

Webinar Q&A Responses



Does compensation for trial participation interfere with the motivation a patient has to complete the study? A financial motive might lead to more dropouts.

Pam Cusick: Patient and caregiver time is valuable. Their motivation may be to further science and of course, to improve products and services, but the time they invest in clinical trial participation is significant and can be costly. Often, they are taking time off work, paying for child and/or pet, as well as other expenses which may not be covered - all of which comes out of their pockets. It seems like financial compensation might lead to better retention rates.

Grace Charrier: I would say the contrary. I find that most patients in my community tend to believe that compensation for their convenience, time, and willingness to participate in a clinical trial (albeit for their survival) depicts ample trust on the part of the researcher. As I had mentioned earlier in the webinar, clinical trials have an element of risk, and this factor must be keyed into when enrolling patients.

Would patients be more interested in participating if there was a company that handled their travel and reimbursement logistics and provided a point of contact?

Pam Cusick: This seems like a great idea. Making travel arrangements is always stressful. Booking rooms and flights and other logistics can be very complicated. When one has to contend with the added complexity of an illness, a wheelchair or walker, feeding tubes and the like it can be even harder. Add on to that, multiple visits and it can become overwhelming (and costly!). A company that handles all of these travel logistics along with a specific point of contact if things go wrong would be ideal!

Grace Charrier: Absolutely, as this would certainly lighten the load for the patients and their caregivers while they concentrate on getting well.

Not only is it important to state what is reimbursed and compensated for, but also when participants can expect to receive payment. Often, this is not communicated and for many communities, people really need that money and expect that it is provided asap, in a form (cash, Cash App vs. Amex gift card) that is easy for them to use.

Pam Cusick: Agreed! Knowing when and how one will be compensated is key. Nobody wants to wait 30-60 days for money they spent today! Letting patients and caregivers know when they will receive payment should be communicated up-front, so they are not worried about the additional expenses. We do not need to add to the patient and caregiver burden!

Grace Charrier: I totally agree as this is considered as some form of income. Many patients survive on funds such as this as they have financial burdens and deadlines around the clock.

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It is extremely important for them to be informed specifically when these payments will be made to enable their peace of mind which is key to healing and recovery.

Financial toxicity for the patient is like the hangman's noose.

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