

Starting the Conversation: Compensation in Family Partnership

A Primer for Family Partners Engaged in Research

WHAT IS FAMILY PARTNER COMPENSATION?

Compensation in family partnership is a form of payment that is used to recognize the unique perspectives, relevant expertise and time that family partners bring to the research project. It can take different forms, including money (honoraria, salary, stipend, pay at a fixed rate), in-kind payments (eg., tuition to take course, conference fee), or gifts (eg., gift cards). Compensation is separate from and should not be used for reimbursement of expenses incurred during the project (eg., travel, childcare).



WHY IS IT IMPORTANT?

Compensation is an important way to recognize the real value you add to the research with your lived experience and other contributions. It also promotes equity in the relationship with researchers, who traditionally hold more power. As a family partner, you may have other reasons you feel it is important to be compensated—e.g., putting in long hours, making a long-term commitment to a project, being from a traditionally undervalued group, or other relevant expertise besides your lived experience.



WHEN SHOULD THE CONVERSATION HAPPEN?

The conversation about compensation should ideally happen at the beginning of the family engagement process—or at least, as early as you can. Sometimes the research project lead may not have thought about compensation, especially if they lack prior experience engaging family partners. Even if researchers have not budgeted for compensation, it is good to discuss the topic early, if only to raise awareness and transparency about each others' expectations and constraints.



WHO SHOULD BE INVOLVED?

Family partners should always be involved in the conversation to be able to communicate their needs or preferences—for example, regarding what forms of compensation are most suitable to them. Ideally this conversation should be initiated by the researcher or institution. But family partners should also feel they can start the conversation if the researcher has not done so. It is possible some researchers are unaware that partner compensation is important, or the need for transparency about it. Sometimes family partners may be able to involve a third party, or someone from the research team who they trust to represent their needs and facilitate this conversation.



HOW TO START THE CONVERSATION?

Start an open communication with the research team or research liaison about expectations and responsibilities. Each person's thoughts and opinions regarding the compensation and what they would like to see should be heard and considered. The final decision regarding compensation should be based on a mutual agreement between the researcher and the family partner. Keep your communication direct, clear and judgement free for a transparent and ongoing working relationship. Example question to start the conversation: "Does your institution have a guideline about family partner compensation?"



WHERE TO FIND OUT MORE?

Check out the Canadian Institute for Health Research [Strategy for Patient-Oriented Research](#) for more information, and specifically, [this information](#) on considerations for paying patient partners. [Richards, et al. \(2018\)](#) share the patient perspective in their discussion of the principles to consider in the compensation of family/patient partners. Finally, the Change Foundation created a [decision tool](#) for compensating patient partners in research.

