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Highlights from the 2026 OBI Patient, Youth, and Family Advisory Committees Workshop

(Published: April 2026)

The workshop brought together OBI, IDPs, and Advisors to explore how advisor partnerships have shaped brain health research and identify ways to strengthen ongoing collaboration.

50
Partners in attendance

65%
Patient, youth, family, or community advisors

Attendee Experience

9/10
Average score for recommending to others

100%
Respondents who found it a valuable use of their time

92%
Felt completely or mostly valued as a participant

> **"**The presentations really hit home — even though my own advisory committee gives us feedback, seeing it today made the impact more clear than I'd understood before**"**

Suggestion: Group activity can also be used as an icebreaker

Workshop Group Discussions

- Participants collectively brainstormed ideas across all questions
- Each breakout group then narrowed the list to three recommendations

Group 1:
What should we KEEP doing to ensure changes or true collaboration from advisors?

Group 2:
What should we START doing to increase advisor impact?

Group 3:
How can OBI and IDPs better spotlight advisor contributions?

Questions? Additional thoughts? Reach out to Caroline cabuayyash@braininstitute.ca OR 647 261 2457

Recommendations: What we should keep doing to strengthen advisor impact

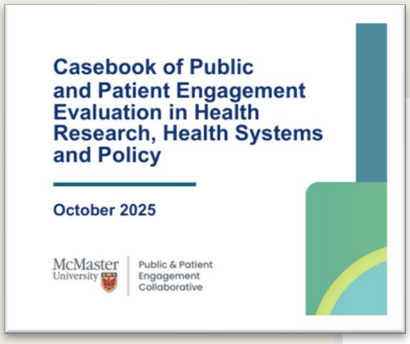
- **Close the feedback loop**
  Ensure advisors hear specifically how their input was used or why it was not
- **Engage advisors from the very beginning**
  Collaborate from point of research conception and before study design
- **Value advisor feedback compensation and travel support**
  Key ways of demonstrating value include compensation and travel support to present at/attend conferences and IDP events

> **"**I was struck not only by the commitment to creating inclusive spaces, but also by the importance of closing the feedback loop. The ways you share the impact of research back with advisors is critical to building trust and sustaining long-term knowledge exchange**"**

OBI' is already doing

- Sharing advisor impact on research in academic and public spheres
- Funding advisor conference attendance
- Facilitating cross-IDP events to build connections
- Exploring opportunities for co-authorship

Example: OBI coordinates submission with advisors and IDPs on a 'casebook' submission. See full article here.



7. Evaluating the impact of patient and family engagement in Ontario Brain Institute-funded research: Insights and recommendations

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Keywords: patient and family engagement; evaluating engagement; Learning Together Evaluation Framework

Recommendations: What we should start to strengthen advisor impact

- **Provide more consistent updates on research progress**
  Keep advisors connected between formal touchpoints through newsletters, website, and short check ins
- **Establish structures that formalize early involvement**
  Involve advisors as early as possible by establishing advisory groups as part of the research team from project initiation
- **Create more gathering opportunities to connect**
  Invest in in-person events that build community and use smaller group formats where all voices can be heard
- **Establish an annual award**
  Use award to recognize the impactful contributions of lived experience advisors

"Advisor impact could be increased by having a Research Advisory group included on the research team early — before the study begins. On top of meetings, we are being included on the wording of questionnaires and mental health resources that will be part of the recruitment process**"**

What the Ontario Brain Institute (OBI) is planning

- Organize an in-person gathering to encourage connection and reflect on the future of engagement and collaboration
- Provide IDPs with educational opportunities that strengthen capacity in engagement and knowledge/updates sharing
- Set up an advisory recognition award

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Recommendations: How to spotlight advisor collaborations

- **Share advisor stories**
  Check in with existing program members to assess interest in participating in interviews or profile stories for external audiences
- **Strengthen cross-collaboration and networking**
  Create more opportunities for IDPs and advisors to connect with each other and with partner organizations working in the same space

Reflection from the Day: Different questions, similar responses

Despite the differently-framed discussion questions of 'keep doing' and 'start doing', similar priorities came up in both discussions:

- Keep advisors informed about progress, updates, decisions
- Engage early
- Acknowledge contributions: compensation, awards, presentations

These commonalities point to a shared vision for engagement, even as IDPs are at different stages and operate within varying structures. They also give OBI a clear, advisor-informed foundation for where and how to best support IDPs.