

Cystic Fibrosis Learning Network

Guidance on Recognition to Patient & Family Partners

The CF Learning Network aims to harness the inherent motivation and collective intelligence of everyone affected by CF to transform outcomes. Everybody who is part of the Learning Network wants to make things better, and this motivation is a powerful force for change. Professionals working in the CF Learning Network (e.g., clinicians and staff) are being paid for their work, yet people with CF and their families often are not.

There is a growing sense, in the context of patient-centered outcomes research and co-production of improvement, that this is not fair and, moreover, that it is contrary to the idea of equal partnership and prohibits true co-production.

How should patient and family partners be recognized for their contributions? The answer is not straightforward, as there are many reasons why a person might become involved in Learning Networks and therefore potentially many ways to reward their contributions. Generally, people want mastery, autonomy, and connection – they want to do good and improve, have self-determination, and be part of something greater than themselves. Their continued involvement in this work will depend on the degree to which these are attainable.

In the pilot phase of the CF Learning Network, CF program participation is subsidized with a subcontract from Cincinnati Children's Hospital off a grant from the CF Foundation. It is up to each program how this subsidy will be distributed. However, in an effort to support true co-production, we recommend recognition for the patient and family partners that will be working as part of CF programs' interdisciplinary improvement teams. As described by the Patient-Centered Outcomes Research Institute (PCORI), "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."ⁱ

Furthermore, PCORI states, "Compensation may vary based on the nature of activities of the patient/caregivers/patient organizations who act as engaged partners and also by the reach of their efforts. For example, engaged 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 partners to choose to decline compensation given restrictions that may apply to them (e.g., restrictions of their employers or affiliated organizations or healthcare benefits)."

The opportunities for engagement and suggested guidelines for financial recognition are outlined in the following table.

Opportunities for Patient & Family Engagement and Suggested Financial Recognition			
Engagement Activity Level	Description	Example	Suggested Financial Recognition*
Inform	Simply informing	Communicating plans to the patient community	\$0
Consult	Consulting on decision	Offering opinions, advice and feedback	\$1,000
Collaborate	Deciding together; acting together	Joint decisions solicited; taking actions jointly	\$1,250
Stakeholder Directed	Encouraging independent / interdependent initiatives	Leading to patient / caregiver / organization generated research	\$1750

*Recommended annual stipend/honorarium

There are a variety of ways for patients and families to engage in the Learning Network. We recommend having conversations with potential partners about their interests and motivations for this work and taking the time to understand their desires for autonomy, mastery, and connection and the role that they would be most interested in playing. Additionally, individual institutions may well have unique guidelines and restrictions for payments to non-employees, and CF Learning Network member programs should seek to understand their institution's policies. As we learn throughout the pilot phase of this work, our intention is to develop a standard set of guidelines and operating principles to guide decision making and a description of the depth and breadth of partnership opportunities.

ⁱ <http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf>