Advisory Committee Perspectives: Findings from the Engagement Experiences Survey

29 September 2025

The Ontario Brain Institute

ONTARIO BRAIN INSTITUTE INSTITUT ONTARIEN DU CERVEAU

OUTLINE

We gratefully acknowledge the valuable contributions of patient, youth, and family advisors. Their input was instrumental in shaping the survey's development, and the time they dedicated to completing it—despite competing demands—has provided meaningful insights that will help guide our work.

1. Background

Highlights

- The Ontario Brain Institute (OBI) funds five clinical research programs called Integrated Discovery Programs (IDPs). Each IDP works with an Advisory Committee composed of patients, families, and community members
- These Advisory Committees provide guidance on research priorities and ensure that the lived experiences of people with brain conditions inform the research process
- OBI surveyed IDP Advisory Committees for the first time to understand their engagement experiences and identify improvements

At the Ontario Brain Institute, we fund and support brain health research through the Integrated Discovery Programs (IDPs), which are large research networks that are designed to integrate the perspectives of people with lived experience of brain conditions. The people with lived (and/or living) experience are patients, youth and adults, families, and community groups with strong advocacy work.

The goal of integrating these perspectives is to ensure that patients, families, and communities are real partners in efforts to improve experiences and outcomes of living with brain conditions. This means supporting meaningful patient-program partnerships to guide research priorities, activities and more.

What are Integrated Discovery Programs?

They are Ontario-wide programs that bring together a diverse group of collaborators including researchers, clinicians, industry (e.g. neurotechnology) partners, and patients and their advocates to lead innovative research. Another priority goal is to move this research into the hands of Ontarians. The topics they focus on are cerebral palsy (CP-NET), concussion (TRANSCENDENT), depression (CAN-BIND), neurodevelopmental conditions (POND Network) and youth multiple mental health conditions (CALM).

An important component of these funded programs is the establishment of advisory committees made up of people with lived experience including patients (youth and adults), caregivers and families, and community groups with advocacy experience.

What are Advisory Committees?

Each IDP has set up an Advisory Committee(s) they closely work with. They include ‘Patient Advisory Committee’, ‘Youth Advisory Committee’, ‘Family Advisory Committee’, and ‘Community Advisory Committee’. These committees share the common goal of offering invaluable expertise and knowledge based on lived experiences of living with a brain condition and/or navigating care journeys. We refer to members of these committees as ‘advisors’.

By bridging the gap between research and lived experiences, advisory committees play a critical role in shaping the direction of our programs. They are intended to foster meaningful connections between research outcomes and patient well-being. This involvement ensures our research stays closely aligned with the needs of our communities.

As part of our efforts to build accountability and identify successes and opportunities for improvement, we sent out a survey asking patient, youth, family, and community advisors about their experiences in engagement and collaborating with the IDPs. The survey results will help us evaluate how effectively Advisory Committees are contributing to and influencing IDP research and activities.

2. Patient, Youth, and Family Engagement Experience Survey

Highlights

- We collaborated with advisors and programs to develop the Engagement Experiences Survey
- Key recommendations from Advisory Committee members included annual surveys, compensation, and clear report-back
- Three-section survey asks about engagement experiences, levels/types of engagement, and demographic information

What is the goal of the survey?

We are collecting this information to help us understand engagement, including ranges of partnerships and support. We are looking for all types of feedback and value input about strengths in engagement, as well as weaknesses or gaps. By having access to this data, OBI can work together with IDPs to identify priorities and action items to improve impactful patient, youth, and family participation and engagement.

In addition to general engagement experiences, we asked questions about:

- ‘Research activities’: Helping shape or guide the research. This can include identifying research questions, giving feedback on materials, reviewing ethics applications, co-authoring papers, or joining research team meetings
- ‘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

How was the survey developed?

The Patient, Youth, and Family Engagement Experience survey, which we also refer to as ‘Engagement Experience Survey’ is an online survey that OBI developed through a combination of existing resources and input from IDPs and patient, youth, and family advisors. We collaborated on refining the questions and data collection process.

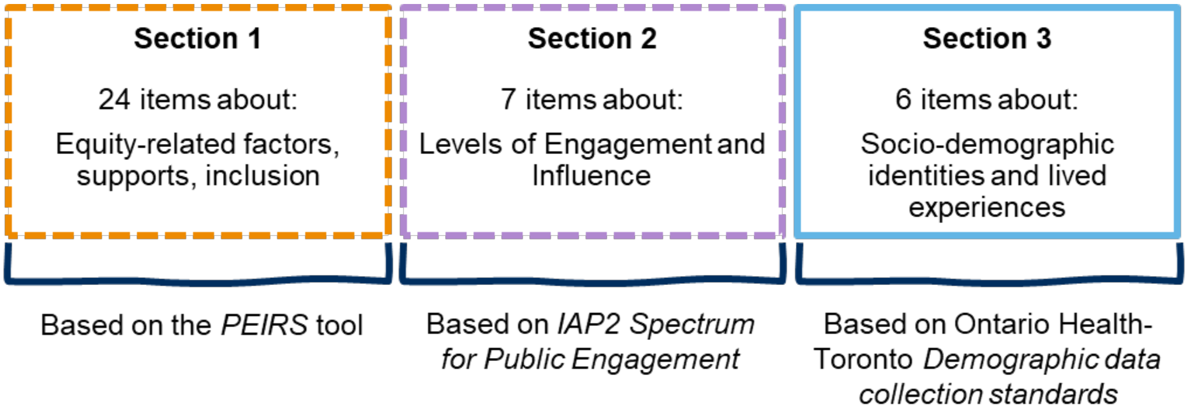
Figure 1. Process for developing the ‘Engagement Experiences Survey’

In addition to feedback about the wording of the items, advisory members provided guidance on how to collect this data:

- Be clear in what is being asked
- Commit to anonymity of those surveyed
- Send survey from OBI once a year
- Keep survey under 30 min to reduce burden
- Report back to PYFAC about findings and related planning
- Provide opportunities to add examples or stories where possible
- Offer compensation to reflect value for Advisory Committee members’ contributions

The survey was made up of 3 sections (Full document is in the Appendix).

Figure 2. Three sections of Patient Engagement Experiences Survey[1,2,3]



3. Survey Participants

Highlights

- 31 advisors participated, representing nearly half of all committee members across programs
- Participants included equal numbers of youth, adult patients, and family/caregiver advisors
- Most participants have been engaged for 1-2 years, with strong representation from all five research programs
- We saw under-representation in the sample, particularly from Indigenous, racial, and gender identities

Who participated in the survey?

This report summarizes responses from **31 participants, who represent 49% of all patients, youth, family, and community advisors in IDPs.** The survey was started by 35 people but four were excluded because they answered 3 or fewer questions.

Missing data, which refers to percentage of unanswered questions, is 3.3% for the sample we used (31 participants). Surveys generally aim for missing data rate below 5% to ensure that our results are trustworthy.

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[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- Ontario Health. (2023, November). 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*

Representation from IDPs

The tables below show how different IDPs are represented in survey responses, such as the size of sample from each IDP, roles, and other information.

Table 1. Survey participation by program.

Program	Number of participants	Out of all survey responses*
CALM	8 participants	22.9%
CAN-BIND	5 participants	14.3%
CP-NET	6 participants	17.1%
POND Network	7 participants	20.0%
TRANSCENDENT	5 participants	14.3%

Note: CALM and POND Network have the two largest advisory committees (over 15 advisors).

Table 2. Survey participation by role in Advisory Committee

Role	Number of participants	Out of all survey responses
Family or caregiver advisor	11 participants	35.5%
Youth patient advisor (Up to 25 years)	10 participants	32.3%
Adult patient advisor (26 years +)	10 participants	32.3%

Note: ‘Patient advisor’ includes community advisors.

Table 3. Survey participation by length of engagement with Advisory Committee

Role	Number of participants	Out of all survey responses
Less than 1 year	5 participants	16.1%
1-2 years	17 participants	54.8%
3-5 years	2 participants	6.5%
More than 5 years	7 participants	22.6%

Note: Two programs are less than 3 years old (CALM, TRANSCENDENT) and CAN-BIND updated their Advisory Committee 2 years ago.

Demographic summary

We asked a range of demographic questions based on the same information that IDPs are collecting from research participants. These questions are based on a community-developed tool for demographic data in healthcare[4].

The charts below show how people responded, including the number of participants who gave each answer and the percentage they represent.

Figure 3. Participant ***age group***

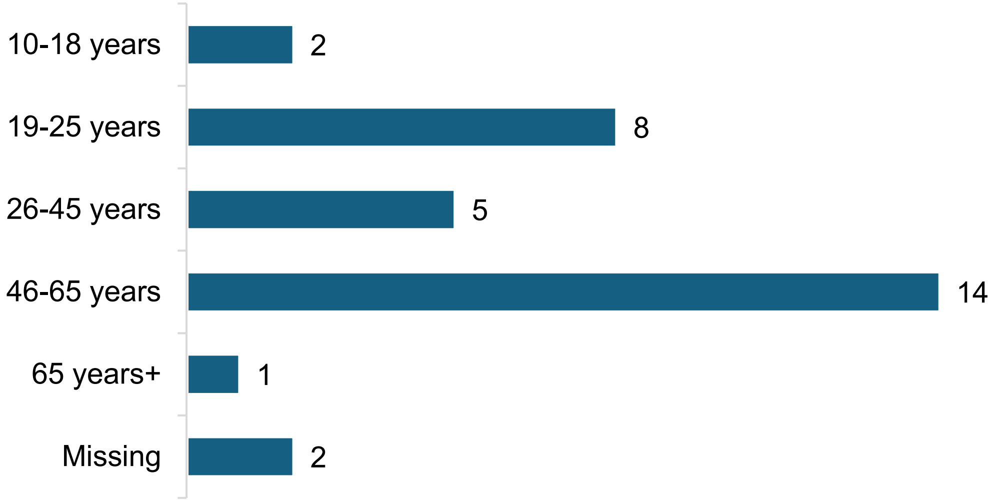
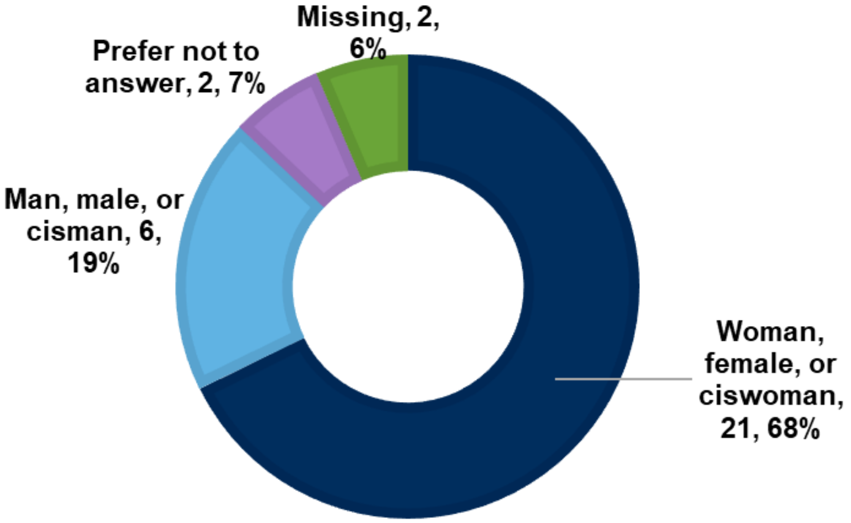


Figure 4. Participant ***gender identity*** *(open-ended question)*



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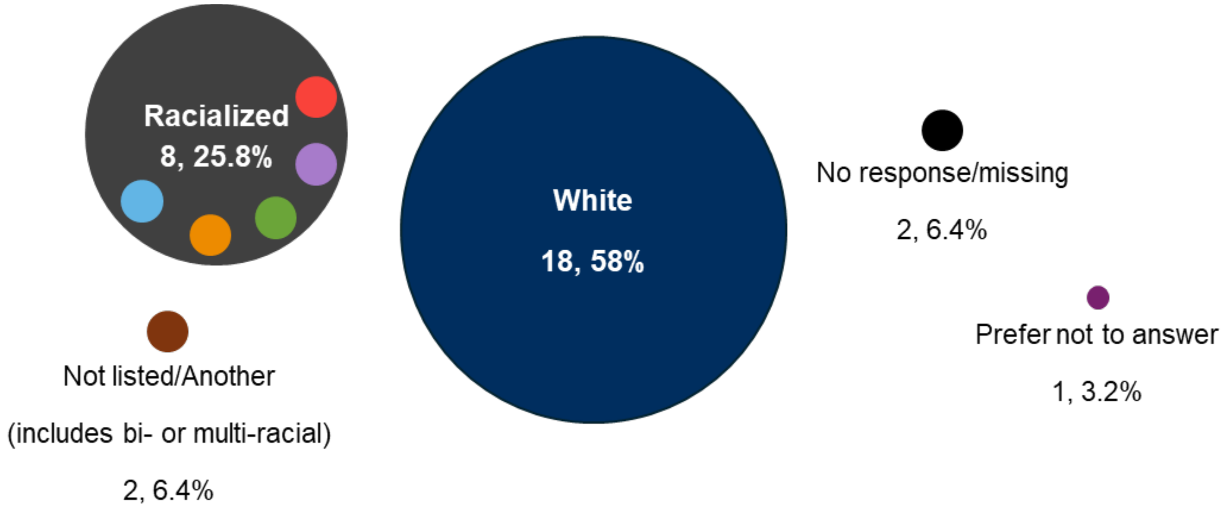
[4] Ontario Health (2023)

The racial identity question was a closed-ended item. That is, participants were asked to choose one of existing options or add in if not listed. See Appendix for all questions.

Figure 5. Participant ***racial identity***



Important note about data in Figure 5: 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 21 unique responses; the largest proportion (10 responses) referred to 'Canadian'.

When asked about **additional identities** that shape advisor experiences, mental health conditions was the most frequently cited lived experience (4 responses).

Thinking about sample size

31 participants make up around half (49%) of all advisory committee members at the time of the survey. While this sample size is small, it can give us valuable insights, identify potential areas for guidance, and reveal clear patterns in the data. To build a more complete and strong understanding of engagement across all advisors and communities, we need to continue these conversations beyond the survey. This means having ongoing discussions with advisors, especially those with greatest barriers to participation to ensure we capture the full range of experiences.

4. Survey Results

4.1. Engagement Experiences

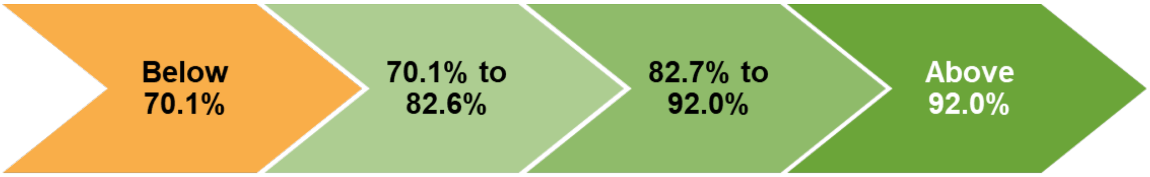
Highlights

- The engagement score across all IDPs is 78.5 out of 100. This translates to "moderately meaningful" engagement across programs
- Areas of strength in engagement experiences include compensation, opportunities to contribute, and accessible meetings
- A consistent gap is communication on how (and whether) advisor input influenced IDP activities and decisions

How We Measured ‘Engagement Experiences’

We created “engagement scores” for each participant using their answers to questions about areas of engagement experiences. Most of these questions come from the PEIRS tool[5], a survey designed with patients and families to evaluate engagement. The tool includes a formula to turn answers into a score out of 100, and it also explains how to understand those scores. The infographic (*Figure 6*) on the next page lays out engagement scores and what they mean.

Figure 6. Levels of engagement based on ‘engagement scores’



Deficient engagement	Moderately meaningful engagement	Very meaningful engagement	Extremely meaningful engagement

Overall Engagement

Average engagement score was 78.5%, meaning that advisors across all IDPs experienced **moderately meaningful engagement** with a range between 44.7% to 100%. (see Figure 6 on how scores translate to engagement levels). See figure below for information on how scores were distributed across different engagement levels.

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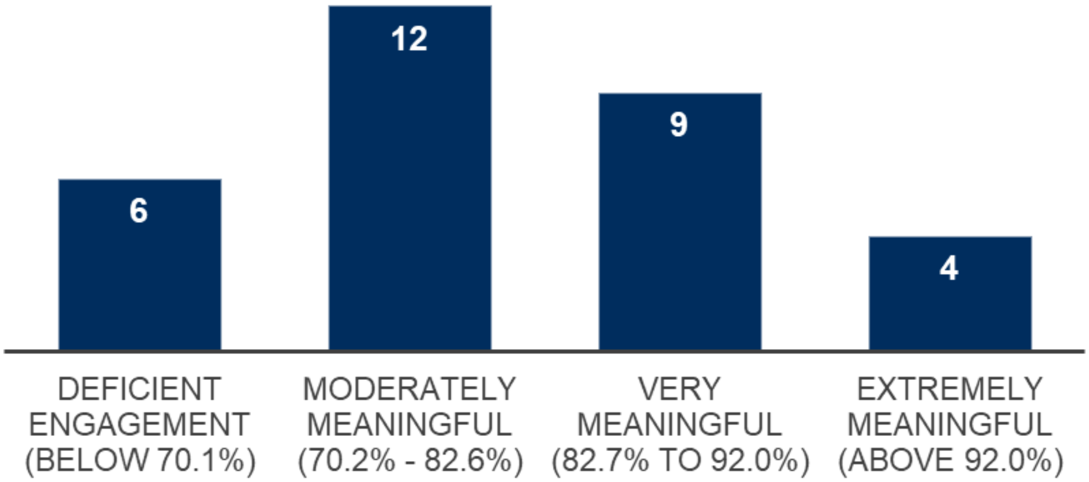
[5] Hamilton et al. (2021)

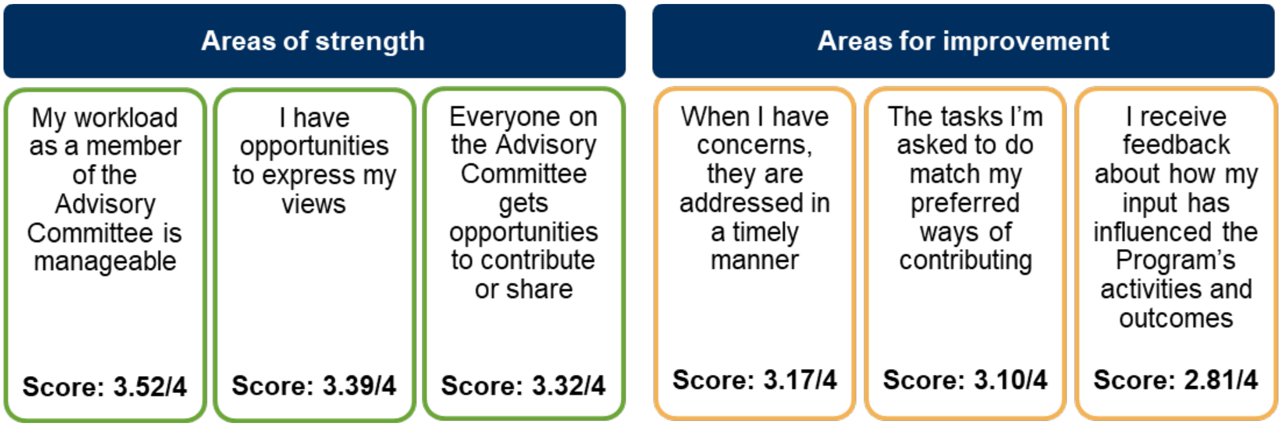
Figure 7. Distribution of engagement scores



Strengths and Gaps in Engagement

In addition to looking at the overall engagement average, we wanted to understand how scores vary within different areas of engagement. This will allow us to identify areas of strength, as well as areas we need to improve (See Appendix for full survey and list of questions).

Figure 8. Areas of engagement: Highest and lowest average scores



Areas of strength			Areas for improvement		
My workload as a member of the Advisory Committee is manageable	I have opportunities to express my views	Everyone on the Advisory Committee gets opportunities to contribute or share	When I have concerns, they are addressed in a timely manner	The tasks I'm asked to do match my preferred ways of contributing	I receive feedback about how my input has influenced the Program's activities and outcomes
Score: 3.52/4	**Score: 3.39/4**	**Score: 3.32/4**	**Score: 3.17/4**	**Score: 3.10/4**	**Score: 2.81/4**

While scores varied between IDPs, one area had consistent low scores: receiving feedback about how input has influenced activities (see Figure 8)

Additional Analysis: Engagement Experiences

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 average score for this item was 3.43/5, making it the second highest scoring item. However, this score fell out of the range of 'areas of strength' when we examined the responses specifically from racialized participants. This drop in scores tells us that participants strongly affected by inequities are not comfortable raising equity-related issues. While the smaller number of racialized participants means we should interpret this finding carefully, it still highlights a key area for action in engagement

Engagement across IDPs

We compared average engagement scores between IDPs and found a few patterns:

- **Range of engagement scores:** IDP engagement scores varied between 70.1% and 87.3%. That is, their engagement levels varied between ‘moderately meaningful’ and ‘very meaningful’.
- **Cluster within middle range:** Three IDPs cluster in the middle range, showing similar moderately meaningful experiences (75% to 81% engagement score).
- **Within-IDP variation:** Two IDPs show a wide range of scores, meaning that participants reported very different experiences within the same program.

Experiences in being supported

We asked about various areas of support that advisors receive and ways that IDPs reduce barriers to their participation in activities. We calculated the average score for each area of support, with 0 = no support to 5 = Excellent support. As results in Table 4 show, the areas with least support are ‘Orientation’ and ‘Learning opportunities’.

Table 4. Average scores for seven areas of supports from strongest to weakest

Support type	Average score (out of 5)
Physically accessible options	4.38
Financial compensation	4.20
Accessible communication	4.18
Opportunities when unable to attend meetings	3.83
Connection with other advisors	3.72
Learning opportunities	3.68
Orientation	3.55

4.2. Engagement Levels

Highlights

- Most advisors are engaged throughout knowledge translation and research processes, not just at the end
- Advisors want more opportunities to lead and/or be involved throughout
- The timing of engagement matters less than having real influence on decisions

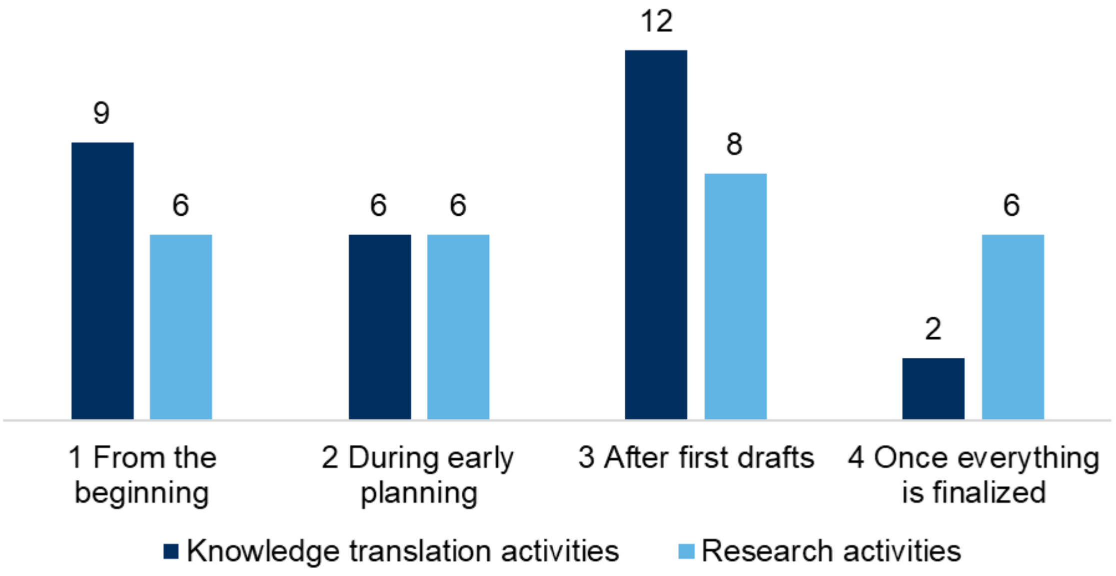
What we Measured with ‘Engagement Levels’

This section on engagement levels looked at two different things:

1. **When** advisors get involved - Are they invited early when projects are being planned, or later when decisions have already been made?
2. **How much influence** advisors have - Do they feel their input changes what happens?"

Questions in this section of the survey relied on the IAP2 Framework of Public Participation[6] and the results are shown in Figures 9 & 10 below.

Figure 9. "In your program, when are Advisors invited to take part in activities?” (Number of responses, excludes ‘prefer not to answer’)



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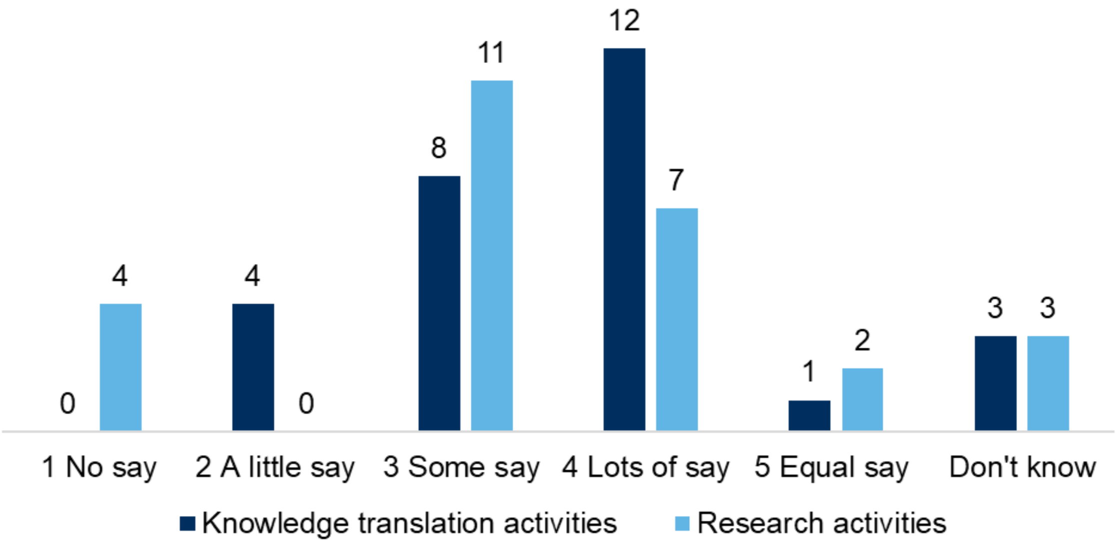
[6] International Association for Public Participation (2018)

As we mentioned earlier, we also wanted to understand how much influence advisors felt they had on the final activities or products.

Figure 10. "How much influence do you feel you have on activities?" (Number of responses, excludes 'prefer not to answer')



According to advisors, the levels of engagement they want to see more of are:

- Being involved throughout the KT or research process (11 responses)
- Leading some activities with support from program team (7 responses)
- Providing feedback on plans already in development (6 responses)

4.3 Understanding Engagement Scores

Highlights

- Advisors with real decision-making power report much higher engagement (99% vs 65%)
- Seeing influence on activities matters more than levels of engagement
- Asking for feedback is not enough. Programs need to show they use it

To better understand engagement scores, we looked at their relationship with two factors: 1. levels of engagement and 2. how much influence advisors feel they have on the IDP's activities.

Levels of Engagement

Based on our analyses[7], there is no relationship between engagement scores and levels of engagement. That is, advisors report similar engagement scores regardless of when an IDP engagement them, e.g. engaging from the beginning of an activity compared to at the final stages. This fits with what advisors have shared- that there is no single 'ideal' stage of engagement, and that they want to see diverse opportunities that align with their availability, skills, etc.

Levels of Influence

Based on our analyses, there is a significant and positive relationship between engagement scores and perceived influence. This relationship exists for both types of activities, knowledge translation activities and research activities.[8]

The few advisors who report having no say in research scored around 65% (i.e. 'deficient engagement'), while those with equal decision-making power are nearly perfectly engaged at 99% 'extremely meaningful engagement'.

What this means

Advisors who feel like they have real influence over research and knowledge translation activities tend to have higher engagement scores. This result is the same regardless at which stage or level they are engaged. That is, IDPs and OBI should demonstrate that they are going beyond asking for feedback, and that what we hear shapes what we do.

Influence also matters to the success of the IDP model. It means research and knowledge sharing integrate the real-world perspectives of people with lived experience of brain health conditions.

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[7] Technical info: We ran a correlation between two variables: engagement scores (0 to 100) and levels of engagement (1 to 4- see Figure 9). For levels of engagement, we looked at two types of activities: knowledge translation ($r = 0.01$; n = 29) and research ($r = 0.11$; n = 26).

[8] Technical info: We ran a correlation between two variables: engagement scores (0 to 100) and perceived level of influence (1 to 5- 'no say' (1) to 'equal say' (5)- see Figure 10). Results pointed to a significant correlation with a large effect size for both knowledge translation activities ($r = 0.55$; $p < 0.01$; n = 25) and research activities ($r = 0.72$; $p < 0.01$; n = 24); analyses achieved ~80-90% power.

4.4 Qualitative Data- Stories & Comments

Highlights

- Successful engagement means feeling like equal partners rather than token participants
- Community connections and supportive relationships are as important as the formal engagement activities
- Clear communication and accessible information make participation smoother
- Many advisors find meaning in turning difficult personal experiences into contributions that can help others

We added several open-text questions after consulting with patient, youth, and family advisors during survey development. We asked about activities, reflections on ‘good’ engagement, and general comments. These findings reveal important insights about the ways that our ‘Advisory Committees’ model has been able (or unable) to meet its intended goal of driving patient, youth, family, and community participation in shaping IDP activities and research. Six main themes came out of these responses:

Well-designed engagement

Advisors valued opportunities to give input on specific questions or decisions. To many, meaningful engagement meant seeing the impact of their participation on the program’s activities and priorities.

> “I really appreciate it when scientists have thought the engagement through in advance and ask for my input on specific items. I enjoy the intellectual satisfaction of that and knowing that I made a difference with my contribution”

Equal partnership

It is important for advisors to see that they are equal partners and that their participation is more than a checkbox.

> “They truly considered the team's (advisors’) feedback and changed their strategy for one aspect based on our input. It was a genuine intellectual exchange and we were equal partners”

Community and connection

Engagement was also about relationships. Many appreciated being part of a supportive community, making connections at summits, and forming friendships through projects.

> “Feeling like being part of a community. And that I have a group of people around me that care about me and my work”

Process and communication

Practical supports—like clear agendas, meeting notes, and timely updates—made the experience smoother. Advisors also highlighted the value of accessible information on studies and opportunities.

> "We need a place where we can access information such as current studies and opportunities such as conferences"

Drawing value from personal experiences

Advisors described how sharing lived experience turned difficult situations into contributions that could shape research and services.

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

Barriers and challenges

Some advisors faced barriers to fully participation, including technical issues with virtual meetings and gaps in knowledge about progress.

> “(After participating in several activities) I need to ask directly for information about how the projects I engage in are progressing”

8. Reflections

Highlights

- This survey on engagement experiences provides a starting point to track changes over time
- Actions can focus on two areas: Growing existing strengths and addressing key gaps
- Annual surveys will track progress while advisors help determine how to make changes

This survey marks the first time OBI and IDPs have worked together to gather feedback from patient, youth, and family advisors about their engagement experiences. It represents an important step in tracking changes over time.

While our final sample size is just under 50% of advisors, it provides a valuable starting point. Ongoing conversations—especially with patient, youth, and family advisors—will be key to deepening our understanding of engagement experiences.

This feedback points us toward actionable next steps we can take to build on what's working and addressing areas where we can improve.

Strengthen What's Working

- Keep providing diverse opportunities for involvement in knowledge sharing and research
- Continue strong support systems already in place (compensation, accessible meetings, communication)
- Expand opportunities for sharing and relationship-building between advisors and with community partners

Address Identified Gaps

- Document and share how, and when, advisor input has influenced IDP priorities and activities
- Improve orientation and learning opportunities for new and existing advisors
- Focus on understanding and improving participation and experiences of advisors from equity-deserving groups

The next step is to work collaboratively—especially with advisors—to determine *how* we can implement these actions in ways that are meaningful and practical. Repeating this survey each year will help us track progress and provide guidance on how to achieve meaningful engagement.

Thinking Ahead: The Purpose of Engagement

We want to wrap up this report by emphasizing 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. The goal is to create the conditions where meaningful involvement drives innovation, generates new insights, and ensures community-centred priorities. When advisors help set research directions, influence study design, or translate findings into accessible formats, their lived experience strengthens the relevance and impact of research for people living with brain conditions.

To ensure impact remains central to our work and address one of the main findings in this report—the importance of sharing if/how engagement translates to meaningful outcomes—OBI is planning to work with IDPs to document concrete examples of how research and activities have been shaped by lived experiences. This will be one of the many ways to demonstrate the tangible ways that Advisory Committees have influenced research activities and knowledge translation efforts.

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.

You Have 3 Full Weeks: This survey is open from today's date (June 2, 2025) until Tuesday, June 24th.

Payment for your time
We expect that the survey will take about 45 minutes to complete—but that's just an estimate. Some people might finish it faster, and others might take a bit longer. You will be compensated $25 per hour based on OBI's Patient Partner Compensation Policy. **Please each out if the survey is taking more than 75 minutes since that will affect compensation**. Click here for more information about 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.

Please submit your payment form by Monday, June 30th. We'll start processing payments on that date.

We care about your privacy
We don't ask for your name or contact details in the survey. We want to keep your answers anonymous (without your name).

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.

Thank you for helping us improve our work!

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	Good	Fair	Poor	Not provided	Not applicable	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 [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. Which statement best matches your usual experiences as an Advisory Committee member?
    - I primarily 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
    - Other
6. 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
7. (**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

8. 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.

For example: Armenian, Canadian, Chinese, Irish, Egyptian, Filipino, French-Canadian, Indian, Jamaican, Jewish, Scottish, Ukrainian, Vietnamese.

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]