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Patient partner compensation in research and health care: the patient perspective on why and how

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Cover Page Footnote

The authors recognize that they live and work on ancestral, traditional, and unceded Indigenous lands. D. Richards has received speaker fees, honoraria, and consulting fees from pharmaceutical companies, not for profit organizations and institutions. I. Jordan has received speaker fees from health charities and academic associations. K. Strain has received honoraria and gift cards from organizations for involvement in initiatives. Z. Press has held numerous paid and unpaid patient advisor and partner roles with multiple stakeholders across the continuum of care. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

Patient partner compensation in research and health care: the patient perspective on why and how

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Abstract

As patient and family engagement activity broadens across the continuum of care and expands around the world, the question of compensation for an increasingly competent advisory community continues to come up. The authors are 4 patients who are highly active in patient and public involvement initiatives internationally. Through our exclusive patient perspective, we provide insight into the reasoning and motivation that many patients are now awakening to as to why lived experience is a value that organizations need to recognize and support in concrete ways. We explore the core principles that an organization needs to consider and adopt when developing compensation policies for their engagement practices with patients and family members. Organizations face an ongoing challenge to achieve diversity among their patient advisors so that all segments of the community they serve are represented. In particular, marginalized populations are confronted with financial and social determinants that are often barriers to full inclusion. Comprehensive compensation policies overcome these barriers. While there is some guidance available from organizations like PCORI, the predominant culture in health care resists the notion of compensation. In addition to defining core principles behind compensation, we outline how to put those principles into practice in a valid, credible manner that honours and values the contributions of patients and families whether in quality improvement or health research.

Keywords

Patient engagement, patient compensation, patient partner, patient advisor, health research, patient and public involvement

Introduction

This article is intended to provide guidance specific to patient compensation for people involved in research or health care system settings and who engage patients as partners/collaborators from the view of patients who have been engaged. For the purposes of this article we have utilized the definition of “patient” from the Canadian Institutes of Health Research (CIHR): “An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.”¹ Also note that to the authors of this article, compensation does not always mean a payment of money and will be explained further alongside our views with respect to payment of expenses.

While documents exist from specific organizations for their own purposes about patient compensation, we are providing our own practical guidance from the perspective of patients and caregivers who have been involved in this capacity and in these settings for the past decade. We have witnessed support and rationale for patient compensation

range the spectrum from being a complete unknown to being offered upfront. Given our own experiences, we feel strongly and are seeing evidence that patient engagement in research and health care creates better projects and outcomes²⁻⁷. For example, a Patient Oriented Discharge Summary co-designed by patients and providers in Ontario which provides patients with access to important information when they leave the hospital⁸. The project began as a pilot at 8 hospitals, has shown patient satisfaction scores related to discharge improved between 9-19% with its implementation, and is now being adopted more broadly in the province⁸. The Change Foundation’s PATH (Partners Advancing Transitions in Healthcare) Project that included intensive community collaboration in Northumberland, Ontario, to co-design a number of solutions that were implemented to improve the experience of progressing through the continuum of care⁹. The principle of patient partnership in the delivery of care is inherently embedded in the concept of patient-centred care. Involving patients in the decisions that affect patient experience is more frequently the norm leading to clear frameworks that have demonstrated improved outcomes

as a result¹⁰. We also support that compensation for patients is a topic that should and must be discussed when engaging patients in these settings as there is emerging evidence that providing compensation encourages participation^{11, 12}.

Background

Involvement of patients in research and/or the health care system as partners and/or collaborators is an area that continues to expand and grow. An organization such as the UK's INVOLVE¹³ may be seen as especially pioneering in this area, while granting organizations such as the Patient-Centered Outcomes Research Institute (PCORI)¹⁴ and CIHR¹⁵ are newer to the space. The maturity of these organizations and their experiences with respect to involvement of patients is reflected by their documents, policies and guidelines developed to help all stakeholders. However, limited guidance exists with respect to compensation for patient partners/collaborators. Furthermore, for many individuals and organizations, compensation for patient partners/collaborators seems like a difficult or perhaps even unknown topic of conversation.

Compensation is an emerging area in patient engagement. Historically, patient involvement has been primarily a volunteer effort (both in research and healthcare environments) so there hasn't been a need for guidance around this topic. In healthcare this stems from the notion that it is a charitable enterprise and continues to be reflected in health care organizational structure and culture. Other forms of engagement like satisfaction surveys or focus groups do not require high level of engagement and are usually tactical strategies to support a particular objective rather than an outcome of a culture committed to patient engaged care. As a result, organizations are struggling to catch up and determine how best to support patients through compensation and are unprepared for this discussion because the appropriate resources, budget and policies have yet to be created. Consequently, this may make it easier to maintain the status quo rather than offer compensation because of the significant shift required in order to support this aspect of patient engagement.

Furthermore, the viewpoints of both patient partners and researchers/health care organizations may affect how compensation is viewed and thus, may result in the topic not being discussed. For instance, patients may find it hard to quantify the worth of their experiences because the experiences gained as a patient are not done in the traditional academic manner (i.e. attending university to develop a skill), while researchers or individuals at health care organizations may assume patients only wish to be volunteers, or are simply happy to be involved. For example, while other team members are viewed in terms

of what skills they bring to a project, for example, students/trainees, researchers may have difficulty framing the value of lived experience in comparison to the rest of the team and many professionals have not received adequate training and skills development in how to partner with patients. There are also power dynamics at play, with patient partners often feeling that they do not have the power in the implied hierarchy (research- or healthcare-wise) to bring up the topic of compensation. Some patients strongly believe involvement that healthcare improvement is done out of a volunteer duty, or sense of altruism, and wish not to be paid. For these reasons, compensation ends up being the proverbial elephant in the room and may sometimes feel like a topic on unstable ground.

In terms of the current guidance or frameworks that exist for compensation (not a complete list, but these represent a number of those often cited), we encourage you to read documents from: INVOLVE¹⁶, PCORI¹⁷, the Strategy for Patient-Oriented Research (SPOR) Networks in Chronic Diseases and the Primary and Integrated Health Care Innovations (PICI) Network¹⁸, BC Centre for Disease Control¹⁹⁻²¹ and the Change Foundation²²⁻²⁴. In particular, the Change Foundation has developed a method and an infographic to help stakeholders determine if pay should come into the equation.

Given our collective experiences, in this article we do not equate compensation to the payment of expenses that allows participation of patient partners/ collaborators and feel there is an important distinction between these. Expense payment is a cost of doing business when patient partners/ collaborators are part of the team. Expenses include items such as transportation, supplies, meals (when part of a meeting or travel related to the engagement), conference registration, and other costs that team members would have covered. Compensation, as will be discussed, is over and above expense reimbursement and recognizes individuals for their time, skills, and energy to participate in and contribute to a particular project or opportunity.

This article has been specifically written to provide practical and pragmatic guidance about patient partner/collaborator compensation. Our collective experiences can be used to demonstrate why this is important and how this can be undertaken. We have not seen another article on this particular topic that has been presented solely from the perspective of patients and caregivers.

Why Compensation is Important

We are patients and caregivers that have been involved in research and health care for over thirty collective years in Canada, and we feel strongly that providing the option for

compensation or recognition of patient partners/collaborators is necessary. Over the years, we have engaged as volunteers and as paid members of the team as this area has matured. We have been vocal within our respective environments about the topic of compensation for ourselves and for others. We have written on various topics related to patients as partners and collaborators^{18, 25-31} in a number of different contexts. We have also been involved as consultants, partners and collaborators in a number of research areas (including arthritis, chronic pain across the lifespan, rare diseases, biobanking, patient partnership in interprofessional education, meaningful patient engagement) and health care opportunities (e.g. membership on a provincial government subcommittee about standardizing policy on e-communications, developing patient engagement strategies for organizations, past co-chair of The Beryl Institute Global Patient and Family Advisory Council, Co-Chair Health Quality Ontario Patient Advisor Co-Design Committee, Expert Patient Advisor to West Toronto Health Link, co-lead for One Community Integrated Care Strategy, Toronto Central Local Health Integration Network, membership on advisory committees and steering committees, speakers). In this section we will explain why we feel compensation is an important consideration.

We ask people to remember that patients bring their lived experiences to the table that are reflective of their own experiences with a disease, that of a caregiver, or their personal experiences in the health care system. Through this PhD in Lived Experience, patients offer invaluable expertise, skills and unique points of view as partners and collaborators. To us, these are the skills, experience, and unique points of view that patients offer as partners and collaborators. Furthermore, we have seen projects improved as a result of our voices being at the table throughout them. We have brought up perspectives and experiences that have directly impacted projects and the outcomes of those projects in a multitude of ways. When people who study a particular topic do not have lived experience with that topic as patients do, items for study/focus may seem important, that are not actually important to patients³². For example, patients who live with arthritis have repeatedly identified pain and fatigue as being two universal factors associated with arthritis that impact their daily quality of life³³. These are two areas of study that were not previously widely acknowledged by researchers until patients elevated them and talked about their importance in managing arthritis daily.

Below, we outline five key principles based on our collective experience that illustrate why compensation should be considered for patient partners/collaborators in research and health care related projects: equity, different motivations, respect for vulnerability, commitment, and barrier removal. Our own experiences in this space have

helped us strive to demonstrate why these principles speak so strongly to us as patient partners and collaborators.

Equity

There is a power imbalance when compensation is provided to all team members except the patient partner/collaborator. Like all others in the team, patient partners/collaborators are bringing experience, expertise and skill to the team, though from a very different perspective. In order to level the playing field, compensation for patient partners/collaborators should be considered. We posit that if everyone else on the project/meeting is paid for their time, skill, etc., why would patient partners/collaborators not be paid for their time, skill, etc. as well? Often to participate in these activities, patient partners/collaborators take time off of work and caregiving duties. Participating may be taking these patient partners and collaborators away from their ability to maintain their regular daily activities. Overall, there is a cost to patient partners/collaborators to be engaged in research and health care projects.

Different Motivations

Patient partners/collaborators often have very different motivations from professionals who are part of the team. Remember that even in cases where professionals are not explicitly paid to be part of a project, this activity is often an implied part of their job that provides them with social capital, increases prestige, and helps to advance their career, etc. These are generally all factors that can be tied to professionals' future earning potential. For patient partners/collaborators, these motivations are generally not the case (depending on what their job is and if they are employed). Assuming the same motivations for professionals and patient partners/collaborations is not suggested.

Respect for Vulnerability

The value and knowledge that patients bring to the table is that of their lived experience. This lived experience brings with it a personal vulnerability that other team members do not share. Patient partners put their painful, awkward, difficult, intimate experiences on the table all in the name of health care improvement and research progress. All of this can surface emotions and memories that have been suppressed, and in some cases, can be extremely traumatic. Patients willingly do this in order to improve research outcomes, systems and health care for others, and deserve the respect that recognizes the value of this kind of work. Compensation helps recognize this value.

Commitment

While some patient partners/collaborators do not wish to be compensated for their work as collaborators, others will view compensation as reflective of the type of commitment that is required. Patient partners/collaborators are often juggling time for medical

duties, jobs, volunteering, etc. Making patient partnership/collaboration a paid engagement will allow them to commit at a more full level given their competing interests.

Barrier Removal

Provision of compensation for patient partners/collaborators is a way to remove barriers and to ensure a more diverse group of patients may collaborate in research and health care system projects. Without compensation, only patients who can afford to volunteer are able to bring their perspectives. While this perspective is valid and valuable, it is also selective and representative of a specific demographic or demographics. Compensation allows others to collaborate if they wish, and thus, the ability for different voices and demographics to be brought to a project, including those of people who may work, go to school, be on a limited income, etc.

How to undertake the conversation about compensation

As patients and caregivers who have been involved in this area for the last decade, we have put together our collective knowledge to create a simple, practical, accessible document on the topic of patient compensation. We provide some tips on how to have the conversation since this is often a topic that can be awkward to discuss. While not all patients wish or are able to be paid, we feel strongly that this conversation should take place. In the cases where patient partners/collaborators do not wish to be compensated, there may be other ways to compensate or recognize patients for their time, skill and efforts.

The Conversation about Compensation

Start the conversation early

We view having the conversation about compensation a 'must have' rather than a 'nice to have.' We recommend that at the beginning of a project, project leads work with their patient partners/collaborators to determine their preferences regarding payment. Project leads should approach the topic first. It is strongly suggested that the lead conducts this conversation one on one with each patient partner/collaborator on the team. Discretion is an important part of this process so that patients are not embarrassed by their requests or situations in front of multiple team members or other patients. Some patients feel they are asking for too much if they bring up this topic, while many patients may not even realize compensation (or some version of it), is an option. Depending on the patient partner, a number of outcomes may occur; for example, they may wish to receive financial payment, no payment, or some other form of compensation/recognition.

Rates

When monetary payment to patient partners/collaborators as a concept has been agreed upon, a rate or lump sum amount needs to be discussed. This conversation may be one of the most difficult conversations about payment for everyone. Here are some things to think about:

- An hourly rate or a project rate (and what you are prepared to provide). Note that these amounts are in Canadian dollars. There is limited guidance on rates. Some examples include: hourly (\$25), half day (\$100 – up to 4 hours), and full day (\$200 – up to 8 hours)¹⁸; partner in a specific research project (\$500-800 per year), member of a committee with a network-wide mandate that includes more meetings/commitment than a research project (\$1,000-1,200 per year), member of a network steering or executive committee (\$1,500 per year)¹⁸; a daily committee fee of \$250 or a daily research work fee of \$250³⁴, minimum wage as an hourly rate²²; \$50 per meeting once a month (personal experience); and, \$2,000 per year for a 2-3 year project to participate in monthly meetings, to provide project input frequently, and to review work plans, papers, etc. (personal experience of the authors).
- Ask patient partners/collaborators if they have their own rate expectations. This may be difficult for some patients given the power imbalance and vulnerability of their situation. Some patient partners/collaborators are simply happy to be part of the experience and will not ask for much or for anything at all. Others may have professional experience in the field, and consequently, may have a usual hourly rate that may be outside of your budget.

Implications of Monetary Compensation

Ensure patient partners/collaborators are aware of the possible tax implications and/or reporting requirements of accepting payment. This may vary depending on their own circumstances and is not necessarily something that you can fully determine for them in advance. For example, if they are receiving Disability payments or benefits from a program such as Worker's Compensation, accepting payment for being part of your project may affect those payments/benefits. They will have to determine implications of compensation in advance of accepting it and there may be ways to help them do so. Given that each situation will be different, we have not provided specific guidance here. In Canada, payments related to this type of work must be declared as personal income for tax purposes, so provide as much information as you can regarding tax reporting (e.g. if a tax receipt will be issued)²⁰.

Non-monetary Forms of Compensation

Unlike others on the team, forms of compensation may vary widely for patient partners/collaborators, which may

not even be something you have considered. If your patient partners/collaborators do not wish to be paid, determine with them if there is another form of compensation or recognition that would be more suitable for them. Some examples may include: gift certificates, donations to health charities or patient organizations, a portion of their phone or internet bill paid to offset for work done for you, funding to attend a conference unrelated to the specific project's work, provision of new skills training/development for example, via a course, etc. Since circumstances within each organization and situation will be unique, some of these forms of compensation may not even be possible depending on the organization that administers payment. It will be up to you to be open to these alternative forms of payment, determine what is possible within your organization and confirm the options with the patient partner/collaborator.

In summary, the conversation about compensation is an important part of establishing a relationship with your patient partner/collaborator. We encourage you to approach this topic early in the project, determine together with your patient partner/collaborators an appropriate rate, consider the implications of compensation in areas such as taxation and disability benefits, as well as options for forms of non-monetary compensation.

Further Considerations

This section presents some other important considerations related to compensation to keep in mind when working with patient partners/collaborators: travel expenses, budget, logistics, and a written agreement. These are all related to engaging a patient partner/collaborator in your work and to compensation in different ways. These may or may not be other items you have considered as you plan for engagement, so we think it is helpful to provide you some additional guidance and our specific views on these.

Travel Expenses

For us, compensation does not equate to payment for travel expenses that are incurred to be part of a project/team. Travel expenses should be part of an overall budget to include patient partners/collaborators. It should not cost someone out of pocket expenses to participate as a partner or collaborator in a project, though unfortunately it is often common for patient partners/collaborators to pay out of pocket for these types of expenses, given that they may be too shy to bring this up, or are not even aware that they can. Travel expenses may include items such as mileage, parking, transit, expenses related to travel for conference presentations, etc. If at all possible, paying for expenses upfront and thus eliminating the need for reimbursement can be extremely helpful. For some patient partners/collaborators, being hundreds of dollars out of pocket and waiting to be reimbursed can be extremely stressful, if not financially impossible.

Budget

Having a budget for the efforts related to patient partners/collaborators and their engagement is a must. If you are writing a grant application, ensure that you account for this - just like you would for all others on the application. INVOLVE has a document that may be helpful for you to determine the types of budget implications that this will have and how to plan for these³⁵. This will allow you to budget for compensation regardless of the format in which it is provided.

Logistics

There are logistical considerations to patient partner/collaborator compensation for which you might not otherwise be aware. These considerations generally overlap with reimbursement of expenses. For this reason, we have included expense reimbursement in this section. These logistical considerations should be taken into account when embarking on compensation/reimbursement discussions within an organization with respect to patient partners/collaborators:

- Before talking to your patient partner/collaborator, find out if your organization has any policies or guidelines relating to the topic of compensation for them. Some organizations might not have policies and/or may need help with understanding why policies are important with respect to patients and compensation. Other organizations may have policies that will need to be adapted for use with patient partners/collaborators. If these policies do not exist or need to be adapted for use with your patient partners, we suggest co-creating the policies/guidelines with the patient partners on your team. In fact, we have worked for organizations where we have helped them create their internal honorarium policies/guidelines in advance of setting up patient advisory committees and other initiatives. In some cases, granting agency terms may need to be abided by with respect to this topic.
- Determine if your organization will issue a tax form or receipt for compensation, and what base amount triggers the issue of a receipt. For personal income tax purposes, a tax form or receipt may have implications for your patient partner/collaborator, and the specifics around this will vary in different countries.

- Understand how the payment/expense reimbursement process works for your organization and what procedures need to be followed. Provide examples or templates to assist with this process, such as an invoice or reimbursement form, as well as an organizational contact your patient partners/collaborators can reach out to for assistance. Areas to consider include:
 - How compensation is claimed. For instance, if an invoice is required for compensation and what details need to be included.
 - How to claim for reimbursement. For instance, if itemized receipts, or an expense form are required. Ensure the reimbursement form includes such things as current rates for mileage, meals etc. offered by your organization.
 - Length of time for your patient partner/collaborator to receive payment for time or expenses. This is especially important if patient partners/collaborators are being reimbursed for out of pocket expenses, but is also important if they have chosen monetary compensation. People should not have to wait months for payment and appreciate you being upfront with them from the start about this.
- Determine which expenses your organization can pay upfront as much as possible to minimize the out of pocket costs for your patient partners/collaborators.

Overall, where possible we encourage you to make logistics related to compensation and expense reimbursement related to project participation as easy as possible for your patient partners/collaborators²¹.

Written Agreement

Lastly, just as with other instances where compensation is involved and there is a written agreement, this case should be no different. In fact, having everything written in one place with agreed to terms, responsibilities, time required, etc., will help all parties. This agreement should include all considerations outlined above and be written in clear and easy to understand language. There should not be legalese in the agreement.

Summary

We know that the topic of compensation (monetary or otherwise) for patient partners and collaborators is relatively new and often novel for all parties involved. It is also not an easy conversation to undertake. This article provides patient and caregiver perspectives related to why compensation for patient partners/collaborators is important, key consideration to consider (summarized in Figure 1) and how compensation can happen. Given our collective experience as patients and caregivers as partners

Figure 1. Key Considerations for Compensation

- May or may not be monetary and may be declined by some patient partners/collaborators
- May be different depending on the level of involvement of a patient partner/collaborator
- Keep processes and paper work simple so as not to burden patient partners/collaborators
- Need to consider local taxation laws/regulations and how these may impact compensation

and collaborators in research projects as well as health care system projects, we offer advice based on our own experiences, to help guide you and make the process easier. We would also like to hear from you, and to update this publication from time to time to keep it up to date and to include other ideas that you have used along your own way.

Acknowledgements

The authors recognize that they live and work on ancestral, traditional, and unceded Indigenous lands. D. Richards has received speaker fees, honoraria, and consulting fees from pharmaceutical companies, not for profit organizations and institutions. I. Jordan has received speaker fees from health charities and academic associations. K. Strain has received honoraria and gift cards from organizations for involvement in initiatives. Z. Press has held numerous paid and unpaid patient advisor and partner roles with multiple stakeholders across the continuum of care.

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