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October 2026

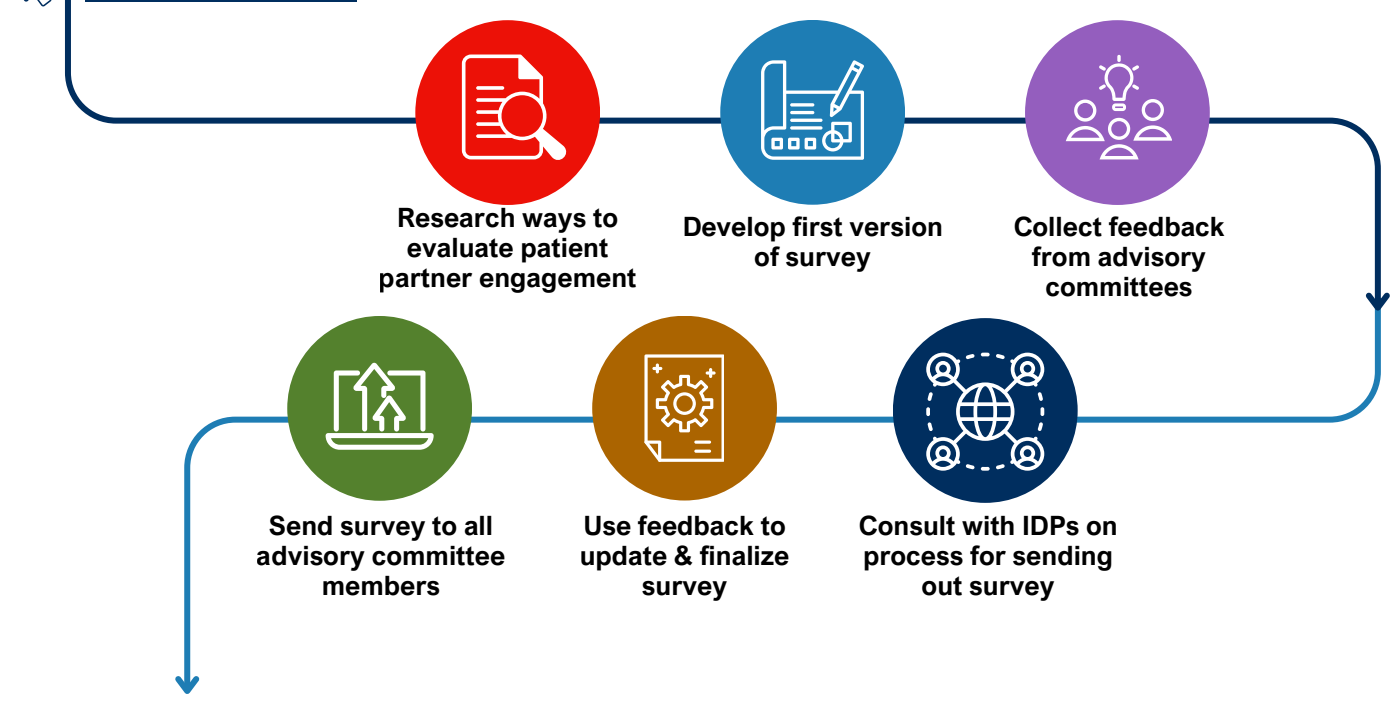
ADVISORY COMMITTEE PERSPECTIVES

Patient, Youth, and Family Engagement Experiences Survey Findings

- The **Ontario Brain Institute (OBI)** funds 5 clinical research programs called **Integrated Discovery Programs (IDPs)**
- Each IDP focuses on a **different brain health condition** and works with an **Advisory Committee** composed of patients, families, and community members
- These Advisory Committees help shape the research process by providing valuable lived experiences as people with diverse brain conditions

> *It felt like everyone worked together super well, rather than patient feedback just being something added at the end - Advisor*

OUR PROCESS



OBI SURVEYED IDP ADVISORS TO UNDERSTAND THEIR ENGAGEMENT EXPERIENCES AND IDENTIFY IMPROVEMENTS, AS PART OF OUR SECOND ANNUAL SURVEY.

WHAT WE HEARD

- We heard from nearly half of all Advisors, with representation from each IDP, different racial groups, gender identities, and ages
- Advisors feel most valued and engaged when they are involved early, can influence decisions, and can see how their input led to change
- Overall, Advisors found their involvement with IDPs to be **moderately meaningful**

WHAT ADVISORS APPRECIATED

"(Participating) in this capacity has been a very positive experience for me and allowed me to make meaning out of a very difficult situation"

- Membership offers a manageable workload
- Opportunities to express personal views
- Feel safe to share unique ideas & perspectives

WHAT CAN BE IMPROVED

"It would be great to receive frequent updates on ongoing projects outside our individual programs and how we can participate"

- Addressing concerns in timely manner
- Providing updates that match information needs
- Sharing how input influenced activities or outcomes

OVERALL ENGAGEMENT SCORE: 78.6%

We want to emphasize that **Patient, Youth, and Family Engagement** is a **means to impact, not an end in itself**. Our aim isn't engagement for its own sake, but engagement that **actively shapes** IDP priorities and activities.

This year, we looked more closely at how engagement happens. IDPs reported **acting** on several recommendations from last year, including:

- Developing a mentorship program that pairs newer Advisors with more experienced members
- Creating a spreadsheet outlining available collaboration opportunities, expected time commitments, responsibilities, and contact information
- Integrating report-back and "closing the loop" practices into meetings to update Advisors

We will need to **continue working together** to sustain these changes and strengthen engagement across programs.

ONTARIO BRAIN INSTITUTE | INSTITUT ONTARIEN DU CERVEAU

Read the full report here, or visit https://braininstitute.ca/resources/reports