# Participant Council Meeting
## October 29, 2026

**12:30-14:30 EDT | 17:30-19:30 CET | 18:30-20:30 CAT | 19:30-21:30 EAT**

## Focus Session Notes: Identifying Council Priorities for 2027

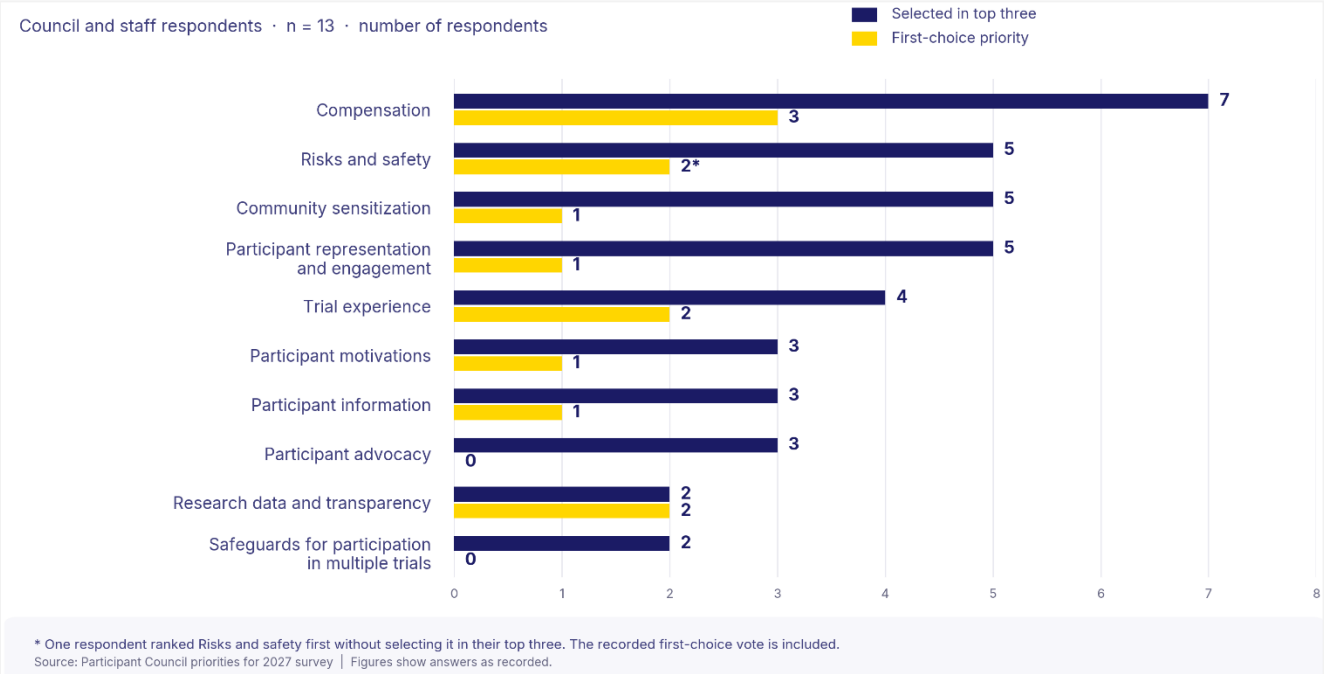
### Context

The discussion aimed to:

- Gather Council members' views on potential priorities for 2027.
- Explore two selected priorities in depth, considering the specific issues the Council could address, potential practical outputs, who would benefit from them, and what would be needed to develop them.

Ahead of the meeting, Council members and 1Day Sooner staff were invited to complete a prioritization survey to help shape the Council's work in 2027. Respondents selected up to three priority topics, identified their highest priority, and shared their views on why it matters, what they would like to change, and potential practical outputs that could be useful across different studies and countries. Staff were also invited to highlight opportunities, obstacles, and connections to existing projects.

### Top priorities identified



## Summary of views on selected priorities

| Priority | Why it matters | Practical Outputs & Audiences |
|---|---|---|
| **Compensation** | Unfair or unclear payments can create barriers to participation. There are widening disparities between countries and a risk of inadequate compensation becoming an established precedent. Builds on the Council's 2026 discussions. | Fair compensation guidelines, checklists, participant survey questions, and potentially regional benchmarks or a position paper.<br>**Audience:** Researchers, ethics committees, sponsors, and participant representatives. |
| **Risks and safety** | Concerns about long-term health effects, uncertainty, and participant anxiety. | Recommendations and a checklist covering participant safety, risk communication, and follow-up.<br>**Audience:** Research teams. |
| **Community sensitization** | Explicit concern about the rise of disinformation, particularly around healthcare and clinical research. | Guidelines for addressing disinformation and misconceptions about clinical trials.<br>**Audience:** To be determined. |
| **Trial experience** | Ongoing concerns about participants feeling supported, reporting problems openly, and receiving appropriate treatment. | Guidelines and checklists covering communication, informed consent, transport, follow-up, and reporting concerns.<br>**Audience:** Research teams. |
| **Research data and transparency** | Difficulty accessing trial results and broader issues around sharing individual data and research transparency. | Recommendations and practical methods for communicating study findings, potentially supported by a checklist.<br>**Audience:** Research teams. |
| **Participant representation and engagement** | An ongoing or “evergreen” issue rather than an urgent one. | Surveys, engagement activities, open letters, and participant involvement in research processes.<br>**Audience:** Research teams and the wider public. |

# Discussions on selected priorities: Compensation and Trial Experience

## 1. Compensation

**The Council suggests focusing on:**

- Compensation transparency: participants often don't know how payments are structured or broken up across visits.
- A standardized formula or checklist for fair compensation across countries and trial types.
- Separating base compensation from reimbursement for travel and other expenses.
- Providing monetary compensation rather than vouchers or gift cards, which were flagged as inadequate.
- Offering post-trial coverage for long-term health impacts or disability caused by participation.
- Whether risk should affect base pay, given concerns that risk-weighted pay could create financial pressure to accept greater risks.

**A useful output could be:**

- A compensation formula weighting key variables:
    - Severity and likelihood of symptoms.
    - Risk of serious complications.
    - Disruption to daily life (quarantine, travel, time away from work/family).
    - Purchasing power parity or average wages in the participant's country.
    - Regional economic and currency changes over time.
- A standardized checklist that research teams can apply across geographies.
- A regional formula or template for research teams.

**The formula and checklist could help:**

- Reduce wide variations in compensation across studies and countries.
- Anchor payments to what money actually buys locally, not a flat global rate.
- Account for changing economic conditions that can make compensation less adequate over time.
- Ensure participants do not have to use their compensation to cover travel to study visits.
- Prevent financial barriers from excluding participants who can't absorb costs upfront.
- Flag uncompensated study activities, such as monitoring days, so they are addressed consistently.

**To develop it, the Council would need to:**

- Review prior Council recommendations and existing internal tools that could support the framework.
- Establish a working group to develop and refine the formula and checklist.
- Decide how to weight each variable (location, trial type, risk, time commitment).
- Determine whether risk should factor into upfront compensation or only trigger post-trial insurance/disability coverage.
- Agree on a benchmark (e.g., national living wage, purchasing power parity, average wages) as the anchor.
- Decide how to adjust for inflation, currency shifts, and changing local economic conditions.

**Questions that still need to be answered:**

- How should risk be handled in compensation?
    - Should it factor into upfront pay, or only trigger post-trial coverage?
    - Potential regulatory restrictions on risk-weighted upfront pay.
    - Participants in countries without universal healthcare face compounding costs if health impacts arise.
- How do we standardize across countries while still reflecting local cost of living fairly?
- How should compensation frameworks account for economic changes during a study?
- How should uncompensated study activities be identified and prevented?

## 2. Trial Experience

**The Council suggests focusing on:**

- Ensuring participants receive trial results after the trial if they wish to.
- Making post-trial communication a standard part of participation, rather than something participants must chase themselves for.
- Distinguishing between two communication needs:
    - Participants receiving their individual results promptly.
    - Participants receiving overall study results later, if they wish to.

**A useful output could be:**

- Standard opt-in language for research teams to use at enrollment.
- A simple recommended process for when and how teams should share results with participants, including a second opt-in/check-in at the final visit, in case participants change their mind or contact details.
- Suggested formats that research teams can add to existing workflows, while leaving participants free to decline.
- A recommendation that research teams provide a single point of contact for participants.

**The opt-in language and process could help:**

- Ensure participants who want results actually receive them.
- Give research teams a concrete process they can implement.
- Reduce situations where participants learn results indirectly or have to call researchers themselves.
- Prevent gaps where participants are told they will only hear back if something is wrong.
- Reinforce that participants should have access to study findings in recognition of their contribution to the research.

**To develop it, the Council would need to:**

- Identify where this fits in existing trial forms and workflows.
- Draft practical language teams can copy into consent or follow-up materials.
- Consider different delivery formats and timing, including whether results should first be shared with participants before wider public release.
- Keep the process workable across different trials and country contexts.
- Clarify the difference between communication of individual participant results and communication of overall study findings.

**Questions that still need to be answered:**

- What prevents some researchers from sharing study results consistently?
- Are the main barriers cultural, procedural, or logistical, such as staff turnover or uncertainty about consent?
- How do we make follow-up communications clearly opt-in, so participants can decline if they wish?
- Should results be shared in stages, for example first with participants and researchers, then publicly later?
- Who should be responsible for making sure participants are informed, and what happens if study staff change or do not follow through?