



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

(Published: August 2025)

VISION

Bring together patients, families, community groups, and program partners to connect, share, and learn about meaningful engagement strategies

52 Partners attended

AGENDA

Discussed three areas impacting engagement: advisory committee orientation, building community- based partnerships, and evaluating engagement

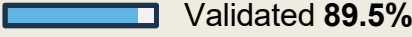
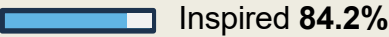
70% Identified as patient, youth, family, or community advisors

Looking Back: Attendee Experience

I felt fully supported to participate in this event



Completely/Mostly agree that “I felt...”

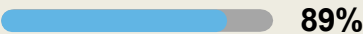


Additional note:

We also heard that the virtual platform, Whova, presented usability and visual barriers to participation. These included difficulty accessing chat and low clarity on how to join video sessions.

Looking Ahead: Future Planning

‘Extremely/Very likely’ to recommend this event

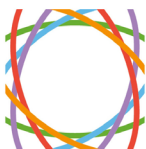


Additional recommendations:

Use an alternative to Whova (ie. Other virtual platforms)

For virtual events: Provide tech support

Keep opportunities for social interactions (e.g. Whova’s ‘community board’ feature)



Discussion Topic: Strengthening external and community partnerships



What we heard

Important for IDPs and OBI to expand or strengthen external and community partnership that will focus on improvement in the following areas:

- Representation in advisor and research roles
- Barriers to participation in IDPs and clinical trials
- Care transition support across the lifespan
- Public-focused communication
- Knowledge sharing



Recruitment at community-based organizations would open up opportunities for those who have been underrepresented in clinical settings (racialized folks, 2SLGBTQIA+, newcomer population)

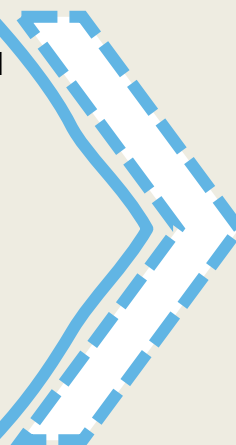


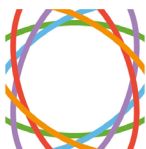
Cerebral Palsy has historically been really treated as a childhood disability, when that's not the case, and now we don't have the research to support what's happening in our adult lives



What the Ontario Brain Institute (OBI) is planning

- Compile a list of organizations and external partners, as suggested by workshop attendees, to share with IDPs
- Organize a webinar for IDPs to share lessons and accomplishments of community-based partnerships
- Collaborate with at least one external or community-based partner on a brain health related event
- Explore how to better integrate community organizations as partners in the design and conduct of clinical trials





Discussion Topic: Strengthening new & existing advisor orientation



What we heard

- Barriers facing advisors when they first join include information overload, jargon, lack of clear roles, disconnect with team members, joining mid-project
- Topics that are important to advisors are: project history, team/program structure, research processes (and their role within them), expectations
- Processes that would be helpful are: mentorship systems from other senior advisors, one-on-one and asynchronous communication, and visual materials rather than 'lecturing'
- Terms of Reference should include: role definition, accountability, user-friendly formatting
- Advisors know they have been through an impactful orientation once they feel confident, a sense of belonging, actively engagement, and have ongoing participation/retention

“

We need to know things like...here is the typical projects like, here is the project cycle for this particular project with this particular subgroup group, and this is here are the different hoops that we're going to jump through

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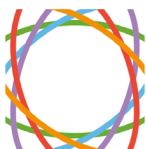
“

what I would not want it to be...a big binder manual...what would be really valuable, I think, in retrospect, is having having one member of the committee...who would be open to almost mentoring

”

What the Ontario Brain Institute (OBI) is planning

- Develop short and easily digestible resources on:
 - OBI and relationship with/between funded programs
 - Examples on Terms of Reference
 - Journey map for advisors going through research and knowledge sharing engagement
- Present to patient, youth, and community advisory committees about OBI activities and vision for advisor engagement
- Collaborate with IDPs on ensuring orientation and refresher activities focus on priority topics



Discussion Topic: Understanding engagement experiences of patient, youth, and family advisors

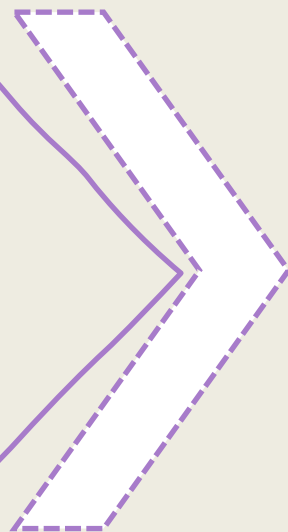


What we heard

- Feedback and surveys should be collected annually and through OBI to ensure confidentiality
- Provide options for filling out the survey (not only online option)
- Compensate advisors for participation to reflect value of their time + knowledge
- Include both closed ended ('quantitative') and open ended ('qualitative') questions to provide opportunities for story sharing/telling
- Report findings back to advisors for transparency and to share planned actions
- Additional note: Participants shared feedback on specific questions/items for inclusion in a survey on engagement experiences

What the Ontario Brain Institute (OBI) is planning

- Send annual survey and maintain participant confidentiality and highlight option of a one-on-one conversation (started in June 2025)
- Offer compensation for patient, youth, and family advisors who complete the survey
- Integrate patient, youth, and family feedback into the engagement experiences survey, including the addition of open-ended questions for story telling/sharing
- Develop several reports for multiple audiences, including patient, youth, and family advisors as well as IDP-specific reports to encourage action



From Workshop to Action: Travel Bursary Funding

Advisors at our 2024 workshop requested better recognition for their contributions. In response, we created the **Patient, Youth, and Family Advisor Travel Bursary** to support conference attendance and presentations.

Each program can nominate **two advisors** to attend large meetings and events/conferences. This fund is available until **March 2026**.

Learn more: [Travel bursary details](#) and [Frequently Asked Questions](#)