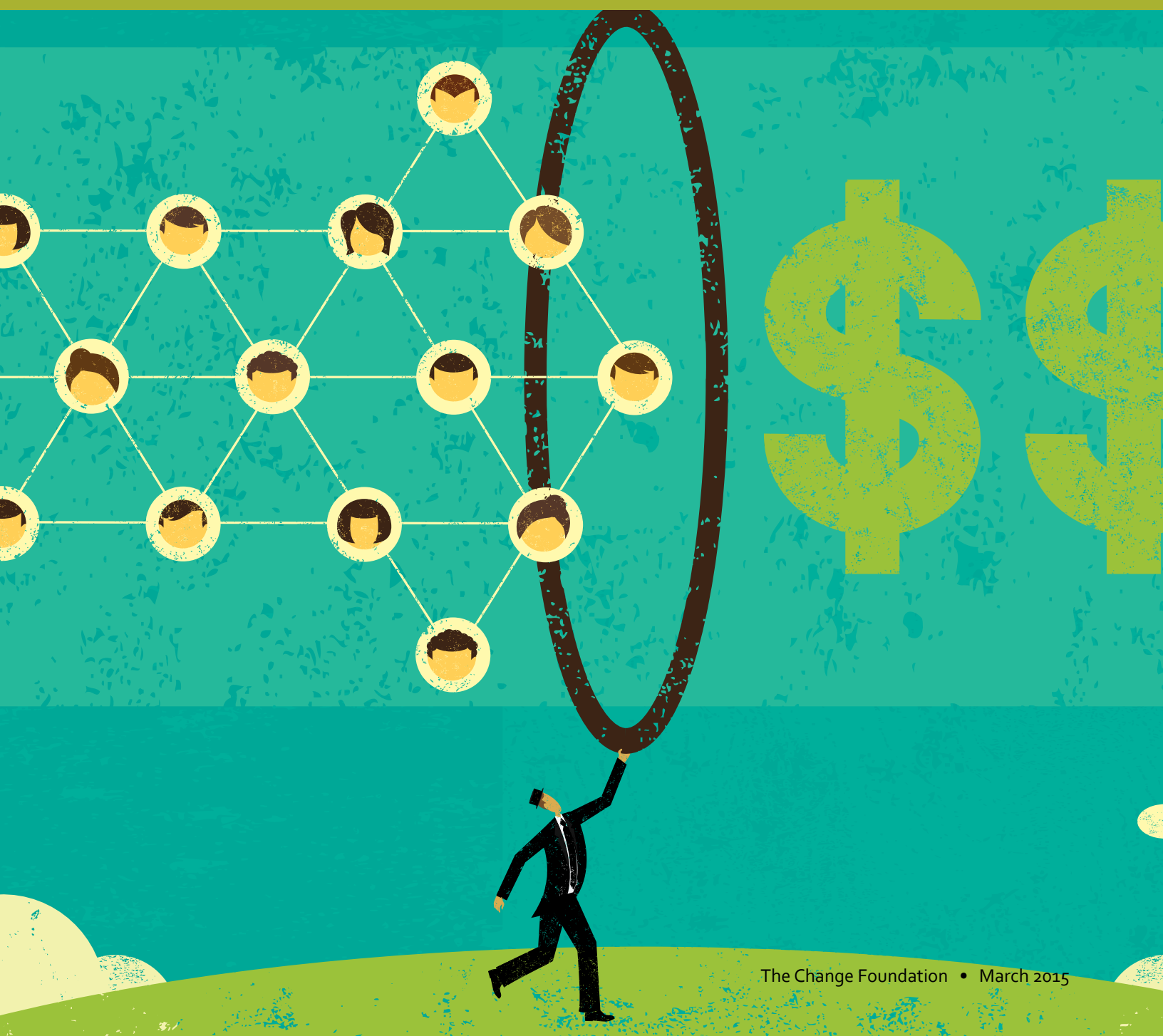




THE CHANGE
FOUNDATION

Should money come into it?

A tool for deciding whether to pay
patient-engagement participants



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ABOUT THE CHANGE FOUNDATION

An independent health policy think tank, The Change Foundation is changing the debate, practice and experience in Ontario healthcare, prompting system-wide, patient-centred improvements. The Foundation engages the stewards, stakeholders and users of Ontario healthcare, advising, supporting and challenging them to work together on shared goals: better health and quality of care; better patient experience and engagement; better value for money. The Change Foundation turns 20 in 2015, ready for its next challenge as a think tank dedicated to doing.

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INTRODUCTION

Patient engagement—it's becoming a guiding principle. More and more often, organizations concerned with healthcare and healthcare policy are consulting, discussing and brainstorming with patients and family caregivers. They are drawing on the wisdom people have gained from lived experience.

The question of compensation is inherent. Should money come into it? Or should the patient/caregiver's role be purely volunteer?

The Change Foundation, as a leader in patient engagement in Ontario, has developed a decision tool for our own use—to help us decide, on a case-by-case basis, whether to pay our patient-engagement participants. We invite you to use it too—as is, or you can adapt it to fit your needs.

Note that we are providing the tool under a Creative Commons license; please read the provisions on page 10 before using or sharing it.

Even if you don't use the decision tool, you may want to make note of its categories, scores, etc., to add to discussions your own organization is having. Practices and protocols around patient engagement—and community engagement more broadly—continue to evolve. We hope this paper, and the tool itself, will be part of an ongoing conversation.

CREATING THE DECISION TOOL

In 2014 we did a literature and database search, to review common practices around the payment/non-payment question. We found much variation in the healthcare field—no payment, hourly payment, lump sum. We found no best practice guidelines, no national or international standards, and no research on participants' views or preferences.

We did find literature on the broader subject of “public deliberation,” but it focused on process in general, with no guidance about payment. We saw that payment was common practice in academic/clinical research, but found no standards for *how much* to pay, and we noted that the context was different, i.e., involving trials and tests, and generally not collaborative.

To develop our own process and tool, we interviewed four professional experts in Ontario: the president of a patient advocacy organization; a public engagement expert; a former VP who headed community engagement at a mental health facility; and a lead in patient-centred care at a general hospital. We also turned to our standing patient engagement panel, the PANORAMA panel. These 31 patients and family caregivers from across the

province advise The Change Foundation. They draw on their own experiences with Ontario's healthcare system—good and bad—to help us in our work to improve the patient and caregiver experience for others. We consulted with PANORAMA panelists three times for help in creating our decision tool.

If you want to learn more about our research process, expert interviews and PANORAMA consultations, please see Appendix A, research process and Appendix B, research results.

Q & A

Before you proceed to the decision tool, it may be helpful to consider these underlying and related questions, and The Change Foundation's responses.

Q: When should the decision around payment be made?

A: At the Foundation, we decide before recruiting for an engagement activity, and we see this as a must for all organizations. Before people sign on, they need to know whether they will be paid.

Q: If paying, how much to pay?

A: Our rate is minimum wage. This is on advice we've received, and because we recruit people based on Ontario residency and experience in the healthcare system, not for specific skills or education. This may be different for your organization.

Q: What about reimbursement for expenses?

A: We reimburse for expenses (e.g., parking, travel, meals) and take it as a given that all organizations do. Whether to pay for participation is a separate question.

Q: What if the organization makes money from the engagement?

A: This isn't an issue for us, as a not-for-profit charitable foundation. If you do stand to benefit financially, we see it as obligatory that you pay participants.

Q: If an organization pays participants in some projects, must it do so in all projects?

A: No. At the Foundation, we consider each project on a case-by-case basis. We see this as a valid approach for other organizations too. What must be consistent, though: you must use the same decision-making process every time.

Q: If payment is offered, can a participant refuse it?

A: At The Change Foundation, yes.

Q: What are the "pros" of offering payment?

A: Some "pros" are that payment shows respect and appreciation; it is usually the most successful way to attract people; it's a way to be "accountable" to participants; it may make it easier—or even possible—for low-income people to take part; and it may increase a sense of equity at the table, since professionals and staff are being paid for their time.

Q: What are the "cons"?

A: Again, there are many. People might sign up for money rather than genuine interest; volunteerism could be harmed (i.e., growing expectations of payment, for roles with the same organization or beyond); possibility of bias (participants feeling less independent and feeling loyal to the organization and its views); and, in the case of government-sponsored activities, added costs for the healthcare system.

Q: What does The Change Foundation think?

A: We are neither for nor against paying. Our concern is to work within the principles of fair, equitable and barrier-free public engagement—and we believe this can happen either way. This is why we decide on a case-by-case basis.

THE DECISION TOOL

This tool **applies** only to patient-engagement activities with a fixed amount of time. It **does not apply** to routine or ongoing tasks, to governance roles such as sitting on a board, to paid patient advocacy, or to contributions of *professional expertise or knowledge* from healthcare providers or others.

It measures eight factors: **Time, Equity, Vulnerable-Group Status, Challenges, Accountability, Positive Impact, Access and Other Forms of Recognition.**

The first five are contributing (+) factors, where a higher score increases the likelihood of payment; the last three are mitigating (-) factors, where a higher score decreases the likelihood of payment.

CONTRIBUTING FACTORS	SCALE	SCORE
TIME This looks at how much time participants will be asked to contribute (in duration and intensity both). NOTE: If you receive the "Automatic YES," that means payment is required and you need not complete the tool.		
<input type="checkbox"/> UNDER 8 hours / month	0	
<input type="checkbox"/> 8 – 16 hours / month for less than 3 months	1 POINT	
<input type="checkbox"/> 8 – 16 hours / month for more than 3 months	2 POINTS	
<input type="checkbox"/> 17 – 40 hours /month for less more than 3 months	4 POINTS	
<input type="checkbox"/> 17 – 40 hours /month for more than 3 months	5 POINTS	
<input type="checkbox"/> OVER 40 hours / month	Automatic YES	
EQUITY The question here is whether participants will work alongside people (e.g., healthcare workers, academics, policy makers) whose employers are paying them to be there. For scoring purposes, this does not include staff of The Change Foundation, who are assumed to be present at all or most engagement events.		
<input type="checkbox"/> No paid individuals at the table	0	
<input type="checkbox"/> Paid individuals at the table	5 POINTS	
VULNERABLE-POPULATION STATUS This scores the degree to which participants will be sought from "vulnerable groups," e.g., those who have chronic physical conditions, mental health problems or addictions; are recent immigrants or belong to racial or ethnic minorities; are Aboriginal; have low socio-economic status; or are homeless.		
<input type="checkbox"/> Not looking to engage vulnerable populations	0	
<input type="checkbox"/> Expect to engage some people from vulnerable populations	3 POINTS	
<input type="checkbox"/> Will mainly or exclusively engaging people from vulnerable populations	5 POINTS	
CHALLENGES This scores the likelihood of challenges for participants (e.g., risk of embarrassment, psychological discomfort) OR for the Foundation (e.g., hard cultural- or geographic-representation criteria to meet, history of similar failed projects, or timeline that may dissuade participants). The emphasis here is pragmatic: using payment to help attract and retain people when it may otherwise be hard to do so. However: NOTE that, regardless of payment, project design should aim to minimize any discomfort for participants.		
<input type="checkbox"/> 0 – 1 challenges foreseen / and/or challenges should be easily dealt with	0	
<input type="checkbox"/> A few challenges identified (2 – 3 challenges)	3 POINTS	
<input type="checkbox"/> Several challenges present (4+ challenges)	5 POINTS	
ACCOUNTABILITY This is pragmatic again: the less "personal" the medium, the more likely that payment is advisable to strengthen participants' commitment/accountability. This also considers the challenge of maintaining commitment/accountability in projects that exceed certain timeframes.		
<input type="checkbox"/> Less than 12 Month commitment – any engagement methods	0	
<input type="checkbox"/> 12 – 24 Month commitment - some or all in-person engagements	1 POINTS	
<input type="checkbox"/> 12 – 24 Month commitment – virtual/remote engagements only (online, phone, etc.)	2 POINTS	
<input type="checkbox"/> More than 24-month commitment - some or all in-person engagements	4 POINTS	
<input type="checkbox"/> More than 24-month commitment – virtual/remote engagements only	5 POINTS	

MITIGATING FACTORS	SCALE	SCORE
POSITIVE IMPACT The more positive impact, the less likelihood of need for financial compensation. This can mean impact on the participant's life (e.g., community-building, travel or learning opportunities) and/or on the healthcare system (bringing prestige or satisfaction for participants).		
<input type="checkbox"/> Low or negligible positive impact expected (personal or system)	0	
<input type="checkbox"/> Medium positive impact (personal or system)	- 3 POINTS	
<input type="checkbox"/> High positive impact (personal or system)	- 5 POINTS	
ACCESS If the engagement gives participants access to specific treatments, healthcare providers' opinions, etc., this can also mitigate against payment.		
<input type="checkbox"/> No – no access to treatments or opinions anticipated	0	
<input type="checkbox"/> Yes – access to treatments or opinions is anticipated	-5 POINTS	
OTHER FORMS OF RECOGNITION This can mean any combination of low-recognition options (thank-you cards, meals, etc.), medium-recognition options (plaques, "souvenir" clothing, etc.) or high-recognition options (trips, scholarships, etc.).		
<input type="checkbox"/> No – no other forms of recognition are planned	0	
<input type="checkbox"/> Yes – other forms of recognition are planned	-5 POINTS	

CONTRIBUTING AND MITIGATING FACTORS	FINAL SCORE (if negative enter "o")
<input type="checkbox"/> All categories have been scored	

COMPENSATION DECISION AND NOTES	SCORE RANGE
Payment not required: Other options to recognize participant contributions are advisable.	0 to 8
Payment advisable but not required: If you prefer not to pay, consider strengthening your mitigating factors or making other changes.	9 to 12
Payment required: This is in addition to any other forms of recognition that may be in place.	13 to 25

USING THE TOOL—LIMITATIONS AND REQUIREMENTS

Limitations

Note that the categories and scores in the tool are informed by factors and experiences specific to The Change Foundation. They are not meant as a standard, and may or may not meet your needs. We encourage you to evaluate each factor, add new ones, change the scoring, etc., to tailor the tool for your organization.

Creative Commons requirements

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APPENDIX A: RESEARCH PROCESS

Although this was not a comprehensive, formal research project, we used three complementary methods to find information.

Literature Review

We did a database search for peer-reviewed scientific literature and also an informal search of reports, policies, etc. For the former, we searched MEDLINE and CINAHL databases. For the latter, we used Google Scholar, the University of Toronto Libraries catalogue and the University Health Network library catalogue, and hand-searched the references of articles we found. We began by searching health policy and administration, but after finding scarce data we expanded our search to two related fields: public deliberation (i.e., public policy, government); and clinical/academic research and innovation.

Expert Interviews

We did informal, open-ended telephone interviews with:

- President of a patient advocacy organization
- Susan Pigott, Former Vice President, Communications and Community Engagement, Centre for Addiction and Mental Health (CAMH)
- Lead for Patient and Family Centred Care at a General Hospital
- Mary Pat MacKinnon, Vice President, Hill+Knowlton Strategies Canada

The questions we asked included, "*What practices have you seen used to compensate participants?*", "*What practices does your organization use?*" and "*What is your opinion of these practices compared with others you have seen?*" We audio-recorded the interviews and synthesized the experts' main views into a summary of key themes.

PANORAMA consultations

We gave the PANORAMA panel a three-page summary of our literature search and expert-interview findings, and a brief presentation on different compensation options and approaches. We met with PANORAMA in three separate consultations (twice online with parts of the group and once in-person with the whole group) to get input based on their experiences as engagement participants, and their thoughts on the pros and cons of financial compensation.

APPENDIX B: RESEARCH RESULTS

Literature search

In all three of the areas we searched—health policy and administration, public deliberation, and clinical/academic—debate and uncertainty exist around volunteer compensation/honoraria.

In the **health** field, individual organizations create their own processes or guidelines on the subject. Of those who pay engagement participants, some base it on number of hours and others provide a lump sum. (All organizations have their own process for expense reimbursement.)

In our findings, those institutions whose guidelines included target-population involvement (e.g., Aboriginal participants), did not give details about participant compensation. They did refer to cultural sensitivity and the importance of net benefit for the participants and community.

Of note, our search within health policy and administration found:

- no reference to any national Canadian standards or international standards concerning participant payment;
- no mention of engagement participants' perceptions or opinions regarding payment.

In the **public deliberation** field, payment is sometimes but not always offered. Some documents show that the context of the work is generally considered when determining compensation; however, we found no baseline or threshold amounts to guide others. The literature generally explored or evaluated the entire process of public participation (or of volunteer involvement in NGOs) and did not focus on compensation practices or their effect. It was noted in the literature that volunteer-participation

standards must be (1) defined, (2) documented, (3) understood, (4) implemented, and (5) maintained. From the literature we found, decision makers in the public deliberation field appeared concerned with achieving low-cost, high-yield consultations, so as not to divert resources away from service delivery and actual implementation of the policy at hand.

Of note, our search within public deliberation found:

- no explicit information about compensation amounts.

In **clinical/academic research and innovation**, the success of a study may well depend on effective participant recruitment, and payment is a strong incentive. It is therefore an accepted practice, and grant application forms generally include a placeholder for compensation/honoraria expenses. If money *per se* is not given, participants will typically receive a gift card.

There is concern in this field about the possibility of “undue influence” related to payment. The federal government’s Interagency Advisory Panel on Research Ethics (<http://www.pre.ethics.gc.ca>), in its *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans*, (2010 edition), neither recommends nor discourages payment or other incentives. It puts the onus on researchers to determine the level of participant incentive, and to disclose and justify it to the research ethics board (REB) of their overseeing institution. (One terminology note that can be seen as illustrative of issues particular to clinical research: In the Statement, the word “compensation” is used in a specific way, to mean payment for research-related injury.)

Note that all academic research institutions have a REB in place to ensure adherence to the Tri-council Policy Statement. Researchers must submit a REB application before the research starts, including participant-payment amounts for the REB to approve or deny. We informally surveyed the REBs at four major Toronto-based institutions—University Health Network, Mount Sinai Hospital, St. Michael’s Hospital, and Sunnybrook Health Sciences Centre—and found no guidelines in place for compensation amounts.

Of note, our search within clinical/academic research and innovation found:

- no matrix, algorithm or guideline involving the specifics of compensation decisions or amounts.

Expert interviews

Below is a summary of the four experts’ views for and against participant payment. Note that this is a compilation of views; *not all* of the opinions shown here were expressed by all of the experts.

Throughout the interviews, the experts emphasized that the payment of engagement participants is, overall, a grey area. They saw it as contextual, i.e., that decisions should be based on the project involved and the time the participants are committing to it. According to these experts, organizations that have created internal policies and guidelines on the subject have done so by:

- considering the practices of other organizations, where relevant or comparable;
- determining the most manageable course of action for their organization and their project budget; and
- Identifying options to recognize volunteer contributions in non-monetary ways.

Overall, the interviews led to no “yes or no” conclusion. It was suggested that an outline of the range of patient engagement roles and activities could be useful. It could help organizations in their decision-making.

Arguments <u>for</u>	Arguments <u>against</u>
<i>Philosophically: Equity</i>	<i>Philosophically: Vantage point</i>
If staff are paid to participate, then patients should receive an equitable acknowledgement for their time as well. If not compensated, patients are considered a “free good,” and historically this has contributed to the patient population being misused by the clinical or policy community.	A participant who is a volunteer is external to the organization and therefore independent and not subject to control. Compensation turns that external, objective participant into an internal, controlled and (perhaps) biased participant.
<i>Pragmatically: Recruitment Incentive</i>	<i>Pragmatically: Role distinction</i>
All things being equal, monetary compensation is the most successful way to encourage participation.	There should be a clear distinction between consultants who are paid to give their opinions and advisors who are invited to share their perspectives in a voluntary capacity.

Consultations with PANORAMA panel

Overall note re the PANORAMA consultations: It was clear by the end of the dialogues that most panelists were opposed to the payment of patient engagement participants, at least in most circumstances.

Below are three questions we asked the panelists, and a summary of the major points they made in response. Note that not all of the opinions shown here were expressed by all of the panelists.

1. Why should an organization consider offering an honorarium to engagement participants? Or why not?

(In this case, we asked all participants to argue both for and against.)

Major points identified in favour:

- encourages people who could use financial support to participate
- demonstrates appreciation for participants
- shares the potential value gained through participants' contributions
- ensures organizations' accountability to participants

Major points identified against:

- risks attracting "the wrong participants"
- harms volunteerism
- could influence participants' opinions
- in some cases, would increase government costs
- could lead to escalating expectations for compensation

2. Does context matter? (e.g., who the organization is, how much time commitment is expected, the specific engagement objectives, who the organization wants or needs in the room)

Major points raised:

- The type of organization may matter, especially with respect to ability-to-pay. The more financial resources it has, the better positioned it is to provide cash or another form of compensation. For-profit organizations may be more obliged to pay than government or not-for-profits.
- Other contextual factors may not matter, as long as participants receive enough information about the context of the engagement to make an informed decision, and know how they will be compensated (if at all).

3. What guiding principles would help organizations assess whether or not to pay? Are some factors more important than others?

Major points raised:

- consider the target populations you want to engage, and any limitations they may have to participation
- ensure that participants feel truly valued by your organization
- be transparent in informing participants of how they will be recognized
- recognize any inconveniences for participants and the impact on their time



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