate participants and in what ways. There is a rich literature that weighs the ethical dimensions of different amounts and forms of compensation. Recent research into the experience of compensation from the perspective of participants suggests a more nuanced understanding of what they believe their contribution to research is. Collins and colleagues (2017) found in their study with individuals living with HIV who use drugs that participation becomes a complex mix of a transaction for service, and a recognition of their time and commitment as part of a study. Here, research income is viewed as a legitimate form of income that is based on their lived experiences and expertise. This work is important as it highlights the need for a critical discussion of the ethics of compensation, and the need for a clearer understanding of what equitable compensation looks like, particularly from the viewpoint of participants.

Ethical Considerations

The *Tri-Council Policy Statement* is an ethical framework for research in Canada that provides primary guidance on ethical principles for researchers and Research Ethics Boards (REBs) that are important to consider when making decisions about compensation for research participants (TCPS, 2014). The TCPS outlines three core ethical principles for research: respect for persons, concern for welfare, and justice. The ethical review processes conducted by REBs are attentive to the intent, scope and methods of conducting research, as well as the more procedural or task-oriented activities critical to research, such as: techniques of gathering informed consent; processes of ensuring confidentiality and data protection. The real-world application of research methods however can yield unanticipated challenges. One area that remains unresolved is the area of research compensation for participants in health and social research.

The TCPS (2014) outlines a number of principles for making decisions about payment, which are important to consider since it is widely used by both institutions that must adhere to it

to be eligible for research funding and other organizations that have adopted it as an ethical framework for their research.

Discussion of participant payment in the TCPS is primarily focused on the use of payment as incentives, which are defined as “anything offered to participants, monetary or otherwise, to encourage participation in research” (TCPS, 2014). The TCPS does not provide specific recommendation about how much payment is appropriate; in fact, it “neither recommends nor discourages the use of incentives.” The Policy does however provide principles to guide decision making about incentives.

The principle that is most central to decisions about incentives is consent. The TCPS advises that individuals must provide consent before participating in research and can withdraw that consent and stop participating at any time. Individuals must understand the purpose, benefits, and risks of the research study and be able to use their judgment when deciding whether to participate. Researchers must as a result ensure that any type of incentive does not compromise an individual’s decision to participate in the research. The TCPS specifies that payment should not be so large that a person would disregard potential risks of the research when deciding whether to participate (i.e. undue influence). Researchers must then provide justification for the type and level of incentives to REBs.

The TCPS distinguishes between incentives, reimbursement that is provided to cover direct or indirect costs of research participation, and research-related injury compensation payment. It does not provide any further recommendation however except that potential participants should be told about any incentives, reimbursements and/or injury compensation associated with participation during the informed consent process.

Ultimately, the TCPS provides a valuable ethical framework for decisions about incentives that focuses on ensuring payment does not compromise a participant’s decision to participate in research (i.e. informed consent). If decisions about payment are approached solely as a means of encouraging recruitment and retention, there are both ethical and equity concerns as the level of payment would be dictated by what is needed to convince an individual to participate. Practically, an incentive approach to payment becomes difficult to determine an acceptable level of payment and rates are likely to vary greatly by study populations, which could reduce fair and equitable treatment of participants. As the TCPS indicates, there are concerns that this approach could contribute to undue influence and compromise informed consent.

Despite concerns about the use of payment, undue inducement had not well defined in the TCPS, nor in the literature making it difficult to determine what level of payment constitutes fair recognition versus undue influence (Fry et al., 2005). Moreover, as noted by Grady (2005) there is a lack of evidence on the extent to which payment can negatively impact participant decision making. Instead, existing evidence suggests that decisions to participate in research are multifaceted and that offers of payment do not necessarily impede an individual’s

perception of research risks or ability to make voluntary decisions (Collins et al., 2017; Grady, 2005). Grady (2005) highlights that attention to informed consent processes to ensure understanding of risks, eligibility screening to minimize misrepresentation, and prorating payments can be used to reduce concerns regarding undue influence.

While the TCPS primarily frames payment as incentives to participate in research, there are in fact a number of different reasons for providing payment. Understanding *why* we provide payment can inform our decisions about *what* and *how* we pay participants. The TCPS's primary focus on payment as incentives to increase participation, does not address the full range of reasons why researchers provide payment to participants.

In addition to an incentive model there are different approaches behind why researchers provide payment including compensation for time and contributions, reimbursement for expenses and/or lost wages, and appreciation (Resnik 2015; Ripley 2006; Grady 2005).

Reducing Financial Barriers to Participation

TCPS defines reimbursement as covering expenses related to participation but does not provide further guidance. Providing payment to reimburse participants, however, is an important consideration for reducing financial barriers to participation.

There are a number of out-of-pocket expenses related to participating in the research, such as travel costs to and from the study location, and child and respite care costs for participants who are family caregivers. Out-of-pocket expenses can create a financial barrier to participation. Furthermore, participation costs may disproportionately impact certain population groups. For example, women are more likely to be family caregivers. Travel costs may be more prohibitive for residents with low income. If out-of-pocket expenses are not reduced or reimbursed, researchers run the risk of creating systemic barriers to participation, which can limit the quality and representativeness of research.

Financial barriers to participation can and should be addressed through reimbursement and/or mitigation strategies to reduce participant costs. Both University of Toronto (UofT) and Toronto Academic Health Science Network (TAHSN) guidelines recommend providing reimbursement to cover reasonable costs related to participation, such as travel, food, and child care (UofT, 2011; Sunnybrook, 2014). TAHSN guidelines specify that participants should not be expected to incur direct costs of participating in research. Researchers can also proactively develop strategies to reduce participant costs. For example, locating study locations near where participants work or live can reduce both travel time and associated costs. UofT guidelines (2011) similarly highlight that researchers can reduce expenses through strategies other than providing payment. For example, researchers can provide food, transit tokens and on-site child care for participants.

Reducing financial barriers to participation is an important consideration for ensuring research is inclusive and equitable. It is important to consider reducing financial costs to reduce financial barriers to participation in research. In this way, understanding the cost that may be involved in participation for the study population and developing strategies to mitigate and cover these costs is an important equity consideration. This fits into wider strategies to make research participation accessible.

Fair Recognition of Participant Contributions

Payment can also serve as a way to recognize participants' time, effort and contributions to research. The apparent lack of consensus and range of payment practices amongst researchers raises concerns about whether participants are being recognized fairly and equitably.

The TCPS (2014) outlines that when making decisions about payment researchers and REBs should be sensitive to decision-making capacity, age, economic circumstances, customs, and probability of harm related to the research. The TCPS further elaborates that for vulnerable participants, modest incentives could reduce the voluntariness of consent, but highlights that researchers should not make assumptions about the vulnerability of individuals and that an over-protectionist approach can reduce fairness and equity in research participation.

Researchers and participants have highlighted concern about practices of insufficiently compensating participants who are deemed “vulnerable” or providing gift cards rather than cash (Collins et al 2017).

In light of these debates, Grady (2005) argues that compensation is the most ethical model of payment as wage-like payments are unlikely to unduly influence participants and allow for a standardized amount of payment that recognizes the contributions of participants to research and the common good. Similarly, UofT (2011) recommends that study participants be compensated with cash for their time spent participating in research. While the guidelines do not specify how much participants should be paid, it does recommend that “compensation should not be set at a level that could be construed as disrespectful of participants' value to the research” (UofT, 2011).

Standardized hourly compensation is an important means of recognizing the fundamental contribution that all participants make to research, regardless of their social location.

Beyond Payment: Additional Considerations

Tokens of appreciation or honoraria, such as gift cards, small amounts of cash, or a culturally significant gift can be offered to individuals to express gratitude for participation and may be

appropriate depending on the study population. Tokens of appreciation alone however do not sufficiently provide fair compensation for participants' contributions and are unlikely to address financial barriers to research. While a culturally significant gift or token of appreciation may be appropriate for some research, this paper highlights the importance of providing payment in order to fairly compensate participants and reimburse financial costs of participation.

While an important equity consideration, payment is only one aspect of ensuring barrier-free research and recognizing participant contributions. Payment and incentives should be considered within broader efforts to make research relevant, beneficial and accessible to participants and communities.

Next Steps

There is limited existing guidance regarding payment for research participants. In Canada, the *Tri-Council Policy Statement (2014)* provides an important ethical framework that foregrounds considerations of informed consent when making decisions about how to pay participants but leaves decisions to researchers and research ethics boards. There is continued debate and variation amongst researchers about how and whether to pay participants. This paper highlights that payment is an important means for reducing financial barriers to participation and fairly recognizing the contributions of participants that can guide decisions about payment.

To build on this work, we have conducted a survey to understand current payment practices among health researchers in the Greater Toronto Area with the aim of identifying promising payment practices for equitable and ethical research and sparking conversation.

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