Introduction to PCORI’s Approach to Budgeting for Engagement

As the Patient-Centered Outcomes Research Institute (PCORI), we are committed to funding studies that meaningfully engage patients, caregivers, and stakeholders. This activity spans all aspects of research to help ensure that PCORI-funded studies generate more useful and usable evidence. To assist applicants and awardees, PCORI provides a variety of resources, including the PCORI Engagement Rubric and access to the Engagement Tool and Resource Repository for Patient-Centered Outcomes Research. This document aims to help applicants budget appropriately for their proposed engagement activities.

When applying for PCORI funding, engagement costs should be included in the proposed budget. If awarded, PCORI will work with the principal investigator to finalize the study budget during the contract negotiation stage. Engagement components of the study will be reviewed as part of this process, and there will be opportunity to refine these details. To help applicants incorporate engagement into their study proposal and budget, this document presents guidance to help researchers identify budgetary items associated with engagement within a research study.

For starters, it is helpful to understand the distinction between patient-centeredness and engagement. By patient-centeredness, we mean that research reflects what is important to patients and caregivers. This comes in the form of research questions, and outcomes, being ones that matter to patients, as well as studies designed to be low burden for participants. By engagement, we make a distinction between research partners and research participants who enroll in a study. There is an expectation that research teams will form active and meaningful partnerships between scientists, patients, caregivers, and other stakeholders to help them improve the feasibility, acceptability, quality, and relevance of the study and its generated evidence. The work performed during this partnership can take a variety of forms which are displayed below:

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Adapted from:
Hanley et al. (2004). Involving the public in NHS, public health and social care research.
Engagement activities should be specific to the proposed research study and adequately defined in the application. Please refer to the PCORI Funding Announcement (PFA) and merit review criteria for more guidance. Likewise, sufficient funds to support these proposed activities should also be included in the application budget, with rationale outlined in the budget justification section.

When planning a study’s engagement activities, there are several categories of engagement-related costs to consider. These include: partner compensation and expenses, project staff that have engagement-related responsibilities, engagement meeting/event costs, and materials/miscellaneous needs. These expenses will vary by study, and sometimes by study phase, as outlined in PCORI’s Engagement Rubric (planning the study, conducting the study, and disseminating and implementing study findings). They can also vary by geography as well as the scope of the study, topic, and target population. To ensure sufficient funds, it is essential to align the budget with the study activities. This includes the engagement line items and activities discussed in more detail below.

**Compensation**

Fair compensation is a recognition that patient, caregiver, and stakeholder partners are valued contributors to the research. When budgeting partner compensation, please consult PCORI’s [Compensation Framework](#). This document outlines considerations for determining appropriate patient/caregiver compensation including time, expertise, and training. Keep in mind that all members serving on the same advisory panel are equal contributors, regardless of their background or education level. If differential compensation is proposed among partners, the rationale for why this is deemed appropriate must be provided. For example, a patient advisor might serve as an engagement lead or be asked to attend additional study meetings. These additional responsibilities would justify a higher compensation amount than a partner who only attends two advisory committee meetings each year. Also, consider the amount of time commitment for each year of the study. Time commitments might vary by study phase, how meetings will be structured and conducted, and work that will be performed in preparation of and in addition to meeting attendance.

**Additional Considerations**

- Should a patient require the support of a caregiver to participate as an advisor/partner, the caregiver should be compensated for their time and contribution as they also bring a unique perspective to the study.
- Compensation can be hourly, per meeting, or an annual stipend. The amount of money should align with the time commitment of the partner to fulfill their role. Drafting a memorandum of understanding, committee charter, job description, or other documentation that outlines the responsibilities and compensation agreements for partners is a recommended practice. Examples can be found in the [Engagement Tool and Resource Repository for Patient-Centered Outcomes Research](#).
- If compensation is in nonfinancial form, such as access to resources, this should be explained and justified. Please refer to PCORI’s [Compensation Framework](#) for more detail.
- Some studies hire or contract patient partners as project personnel. In this case, their time allocation should be budgeted and responsibilities justified in the same manner as other project staff.
Patient and Caregiver Expenses

In addition to compensating partners for their time, sufficient funds should be budgeted to cover the individual out-of-pocket costs associated with serving as an advisor/partner on a study. Typical costs incurred are: local travel to meetings, parking, childcare, respite/caregiving costs, or other expenses associated with healthcare needs or removing barriers to participation. These additional costs should be included in the budget with a clear rationale provided in the budget justification.

Additional Considerations

- Take time to assess partners’ resource needs to attend and be able to fully participate in study meetings, calls, etc. If a partner requires some type of support, such as interpreter services or extra phone minutes, budget these items.
- Plan ahead to reduce the cost burden for participants and out-of-pocket expenses. Rather than requiring that participants submit expenses for reimbursement, consider providing parking or bus vouchers in advance. When long distance travel is necessary for meeting attendance, book airfare/hotel for partners.
- Don’t assume that all partners are prepared to participate in teleconferences or web-based meetings, especially if vulnerable populations are involved. It might be necessary to provide prepaid cell phone minutes or other technological support to enable full participation.

Study Personnel Supporting Engagement

It isn’t enough to just plan engagement and expect it to happen without assigning responsibilities and duties. Study personnel are needed to ensure that engagement activities are planned, organized, and carried out effectively. Activities requiring staff support might include:

- Recruiting, orienting, training, and mentoring patient and caregiver partners
- Coordinating, planning, and preparing for engagement meetings/events with partners
- Incorporating partner feedback into study design and materials and ensuring that partners understand how their feedback was used or could not be addressed
- Serving as a point of contact for partners and communicating with partners between meetings
- Assisting in the development of lay summaries of project progress, disseminating these summaries to partners, and collecting feedback
- Coordinating engagement efforts across project sites or different committees
- Evaluating engagement within a project
- Resolving conflict and building consensus among partners with differing perspectives

Quality engagement requires both planning and comfort with a range of interactions and perspectives. Some investigators prefer to have this work performed by a co-investigator with engagement expertise, a project manager, or a consultant with experience working with patient/stakeholder partners. In the case of project personnel, include the level of effort (i.e., the number of allocated hours) along with a rationale for this level of effort in the budget. If more than one person is responsible, the proposed activities should be distinct rather than duplicative. In the event that the study team does not have the capacity or proper skillset, this work can be performed by a contractor or subcontractor. In this case, the budget should
include the hourly rate, an estimate of hours per project year, and a budget justification for their costs. Their duties should also be described in the application materials.

Understand that there is no “right” model for providing staff support for engagement. What works best for the study depends on a number of factors including the skills and expertise of project personnel, the patient and caregiver population that will be engaging in the project, and the planned engagement activities.

**Additional Considerations**
- In the case of PCORI-funded studies, the provision of preparatory training for patient and caregiver partners has been found to be appropriate. Topics might include research methods, human subjects protection, and best practices for working with diverse groups of people. Likewise, it is meaningful to provide scientific members of study teams information on the value of engagement and general engagement practices. These costs should be included in the budget.
- As the study is being planned, think about materials that will be reviewed by patient and stakeholder partners (e.g., recruitment scripts, consent forms, patient education materials/videos, follow-up questionnaires). Build in enough time and budget resources to integrate their input into materials.

**Meetings and Activities Costs**

As shown in the continuum table in the introduction, engagement takes a variety of forms which will require support. Costs associated with meetings and events might include venue/room rental, food costs, facilitator fees, and meeting materials. Depending upon the scope of the study, airfare/hotel costs might be necessary for in-person meetings.

**Additional Considerations**
- When selecting a meeting location, consider the needs of partners with disabilities or other special healthcare needs.
- When selecting meeting sites, consider locations that are convienient and welcoming for community partners. Locations should provide a sense of equilibrium and promote inclusiveness and equity among all meeting participants/research partners.
- Food and nonalcoholic beverages are allowable costs. The type of food and amount should be appropriate for the length of the meeting. For example, it is reasonable to provide both breakfast and lunch for an all-day in-person meeting or dinner for an after-work meeting.
- Large meetings and settings might require AV support.

**Miscellaneous Costs**

Use this category if there are planned engagement expenses that do not fit into other categories. These items should be adequately explained in the budget justification.