

Patient Payment, Perk and Reimbursement Guideline for the Greater Plains Collaborative

Background:

Without clear guidance on the amount or type(s) of reimbursement appropriate for patient partners, individual GPC sites reported using a variety of approaches to decide how to recognize these individuals' expertise, time and efforts. The engagement core for the GPC developed a survey to administer to all Patient Engagement Officers to standardize the collection of information on current strategies and to serve as a basis for group consensus that could lead to a guideline. The engagement core also requested comparable data from the PCORnet Engagement Committee lead organization, Genetic Alliance, to be able to put the GPC practices in context with other PCORnet organizations.

Survey and Discussion Results:

1. To develop a guideline/policy, sites used: 1) guidance provided by their Clinical and Translational Science Award community engagement key function experts; 2) prior site experience with community advisory boards, panels and individual partners for project-specific collaboration; 3) allocated budgets and retrospectively assessed the amount of funding for patient partners and 4) information provided by the site's research office.
2. Sites recognize the value of non-monetary remuneration or "perks" (free/valet parking, meals) that can make participation in local engagement more pleasant and/or practical for patient partners. Sites also identified ways to maintain social connections to participants that affirm the value the academic research team places on the patient partners' contributions. For example, some sites send personal cards in the mail or providing small gifts as demonstrations of appreciation.
3. GPC site practices distinguish reimbursement and remuneration/stipends, and often have guidelines for each. Only a few sites offer patient partners compensation.
4. Processes required to make payments to patient partners at individual GPC sites are quite variable and sometimes logistically difficult. For example, some sites permit the use of gift cards but vary with respect to requiring recipient signatures, social security numbers, mailing addresses etc. Some sites permit using cash (some specifically disallow cash), and even when permitted, requirements for oversight (i.e., multiple in-person staff observers during disbursement) are difficult. Cards that can be re-loaded based on time or effort (e.g., ClinCard) are sometimes allowed, but GPC PEOs have variable experience with respect to how straightforward the use of such cards is for payments. GPC sites have the ability to provide payment using checks, but the amount of personal information required is variable as well as whether a direct deposit option can be offered. Gift cards (gas cards, superstore cards (e.g., WalMart, Target)) sometimes are offered.
5. Not all patient partners can accept payments. Their issues may include concerns about sharing/having a social security number or pragmatic concerns about federal and state tax reporting as they may lose qualification for certain programs if their income exceeds a certain annual amount. Attempting to ensure equal recognition to all patient partner participants is challenging when patient partners have to decline remuneration for their time and effort.
6. GPC practices for payment fit within PCORnet-wide ranges collected by Genetic Alliance for providing remuneration to patient partners.

Findings and Recommendations:

1. Language used to describe how patient partners are paid, recognized or offered funds to cover their costs to participate is inconsistent. GPC and PCORnet-wide summary data refer to stipends, compensation, reimbursement, remuneration, hourly fee, incentives (cash), perks and gifts, and it is clear from descriptions that these words do not always refer to the same thing. A glossary would be tremendously helpful to all of the patient engagement leaders across PCORnet.
2. The GPC engagement participants recognize that local practices guide, and in some cases limit, their capacity to be responsive to patient partner preferences. University or organization-specific rules for payments of cash or cash equivalents (like gift cards) may result in time-consuming or complicated processes that do not feel patient-centered to either the patient engagement officer at the site or to the patient partner. Advocating for patient-friendly options, processes and reporting is an activity that the GPC patient engagement officers have had to do at many sites.
3. Consensus yielded the following guidelines for the GPC (with the caveat that local restrictions apply):

Payments	
Hourly payment	\$20-\$50
Per meeting	\$25-\$50
Per day (participation in all day or an event-related activity)	\$100-\$200
Per year (longer term advisory team patient partners/members)	\$2000
Travel expenses	Reimbursed according to guidance provided prior to incurring costs (bus/taxi, airfare, per diem, mileage, food receipts, permission to purchase alcohol, etc.)
Parking	Reimbursed according to guidance provided prior to incurring costs (valet fee, airport options, validation of ticket in specified lots, etc.)
Perks	
Site parking	Free or valet service offered
Child care	Free or reduced price
Meals	Meals appropriate to the hour of the meeting; offer healthy snacks and beverages regardless of hour
Include participant on listservs that provide information about educational opportunities (like lectures; Grand Rounds)	No cost
Library access	No cost
Conference/meeting fee waiver	To encourage participation locally, regionally and nationally, offering conference and meeting opportunities for enrichment

Conference/meeting attendance as collaborator	Costs covered as would be the case for other attendees from the research team (travel, lodging, parking, food, per diem, etc.)
Small appreciation gifts and cards	~\$10 value or less
Public recognition or certificate	No cost
If patient participant is also compensated staff, release time to participate in a research study	Benefit ours as flexible time allowable; increase community benefit angle