Advisory Committee Perspectives: Findings from the 2026 Engagement Experiences Survey

> *[Participating] in this capacity has been a very positive experience for me and allowed me to make **meaning** out of a very difficult situation*

This report summarizes what our Advisors our saying, contextualizes their input, and discusses future direction.

October 2026
The Ontario Brain Institute

ONTARIO BRAIN INSTITUTE | INSTITUT ONTARIEN DU CERVEAU

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Abbreviations

IDPs	Integrated Discovery Programs
KT	Knowledge Translation
OBI	Ontario Brain Institute

Terminology

Advisor	A member of an Advisory Committee. Advisors may be patients, youth, family members, caregivers, or community members with lived or living experience.
Program(s)	Refers to OBI's five Integrated Discovery Programs: CALM, CAN-BIND, CP-NET, POND Network, and TRANSCENDENT.
Research Activities	Activities that help shape or guide the research. For example, identifying research questions, giving feedback on materials, reviewing research ethics applications, co-authoring papers, or joining research team meetings.
Knowledge Translation Activities	Activities that help turn research and trusted knowledge into resources, tools, or events that people can use in the real world. Examples include developing videos, written materials, tools, or events for clinicians, patients, and policymakers.

We appreciate the insights and leadership of the patient, youth, family, and community Advisors who helped shape the survey and took the time to complete it. Their feedback provides valuable direction for our work.

1. Background

Highlights

- The Ontario Brain Institute (OBI) funds five research networks called Integrated Discovery Programs (IDPs).
    - Each IDP works with one or more Advisory Committees made up of patients, youth, family members, caregivers, and community members. We refer to committee members as Advisors.
- Advisory Committees help ensure that lived and living experience informs research priorities, activities, and knowledge sharing.
- For the second year, we surveyed Advisors about their engagement experiences, areas for improvement, and changes since 2025.

The Ontario Brain Institute (OBI) funds and supports brain health research through five Integrated Discovery Programs (IDPs). These large research networks focus on different brain health conditions.

IDPs bring together researchers, clinicians, industry partners, patients, families, and advocates. Each IDP works with one or more Advisory Committees. Committee members, called Advisors, draw on lived or living experience to guide research and knowledge-sharing.

Learn more about our Integrated Discovery Programs here.

How do Advisory Committees work?

Each IDP works closely with one or more Advisory Committees. Advisors may include youth and adult patients, family members, caregivers, and representatives from community organizations.

Collaboration between IDP teams and Advisors continues to evolve. Advisory Committees help connect research with patient and community priorities and support information sharing in two directions:

1) **Into the program**: Advisors bring patient, family, and community perspectives and priorities into the work.

2) **Out of the program**: IDPs and Advisors share findings with people who can use them, including patients, families, health-care providers, and advocates.

Learn more about our Advisory Committees here.

IDPs have shared many examples of how Advisory Committees strengthened their work. We also wanted to understand Advisors' experiences and how OBI and the IDPs can make engagement more supportive and meaningful.

OBI invites all Advisors to complete an annual survey about their engagement experiences with the IDPs. This report shares what we heard, where engagement is working well, where it can improve, and how feedback from the previous survey has been used.

2. Patient, Youth, and Family Engagement Experiences Survey

Highlights

- Advisors and IDP teams helped develop the Engagement Experiences Survey, including how the engagement score is calculated.
- The survey asked about engagement experiences, levels of involvement and influence, and demographic information. It included multiple-choice and open-ended questions.

What is the goal of the survey?

The Engagement Experiences Survey gathers feedback from Advisors across the five IDPs. It helps us understand what engagement looks and feels like from their perspective, including what is working well and what could improve.

The survey also allows us to calculate an engagement score and understand how Advisors are involved in research activities and knowledge translation (KT) activities.

How did you develop the survey?

OBI drew on existing research and practices to develop a first draft. Advisors and IDP teams then helped refine the survey, so it reflected how we work together.

Figure 1. Process for developing the "Engagement Experiences Survey"

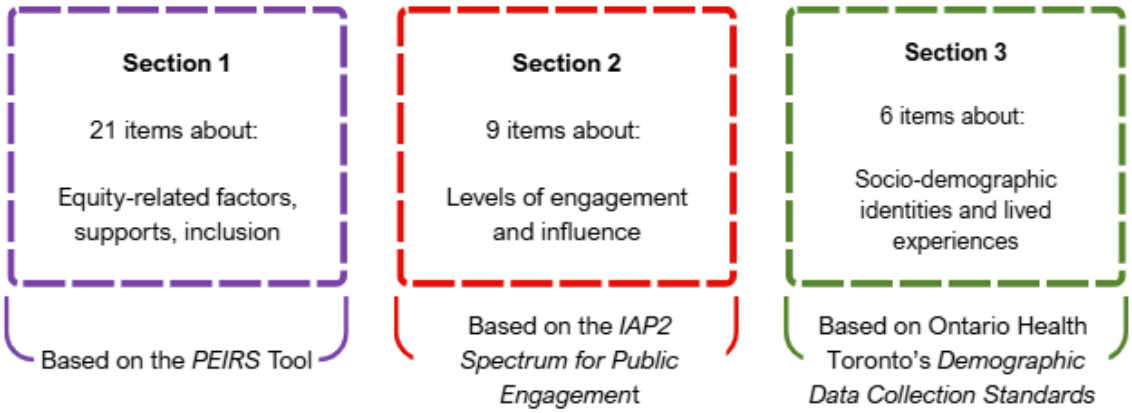


In addition to feedback on the survey design, Advisors also provided guidance on how to collect this data:

- Make it an anonymous and annual survey
- Keep survey under 30 min
- Report back to Advisory Committees about findings and planning
- Offer compensation to reflect value for Advisor contributions
- OBI should send the survey and analyze the data

The final survey had three sections, shown in Figure 2.

Figure 2. Sections of the Survey[1,2,3]



You can find the complete survey in the Appendix.

Following up on the 2025 Engagement Experiences Survey

We followed up with the IDPs to ask about how they used feedback from the 2025 Engagement Experiences Survey report, and findings will be discussed later in Section 5.

[1] Section 1 – Hamilton, C. B., Hoens, A. M., McKinnon, A. M., McQuitty, S., English, K., Hawke, L. D., & Li, L. C. (2021). Shortening and validation of the Patient Engagement in Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. Health expectations: an international journal of public participation in health care and health policy, 24(3), 863–879. https://doi.org/10.1111/hex.13227

[2] Section 2 – International Association for Public Participation. (2018). IAP2 spectrum of public participation. https://iap2.org/resources/spectrum/

[3] Section 3 – Guide to Demographic Data Collection in Healthcare Settings. Ontario Health - Toronto. https://torontohealthequity.ca/wp-content/uploads/2025/03/Implementation Guide-Demographic-Data-Collection.pdf

3. What We Heard

Engagement Experiences

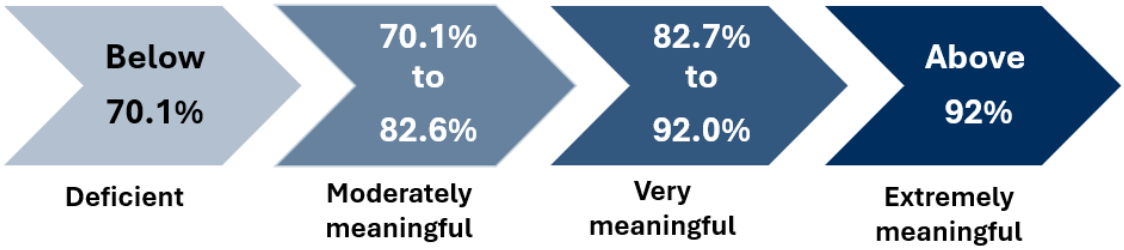
Highlights

- Thirty-seven Advisors completed the survey.
- The average engagement score across all five IDPs was 78.6%, which falls within the "moderately meaningful" range.
- Key strengths included manageable workloads, opportunities to share views, and feeling safe when sharing unique perspectives.
- Key areas for improvement included responding to concerns promptly, providing useful updates, and explaining how.

How did we measure "Engagement Experiences"?

Each Advisor who completed the survey, also called a 'participant', received an 'engagement score' based on their answers in Section 1. The tool includes a formula to turn answers into a score out of 100, and it also explains how to interpret those scores. Figure 7 below lays out engagement scores and what they mean.

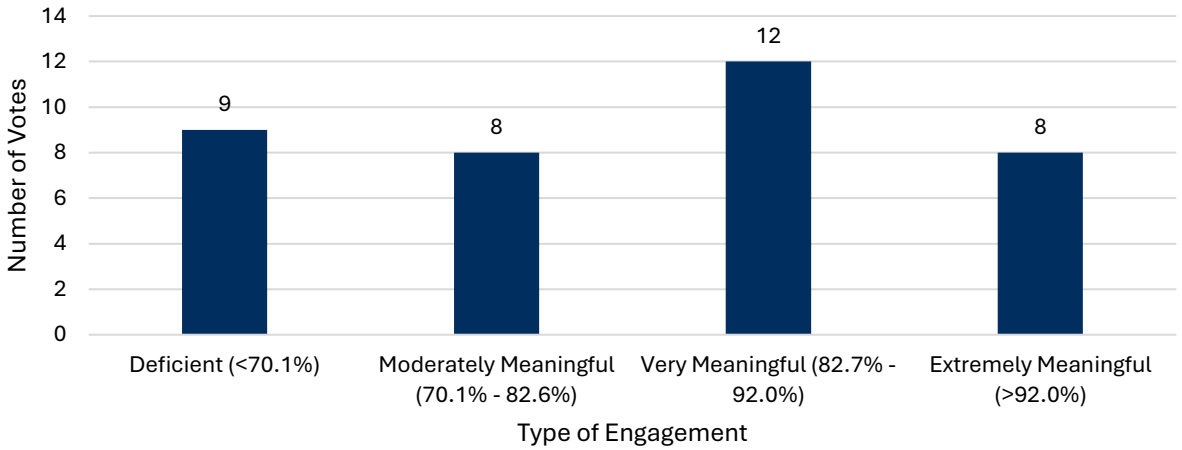
Figure 7. Levels of engagement based on "Engagement Scores" informed by PEIRS[4]



Overall engagement

The average engagement score among the 37 survey participants was 78.6%, similar to the 2025 result. This falls within the "moderately meaningful" range. Individual scores ranged from 34.2% to 97.5%, compared with 44.7% to 100% in 2025. Figure 8 shows how many participants fell within each engagement range.

Figure 8. Distribution of engagement scores

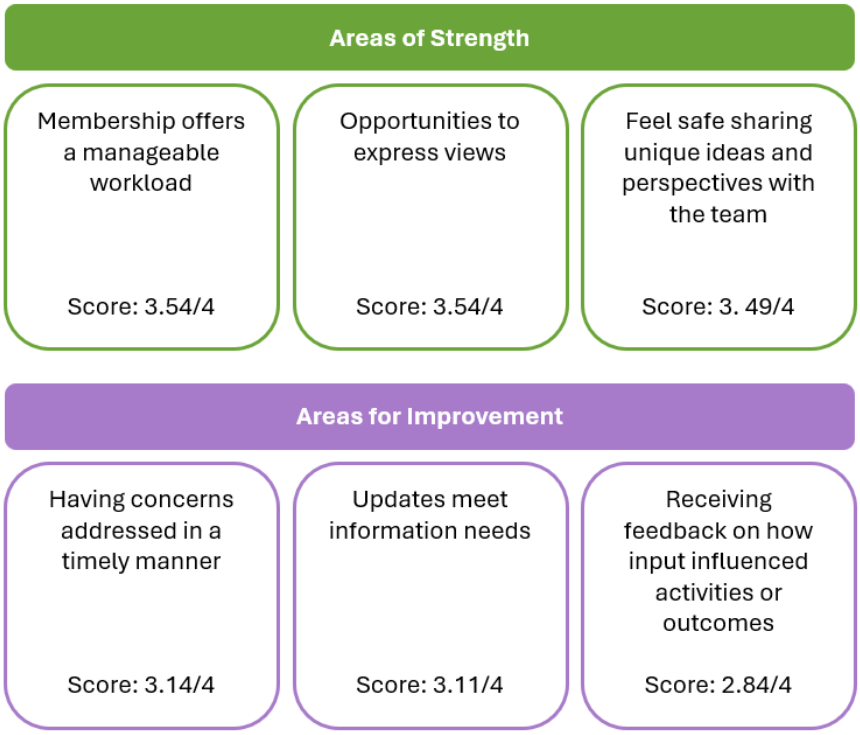


Strengths and gaps in engagement

We also looked at how Advisors rated specific areas of engagement. This helped us identify strengths and areas for improvement.

While scores varied between IDPs, one area consistently received lower scores: "Receiving feedback about how input has influenced activities and/or outcomes". See Figure 9 below.

Figure 9. Key areas of strength and improvement, based on highest and lowest scores



Equity analysis

The survey included one equity-focused item "I am comfortable raising topics related to human rights and health equity, like diversity and representation." The overall (average) score for this item was 3.38/5, close to being considered an area of strength.

However, the score drops when we look at scores for racialized participants, meaning they were less likely to feel comfortable raising equity-related concerns. While the number of racialized participants was small, this finding fits with research on equity in engagement. It's important to note that this pattern emerged in 2025 as well and gives us an important area for improvement as we continue to evolve and collect feedback.

Engagement across IDPs

We compared overall engagement scores between the five IDPs to uncover any trends or patterns. We found that one IDP consistently received high ratings, including for involving Advisors early. Experiences varied more among Advisors in the other four IDPs.

Levels of support analysis

We asked Advisors about whether they felt supported in several areas, including those where they have barriers to participation. We calculated the overall (average) score for each item, listed in Table 4 from strongest to weakest area of support.

Table 4. Overall (average) scores for seven areas of support from strongest to weakest.

Support Type	**Average Score out of 4** **(0 = poor support; 4 = excellent support)**
Physically accessible options	3.21
Financial compensation	3.03
Accessible communication	2.97
Opportunities when unable to attend	2.92
Learning opportunities or supports	2.68
Orientation	2.57
Connection with other Advisors	2.56

Note: The data and rankings are consistent with the survey findings from 2025.

Levels of Engagement and Influence

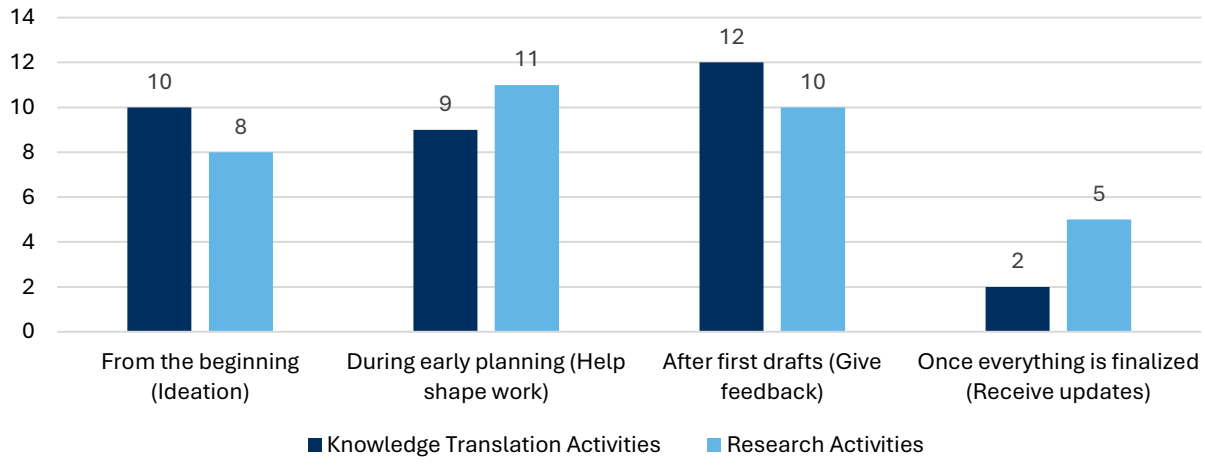
Highlights

- Most Advisors reported being involved during early planning stages rather than only after decisions had been made.
- Advisors generally perceived having "some" or "lots" of influence on both research and knowledge translation activities.
- Advisors expressed a strong desire for deeper involvement, particularly through equal partnership in decision-making and opportunities to lead activities with support from program teams.

This section looks at two parts of engagement:

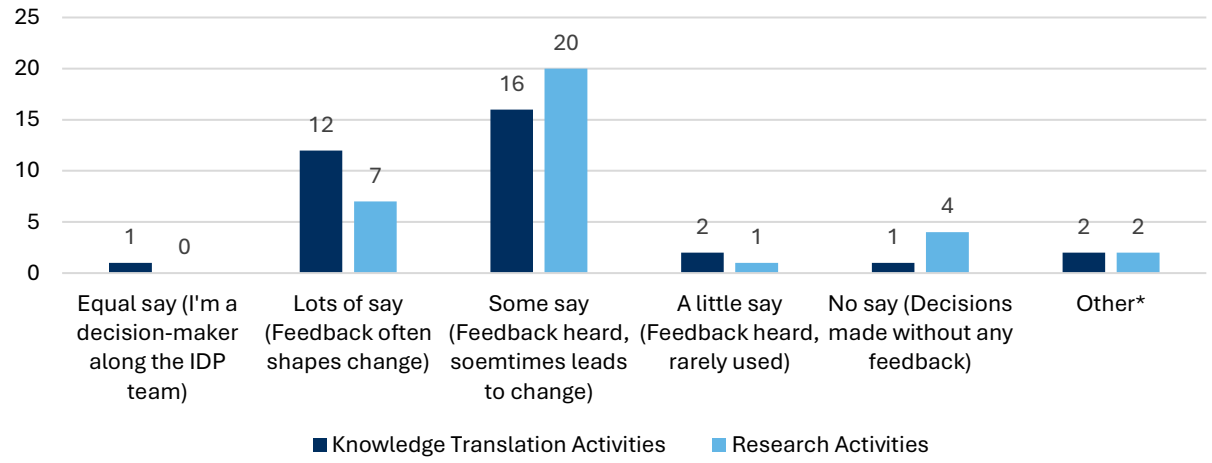
1. **Level of involvement: When Advisors are invited to take part.**
   Are Advisors invited early, while work is being planned, or later, after decisions have been made?
2. **Level of influence: How much Advisors can shape decisions or outcomes.**
   Do Advisors feel their input changes what happens?

Figure 10. "In your program, when are Advisors usually invited to take part in knowledge translation activities?"



Note. Number of responses. Excludes "prefer not to answer".

Figure 11. "How much influence do you feel you have on knowledge translation and research activities?"



Note. Number of responses. Excludes "prefer not to answer".
*Other: Aware of opportunities but not able to get involved due to time constraints; Have not had ideas that would have contributed to the program.

Following this, we asked which levels of engagement Advisors would like to see more of going forward. The highest voted items were:

1. Partnering equally in all aspects, including developing alternatives and deciding on solutions (18 responses, 51.4%)
2. Leading some activities or decision, with support from the program team (16 responses, 45.7%)
3. Talking with the team about decisions before they are made (13 responses, 37.1%) and Receiving information about the program's decisions, activities, and findings (13 responses, 37.1%)

The lowest rated engagement item was "Providing feedback to the program on plans or materials that are already made" (5 responses, 14.3%). The results indicate a desire for Advisors to be involved early in program discussions, with greater influence.

Relationships Between Engagement Scores

We looked at the connection between engagement scores and two aspects of collaboration, 'levels of engagement' and 'levels of influence'. We hope that this will help us better understand how different aspects of engagement are connected.

We found that higher engagement scores were related to the following factors:

- **When Advisors were more involved through diverse levels of engagement**
- When Advisors reported being part of discussions and decision-making, rather than only receiving information.
- When Advisors perceived having more influence over decisions and activities.
    - Those who perceived a high level of influence had an overall (average) engagement score of 88%, compared with a score of 65% among those who perceived a low level of influence.

While these connections do not confirm cause and effect, they can still provide some guidance when we think about priority areas for improvement.

Advisor Stories & Comments



Communication & Follow-through on Feedback

What advisors appreciate	What can be improved
• Advisors appreciated when their committees listened to feedback, acted on suggestions, and communicated how input had shaped improvements. • These experiences contributed to increased confidence, learning, and a sense of purpose.	• Advisors expressed a desire for clearer communication about available opportunities, program activities, expectations, and where they fit within the broader research landscape. • Some expressed frustration when ideas were acknowledged but did not appear to result in visible change.
"I really feel like they took our ideas and put them into practice. I could see right away for example they wanted to have better closed-loop communication with the committee" *"Seeing the change made a huge difference."*	*"Lots of unheard ideas being acknowledged as good but nothing coming out of them."* *"It would be great to receive frequent updates on ongoing projects outside our individual programs and how we can participate."*



Equitable Engagement as Partners

What advisors appreciate	What can be improved
• Many advisors described working alongside researchers and staff as collaborators rather than being consulted only at the end.	• Some advisors, particularly caregivers, wanted to be engaged earlier in research planning and decision-making processes.
"It felt like everyone worked together super well, rather than patient feedback just being something added at the end."	*"Create more opportunities for advisors to be involved beyond the monthly meetings. Much of my participation has focused on reviewing... which has been valuable but can sometimes feel repetitive"*



Connection, Role Clarity, and Opportunity

What advisors appreciate	What can be improved
• A strong sense of community emerged across responses. • Advisors appreciated connecting with peers, sharing experiences, learning from one another, and seeing respect for diverse perspectives.	• Some advisors suggest having a more structured orientation process that can include mentorship and managing expectations. • Advisors want to see, where possible, closer alignment between the work and their interests/skills.
"The collaboration and welcoming forum is what makes the experience so meaningful."	*"I would like a meeting where the agenda is brushing up on the bigger picture."*

4. Who Did We Hear From

Highlights

- 37 Advisors participated, representing nearly half of all committee members across programs
- Respondents were a mix of family and patient advisors, including youth.
- Most participants have been engaged for 1-2 years, with strong representation from all five research programs
- We saw under-representation in the sample from equity-denied groups particularly Indigenous and racialized groups

Who participated in the survey?

This report summarizes responses from 37 Advisors, representing 45% of all patient, youth, family, and community Advisors across the five IDPs.

Across the 37 survey responses, an average of 2.1% of questions were unanswered. This is below the commonly used 5% benchmark and supports confidence in the results.

What is the representation from each IDP?

The tables below show participation by IDP, Advisor role, and length of involvement.

Table 1. Survey participation by program

Program	Number of Participants	Proportion of Advisory Committee (%)	Proportion of all Survey Responses (%)	Change from 2025 Report (%)
CALM	8	67	21.6	↓1.3
CAN-BIND	7	47	18.9	↑ 4.6
CP-NET	5	33	13.5	↓ 3.6
POND Network	10	40	27.0	↑ 7.0
TRANSCENDENT	7	47	18.9	↑ 4.6

Note. All IDPs have 15 or more Advisors, with the exception of CALM, which has 12. POND Network has the largest advisory committee, with 25 members.

Table 2. Advisor roles of survey participants

Advisor Role	Number of Participants	Proportion of all Survey Responses (%)
Youth-patient (25 years and younger)	7	18.9
Adult-patient (26 years and older)	12	32.4
Family or caregiver	15	40.5
Community group	2	5.4
Other*	1	2.7

Note. *Specified role: "Family and community group." Change from 2025 report not shown due to added option, "Community group."

Table 3. How long have participants been involved with the Advisory Committee

Duration of Involvement (years)	Number of Participants	Proportion of all Survey Responses (%)	Change from 2025 Report (%)
Less than 1	3	8.1	↓ 8.0
1-2	17	46.0	↓ 8.8
3-5	12	32.4	↑ 25.9
More than 5	5	13.5	↓ 9.19

Note. Two programs, CALM and TRANSCENDENT, are less than 4 years old.

What was the demographic profile of survey respondents?

The demographic questions were adapted from questions used by the IDPs and a community-developed tool for collecting demographic data in health-care settings. Overall, the patterns were similar to the 2025 survey findings.

We asked for information on age, gender, Indigenous identity, racial identity, ethnicity, and an open-ended item for additional dimensions. Questions were a mix of open-ended fields (e.g., gender, ethnicity) and selecting from a list of options (E.g., Indigenous identity, racial identity). In all cases, 'Prefer not to answer' was included. See Appendix for all questions.

*Figure 3. Distribution of participant **age at time of survey**, by age group*

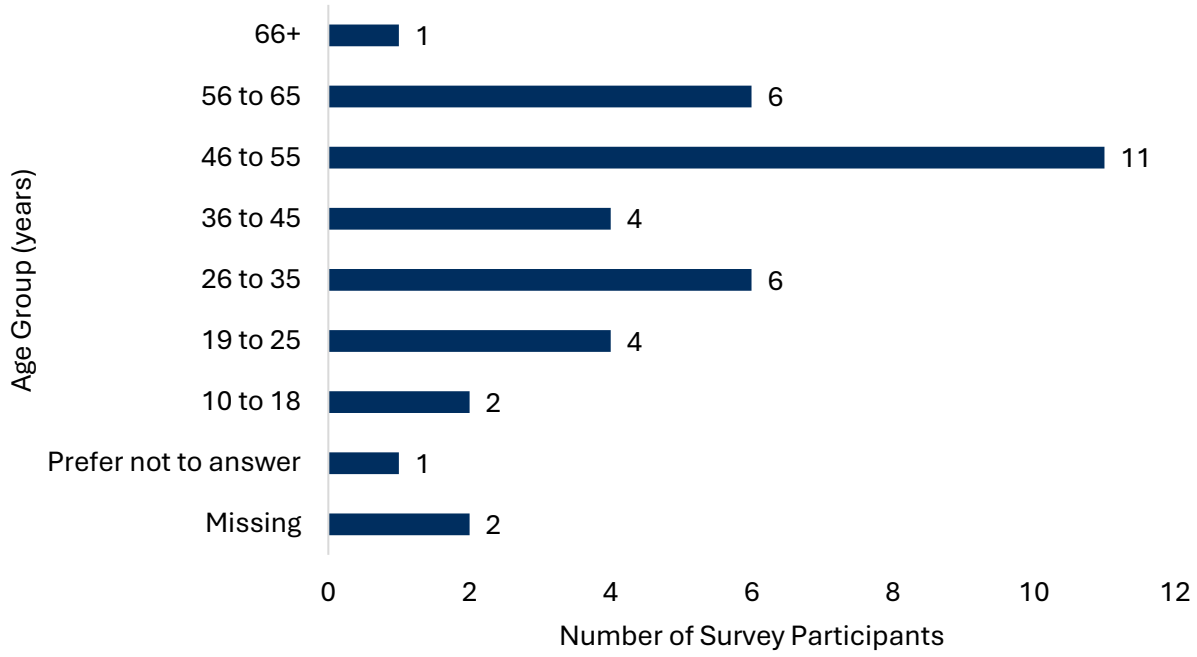


*Figure 4. Distribution of participant **gender identity***

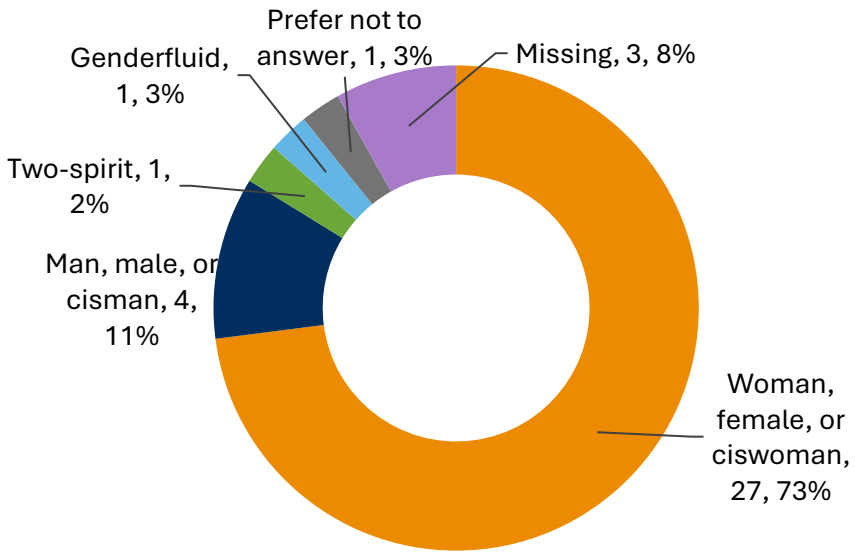


*Figure 5. Distribution of **Indigenous Identity***

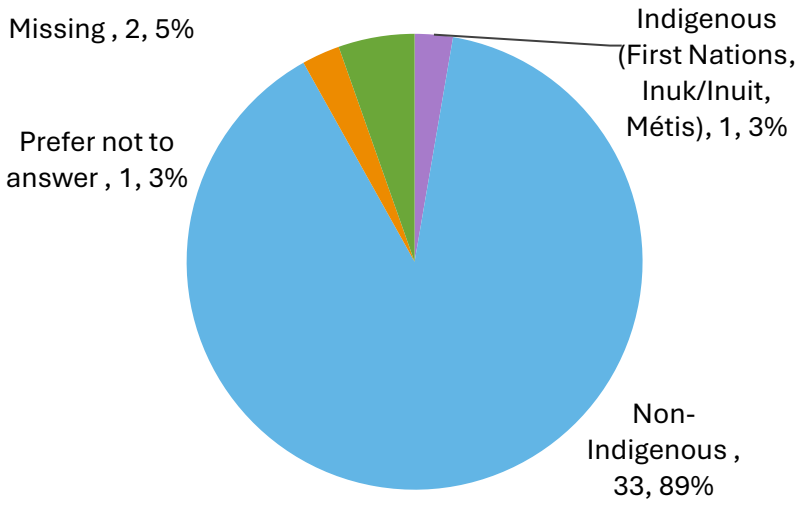
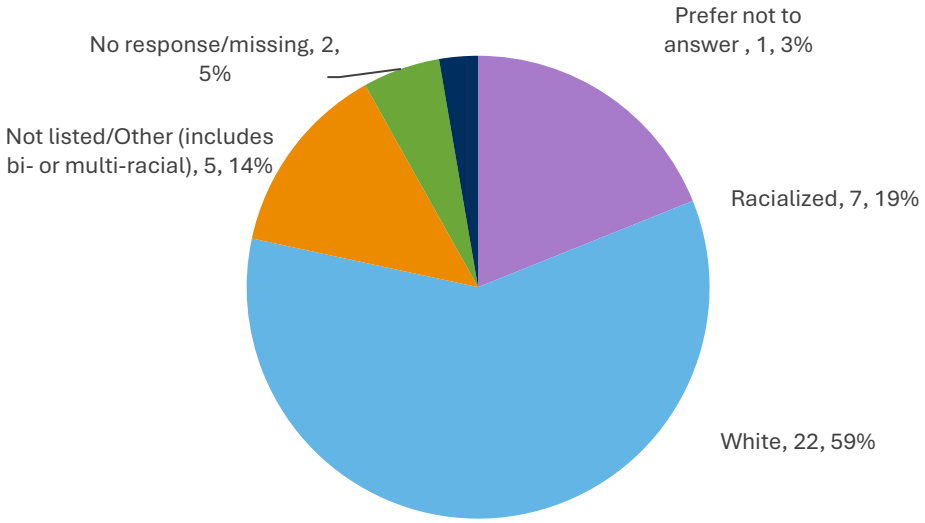


*Figure 6. Distribution of **racial identity***



Important note about data in Figure 6: To protect privacy, we grouped the answers into two categories— "racialized" and "white"—because the number of responses across 5 racialized categories was too small to report separately.

For the **ethnic identity** question, participants provided 22 unique responses; the largest proportion (13 responses) indicated "Canadian".

When asked about **additional experiences** related to human rights and health that may shape their experiences as an Advisor, participants cited disability (1 response), caregiver

responsibilities (3 responses), neurodivergence (1 response), trauma (1 response), and limited access to in-person events (1 response).

Thinking about sample size

In total, 45% of advisory committee members participated in the survey. While slightly below half, results can still provide valuable insights including data on what we are doing well and where we can grow. To build a deeper understanding of engagement we will continue ongoing discussions with Advisors on how we can support participation, especially for those with the greatest barriers.

5. Closing the Loop: IDP Action on 2025 Survey

Highlights

- IDPs reported using Advisor feedback to improve onboarding, peer connection, communication, and opportunities for earlier involvement.
- Changes included mentorship planning, clearer ways to share updates, and more opportunities matched to Advisor interests and skills.
- Funding, staff capacity, and Advisory Committee turnover affected how quickly some IDPs could respond.

The Engagement Experiences Survey was first launched in 2025. This report combines findings from Advisory Committees across OBI. Each IDP also received results from its own Advisory Committee or Committees so it could focus on feedback that reflected its context and identify priorities for action.

To show how Advisor feedback is shaping collaboration, we asked each IDP how it had used, or planned to use, its 2025 survey findings.

Several IDPs discussed their program-specific findings with Advisors through one-on-one conversations, group discussions, or Advisory Committee meetings. KT leads reported similar priorities across these conversations: onboarding and orientation, peer connection, earlier involvement and co-creation, access to information, and closing the feedback loop.

In response, several IDPs introduced or improved practices. Examples are listed below.

▶ **Onboarding and orientation:**

- Creating an onboarding working group to brainstorm ideas for improving new Advisory Committee member experiences
- Looking to develop a mentorship program that pairs newer Advisors with more experienced Advisory Committee members

🔗 **Connection and peer support:**

- Developed a resource of Advisor contacts so they can connect with one another outside of meetings

📞 **Communication and follow-through:**

- Built report-back and “closing the loop” practices into meetings, including dedicated time for updates and plans for web-based communications
- Developed an online central resource where Advisors can access updates, resources, and information in one place
- Moved advisory resources to SharePoint (replacing Google Drive) to provide a more secure data sharing platform.

Matching opportunities to Advisor interests and skills:

- Introduced one-on-one meetings between KT leads and Advisors to discuss interests and identify opportunities for involvement across the group.
- Created a spreadsheet outlining available collaboration opportunities, expected time commitments, responsibilities, and contact information.

Co-creation and earlier involvement:

- Involved Advisors earlier in setting research priorities and questions through a co-creation approach.
- Increased opportunities for Advisors to contribute to grant and conference submissions.

We also asked IDPs about barriers to responding to Advisor feedback. They identified the following:

- **Access to funding**, especially for open-access publication and conference presentation fees.
- **Capacity for committee coordination** using existing staffing resources.
- Ensuring members have the **capacity** to be mentors.
- Retaining Advisory Committee members and recruiting new members when needed.
- Having distinct committees with different demographics and goals; it is **difficult to apply the same feedback** to each.

6. Reflections

The survey asks whether Advisors feel engaged, valued, and able to contribute meaningfully to their IDP's work. Overall, Advisors continued to report positive and meaningful engagement experiences. The average engagement score was similar to 2025, suggesting that many strengths have been maintained.

Across the survey results and written comments, one message was clear: Advisors feel most valued and engaged when they are involved early, can influence decisions, and can see how their input led to change. Positive experiences were linked to collaboration, partnership, mutual respect, and clear follow-through on feedback.

Several areas for improvement were also consistent with the 2025 findings. These included orientation, learning opportunities, connections among Advisors, and communication about how feedback is used. Advisors also wanted deeper partnership, including more opportunities to make decisions and lead activities.

This year, we looked more closely at how engagement happens, not only what Advisors experience. IDPs reported acting on several 2025 recommendations, including changes to onboarding, mentorship, communication, feedback loops, and co-creation. OBI, IDPs, and Advisors will need to continue working together to sustain these changes and strengthen engagement across programs.

APPENDIX: Engagement Experiences Survey

Information Page
At the Ontario Brain Institute (OBI), we support and work with research networks called Integrated Discovery Programs (IDPs). These include CALM, CAN-BIND, CP-NET, the POND Network, and TRANSCENDENT. Each of these programs partners with patient, youth, family, or community Advisory Committees—and that's where you come in. We're reaching out to hear about you experience as an advisor (i.e. as a member of Advisory Committees). You can click here to learn more about IDP Advisory Committees.

What can I expect?
The survey asks about your experiences as a patient, youth, family, or community advisor. This includes engagement, working together, and receiving support from your IDP (CALM, CAN-BIND, CP-NET, POND Network, or TRANSCENDENT). Taking part is your choice. You can skip any question by choosing 'prefer not to answer'. You can also start the survey and come back to finish it later.

The survey has 3 sections. Most questions will ask you to pick from a list of answers, but a few will give you the option of writing out additional answers.

Payment for your time
We expect that the survey will take about 15 minutes to complete though the time may vary from person to person. Some people might finish it faster, and others might take a bit longer. Please note that you can start now and finish it later--your progress will be automatically saved. Accordingly, you will be compensated $35 per hour based on OBI's Patient Partner Compensation Policy. **Please reach out if the survey is taking more than 75 minutes since that will affect compensation**. Click here for our compensation policy.

At the end of the survey, you will get a separate link to claim your payment. This link takes you to a different page that is not connected to your answers. This means your answers will stay separate and private.

We care about your privacy
As with last year, this data is not traceable to you; OBI collects and stores grouped data. We won't ask for your name or contact information, and all responses will be kept completely confidential when we share our findings. You can also select ‘prefer not to answer’ to all questions.

However, some of your answers - like which IDP you work with or details in your responses - might still be personal. That's why we take extra care to keep your information private and confidential. We will only share results as a summary. This means your answers will be combined with others from the same IDP or from all IDPs. We will remove any information that could identify you. Where your information is kept: OBI will store all your survey answers safely. We will never share your individual answers with anyone else. We only share summary information that combines everyone's answers together.

After the survey:
We'll share a summary of findings with Advisory Committee members and IDPs, then work together to identify priorities for strengthening engagement and growing the activities that are most successful.

If you have questions or concerns, please contact Caroline Bennett-AbuAyyash Email: cabuayyash@braininstitute.ca | Phone: 647-261-2457

Instructions

Thank you for taking the time to fill out this survey about your experience as a member of a patient, youth, family, or community Advisory Committee. Your answers will help us understand many areas of work such as engagement, partnerships and support. We are looking for all types of feedback and value input about strengths AND weaknesses or gaps. By completing this survey, you will help us understand what we do well and how we can do better.

Please try to answer each question honestly based on your most recent experiences. Some questions let you share stories or examples. This is optional and will help us learn more.

Information about terms:

'Program': Refers to all Integrated Discovery Programs- IDPs: CALM, CAN-BIND, CP-NET, POND Network, TRANSCENDENT.

'Program team': Refers to the staff, researchers, and various members of the Program.

'Advisory Committee': Refers to all types of committees including patient, youth, family, and community advisory committees

'Advisor': Refers to members of patient, youth, family, and community advisory committees

We appreciate your participation!

How long have you been part of the Advisory Committee?

Less than 1 year	1-2 years	3-5 years	More than 5 years	Prefer not to answer

Which research program are you most involved with as an Advisory Committee member?

TRANSCENDENT	POND Network	CP-NET	CAN-BIND	CALM	Prefer not to answer

I would describe my role as

Patient-Youth	Patient-Adult	Family or caregiver	Community group	Other (Specify)	Prefer not to answer

Section 1: Participation and Engagement Experiences

As a member of the Advisory Committee, you take part in different activities with your Program. This can include things like going to meetings, sharing your ideas, working with researchers, or getting help in your role. There are many ways to be involved, and all experiences matter.

This section asks about ways that Advisory Committee members work with IDPs and receive support. Please read each statement and pick only one answer for each. If you're not sure which answer to pick, choose the one that feels most right to you.

[Procedures]

1. I have opportunities to contribute to the Program

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

2. The tasks I'm asked to do match my preferred ways of contributing

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

3. The updates I receive from the Program meet my information needs (for example: helpful summaries or meeting recaps)

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Convenience]

4. I have opportunities to express my views

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Contributions]

5. My workload in the Advisory Committee is manageable

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Team environment and interactions]

6. I feel valued as a member of the Advisory Committee

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

7. Everyone on the Advisory Committee gets opportunities to contribute or share

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

8. I feel safe sharing my unique ideas and perspectives with the Program team (for example: different viewpoints are welcomed, disagreement is respected)

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

9. I am comfortable raising topics related to human rights and health equity, like diversity and representation within the Advisory Committee or in research.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Optional follow up] Do you have any additional comments or experiences related to human rights and health equity that you want us to know? [Text box]

[Supported]

10. When I have concerns, they are addressed in a timely manner

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

11. Please share how supported you feel in the areas below

	Excellent	Very good	Good	Fair	Poor	Unsure	Prefer not to answer
Orientation (Program information, my role, my responsibilities, etc)							
Learning opportunities or supports (Training, readings, webinars)							
Connection with other Advisors							
Financial compensation							
Accessible communication							
Physically accessible options (meeting spaces, online platforms)							
Opportunities to contribute when unable to attend meetings							

[**Feel valued]**

12. I receive appropriate recognition for my contributions (for example: acknowledgment in meetings, authorship opportunities when applicable)

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

13. I receive feedback about how my input has influenced the Program's activities and outcomes

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Benefits]

14. By participating, I have gained valuable knowledge about the Program's topic of research

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

15. My involvement has positive impacts on my life

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Prefer not to answer

[Optional] Your stories help us understand what's really working—and what isn't. Can you share a moment from your time as an advisor that stands out? It could be when you felt truly heard, when collaboration clicked, or when things didn't go as well as they could have. We also appreciate hearing what would make your advisory experience even better. If you prefer, you are welcome to attach a voice note instead. *Add note on how it will be used.* [Textbox]

Section 2: Level of Engagement in KT and Research

As a member of the Advisory Committee, you may be involved in different levels of engagement with the Program. This can include receiving research updates, being asked for feedback on a document, helping shape how research is done, or contributing to how research findings are shared. There are many ways to be engaged, and all contributions are valuable.

This section of the survey asks about the different levels of engagement you have experienced in two key areas: 1. Knowledge translation and 2. Research. Please answer the following questions based on your experiences as a member of the Advisory Committee.

Knowledge translation: For each question, select the option that fits best

'Knowledge translation activities' = developing tools, videos, reading materials, events, and other ways to share research findings and evidence with the public and the health system.

1. In your program, when are Advisors usually invited to take part in **knowledge translation activities**?
    - Once everything is finalized (to receive updates)
    - After first drafts are made (to give feedback)
    - During the early planning stages (to help shape the work)
    - From the very beginning when ideas are being explored
2. How much influence do you feel you have in **knowledge translation activities**?
    - No say (decisions are made without my feedback)
    - A little say (my feedback is heard but rarely used)
    - Some say (my suggestions sometimes lead to changes)

- Lots of say (my feedback often shapes what happens)
- Equal say (I'm a decision-maker alongside the Program team)

Research-related Activities

'Research-related activities' = helping shape or guide the research. This can include things like identifying research questions, giving feedback on study design, reviewing ethics applications, co-authoring papers, co-presenting, or joining research team meetings.

3. In your program, when are Advisors usually invited to take part in **research-related activities**?
    - Once everything is finalized (to receive updates)
    - After first drafts are made (to give feedback)
    - During the early planning stages (to help shape the work)
    - From the very beginning when ideas are being explored
4. How much influence do you feel you have on **research activities**?
    - No say (decisions are made without my feedback)
    - A little say (my feedback is heard but rarely used)
    - Some say (my suggestions sometimes lead to changes)
    - Lots of say (my feedback often shapes what happens)
    - Equal say (I'm a decision-maker alongside the researchers)

General questions: Select the option that fits best

5. How do the opportunities as an Advisory Committee Member align with your own personal interests and/or and work responsibilities? *If you are finding minimal alignment, please provide suggestions for involvement under question 10.*
    - No alignment (I find myself providing input on topics that are not relevant to me)
    - A little bit of alignment
    - Mostly aligned
    - In full alignment (The topics I am providing input on are significantly relevant to me)
6. As an Advisory Committee member, how often are you engaged in each of the following ways?

	Never	Rarely	Sometimes	Often	Very Often	Unsure

I receive information about decisions, activities, and findings						
I am asked for my opinions or feedback after initial plans are developed						
I work directly with the team throughout the process, and my concerns are consistently considered						
I partner equally in all aspects including developing alternatives and identifying preferred solutions						

7. Looking at these different ways Programs engage with Advisors, which would you like to see more of?
    - Informing you about what's happening
    - Inviting you to give feedback on plans or activities already in development
    - Asking you to be involved throughout the KT or research process (beginning to end)
    - Having you an equal partner in all decision-making
    - Asking you to lead some activities with support from the Program teams
8. (**Optional**) Thinking about your most meaningful engagement experience with our research network, please use a few short sentences to describe:
    - What was the activity?
    - How were you involved?
    - What made this experience particularly effective or meaningful? (Open text response)

Final Thoughts

9. Is there anything else you would like to share about your experience as a patient, youth, family, or community Advisor or any suggestions on how we can improve engagement? (Open text response)

BACKGROUND INFORMATION

This section asks about your background and will help us understand the different identities and experiences of people on Advisory Committees. These questions closely match the background information we collect from research participants. Your answers will help us get a complete picture of the patients, youth, and families involved in research, engagement, and collaboration.

We combine all responses so individual answers cannot be traced back to you, and like your earlier responses, the answers will only be included in our overall summary. You can choose 'prefer not to answer' to all questions.

Thank you for sharing this information with us.

1. **Age**

What is your age? Please select one only

- 10 – 18; 19 – 24; 25 – 34; 35 – 44; 45 – 54; 55 – 65; 65+; Prefer not to answer

2. Indigenous identity

Do you identify as First Nations, Inuk/Inuit and/or Métis? Select all that apply.

- Yes, First Nations; Yes, Inuk/Inuit; Yes, Métis; No; Do not know; Prefer not to answer

3. Ethnic background

Ethnic origin is about a person's ethnic or cultural background. Ethnic groups share a common identity, heritage, ancestry, or history. Also, they often share cultural, linguistic, and/or religious characteristics.

What is your ethnic or cultural origin(s)? [OPEN ENDED] Prefer not to answer

4. Racial group

Which of the following best describes your racial group? Please select one only.

- Black (e.g., African, Afro-Canadian, Afro-Caribbean, Afro-Egyptian etc.)
- East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.)
- Latin American (Hispanic or Latin American descent)
- Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Kurdish, Syrian, Turkish etc.)
- South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.)
- Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.)
- White (e.g., European descent)
- Another race/ethnic group (please specify): _____
- More than one race category or mixed race, please describe: _____
- Not Applicable (e.g., Identified as Indigenous in question #3)
- Do not know
- Prefer not to answer

5. Gender

Gender identity is the gender that people identify with or how they perceive themselves. This may be different from their sex assigned at birth. For example: Genderqueer, Man, Nonbinary, Two-spirit, Trans, Woman.

What is your gender identity? [OPEN ENDED] Prefer not to answer

6. Not listed

We have limited space in this survey and might miss important lived experiences that affect your role as a patient or family partner. These “Lived experiences” can refer to identities people hold or the environments where they live, work, and grow.

Do you want to add any related factors that impact your experiences as a patient or family partner? For example: caregiving needs, family circle, geography, housing, language, mobility, pay/income/wealth, sexual orientation, etc. [OPEN ENDED]


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