Equality and Equity in Compensating Patient Engagement in Research: A Plea for Exceptionalism

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Abstract
Engaging citizens and patients in research has become a truism in many fields of health research. It is now seen as a laudable—if not compulsory—activity in research for yielding more impactful and meaningful citizen/patient outcomes and steering research in the right direction. Although this research approach is increasingly common and commendable, we recently encountered a major obstacle in obtaining an ethics certificate from an institutional review board (IRB) to conduct a study that places citizen/patient perspectives on equal footing with those of academic/policy experts. The obstacle was the interpretation of fairness in terms of compensation for research participation (i.e. honoraria). In terms of research ethics, this raised an important question: Should all types of participants be compensated

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equally, or should exceptions be made for citizen/patient participants? We argue that there are good reasons for exceptionalism and that clearer guidance on citizen/patient engagement in research should be embedded into research ethics doctrine.

**Keywords**
Patient engagement, exceptionalism, IRB, participant compensation, ethical guidance, TCPS2, stakeholder engagement

Engaging citizens and patients in research has become a truism in many fields of health research (Rouleau et al., 2018; Stephens and Staniszewska, 2015). This is now seen as a laudable—if not compulsory—activity in research for yielding more impactful and meaningful citizen/patient outcomes and steering research in the right direction (Crocker et al., 2017; Hardavella et al., 2015; Shippee et al., 2015). We clearly do not need to lecture the audience of *Research Ethics* on the merits of engaging citizens/patients in research. Although this research approach is increasingly common and commendable, we recently encountered a major obstacle in obtaining ethics approval to conduct a study that places citizen/patient perspectives on equal footing with those of academic/policy experts. The obstacle was the interpretation of fairness in terms of compensation for research participation (i.e. honoraria). In terms of research ethics, this sparked an important question: Should all participants be compensated equally, or should we allow exceptionalism for citizen/patient participants?

While kickstarting a new research project to investigate citizens’ and patients’ normative perspectives on the applications of artificial intelligence (AI) in population health, we sought to create an advisory board. This board would help design an innovative deliberative tool to inform public health decision-making and their role would be to oversee and counsel our team at every step of the tool’s design. The board would be composed of experts in ethics, AI, and population health, as well as public decision-makers and citizens/patients.¹ For the duration of the prototyping phase of our project (i.e. year 1), these board members would be considered part of the extended research team.² We decided to offer a modest compensation solely to citizens/patients (i.e. C$35 per online research activity) which is consistent with consultation and citizen/patient engagement practices in certain public organizations.

Before initiating the empirical phase of the project which would involve the board, we applied for research ethics approval. All three of us are bioethicists and we consider ourselves quite versed in research ethics. However, to our astonishment, the institutional review board’s (IRB) were unwilling to approve our citizen/patient compensation strategy. The IRB demanded that all participants be compensated equally. They invoked a lack of fairness in compensating solely citizens/patients and not the other experts.
This surprised us. We would have been less taken aback had the IRB considered the compensation too modest, not that it was unfair to the other participants. Holding our ground, we replied that the issue of financial compensation is a thorny one. We informed the IRB that we had adopted a posture of equity and not equality to encourage the involvement of people who, due to various personal and financial barriers, might not otherwise participate in research. We ended by stating that the exceptionalism of compensating citizens/patients is justified in response to these potential socioeconomic inequalities.

The IRB responded with further explanation of their rationale for asking that all participants be compensated equally. They stated that all persons recruited, regardless of who they are representing, remain participants and should be compensated in the same manner for the time invested. They invoked the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)—the leading Canadian framework for research ethics (Canadian Institutes of Health Research et al., 2018)—which defines justice as the obligation to treat participants fairly. The IRB’s interpretation of the TCPS2’s imperative of fairness was strict equality. As such, the IRB remained of the view that we should offer the same compensation to all participants, and that individuals would have to be the ones deciding whether they accept or decline it.

In our opinion, the primary purpose of compensation for citizens and patients is to address the socioeconomic disparity and other societal barriers that may prevent them from participating in the oversight of a study. Equal compensation for all participants would go against that. Consequently, we found ourselves between a rock and a hard place. First, due to budget restraints, we could not fulfill the obligation imposed upon us. Second, even if we had had the means, we would have preferred to increase both the amount of compensation and the number of citizens/patients involved. We were thus in complete disagreement with the IRB. Sadly, time constraints did not permit further dialog with the IRB and we decided not to compensate any of our advisory board members.

The philosophy behind citizen/patient engagement comes from the realization that structural inequalities exist in the research ecosystem (Bélisle-Pipon, Rouleau and Birko, 2018). These barriers have created an unhealthy distance between those experiencing and those expertizing. For too long, the narratives of researchers/experts and citizens/patients have been tangential (Bélisle-Pipon, Del Grande and Rouleau, 2018). “Patient engagement in research,” “patient-oriented outcomes,” “patient and public involvement,” and the like all attempt to address the long-overdue reversal of epistemic devaluation of so-called “lay” peoples. While endeavoring to place everyone on equal footing (epistemically and opportunity-wise), the pursuit of equitableness rather than strict equality could be perceived, by some, as being counterintuitive to fairness and justice. However, this would inevitably lead to a situation where privileged people can afford to participate in
projects while others cannot. We view this as a threat to the democratization of research. Exceptionalism should be permitted for citizen/patient engagement if the goal is to encourage participation and elevate all to the same level. Elsewhere, one of us argued that citizen/patient involvement should be awarded due regard to cultivate a feeling of being valued (Smith et al., 2019). This basic requirement eases most concerns (Hamilton et al., 2018), since it permits both altruistic participation and/or differential treatment to widen citizen/patient engagement. In our opinion, where the IRB erred—beyond their interpretation of fairness—is in failing to recognize that two distinct imperatives are not necessarily contradictory and might both be pursued at the same time. In this case: the need to acknowledge all participants (experts and citizens/patients) and the need (promoted by citizen/patient engagement movements) to provide a dedicated means to foster citizen/patient participation in research.

We consider that the IRB’s interpretation of differential treatment would be especially problematic for projects that seek to provide citizens/patients with an equal voice in research that might directly affect them (in this case, AI applications in population health).

Not all universities in Canada take the same stance on fairness in compensation. For instance, the University of Toronto (2019) allows its researchers to request differential compensation for professionals (i.e. higher monetary compensation for employed individuals that participate in research, either paid to the individuals or to their employer) to offset the work-time lost. Since the University of Toronto is also subject to TCPS2, it appears that the TCPS2 requirement for fairness is open to interpretation. In our case, we consider that AI developers, bioethicists, lawyers, scholars, or public servants are much more able to bear the costs of participating than citizens/patients. Furthermore, the former may be rewarded in other ways as their participation could represent both a currency for professional advancement and an opportunity to contribute to new knowledge having direct benefits to their practice and activities. We do not wish to imply that citizens are less motivated or inspired by research than other stakeholders, simply that providing basic means to minimally offset socioeconomic disparities might ensure wider participant diversity.

There are some good reasons for citizen/patient exceptionalism and there are some bad reasons for preventing research teams from engaging in such practices. To claim that all participants must be treated equally in the strictest sense is a bad reason. Furthermore, we remain convinced that prioritizing citizens/patients in an already tight budget was the ethical thing to do. There is a need to involve patients and citizens more widely in research by providing them with the (epistemic and financial) means to participate and by actively promoting and recognizing their contributions (Bélisle-Pipon et al., 2019). This project was a missed opportunity to walk the talk. But more worrisome is that an academic IRB at any university may have the power to hinder differential citizen/patient compensation which is attempting to mitigate socioeconomic divides. It is highly problematic from our
perspective that justice be interpreted as strict equality, without providing room for considering citizen/patient exceptionalism. The only way to address that is to change the guidance that IRBs are relying on.

Of course, being cognizant of the issue is the very first step to addressing the issue but much more has to be done because diversity is key to effective engagement (Wilson et al., 2015). And this is not the first call for change (Bélisle-Pipon et al., 2019; Rouleau et al., 2018). It is time to revisit ethical frameworks (such as TCPS2 in Canada) to ensure they provide clear, relevant, and actionable guidance on how to involve citizen/patient in research ethically, meaningfully, and equitably.

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All authors conceptualized the study and protocol that are discussed in the article. JCBP wrote the first draft. VC and MCR substantially revised the article. All authors approved the final version of the article.

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Notes
1. In our study, we sought to recruit a mix of citizens and patients to provide experiential knowledge and first-order perceptions on the ethical, legal, and social implications (ESLI) of AI in population health.
2. In terms of level of expected engagement, we consider that they will be “involved” as per the International Association for Public Participation (IAP2) Spectrum of Public Participation (IAP2, 2018). Participants’ concerns, informed opinions and aspirations will be considered, and their inputs will directly impact the project’s outcomes.
3. Certain Canadian stakeholders are providing non-binding compensation guidelines, in which optimally patients and the public should receive CA$50 per event. See, for example, CHILD-BRIGHT Network (2020).
4. There are various categories of recognition: financial, personal, knowledge, academic, and altruistic. These categories are not mutually exclusive and can acknowledge the contribution of people’s involvement in research, based on what they find most satisfying and useful; see Smith et al. (2019).

5. We refrain from using representativeness as this is way too connoted and virtually impossible to attain with such a small sample.

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