

Highlights: OBI Annual P/CAC Workshop (2024)

WHAT WE HEARD, WHAT WE LEARNED, WHAT WE ARE PLANNING

VISION

Gather patients, families, community groups, and program partners to connect, share, and learn on fostering mutually beneficial relationships

ACTIVITIES

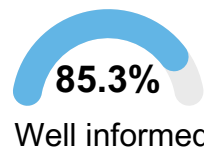
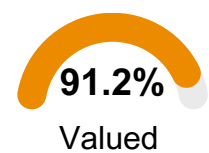
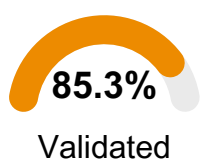
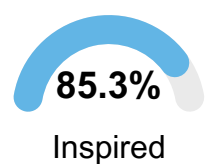
Break out into groups to discuss ways to ensure and strengthen mutually beneficial relationships

PARTICIPANTS

Workshop had 38 in-person & 10 online attendees; 51% identified as 'patient/family/community partners'

Attendee experiences

Completely/Mostly agree that "I felt..."



Reflection: Future Workshops

I am extremely/very likely to recommend this event 94.2%

Additional recommendations:

- Shorten day
- Include 'report back' time
- Separate in-person and on-line

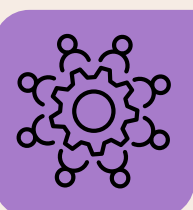
WHAT WE HEARD:

MUTUALLY BENEFICIAL COLLABORATIONS IN BRAIN HEALTH



Strengthen actions and processes to recognize patient + family expertise

- Develop clear and flexible compensation policies that reflect value for patient/family time and expertise
- Acknowledge patient/family contributions (e.g. publications, conferences)
- Provide range of participation opportunities
- Keep patient/family partners informed as you would all partners



Encourage patient + family-centred relationship building and collaboration

- Recognize and minimize power imbalances in collaborations
- Create spaces for patients to come together and share experiences and/or knowledge.
- Encourage wider collaborations with other programs and patient/family advisory groups.
- Invest in 'real' co-design with patients/families (i.e. beyond 'review' activities).



Support patient + family partners' skills and education

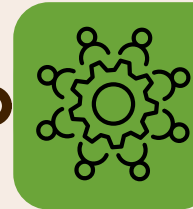
- Work with patient/family partners to identify education that can enable full participation
- Implement education-focused orientation for new partners
- Support patient professional development goals, such as building experience in data collection or other research activities
- Support patient skills in using research to advocate (personally, in community...)

AREAS OF ACTION FOR THE ONTARIO BRAIN INSTITUTE (OBI)



Support best practices in patient compensation policies

- Develop OBI patient honorarium policy with clear and concise instructions and information
- Review and summarize existing compensation/honoraria policies in Ontario and Canada. Share with all Integrated Discovery Programs.
- Look for opportunities to build patient awareness on compensation information, such as impact on tax returns, disability payments, etc



Share collective wisdom and experience of OBI partners in promoting patient-centred collaborations

- Host discussions (e.g. webinars) with OBI partner programs on ways they have created safe and collaborative spaces
- Draw on existing information (e.g. feedback from patients, evaluation activities) to promote the meaningful integration of patient roles in all program activities



Explore opportunities for patient-centred education and training

- Don't re-invent the wheel: Look for, and share, existing training opportunities for patient + family partners to support full participation, advocacy, and research
- Work with OBI partners (IDPs) to identify existing education-focused practices and patient + family education interests and needs

WHAT ELSE ARE WE PLANNING POST-WORKSHOP?

Develop at least one tool from the OBI P/CAC workshop. For example, draft a checklist outlining key aspects of integrating equity in knowledge sharing and engagement.

Follow up with a few attendees to gain a deeper understanding of their perspectives and expertise

Use attendee input to shape how we measure the strength of patient/family engagement in research, knowledge sharing, and other activities.

