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Patients and Families as Partners in Patient-Oriented Research: How Should They Be Compensated?

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Abstract Patient and family engagement has become a widely accepted approach in health care research. We recognize that research conducted in partnership with people with relevant lived experience can substantially improve the quality of that research and lead to meaningful outcomes. Despite the benefits of patient-researcher collaboration, research teams sometimes face challenges in answering the questions of how patient and family research partners should be compensated, due to the limited guidance and lack of infrastructure for acknowledging partner contributions. In this paper, we present some of the resources that might help teams to navigate conversations about compensation with their patient and family partners and report how existing resources can be leveraged to compensate patient and family partners fairly and appropriately. We also present some of our first-hand experiences with patient and family compensation and offer suggestions for research leaders, agencies, and organizations so that the health care stakeholders can collectively move toward more equitable recognition of patient and family partners in research. (*J Patient Cent Res Rev.* 2023;10:82-90.)

Keywords patient engagement; family involvement; health research; partnership; compensation

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An increased interest in patient-oriented research (POR) is driving more inclusion of patients and families as active partners in research. This type of collaboration has been supported by several initiatives and organizations around the world, including Strategy for Patient-Oriented Research (SPOR) in Canada, Patient-Centered Outcomes Research Institute (PCORI) in the United States, and INVOLVE in the United Kingdom. POR is "a continuum of research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes."[1] Research conducted in partnership with people with lived experience (eg, patient and families) can improve the quality of research and lead to outcomes that matter to patients and families.[2,3] Consistent with the principles of patient- and family-centered care, we acknowledge that patient engagement in research sometimes also means the engagement of family members or other caregivers important to the patient. Therefore, in this paper, we will use the term POR to refer to the involvement of patients and/or their families/caregivers.

Although POR has gained traction as a means of improving health care systems, practices, and patient outcomes,[1] the need for POR initially arose from moral, ethical, and political arguments.[4] Those include patients' and families' fundamental right to be engaged in research as partners, the need to engage actively those who are most affected by the research process, and improved transparency and accountability, particularly with regards to the use of public research funding.[4] One particularly challenging aspect of POR is how to compensate partners adequately and equitably for their partnering contributions in the research process. Compensation is an important way to acknowledge the

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value and contributions that patient and family partners bring to research projects[5,6] and may be used as a mechanism to facilitate the inclusion of patient and family partners who are typically underrepresented in health research.[7] Offering compensation and reimbursement for parking and child care or other accessible ways to engage (eg, language interpretation) may provide patient and family partners who face social and financial disparities with more opportunities for engagement. While there is a growing body of literature on POR implementation and related strategies,[6,8,9] there is little guidance for researchers on the means, mechanisms, barriers, and importance of recognizing the contributions patient and family partners provide to research.

The impetus for reviewing POR compensation literature was born in late 2020 at one of monthly student meetings held by the CanChild Centre for Childhood Disability Research (McMaster University, Ontario, Canada). These meetings involve researchers, graduate trainees, postdoctoral fellows, and family members. Experiences with compensation in POR that were shared in our group discussion had a lot of commonalities, and we assumed that other research teams likely encounter the same challenges when utilizing a POR approach, potentially leaving them without solutions for compensating their patient or family partners. Reflecting on our POR experiences, we wanted to distill several considerations and possible approaches for patient and family partner compensation at the project, organizational, and institutional levels.

This topic synopsis sought to serve two objectives. First, we present some frameworks and resources that can assist research teams in developing compensation strategies for patient and family partners. Second, we identify current challenges related to compensation and offer possible solutions. Given that compensation in research can come in many forms — and is not limited to monetary remuneration — we will discuss various ways to recognize and acknowledge the contributions of patient and family partners.

Frameworks and Resources Addressing Compensation in POR

Applying a framework can help researchers explore options for compensation, guide discussions, set clear expectations, and ensure that patient and family partners are compensated fairly and consistently. Two models have often been described: 1) compensation by unit of time or event; and 2) compensation by level of engagement.[10] When compensated by unit of time, partners can be paid by the hour, half day, or full day. Patient and family partners can also be compensated by their participation in single events, such as a flat rate for participating in training activities or presentations.

Alternatively, partners can be compensated by their level of engagement in specific activities, which may depend on their availability for commitment and scope of activity. Compensation may be offered in different forms, such as a fixed service income (eg, fixed rate per hour or per day), salary/stipend, honoraria (eg, one-time payment), in-kind payment or gifts (eg, gift cards, conference attendance, personal development courses), or any combination of these (eg, honoraria, a culturally appropriate gift for Indigenous Elders/Knowledge Keepers).[11] While funding organizations offer guidelines that specify what compensation level or type is acceptable, those guidelines vary significantly (Table 1).[10-15] As a result, researchers might find they need more guidance to decide how to compensate patients and family partners.

While using compensation frameworks, several key principles should be observed. These include (a) offering fair and equitable payment, (b) being flexible, (c) supporting informed choices, and (d) differentiating compensation from reimbursement.[11,12,15]

Fair and equitable payment means that compensation is reflective of patient and family partners' time and effort contributed to a project.[11] Both INVOLVE[15] and PCORI[12] encourage compensation at rates that are consistent with those for other members of the research team. At levels of engagement involving higher responsibilities, such as leadership or decision-making roles, this could mean payment at the same rate as researchers and professionals. At less intensive levels of engagement, such as a consultant or advisor role, stipends and in-kind payments may be appropriate.[12] There are tools to help researchers and patient and family partners determine their level of engagement.[16,17]

Providing patient and family partners the freedom to choose the means by which they are compensated entails important considerations. Researchers should offer choices and *flexibility* that take into account patient and family partners' preferences and any benefits program they may be receiving (eg, on disability supports). Payment should be offered in a manner that allows patient and family partners to make an *informed decision* about their level of involvement in a project. Discussions about payment and potential tax or benefit program implications would ideally occur before the start of the project.[11] Researchers have a responsibility to create an environment in which patient and family partners feel comfortable inquiring and expressing concerns about compensation. This can be done, for example, by providing patient and family

Table 1. Examples of Compensation Guidelines From POR Organizations and Programs

	CIHR[11]	PCORI[12]	BCCDC Peer-Engagement[13]	SPOR-EA[10]	CHILD-BRIGHT[14]
POR compensation model	By unit of time or level of engagement.	By unit of time or level of engagement.	By unit of time or level of engagement.	By unit of time or event.	By unit of time or level of engagement.
Types of compensation and suggested rates					
Per hour rate	No rates suggested. Determined via consultation with patient and family partners, while following institutional and governmental policies.	No rates suggested. At high levels of engagement, comp may be consistent or equal to research, other professional staff.	\$25–\$50 per hour. When tasks exceed 1 hour, payment should be at least living wage (varies by location).	\$25 per hour.	
Per day, event, or activity attendance rate				\$100 per event for delivering a presentation or participating in a panel. \$100 per half-day event. \$200 per full-day event.	\$100 per event (eg, preparation or delivery of a formal presentation). \$50 per event for participating in a panel. \$75 per half-day event; \$150 per full-day event.
For annual memberships or commitments					\$100 per year for membership in the CHILD-BRIGHT Network. \$500–\$1500 per year for commitments to a committee or project.
Additional compensation options	There are other possible options to consider, including fixed service income, salary/stipend, honoraria, in-kind payment, or gifts.	Salary, stipend, in-kind payment, or fixed service income.	Several payment options should be considered. Transportation and child care costs can be covered.	Cash or cash equivalent for fixed service income and honoraria, in-kind payment, or gifts (eg, free course access, conference fee support).	Salary/stipend based on the individual's preference.

All monetary values in the table are expressed in Canadian dollars (CAD).

BCCDC, British Columbia Centre for Disease Control; CIHR, Canadian Institutes for Health Research; PCORI, Patient-Centered Outcomes Research Institute; POR, patient-oriented research; SPOR-EA, Strategy for Patient-Oriented Research Evidence Alliance.

partners with clear expectations from the outset about compensation guidelines, responsibilities, and the process for requesting appeals or additional information.

Lastly, it is important to recognize the clear *distinction between compensation and reimbursement*. In this paper, we use the term *compensation* to refer to monetary or nonmonetary remuneration that is offered to patient and family partners as consideration for contributing their time, skills, and expertise to the research project.[11] On the other hand, *reimbursement* refers to payment to cover out-of-pocket expenses, such as travel, parking, meals, and child care, rather than payment for time and effort.[18] According to the Canadian Institutes of Health Research, reimbursement of expenses should not be used in the place of payment or compensation of patient and family research partners.[11]

Box 1.

Example: McMaster Co-Design Hub[19]

The McMaster Co-Design Hub aims to advance co-design in health and social services with researchers and community partners from various organizations who engage in co-design with structurally vulnerable populations. "Structural vulnerability" is determined by the social systems and environments that position people with respect to their identity, privilege, and oppression (eg, youth and adults with mental health challenges, parents of children with disabilities). Participating in research with the Co-Design Hub may be of benefit to academic and nonacademic partners in monetary and nonmonetary ways (eg, through skill-building and capacity development in co-design, and network development). These activities include monthly speaker series events, co-design-focused multidisciplinary workshops, social media, and 2 "Co-Design Cafés." These events were held virtually in the fall of 2020, at which various stakeholders from the community joined 1.5-hour-long café-style discussions.

Individuals shared their experiences with co-design projects, successes and challenges, and ways in which the Co-Design Hub could support community-based co-design efforts with structurally vulnerable populations. Ideas were generated to guide the goals and activities of the Co-Design Hub. People who participated in these sessions were compensated monetarily for each session they attended if they identified as a service-user and agreed to receive compensation (3 people at the first session and 4 at the second). They were compensated to honor their time and willingness to share their experience. Moreover, 2 individuals with lived experience who attended the cafés and who work in roles that involve co-design with community organizations agreed to continue working with the Hub as core team members. These individuals receive monetary compensation in salaried positions for their roles as project team members, which include attending meetings and sharing their ideas, collaborating on tasks such as grant review(s), and helping to form partnerships with other community members. This compensation adds equity, as all other Hub team members participate in paid academic roles, and demonstrates appreciation for the time, experience, insights, and skills that our lived-experience partners contribute.

Challenges experienced by the Hub in compensating community members financially include paying people in the way that best suits their preferred method (eg, gift card vs cash transfer) and ensuring that compensation does not negatively impact social assistance payments.

For example, offering to support conference fees that are not directly related to the project may be a form of in-kind payment as compensation, whereas covering the costs for a patient or family partner to represent the research team at a conference would be considered reimbursement.[11] Regardless of how patient and family partners are paid, it is important to recognize the value of their contributions beyond monetary provisions. Box 1 includes an example of project payments for POR efforts.[19]

Challenges in Compensating Patient and Family Partners

Despite understanding the key frameworks and principles in POR compensation, our research team has encountered several barriers when navigating compensation for patient and family partners throughout the research process. In this section, we expand on these challenges to highlight the complexity of patient and family partner compensation in the hope that these reflections can inform engagement planning. Some of the ideas presented are consistent with the recent work by Richards et al, in which potential barriers and solutions to compensation in POR were outlined.[6] Our unique angle to these issues aims to address the challenges and alternatives that go beyond payments only, with a particular focus on how compensation is addressed at different stages in the research process.

Barriers can arise from the start: at the idea inception and grant preparation. Ideally, patients and families should be engaged at the earliest stage of project planning to ensure that the research question, project plan, and budgets are patient-oriented and support partnering with patient and families for the duration of the study.[20,21] For researchers who do not have a preexisting relationship with patient or family partners, identifying where to network and establish connections can be an initial obstacle. Establishing meaningful engagement with partners also requires time and flexibility, which may be challenging since grant applications often have set deadlines. Without funding to support project planning, researchers may find themselves unable to compensate partners for their time during grant preparation. This is a major consideration when partners are engaged as co-investigators on the grant, which demands significant time commitment upfront (eg, to complete research ethics training or prepare an academic curriculum vitae). As there is no guarantee of the project being funded, engagement can involve a lot of work with the potential for disappointment if the project is not funded. Due to long grant timelines, engaging at these early stages can add months to the partnership while waiting for grant decisions and ethics review. To minimize disappointment or inconvenience caused to patient and family partners, researchers may only engage partners in later phases of the project, potentially leading to inauthentic partnership or tokenism (ie, simply putting the partner's name on the grant application).[5,22]

As discussed above, funding organizations adopt different frameworks and set varied levels of compensation for patient and family partners (Table 1). Across funding agencies that do support compensation of partners, the acceptable level of compensation differs significantly. This includes differences in the recommended hourly rates, maximum allowable limit, and allowable expenses concerning partners' reimbursement (eg, child care, nursing care, transportation, interpreter, multilingual materials). Furthermore, some funding agencies set upper limits for partners' compensation but not for other research expenses (eg, consulting business, analytical software licenses). Apart from organizational differences in funding models that include patient and family compensation budgeting, some organizations that have not yet recognized POR as an approach to research might lack infrastructure for compensating patient and family partners.

Even once a grant is obtained, issues can arise at the level of research organizations or institutions. Human resources and payroll systems may not be aligned with the employment categories and compensation guidelines of funding institutions. For example, a university's payroll system may not be set up to recognize "patient or family partner" as an employment category. Classifying patient and family partners as "employees" introduces another set of legal or human resource challenges (eg, with recruitment, if the position needs to be formally advertised). Depending on how monetary compensation is provided, it may need to be declared as income, which may affect social supports and disability benefits of patients or families. Geographic barriers may exist that make it more challenging or illegal to transfer funds (see Box 2 for an example and further details[23,24]) if the partner

Box 2.

Example: : ENabling VISions And Growing Expectations (ENVISAGE)-Families Croatia[23,24]

Since 2017, an Australian-Canadian research team of parents, clinicians, and researchers has worked together to develop and explore a new online group program, ENVISAGE-Families, for parents of children with disabilities that aims to empower parents and provide opportunities for connecting with other parents. With the program's growth, there was an international interest to adapt ENVISAGE in settings beyond those in which it was primarily developed, including Croatia. In 2019, a CanChild PhD candidate from Croatia and a co-author of this paper (M.N.P.) started a multiphase research project of translating and adapting ENVISAGE to the Croatian language and culture. As part of this research initiative, 6 Croatians joined the ENVISAGE team, 2 of whom were mothers of children with a neurodevelopmental disability.

Due to the geographical and systems barriers to monetary compensation for family partners outside of Canada, we sought alternative ways to acknowledge our partners' contributions. When initial conversations with our family partners about potential collaboration started, we were fully transparent about the restrictions in paying for their work, given that it is illegal in Croatia to receive compensation for work that is not directly paid by a registered and regulated Croatian organization or company. Since CanChild is based in Canada, there was no legal way of transferring the funds to our partners in Croatia. We made sure that we took enough time to discuss this reality with our partners as well as to hear their expectations before the partnership began.

Partners were encouraged to share how their involvement can benefit their personal or professional goals and desires. Since this was their first experience as partners in research, both family partners expressed a desire to co-lead synchronous ENVISAGE group workshops and connect with other parents of children with disabilities from Croatia, as well as to take part in research activities under supervision. We discussed that they were an equal team member and, therefore, would be acknowledged as co-authors on publications and presentations. We also made sure that our family partners could freely and openly communicate their needs or change their nonmonetary compensation wishes throughout the research collaboration.

As a team, we developed an engagement matrix, in which each team member shared what skills they believe they already possess, which ones they would want to develop as part of the research project, what their values are, and how they would like to be compensated. At regular biweekly team meetings, we dedicated time to talk about positive things that happened to each member since the last meeting. This activity strengthened relationships and has become a highlight of every meeting.

is located outside of the country where funds are held. An alternative may be use of a fiscal agent external to the academic institution, but this may not always be possible.

Ultimately, power still resides with those making funding and payment decisions (eg, agencies, researchers, human resources, employee relations services); their policies determine when patient and family partners are needed and whether they are compensated. However, limiting participation on a project can be experienced as tokenism, as patient and family partners may feel that they are being used and are only allowed to contribute in a limited capacity. Being at the table is the best way to be heard; being invited to the table for only certain decisions does not do that.

Alternatives to Monetary Compensation

Given the challenges with monetary compensation that may impede payment as an option, it is useful to consider other means of recognizing patient and family partners' contributions. In fact, nonmonetary compensation can and should be provided even in cases when monetary compensation is possible. Consulting with patient and family partners on their expectations and what matters to them can help generate ideas for nonmonetary alternatives or additions.

What is considered to be meaningful nonmonetary compensation may vary based on age and interests.[25] For instance, children and youth may value group bonding opportunities (eg, play, volunteering certificates);

Table 2. Alternative (Nonmonetary) Forms of Compensation

Form of compensation	Description	Examples
Skill development	Patient and family partners can increase their knowledge on research-related topics or gain, improve, or practice skills (eg, the process of research or knowledge translation, presenting study results, sharing partnership experiences at meetings or conferences[5]).	*McMaster Co-Design Hub*[19] • Invitations to monthly speaker events and co-design focused workshops. These workshops covered topics such as co-designing policy and online engagement in co-design. *READYorNot™ BBD Project*[28] • Members of the PFAC attended conferences related to childhood disability research with costs covered by the project (registration fees, travel, accommodations). This allowed them to practice presentation skills, network with other research teams and stakeholders, and gain new knowledge in the research area of their interest.
Academic recognition and inclusion	Partners can engage with the academic community through: - coverage of their registration fees, co-presentations at conferences;[5] - co-authorship or acknowledgment on publications;[6] and - recognition of role as partner on academic projects and grant applications.	*McMaster Co-Design Hub*[19] • Partners who hold a sustained role with the Co-Design Hub have their profiles included on the team's website. They are named co-authors on project publications and collaborators on grants. *READYorNot™ BBD Project*[28] • PFAC members co-presented at academic conferences about their experiences in partnering in a project. *BEST SIBS: Sibling Youth Advisory Council*[26,27] • Sibling partners co-presented the research at academic conferences.
Team building	Partners can benefit from meaningful activities that build relationships with other patient and family partners, researchers, clinicians, or community organizations. Supportive networks and communities that offer information sharing and empathetic understanding can be developed. Informal activities, such as social get-togethers or thank-you care packages can help to build and nurture team relationships. Training materials and resources (eg, from PCORI[29]) exist that can support research teams to work together.	*McMaster Co-Design Hub*[19] • Virtual café-style events to develop theory of change (monetary compensation offered for attendance). *BEST SIBS: Sibling Youth Advisory Council*[26,27] • Researcher and partners received care packages (eg, mugs and cookies that meet dietary restrictions among all group members) and opened them together at a virtual event. • E-gift cards sent to all group members to purchase a meal and have a virtual social dinner.

PCORI, Patient-Centered Outcomes Research Institute; PFAC, Patient and Family Advisory Council.

young adults may value professional development (eg, workshops) or references for college, universities, or employers; adults or parents may value recognition as an expert (eg, co-presenters, co-authorship) or further training to gain research or new skills.[5,25]

Table 2 presents some of these alternative approaches to compensating patient and family partners, together with examples of our first-hand research project experiences of acknowledging our patient and family partners' contributions.[5,6,19,25-29] Also provided are examples of how patient and family partners have been compensated in two research projects at CanChild (Box 1[19] and Box 2[23,24]).

Important Considerations and Call For Action

In summary, barriers to compensating patient and family partners pose limitations to achieving authentic patient-oriented research. As discussed, a lack of funding and difficulty in grant budgeting are not only inconvenient to both parties, but also may lead to tokenism and perceived undervaluing of the role of patient and family partners.[5] This topic synopsis outlines a variety of forms of compensation and recognition to address some of these barriers. Action-oriented recommendations that address compensation to illustrate how patient and family partners can be supported to fulfill their desired roles and support developments in the field of POR are highlighted.

Table 3. Summary of Recommendations and Important Considerations for Researchers, Grant/Funding Agencies, and Academic Institutions

Stakeholder group	Recommendations and considerations
Research leaders/ coordinators	• Initiate early and ongoing conversations in each partnership to establish expectations, responsibilities, and methods for compensation. • Use communication tools to facilitate transparent conversations about expectations and preferences regarding the involvement of patient and family partners (eg, Involvement Matrix for researchers and partners to distinguish different levels of engagement[17]). • Use POR organization guidelines to inform methods of compensation (Table 1). • Enable patient and family partners to fulfill their desired roles by providing relevant training and support when necessary. • Develop relationships built on mutual trust with patient and family partners to support meaningful engagement. Such relationships can take time and effort. While this may be challenging, team-building activities can support the process (Table 2). • Include patient and family partners as members of research team (eg, invite to meetings and social events). Rather than making assumptions about partners' availability and interests, let them be the decision-maker of their own agendas.
Grant/Funding agencies	• Create funding mechanisms that support partners' compensation during the grant development process (eg, CHILD-BRIGHT program's 2-step application process whereby selected letters of intent from Step 1 of a grant application provides funding to engage partners to develop a full application). • Be accommodating with requirements for patient and family partners to be named on applications (eg, requiring academic curriculum vitae can be a barrier that restricts listing some partners as co-investigators on grants). • Allow for and encourage nonmonetary compensation and other forms of recognition. • Create guidance for grantees on how to handle compensation. • Require research applications to include discussion of compensation in their project budgets.
Research and academic institutions	• Establish networking opportunities to connect patient and family partners with researchers (eg, McMaster University Co-Design Hub, Parents Partnering in Research Facebook Group, disease- or condition-specific organizations). • Create employment opportunities, appropriate human resources procedures, and payroll structures to formally recognize the role of patient and family partners in research studies and enable fair and equitable monetary compensation. • Allow for and encourage nonmonetary compensation and other forms of recognition.

POR, patient-oriented research.

A snapshot of recommendations and important considerations is provided in Table 3. Literature in this topic has been primarily comprised of commentaries and case examples, and future research in this area would benefit from a more systematic or scoping review of the research literature. Further, formal evaluation of compensation strategies that include experiences and perspectives of patient and family partners at various levels that research is conducted (eg, organizational, funder, policy) should be undertaken.

Patient-Friendly Recap

- Patient-oriented research (POR) is defined by the involvement of patient or family partners in the planning and conduction of a research study/project. For certain levels of engagement, partner compensation or other recognition may be warranted.
- Authors reviewed the known types of POR compensation as well as logistical pitfalls.
- There are numerous ways to compensate patient and family partners in research for their project contributions, including stipends, paid course or conference registration fees, academic credit, etc. Establishing roles and preferred compensation up front is prudent.

Author Contributions

Study design: all authors. Data acquisition or analysis: all authors. Manuscript drafting: all authors. Critical revision: all authors.

Conflicts of Interest

None.

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