

Patients as Partners in Research: How to Talk About Compensation With Patient Partners

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Imagine you are the only person on a research team who does not work in academia or health care—that is, your participation on the team is not part of your job. Because the team meetings are held during your normal working hours, you must take time off work or make up for missed work to attend. You need hours to prepare for each meeting: to read the agenda and materials, research many of the terms, and look up information. On most project calls, you worry that the questions and comments you have will sound silly, off topic, or irrelevant.

For the annual in-person team meeting, you need an additional day of travel on each side of the meeting due to your medical condition's debilitating fatigue, which is something you need to ask for and justify. The meeting format of 8 AM to 5 PM, along with a dinner off site for 2 days straight, is exhausting. You are passionate about the research and want to contribute the sole patient perspective to the team.

As patient partners, we thank JOSPT for efforts to help readers learn more about patient engagement in research. Through the original call to action¹ for patients as research partners and an editorial⁶ sharing resources to facilitate patient engagement, it is clear the editorial team “walks the talk.”

Our editorial builds on the previous editorials in the patient partnership series, and aims to share practical advice related to compensation for patient research partners. We started writing about this issue in November 2018.⁸ Our paper was written strictly from the patient perspective, without institutional support or funding, is based on the passion of 4 volunteers in different parts of Canada, and is the result of numerous hours of back-and-forth discussion in Google Docs (Alphabet Inc, Mountain View, CA), the same approach used for this editorial. We are pleased that our previous paper has been widely used and shared.^{6,9} We appreciate that more information is sought on this topic, especially because, as patient partners, we are the first to bring up compensation in nearly every project in which we have been involved.

Why Compensating Patient Partners Is Important

Compensation promotes equity, removes barriers, and demonstrates respect for the vulnerability of being a patient partner. Patients and caregivers have a “PhD in Lived Experience,” and compensation acknowledges their perspectives based on these personal experiences, not professional ones.² Expertise is not interchangeable with the notion that patients and caregivers are experts at managing their conditions; rather, they manage their circumstances as best they can and share these experiences. We believe our guidance on how to have a conversation about compensation with patient partners is required to help build expertise in this area—an area in which the research community lacks confidence, evidenced by frequent requests for more concrete guidance, including examples.

How to Have a Conversation About Compensation

The **FIGURE** is intended to guide a conversation with a (potential) patient partner about compensation. As the paid professional, we advise you to take care of as many details as possible in advance and

be prepared for the conversation. Patient partners will appreciate your efforts to make the process seamless for them and your willingness to do additional homework on this topic if required.

Budgeting

Budget for patient partner engagement, including compensation, like you would for any other aspect of your research. Consider whether you need to include costs associated with the patient partner's transport to meetings (eg, transit, mileage, parking, etc), extra days for travel to a meeting or conference (depending on their health condition), considerations for caregiver travel, etc. Covering the expenses associated with a patient partner's involvement is not the same as compensation. Tools are emerging that provide help and excellent templates.^{4,5}

A Culture of Partnership

We have become advocates thanks to our health conditions and circumstances. We will continue to advocate in the field of patient engagement with respect to compensation and other areas. We encourage leaders of organizations and communities to join us in our vision. Let us work together to build capacity in research and health-care environments (including for patient partner compensation), so researchers and patient partners can focus on codeveloping projects rather than on navigating different policies and associated logistics.^{3,10}

Summary

In our first publication on patient partner compensation in research and health care, we presented the “why” and “how.”⁸ Here, we build on the “how” to help alleviate the awkwardness of that conver-

sation. The compensation conversation, as a regular part of this type of partnership, allows teams to codevelop projects and focus on the output and outcomes of their collaborative work. ●

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1. Initiate the conversation. Ask patient partners how they would prefer to discuss compensation (eg, in person, phone, videoconference, e-mail, etc).



2. Be prepared. Find out as much as possible about logistics in advance, including: what is possible, what are the potential implications (eg, additional income, disability payments, etc), when does payment happen, what is required (eg, paperwork, invoice, etc)?



Compensation

Monetary considerations:

- Lump sum or hourly rate
- Date(s) of payment, etc

Nonmonetary considerations:

- Gift cards, payment of phone bills/internet bills, attendance for a course/conference of their choosing, etc



No compensation

Considerations:

- What other forms of recognition are available? For example, authorship or acknowledgment if appropriate?
- Is the patient partner okay with these other forms of recognition? Decisions around acknowledgment should remain with the patient partner (eg, if someone lives with a stigmatized condition, then he or she may have preferences around public acknowledgment)



4. Take care of the details. If you encounter any issues at your institution/organization, be honest with the patient partner about these and be prepared to do required follow-up.

FIGURE. Steps to having a conversation about compensation with a patient partner.