



FINANCIAL COMPENSATION OF PATIENTS, CAREGIVERS, AND PATIENT/CAREGIVER ORGANIZATIONS ENGAGED IN PCORI-FUNDED RESEARCH AS ENGAGED RESEARCH PARTNERS

Research and other research-related activities funded by the Patient-Centered Outcomes Research Institute (PCORI) should reflect the time and contributions of all partners. Fair financial compensation demonstrates that patients, caregivers, and patient/caregiver organizations' contributions to the research, including related commitments of time and effort, are valuable and valued. Compensation demonstrates recognition of the value, worth, fairness of treatment with others involved in the research project, and contributes to all members of the research team being valued as contributors to the research project.

PCORI expects that any research proposal submitted to PCORI will include a plan and related budget for fairly compensating patients, caregivers, and patient/caregiver organizations engaged as partners in the project. The nature, amount, and details of compensation should reflect the circumstances and input of the engaged research partners.

Note that engaged research partners are distinguished from research study participants (also referred to as "human subjects" or "human research participants"). Compensation of research study participants is a separate matter and subject to review and approval by the applicable Institutional Review Board.

Engaged patients, caregivers, and patient/caregiver organizations provide services to the research project through activities such as chairing or serving on a committee with researchers or professionals, designing studies, providing training, recruiting human research participants, drafting reports, giving presentations, consulting, or designing or running focus groups. Patients and caregivers who provide a representative view and constituency or organizations who represent the interests of many stakeholders may be valued for their ability to engage their community, their understanding of issues deemed important by that community as they relate to the research project, their patient expertise and knowledge of the disease and its impact on the community, or may provide socio-cultural or other expertise, or leadership in communities relating to the research project.

Compensation of engaged research partners should reflect the level of expertise, commitment, responsibility, the type of work involved, and the degree of participation contemplated. Fair compensation typically extends beyond the partners' reasonable out-of-pocket expenses and should reflect their role in the research project, skills and capabilities.

Considerations include contribution to the effort, experience, skill level, time commitment (including preparation), comparable levels of pay and responsibility of participating professionals, local prevailing wages, and national minimum wage restrictions, informed by principles of equity.



Engaged research partners should receive compensation at rates reflecting their level of engagement consistent with other members of the research team. At the highest level, patients who are acting as engaged research partners in a research project and who share in making decisions relating to the research, taking actions, and taking independent initiative may be compensated consistent with other professionals on the team. At the less active end of the continuum may be patients acting as engaged research partners who simply inform others, where stipends or in-kind vouchers may be more reflective of the value made to the research endeavor. Table 1 provides a model capturing various levels of engagement and their relationship to compensation levels.

Table 1. Sample Model Addressing Fair Compensation for Engaged Research Partners: Engagement Spectrum with Examples: An Ideal Moving Toward Greater Collaboration

Engagement Activity Levels	I. INFORM	Simply informing	Communicating plans to the patient community	Varying Compensation Levels
	II. CONSULT	Consulting on decision	Offering opinions, advice, feedback	
	III. COLLABORATE	Deciding together Acting together	Joint decisions solicited Taking actions jointly	
	IV. STAKEHOLDER DIRECTED	Encouraging independent initiatives	Leading to patient/caregiver/organization generated research	

Compensation may vary based on the nature of activities of the patient/caregivers/patient organizations who act as engaged research partners. For example, Engaged Research Partners may be compensated on an hourly basis, by the half or full day, or by stipend. Additionally, advancement of out-of-pocket expenses may be appropriate if circumstances warrant. Compensation models should allow for some flexibility, such as allowing engaged research partners to choose to decline compensation given restrictions that may apply to them (e.g., restrictions of their employers or affiliated organizations).

Please note that all income, regardless of amount, is subject to relevant tax laws and regulations. Please consult the appropriate tax authorities to ensure compliance.