Budgeting for Engagement Activities

Published June 2016
PCORI is committed to ensuring that patients and caregivers are meaningfully engaged in all aspects of research. To achieve this, PCORI requires that its funded projects demonstrate a commitment to engagement and builds this commitment into the contracts of our awardees (for more information, see PCORI’s Engagement Rubric). Appropriate funds to support engagement activities should also be included in the budgets of applications to PCORI.

When planning a study’s engagement activities, there are several categories of engagement-related costs that research teams should consider: compensation and recognition, partner expenses, project staff, engagement event and/or meeting costs, and incorporating partner feedback. PCORI recommends that budgeting for engagement activities follow the phases of research as outlined in PCORI’s engagement rubric (planning the study; conducting the study; and disseminating and implementing study findings). Aligning a detailed budget with the activities for engagement outlined in your engagement plan will ensure that you have sufficient funds to support the engagement activities in your project.

Compensation and Recognition

Fair compensation demonstrates that the contributions made by patient and caregiver partners to the research team, including related commitments of time and effort, are valuable and valued. Please consult PCORI’s Compensation Framework, which outlines considerations for determining appropriate patient/caregiver compensation.

Patient and Caregiver Partner Expenses

In addition to compensating your partners for their time and contribution to your project, you should budget sufficient funds to cover expenses that are associated with engagement in your project. These expenses include such items as travel to meetings and parking costs, hotel accommodation, childcare or respite/caregiving expenses, and other expenses for partners with special healthcare needs or disabilities to ensure accessibility.

PCORI recognizes that engaging patients and caregivers in research requires resources, and we will support you in addressing the needs of the population that you are engaging. If, for example, you are trying to engage caregivers of individuals with dementia, offering to cover the cost of respite care may increase the likelihood that caregivers are able to participate. It is appropriate to budget for these costs given that a clear rationale on why they are needed is provided.

Considerations

- Don’t let the cost of participating in research be a barrier to engagement. Talk with your partners about what would make it easier to engage in your project.
• Try to cover as many of your partners’ costs directly as possible. Offer parking vouchers at meetings or provide bus passes ahead of time. If your project requires plane or train travel, book this travel for your partners so that they don’t have to pay out of pocket.
• If your partners are participating in teleconferences or web-based meetings, consider covering the cost of phone and/or Internet. For example, consider prepaying cell phone minutes, as lack of minutes might be a barrier to participation.

Project Staff

When planning your engagement activities, consider who on your project staff is going to be responsible for ensuring that they occur. Activities requiring staff support may include:

• Recruiting, training, and mentoring your patient and caregiver partners;
• Coordinating, planning, and preparing for meetings and events with your partners;
• Serving as a point of contact for partners and communicating with your partners between meetings;
• Assisting in the development of lay summaries of project progress and disseminating these summaries to your partners;
• Coordinating engagement efforts across project sites;
• Evaluating engagement within a project; and
• Resolving conflict among partners with differing perspectives.

Budget for personnel to support your engagement activities just as you budget personnel to support your research activities. Individuals and/or organizations supporting engagement activities may be project personnel or contract employees/organizations. For those who are project personnel, include the level of effort required to support engagement activities, along with a rationale for this level of effort and the proposed activities that each individual supporting engagement will be responsible for. For those who are contract employees or organizations, include the hourly rate that will be paid, an estimate of hours in each project year, and a rationale that supports the budgeted amount.

Considerations

• As you develop your engagement plan, think through how much staff time will need to be devoted to supporting the activities that you propose. You may find the budget documents included in your application materials to be a helpful tool in this exercise.
• In addition to thinking about the time that it will take to support your engagement plan and activities, consider the skill set necessary to support the engagement in your project. Evaluate whether these activities are best supported by someone who is part of your study’s personnel (perhaps a co-investigator with engagement expertise, or a project manager or coordinator) or
contracted to an individual or organization with specific expertise on the patient and caregiver community that you are engaging in your study.

- There is no “right” model for providing staff support for engagement. What works best for your study depends on a number of factors including the skills and expertise of your project personnel, the patient and caregiver population that you are engaging in your project, and the engagement activities that you have planned.

**Engagement Event Costs**

In addition to budgeting to cover the cost of patient and caregiver partner travel to meetings and events, don’t forget to include meeting and event expenses themselves in your budget. Face-to-face team meetings, training events for your partners, and town halls to share information about the project are all examples of the kind of engagement events that you should budget for. Costs associated with these events may include venue rental, catering costs, facilitator fees, and expenses for materials.

**Considerations**

- You may wish to select a venue that is convenient to public transportation or has readily accessible parking. Likewise, consider whether the venue meets the needs of people with disabilities or other special healthcare needs.
- Note that food and beverage (excluding alcoholic beverages) costs tied to research project meetings and events are allowable costs under PCORI contracts.
- Many PCORI-funded projects have found it quite useful to provide training on research methods, human subjects protection, and best practices for working with diverse groups of people to their patient and caregiver partners. Include costs associated with these trainings, as appropriate, in your budget.

**Incorporating Partner Feedback**

One of the key goals of engaging patient and caregiver partners in the research process is to get their input in order to ensure that your study is relevant, timely, and feasible. Many PCORI-funded research teams have found that seeking feedback from their partners on study protocols and materials (e.g., focus group discussion guides, recruitment scripts, consent forms, follow-up questionnaires, etc.) yields helpful modifications. Integrating these improvements into study materials and processes, however, requires both time and financial resources. As such, you should budget for this as you plan your study.

**Considerations**

- As you plan your study, think about what materials will be reviewed by your patient and stakeholder partners and when. Build in enough time and staffing resources to integrate their suggestions into your final materials.
- Integrating partner feedback into some materials (e.g., patient education materials or videos) may require additional resources. Take this into consideration as you plan your project.