THE **CHANGE** FOUNDATION

## SHOULD MONEY COME INTO IT?

# The
# Decision Tool

More and more often, healthcare organizations delivering care, conducting research and evaluation, and policy organizations are consulting, discussing and brainstorming with patients and family caregivers. Research of this nature raises the question of compensation. Should the patient or caregiver be compensated or should their role be purely voluntary?

To help organizations answer the payment/non-payment question, we developed *The Decision Tool*, which first appeared in the report *Should Money Come into It?* To create the tool, we consulted with four professional experts in Ontario as well as our standing patient engagement panel, the PANORAMA panel.

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
- Other forms of recognition

The first five questions look at contributing (+) factors, where a higher score increases the likelihood of payment. The last three questions focus on mitigating (-) factors, where a higher score decreases the likelihood of payment.

# CONTRIBUTING FACTORS

**TIME** | **Q1** | How much time will participants be asked to contribute?

NOTE: If you receive the automatic "YES," that means payment is required and you need not complete the tool.

| | POINTS |
|---|---|
| Under 8 hours/month | 0 |
| 8–16 hours/month for LESS than 3 months | 1 |
| 8–16 hours/month for MORE than 3 months | 2 |
| 17–40 hours/month for LESS than 3 months | 4 |
| 17–40 hours/month for MORE than 3 months | 5 |
| Over 40 hours/month | YES |

+ _____ SCORE

**EQUITY** | **Q2** | Will participants work alongside people who are being paid to be there (e.g., healthcare workers, academics, policy makers)?

NOTE: For scoring purposes, this does not include staff hosting the engagement.

| | POINTS |
|---|---|
| No paid individuals at the table | 0 |
| Paid individuals at the table | 5 |

+ _____ SCORE

**VULNERABLE GROUPS** | **Q3** | Will you seek out participants from "vulnerable groups"?

EXAMPLE: Those who have chronic physical conditions, mental health problems or addictions; are recent immigrants or belong to racial or ethnic minorities; are Indigenous; have low socio-economic status; or are homeless.

| | POINTS |
|---|---|
| Not looking to engage vulnerable populations | 0 |
| Expect to engage some people from vulnerable populations | 3 |
| Will be mainly or exclusively engaging people from vulnerable populations | 5 |

+ _____ SCORE

## Q4 — CHALLENGES

**Are there any challenges for either participants or the organization?**

EXAMPLE: For participants–risk of embarrassment, psychological discomfort. For organizations–cultural or geographic representation criteria to meet, history of similar failed projects, or timeline that may dissuade participants. NOTE: Regardless of payment, project design should aim to minimize harm for participants.

| | POINTS |
|---|---|
| 0–1 challenges foreseen and/or challenges should be easily dealt with | 0 |
| A few challenges identified (2–3 challenges) | 3 |
| Several challenges present (4+ challenges) | 5 |

+ ____ SCORE

## Q5 — ACCOUNTABILITY

**What level of commitment are you expecting from participants?**

NOTE: 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.

| | POINTS |
|---|---|
| Less than 12 Month commitment–any engagement methods | 0 |
| 12–24 Month commitment–some or all in-person engagements | 1 |
| 12–24 Month commitment–virtual/remote engagements only (online, phone, etc.) | 2 |
| More than 24-month commitment–some or all in-person engagements | 4 |
| More than 24-month commitment–virtual/remote engagements only | 5 |

+ ____ SCORE

# MITIGATING FACTORS

## Q6 — POSITIVE IMPACT

**Will the engagement positively impact the participant's life or the healthcare system?**

EXAMPLE: Community-building, travel or learning opportunities, or bringing prestige or satisfaction for participants. Positive impact decreases likelihood of need for compensation.

| | POINTS |
|---|---|
| Low or negligible positive impact expected (personal or system) | 0 |
| Medium positive impact (personal or system) | 3 |
| High positive impact (personal or system) | 5 |

- ____ SCORE

## ACCESS | Q7

Does the engagement give participants access to benefits that can mitigate against payment?

EXAMPLE: Specific treatments, healthcare providers' opinions, etc.

| | POINTS | |
|---|---|---|
| No–no access to treatments or opinions anticipated | 0 | - _____ |
| Yes–access to treatments or opinions is anticipated | 5 | SCORE |

## OTHER RECOGNITION | Q8

Will you be giving participants any other forms of recognition?

EXAMPLE: 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.).

| | POINTS | |
|---|---|---|
| No–no other forms of recognition are planned | 0 | - _____ |
| Yes–other forms of recognition are planned | 5 | SCORE |

# FINAL SCORE

| 8 or less | No | **Payment not required.** Other options to recognize participant contributions are advisable. |
|---|---|---|
| 9–12 | Maybe | **Payment advisable but not required.** If you prefer not to pay, consider strengthening your mitigating factors or making other changes. |
| 13–25 | Yes | **Payment required.** This is in addition to any other forms of recognition that may be in place. |

_____
FINAL SCORE

Visit *Should Money Come into It?* to read the full report.