

Canadian Brain Research Strategy Lived Experience Sessions

Summary Document

May-June 2022

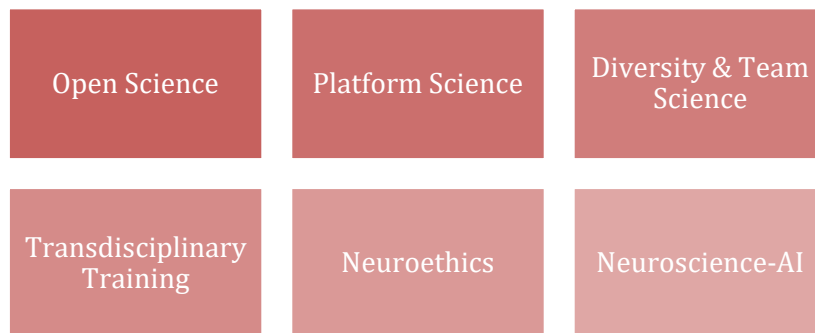
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Table of Contents

| | |
|--|-------------------------------------|
| Introduction | 3 |
| Session Objectives | 5 |
| Session 1 - Introductory Workshop Objectives | 6 |
| Session 2 - Focus Group Objectives | 6 |
| Code of Conduct | 6 |
| Future State of Brain Research | 7 |
| Feedback on Transformative Initiatives | 10 |
| Executive Summary | 10 |
| Feedback on Open Science | 11 |
| Feedback on Platform Science | 12 |
| Feedback on Diversity & Team Science | Error! Bookmark not defined. |
| Feedback on Transdisciplinary Training | 14 |
| Feedback on Neuroethics | 15 |
| Feedback on Neuroscience-AI | 16 |
| Feedback on Engaging People with Lived Experience in Brain Research | 18 |
| Key Recommendations | 18 |
| Key Resources Needed | 19 |
| Appendix A: Descriptive Words Voting Results | 20 |
| Appendix B: Takeaway Messages | 23 |
| Appendix C: Lived Experience Engagement Participants | 24 |
| Audience Demographics | 24 |
| Attendees | 26 |

Introduction

The Canadian Brain Research Strategy (CBRS) is creating a national vision to advance brain research in Canada to inspire and to guide the Canadian government on how to invest in brain research. This national brain strategy will help research meet the societal and economic challenges of today, and tomorrow, to benefit the neurological and mental health of all Canadians. As part of the strategy, the CBRS has identified six Transformative Initiatives that they believe can transform Canada into a world leader for brain research and help improve the health of people living with brain conditions. These transformative initiatives are:



The CBRS is engaging different groups of stakeholders to inform the strategy, and input from people with lived experience of brain conditions is of particular importance to ensure that they collectively shape the future state of brain research. People who live with or have experienced a brain condition, and those who support them, have unique expertise in the everyday challenges of their condition and navigating healthcare and society.

The CBRS hosted a series of consultation sessions with people with lived experience of brain conditions, family and caregivers, patient representatives, and advocates to gain their input on the development of the national strategy. Participants were selected to represent diversity across geography, gender, age, race, perspective, income range and brain condition (Appendix C).

In May 2022, the CBRS held an Introductory Workshop to provide an opportunity for participants to learn more about the CBRS, the purpose of the initiative, and the work done to date that will feed into the national brain research strategy. Participants shared their thoughts on the future of brain research and the emerging themes for how to improve brain research in Canada. Following the Introductory Workshop, the CBRS hosted a series of 6 focus groups in June 2022, for both lived experience participants and brain researchers, with each focus group centered on one of the CBRS' Transformative Initiatives. Focus group participants were asked to share their feedback on the importance of their designated Transformative Initiative and discuss how it has the potential to impact brain research and the lives of people living with brain conditions. They were also asked to provide feedback on how people with lived experience should be engaged in brain research in the future and what recommendations should be made to the government.

This document summarizes the feedback received from people with lived experience in the Introductory Workshop and all 6 Transformative Initiative focus groups. The feedback is aggregated and anonymized to ensure that the privacy of participants is respected, while staying true to the nature of the discussion.

Session Objectives

A national brain research initiative is needed to make meaningful advances in our understanding of the brain - in health, development, disease, and resilience. If we were to achieve a brain research initiative for Canada, what would it look like through the lens of people with lived experience, as the ultimate end-users of research outputs?

In designing these lived experience sessions, **CBRS** asked “What do we need to keep in mind as we create a brain research initiative to:

- Engage people with lived experience in the transformative initiative?
- Ensure that advances in the transformative initiative benefit the neurological and mental health of Canadians?”

Session 1 – Introductory Workshop Objectives

The aims of the Introductory Workshop were for people with lived experience to:

- Learn about the larger aims of the CBRS
- Discuss the opportunities, successes, and challenges for the future of brain research
- Learn about and provide feedback on the importance of the six Transformative Initiatives
- Receive background information to prepare for focus group discussions

Session 2 – Focus Group Objectives

Each focus group centred on one transformative initiative with the following objectives for

Participants with lived experience:

- 1) To learn more about the transformative initiative and why researchers think it is important
- 2) To provide feedback on the importance of the transformative initiative as an area to advance in brain research in Canada
- 3) To describe whether and how they feel the transformative initiative can address the needs of people living with brain conditions
- 4) To discuss why patient engagement in brain research is important and what is needed to continue their involvement

Researcher Representatives:

- 1) To participate in a patient engagement process
- 2) To understand how people with lived experience interpret the transformative initiative
- 3) To hear feedback on the importance and value of the transformative initiative
- 4) To discuss how participants envision the future of patient engagement in brain research

Code of Conduct

At the Introductory Workshop participants were asked to co-create a Code of Conduct for how they would like to interact in the space to create an environment of mutual respect. This Code of Conduct was used throughout the introductory workshop and focus groups.

We will create an environment of mutual respect and we agree to:

- Listen with respect
- Exercise empathy and no judgement
- Confidentiality
- Patience, tolerance, encouragement
- Creating a place where everyone's voice can be heard and acknowledged
- Give everyone a chance to speak, and try not to monopolize time
- Keeping an open mind
- Be mindful of sharing personal stories
- Exist in a brave space and a safe space
- Embrace the views of others even if not shared personally

Future State of Brain Research

Workshop participants were asked to discuss the opportunities, successes, and challenges of brain research in Canada. Participants provided a lived experience perspective on the current and future state of brain research in Canada. They provided feedback and input on how brain research can support people with lived experience of brain conditions, what is holding Canada back from this support, and what Canada already does well in brain research.

1. In a dream world, how is brain research done so that it best supports people with lived experience in brain conditions?

Discussion themes

Education, resources, and access

The public is provided with education on how research happens. Current research and relevant research findings are available and easily accessible. Education is also provided for medical professionals and caregivers to support those living with brain disorders. More funding and resources are available for anyone who needs it.

Inclusive and diverse involvement

People with lived experience are involved from the beginning of the research process so that their experiences inform who and what should be studied, research design, and knowledge translation. Patient partners are also involved in funding committees, steering committees, ethics committees and

as co-applicants for grants. Research participant populations are diverse.

Transdisciplinary, applicable, and relevant research

Research is more transdisciplinary and interdisciplinary to involve other medical specialists and allied healthcare providers to represent the full human experience. Research is also more applicable and relevant. It includes more qualitative analysis and non-traditional methods that reflect real world experiences. It translates into clinical practice and makes knowledge transfer easy, and it focuses on prevention, quality of life, cures, holistic complementary practices, and nutrition.

2. What is holding us back from achieving this dream world where brain research supports people with lived experience in brain conditions?

Discussion themes

Current design of research system

Research silos and the lack of collaboration and interdisciplinary work are holding us back. The pace of research and clinical trials is slow, and there is a lot of duplication of research efforts. Researchers are also not accustomed to engaging people with lived experience and there is a lack of education, social skills training and recognition of what people with brain conditions are experiencing. Governments and politics influence the way research is conducted and funded.

Health and pharmaceutical environment

There is a lack of knowledge from medical professionals on how to diagnose and manage some neurological conditions and a lack of access to research-informed healthcare providers especially in isolated areas. There is a lack of continuity of care, doctors are overworked, and some people with lived experience experience medical gaslighting. In the pharmaceutical environment, there is secrecy in pharmaceutical research. It is difficult to get insurance companies to approve new conditions, and there is a lack of collaboration and interest in incorporating alternative therapies in addition to traditional pharmaceuticals, leaving full costs on patients and families.

Research is not representative

Research is not representative of everyone and participant numbers are limited. A lot of research previously focused on males, and left out other groups such as young people and people with less complex conditions. Communications are limited to physician-patient interactions; patients are not in contact with researchers.

Lack of awareness, access, and funding

There is a lack of awareness of research opportunities for people with lived experience, and also a stigma and cost to speaking out. There is a lack of access to appropriate technologies and limited communication of information, for example on ineffective methods. There is also a lack of funding, for example from non-government sources for neurology wards and equipment.

3. Is there anything listed that Canada already does well in brain research?

Discussion themes

Collaboration

Some organizations and hospitals in Canada are working collaboratively. For example, Parkinson's research centres have started the Canadian Open Network so that researchers across the country are connected.

Access to education and resources

Access to education and resources about brain conditions and brain injuries is improving. For example, mental health and epilepsy groups offer free resources to all Canadians, including in rural areas. Education and resources provide clarity around facts related to different conditions.

Some healthcare access

There is access to neuroimaging and neurosurgery with the latest techniques, and without patients having to pay out of pocket. There are great rehabilitation hospitals, and the focus on pediatric brain disorders can be good. Connections with mental health are developing.

Areas of brain research

There are areas of brain research that can be highlighted as strong points, for example brain cancer research seems to be quite diverse and ever-evolving, rare diseases and disorders are getting more interest, and the Brain Tumour Foundation of Canada has started a brain tumour registry. There are also examples of open science practices at institutions in Canada, for example the Montreal Neuro.

Feedback on Transformative Initiatives

Participants were divided into six focus groups, one for each of the six CBRS Transformative Initiatives. Participants were asked to further discuss the importance and value of the Transformative Initiative, raise any considerations that may be missing from current discussions, and to describe who they felt would benefit from the Transformative Initiative. The summaries combine the feedback shared in the Introductory Workshop and the focus group for each Transformative Initiative.

Executive Summary

Each focus group discussion centred on one Transformative Initiative, but common themes arose in discussions across multiple Transformative Initiatives. The following themes were brought up by participants in many focus groups on how the Transformative Initiatives can advance brain research in Canada and support people with lived experience of brain conditions.

1. Collaboration with diverse perspectives

The Transformative Initiatives create an opportunity to bring in and collaborate with diverse perspectives. The complexity of brain research necessitates many perspectives and collaboration across disciplines, departments, and experiences. Working together and building upon each others' expertises can increase research efficiency and lead to better solutions for people living with brain disorders.

2. Efficiency of research

The Transformative Initiatives are crucial to improve the efficiency of research. They accelerate the pace of discovery, decrease the duplication of efforts, make research more cost effective, allow for sharing of high quality equipment and tools, and recruit participants for clinical trials faster. As a result, the practices and benefits can be brought to people with lived experience quicker.

3. Impacting care and service delivery

The Transformative Initiatives give brain research the potential to impact care and service delivery in health. Collaborative research allows for more diverse perspectives to inform approaches and management of brain disorders in health. Access to more shared data, tools, and technology can help physicians better understand and diagnose issues. The Transformative Initiatives can help a fragmented health system and support continued and inclusive care.

4. Equity

The Transformative Initiatives create equity in information access, allowing access to knowledge and tools for everyone: the public, people in rural areas, researchers. The Transformative Initiatives can also bring equity to research by helping connect patients with research, improving the accessibility of participation and contribution in research from underrepresented groups. A more equitable research system will be inclusive and supportive of all.

5. Already happening in Canada

Many of the Transformative Initiatives have already started happening in Canada and show a lot of potential. Canadian institutions have begun setting the groundwork, and this strategy can build upon these strengths and infrastructures. Globally, COVID-19 was an example of how sharing information is possible and can accelerate discovery. Canada has a role to play in setting an example for other countries who look to us for research standards.

Feedback on Open Science

Discussion Themes

Accelerating the pace of research

Open science is crucial for accelerating the pace of discovery, as traditional research work in silos has not moved quickly. COVID-19 was an example of how sharing knowledge across the globe can accelerate discovery. Open science can also help recruit participants for clinical trials faster and decrease the duplication of efforts, freeing up time for researchers to focus on other under researched topics (e.g., wellbeing, quality of life). Open science can bring results and practices to people with lived experience quicker and results-oriented improvements to healthcare faster.

Building upon others and their knowledge

There is strength in numbers, and open science creates an opportunity to learn from and build upon the knowledge of many people and the research already being done. Open science can accelerate inspiration and create opportunities for international collaboration.

Equity in information access

Open science allows everyone to have access to the latest information. There is a lot of information already available, and sharing it can make a huge impact. For example, gaining access to research about one's condition can be helpful to people with lived experience.

Considerations

With more open access to science, there is room for misinterpretation of research and data from the public or the media. There is a need for lay translations of research in order to help properly interpret findings.

Examples of who Open Science would matter to

People who have not yet received diagnoses

There would be better support for families and caregivers by having more access to information and helping answer unknown questions, for example parents who have a child with a developmental delay that was never diagnosed. The accelerated pace of discovery with open science would mean getting access to tools and treatment sooner.

Government

Decreasing the duplication of work would save the government money. The government has an accountability to the taxpayer, and open science would allow research to be more accessible and could get treatments and therapies to people sooner.

Feedback on Platform Science

Discussion Themes

Foundations for platforms already exist

Platform science is already happening in Canada and many institutions are setting the groundwork to create more national platforms. The COVID-19 pandemic response demonstrated that sharing information across boundaries is possible and can be done quickly with the right resources.

Cost effective and reduces duplication

Sharing research equipment is practical and efficient and will facilitate more research leading to new discoveries. It also allows for investment into higher quality equipment and tools that can be shared.

Equity in information access

Platform sciences creates equity in information access, for example allowing access to knowledge and tools in rural areas. Platforms could also help connect patients with research and improve accessibility of participation and contribution in research by elevating burdens of travel and mobility.

Collaboration leads to knowledge efficiency

Platforms lead to knowledge efficiency by reducing silos in research and creating opportunities for collaboration. Technology advances so quickly that having scientists learn everything to do their research is not efficient. Sharing expertise across disciplines, and beyond the major research institutions in Canada, allows scientists to work with specialized experts, share learnings and share questions to source the right answers. When doing renovations on your house, you wouldn't want the plumber putting in ceiling lights, you want an electrician to do that - they need to work together!

Considerations

Platforms lead to collaboration and research institutions should be mindful of data sharing and the possibility of data breaches when information is shared across countries. Universities sharing data might not have the same security and privacy protocols. People with lived experience are freely giving information when participating in research, and some may be hesitant to participate in platforms if there are not appropriate data protocols in place.

Examples of who Platform Science would matter to

Rural and remote populations

Not all cities have major research programs and clinics resulting in limited access to research outside large urban areas. You have to travel to participate but if you have a disease where you cannot travel it is hard to be involved. Platforms can help connect researchers to smaller communities including northern remote areas, the territories and rural towns. This will support consistency and provision of benefits to everyone across Canada.

Youth and others who experience care transitions

Platform Science can help youth, or others who are experiencing care transitions, who are going across different care providers keep things consistent. It will allow for researchers to collaborate, share and monitor these transitions.

Feedback on Diversity & Team Science

Discussion themes

Different perspectives deepen understanding

The complexity of brain research needs a diversity of involvement. People can have very different experiences with the same conditions, and these perspectives deepen understanding and must be respected. A transdisciplinary approach would allow for many different perspectives and find common themes across everyone. Clinicians should also be included in research, bridging the gap between research and clinicians.

Research and care needs to be inclusive of all

The population of Canada is continuously changing and becoming more diverse, but research has historically been limited to and only based on certain groups of people, with minority groups being poorly represented. There is currently a lack of diversity and people are falling through the cracks resulting in underrepresentation in research and inadequate care. Research and health should be inclusive of all in order to support everyone.

Canada can set an example for the world

Examples of diversity and team science in brain research are already happening in Canada. Globally, many other countries follow the standards set by countries such as Canada and the USA, therefore it is important that the research is based on a diverse subset of the population to better represent the global population.

Examples of who Diversity & Team Science would matter to

People who have been left behind in research and health

Diversity and Team Science would help brain research include and address many groups of people who have historically and are still currently left behind. For example young people with neurological conditions that are not typically associated with younger populations, racial minorities, LGBTQ+ individuals, people who are double minorities (e.g., Black and transgender), and disabled individuals.

Caregivers

There is a high burden and reliance on caregivers, and many experience burnout and loneliness in trying to find the best course of treatment for those they care for. Diversity and Team Science would help provide more knowledge to the community and support families and caregivers.

Everybody

If we can create more diversity and teamwork between researchers, clinicians, and people with lived experience we will start seeing radical changes in the way we do healthcare. It will give people with brain conditions more opportunities to engage in research. With more research evidence generated, there will be more validity of research and support for brain conditions.

Feedback on Transdisciplinary Training

Discussion themes

Brain disorders are complex and span across disciplines

Research and care delivery should not be working in isolation, as brain disorders span across departments and disciplines and these should be connected. Brain conditions are too complex to be solved by any one person or specialty. Therefore a transdisciplinary approach is especially important to find better solutions and to include other perspectives on how to approach brain research and care.

Collaboration provides a diversity of perspectives

Patients, researchers and clinicians have similar goals, therefore working together can be beneficial for so many and needs to be encouraged. We need teamwork, communication, and collaboration to be able to capture the perspectives of a diversity of people.

There are barriers to achieving a transdisciplinary approach

There are few systems and training in place that facilitate collaboration, and there are concerns around researcher and clinician mindsets that do not create an environment conducive to collaboration and listening to patients. Barriers include the competitive funding landscape, large amounts of data, the limited impact of publications and issues around equity, diversity and inclusion.

Considerations

Mental health is often understudied and there is not a lot of collaboration between mental health research and neuroscience research. Depression and anxiety are often comorbidities with other brain conditions (e.g., epilepsy) and should be considered in a transdisciplinary approach.

Examples of who Transdisciplinary Training would matter to

Patient with a brain tumour

With more transdisciplinary training, patients would be able to get more knowledge about their condition and not be left alone with unanswered questions and having to do their own research. Treatments would be more well-rounded and care could continue beyond the principal treatment.

Parents and caregivers

With more transdisciplinary training, parents and caregivers would not have to take on the responsibility of having to teach medical professionals about the brain condition or diagnosis of the person they care for.

People living with brain conditions

Transdisciplinary training would increase patient outcomes and improve quality of life. There would be a faster translation of research from lab to bedside. There would also be less stigma of brain conditions if more people are involved.

Feedback on Neuroethics

Discussion Themes

Neuroethics protects people with lived experience

Neuroethics helps avoid inequalities, and protects anonymity and confidentiality. A neuroethics approach helps balance the exploratory nature of research by ensuring that the research and findings are relevant and transferable to people with lived experience. It ensures that accountability and transparency are built into the research process.

The human side of research

Neuroethics allows the voices of people with lived experience to be heard and creates a sense of humanity. In many cases a person is impacted by their environment and their upbringing and that should be considered when doing research and providing care. Research is not a one size fits all solution, and advancing research requires learning about the human side of a condition because each individual will have their own experience with a brain condition. Researchers should consider changing the label from research subjects to “participants” or “collaborators”.

Neuroethics is vital for the success of research

Brain research must respect the risks, harms and ethical breaches of the past. Science is developing rapidly and it is important to pause and reflect on the ethics of the work. Neuroethics must be of the highest standard for continued trust in the research and medical system. If researchers are able to ensure a high standard of neuroethics, people with lived experience will be more willing to participate and this can generate more data and lead to better outcomes. Talking about benefits, risk, and impact can lead to new ideas from a combination of ethical approaches and research.

Considerations

It is not efficient to do neuroethics but it’s important to do so and take our thinking beyond lab-based research and consider the experiences of people with brain conditions.

Examples of who Neuroethics would matter to

People with a brain condition

Neuroethics provides comfort for participants contributing data which allows researchers to find further uses of research data (stripped of personal information). This can lead to more discoveries to improve quality of life, help manage symptoms, and even find cures. Neuroethics can also help bring stories of people with brain conditions to the forefront, especially those with invisible neurological conditions.

Families and friends of people with brain conditions

Family members are involved in providing care, and they experience constant stress and worries about whether their family members with brain conditions will be okay. Families and friends also worry about people with brain conditions getting lost in the shuffle as they navigate research and care. Neuroethics creates peace of mind that appropriate considerations are being made for their loved ones.

Caregivers and care partners

For many brain conditions, care partners or caregivers are actively involved in the decision-making and determining if they should be involved in research studies or their approach to care. Care partners have to think about the benefits, risks and impact of the studies people with brain conditions participate in.

Feedback on Neuroscience-AI

Discussion Themes

AI has a lot of potential and needs to be taken seriously

AI shows a lot of potential as it already has many advances and is on the leading edge of research. It allows researchers to manage large amounts of data and simulate everyday life which can lead to significant changes in healthcare. AI takes a long time to be developed and needs to be taken seriously and funded well now. There is not enough urgency around developing neuroscience-AI.

There are risks

There are risks of bias in the design of AI systems and there is a lot of grey area with many unknowns. AI is moving at a fast pace but needs to be better understood and managed as even small malfunctions can lead to disasters. Researchers need to consider how to protect us from current risks and risks that we are not yet aware of. Neuroscience-AI needs to be perfected before being used in human treatments and diagnoses because the brain is the most important organ of the body. There will inevitably be hesitancy from some people with lived experience when it comes to AI.

AI is a promise of hope

AI can produce opportunities and reach places where humans are otherwise limited. There is hope and excitement for discoveries through AI (e.g., new drug treatment option, effective treatment pathways) and quality of life treatments (e.g., speech and language support, memory mining, personalised mental healthcare). AI has the potential to improve the process of getting a diagnosis, reduce the time it takes to be diagnosed, and navigate the unknowns and complexities of certain brain disorders.

AI needs to directly impact people with lived experience

There needs to be harmony between the development of AI and how it will impact people with lived experience. Researchers need to consider how people with lived experience will benefit from advancements. AI discoveries need to be translated from researchers to clinicians to ensure that it impacts care for people with brain conditions.

Considerations

AI is complex and complicated and creating a common understanding and common terminology can help bridge the gap between research, clinical care and people with lived experience.

Examples of who Neuroscience-AI would matter to

People with brain conditions

AI can help people with brain conditions, for example those who have lost their ability to speak, communicate or process language. AI could help solve “the why” for people with cryptogenic diagnoses and help people be more comfortable with their diagnosis. For people with high-function brain disorders, AI may help find better treatments. AI allows researchers to develop and test treatments before moving to animal/human models. Future generations will have to deal with increasing brain health issues and AI can help better treat the masses.

Family members of people with brain conditions

Putting brain conditions in the context of technology and AI may help family members who are not as familiar with brain conditions better understand what is happening to their loved ones. AI could help determine genetic causes behind brain disorders (e.g. strokes). In cases where there is no genetic link,

you could reassure family members. If there is a genetic trait to a condition, AI can help with treatments and genetic editing to ensure the condition is not passed on to future family members.

Employers

Helping people who hire people with brain conditions know how to interact with them better, and understand their brain conditions. Sometimes employers do not find it ideal to hire people with brain conditions and AI can make it easier.

Feedback on Engaging People with Lived Experience in Brain Research

Overall, participants commended the CBRS on its efforts to involve people with lived experience in the development of the national brain strategy. They felt the CBRS' involvement of people with lived experience recognizes the unique experiences of people with brain conditions and allows them to be involved in research beyond being subjects. They requested continued collaboration and involvement as the strategy is developed and called for further engagement of people with lived experience in the future state of brain research.

Key Recommendations

1. Involve people with lived experience as equal voices throughout the research process to help shape the direction and execution of research

Include people with lived experience as equal voices (co-researchers and co-applicants) from beginning to end of the research process. They can be involved in prioritizing what is researched and reviewing grants, setting research agendas and questions, developing the study and methods, and determining if outcomes can make a difference in their lives. Consider incorporating approaches from qualitative and participatory research.

2. Listen to people with lived experience to ensure research is relevant

Collaborating with people with lived experience gives them a voice and helps researchers understand what people with brain conditions are fighting for and what they're living through. Doctors and researchers need to "walk a mile" in the shoes of a person with brain conditions to understand what they are experiencing. Some researchers may have never even met people living with the conditions they are researching. Researchers also need to consider equity, diversity and inclusion when engaging people with lived experience in research. The researchers' role is not just to explain what they are studying and what is needed, but to also listen. Researchers just need to ask and provide an open invitation for people with lived experience to be involved and it will be appreciated and accepted.

3. Engage people with lived experience to support the advancement of research

People with lived experience are an asset to support the advancement of research. They can share their stories and campaign with research funding institutes and governments to show that brain research is as important as other issues and demonstrate how much and what is needed.

4. Provide support for caregivers

Caregivers (e.g. carers, family, parents) of people with brain disorders often lose their sense of self and experience burnout. Caregiver work is not considered expertise and their learnings from caring for people with brain conditions are not accepted as valid contributions or experience. This expertise should be recognized as a valuable contribution to science and research.

5. Understand that people with lived experience are not just their brain conditions

By demonstrating the capabilities of people with lived experience it can help others learn more about what brain conditions are really like and recognize that they are people beyond their conditions. Many people with brain conditions experience discrimination and bullying for their conditions. Research can support learning and acceptance of people with brain conditions and not just tolerance.

6. Research communities need to work closer with medical professionals and support groups

There is a gap between researchers and clinicians which creates a lag between research and implementation of findings. Researchers need to work with medical professionals to move new

findings into care. Medical professionals and support groups are also usually the first point of contact with people with brain conditions and a trusted source to help disseminate this information and recruit for engagement activities. Go to where people with lived experience are and receive care and connect through support groups, local charities, community groups, clinicians, and specialized clinics. Medical professionals should also work closely together, as patients with brain conditions report to many different specialists and their information and care is not centralized.

Key Resources Needed

1. National registry

Create a national registry or database for people with lived experience to participate, stay informed of research and connect with others with the same condition. It can assist researchers with recruiting lived experience advisors and study participants and show commonalities or patterns in disorders or symptoms.

2. Researcher champions

Find researcher champions who understand the value of engagement. Researchers who understand the value of patient engagement can advocate for and help get other researchers involved in patient engagement

3. Tailored communications

Create tailored communication and advertising to share relevant research and information on engagement opportunities. Use social media to recruit more people with lived experience. Face-to-face contact between researchers and people with lived experience is needed. Consider language and accessibility barriers that may exist to ensure equitable involvement with immigrant groups and people with disabilities

4. Lived experience and researcher training

People with lived experience need training to be part of the research process and understand what their role is and what researchers want to hear from them. Researchers need training to understand how to appropriately involve people with lived experience

5. Validated methods for patient collected data

Develop ways to validate patient collected data as people with lived experience have data collected by so many devices and technologies which can help further research

6. Funding

Funding is needed to support further engagement of people with lived experience in research and ensure they can be involved to their capacity

7. Common terminology

Develop common terminology for complex brain research topics like AI to bridge the gap between the researchers, clinicians and people with lived experience. Common understanding can help reduce hesitancy and reluctance and support the process of receiving consent. Researchers can talk to patients about the procedures and processes to help them understand if they'd be comfortable with their data and test results being used in research.

Appendix A: Descriptive Words Voting Results

Table 1. Dimensions of Importance for Open Science. In the Introductory Workshop, lived experience participants voted that Open Science is progressive.

| Dimensions of Importance - Open Science | | |
|--|--|---|
| Relevant - 7/27 to people with lived experience | Revolutionary - 8/27 able to impact change | Urgent - 6/27 timely and needs to be done soon |
| Progressive - 19/27 will move things forward | Achievable - 4/27 is likely to be successful | Efficient - 10/27 best use of resources, not wasteful |
| n=27, each participant voted for up to 2 descriptive words | | |

Table 2. Dimensions of Importance for Platform Science. In the Introductory Workshop, lived experience participants voted that Platform Science is achievable and efficient.

| Dimensions of Importance - Platform Science | | |
|--|---|---|
| Relevant - 4/26 to people with lived experience | Revolutionary - 6/26 able to impact change | Urgent - 3/26 timely and needs to be done soon |
| Progressive - 9/26 will move things forward | Achievable - 14/26 is likely to be successful | Efficient - 16/26 best use of resources, not wasteful |
| n=26, each participant voted for up to 2 descriptive words | | |

Table 3. Dimensions of Importance for Diversity and Team Science. In the Introductory Workshop, lived experience participants voted that Diversity & Team science is relevant, urgent and achievable.

| Dimensions of Importance - Diversity & Team Science | | |
|--|---|--|
| Relevant - 14/27 to people with lived experience | Revolutionary -8/27 able to impact change | Urgent - 14/27 timely and needs to be done soon |
| Progressive - 2/27 will move things forward | Achievable - 13/27 is likely to be successful | Efficient - 2/27 best use of resources, not wasteful |
| n=27, each participant voted for up to 2 descriptive words | | |

Table 4. Dimensions of Importance for Transdisciplinary Training. In the Introductory Workshop, lived experience participants voted that Transdisciplinary Training is revolutionary.

| Dimensions of Importance - Transdisciplinary Training | | |
|--|--|--|
| Relevant - 8/27 to people with lived experience | Revolutionary -13/27 able to impact change | Urgent - 10/27 timely and needs to be done soon |
| Progressive - 11/27 will move things forward | Achievable - 4/27 is likely to be successful | Efficient - 8/27 best use of resources, not wasteful |
| n=27, each participant voted for up to 2 descriptive words | | |

Table 5. Dimensions of Importance for Neuroethics. In the Introductory Workshop, lived experience participants voted that Neuroethics is relevant.

| Dimensions of Importance - Neuroethics | | |
|--|--|--|
| Relevant - 21/27 to people with lived experience | Revolutionary -6/27 able to impact change | Urgent - 10/27 timely and needs to be done soon |
| Progressive - 6/27 will move things forward | Achievable - 8/27 is likely to be successful | Efficient - 1/27 best use of resources, not wasteful |
| n=27, each participant voted for up to 2 descriptive words | | |

Table 6. Dimensions of Importance for Neuroscience-AI. In the Introductory Workshop, lived experience participants voted that Neuroscience-AI is progressive.

| Dimensions of Importance - Neuroscience-AI | | |
|--|--|--|
| Relevant - 5/27 to people with lived experience | Revolutionary -17/27 able to impact change | Urgent - 3/27 timely and needs to be done soon |
| Progressive - 22/27 will move things forward | Achievable - 3/27 is likely to be successful | Efficient - 3/27 best use of resources, not wasteful |
| n=27, each participant voted for up to 2 descriptive words | | |

Appendix B: Takeaway Messages

Participants were asked to write one takeaway sentence: What does the government need to know to advance engagement of people with lived experience in brain research? Takeaway messages are anonymized but not aggregated.

- There is knowledge to be gained from different groups (i.e. lived experience). Even if [people with] lived experience [are] not trained, they can bring important practical perspectives.
- We are taxpayers aware and familiar with conditions, [and we] can offer insight into what research needs to focus on and what government services should be provided. So much money can be saved with lived experience perspective is brought in to design in government.
- Many hands make lighter work.
- People with brain conditions deserve to be heard, they want to be heard.
- Science and technology should integrate the voice of people of lived experience regularly including ancestral aspects of spirituality and find the way that leads [to] better collaborative brain research development.
- Every single person's voice in this conversation matters.
- Pay attention to what we have to say and don't disregard it!
- The cost of not acting NOW is going to be huge.
- Dear Government (and CRA) - allow access to the programs you have in place and make it less difficult on patients and clinicians to access these programs.
- That the patient needs to be involved, they are not just a number.
- Brain research is underfunded, and under supported, we are a significant group that matters.
- Brain research has an impact on the everyday lives of all the population, not only the diagnosed patients, but everybody.
- More research (and thus, funding) is needed as highlighted by these focus groups. In fact, research needs to be interdisciplinary, and incorporate persons with lived experience from [patient-oriented research] to community-based models, and patients should be involved in ALL research stages (from conceptualization of research questions/hypotheses to knowledge translation).
- Action is needed now; more funds for basic research; higher grants for young researchers'; more interdisciplinary training MD PhD, computer scientists and biology; establish a prestigious Prize for best interdisciplinary work or research.
- Brain research is essential, timely, and important to the health of Canadians.
- Please help CBRS help advance brain research to help make a difference in the lives of we patients living with a variety of brain disorders.
- A collaborative approach will save money on Brain Research and allow more research to take place and help remove duplication of resources.
- We're your primary resource to advance and further research.
- Important to include people with lived experience, many years have passed and not been approached to engage in research.
- The government needs to know how much people are being affected by brain related issues, almost everyone is or knows someone who is struggling with it. Do not underestimate it just because not everyone talks about it (ex. depression).
- Engaging with patients in brain research is necessary to best advance relevant and transformational healthcare for Canadians.
- Brain research has become increasingly urgent but requires the patience of scientists and researchers to perfect treatment development.

Appendix C: Lived Experience Engagement Participants

Audience Demographics

| Province | Number of participants |
|---------------------------|------------------------|
| Ontario | 9 |
| British-Columbia | 5 |
| Quebec | 4 |
| Alberta | 5 |
| Saskatchewan | 2 |
| Manitoba | 2 |
| Nova Scotia | 4 |
| Newfoundland and Labrador | 2 |
| New Brunswick | 1 |
| Total | 34 |

| Gender | Number of participants |
|--------|------------------------|
| Woman | 23 |
| Man | 11 |
| Total | 34 |

| Perspective | Number of participants |
|------------------|------------------------|
| Lived experience | 29 |
| Caregiver/family | 8 |
| Advocate | 5 |
| Total | 42* |

| Age | Number of participants |
|-------|------------------------|
| <16 | 1 |
| 16-24 | 3 |
| 25-34 | 8 |
| 35-44 | 7 |
| 45-54 | 5 |
| 55-64 | 8 |
| 65-84 | 2 |
| Total | 34 |

| Racial identity | Number of participants |
|--------------------------|------------------------|
| White | 21 |
| Indigenous | 4 |
| Black | 2 |
| East/Southeast Asian | 2 |
| Middle Eastern | 3 |
| South Asian | 3 |
| Latin | 1 |
| Prefer not to say | 2 |
| Other-Ashkenazi - Jewish | 1 |
| Total | 39* |

*Participants were requested to select all that apply for these demographics which resulted in totals that were larger than the total number of participants.

Audience Demographics

Continued

| French identify | Number of participants |
|-----------------|------------------------|
| Yes | 2 |
| No | 32 |
| Total | 34 |

| Living with a disability | Number of participants |
|--------------------------|------------------------|
| Yes | 22 |
| No | 12 |
| Total | 34 |

| Household income | Number of participants |
|-------------------|------------------------|
| Less than 25,000 | 6 |
| 25,000 - 49,999 | 4 |
| 50,000 - 74,999 | 4 |
| 75,000 - 99,999 | 4 |
| 100,000 -149,999 | 4 |
| More than 150,000 | 5 |
| Prefer not to say | 7 |
| Total | 34 |

| Education completed | Number of participants |
|--------------------------------------|------------------------|
| Elementary School | 3 |
| High School | 1 |
| Post-secondary degree or certificate | 17 |
| Graduate degree | 12 |
| Other | 1 |
| Total | 34 |

| Do you work in healthcare, government or research | Number of participants |
|---|------------------------|
| Yes | 2 |
| No | 32 |
| Total | 34 |

| Familiarity with Research | Number of participants |
|---------------------------|------------------------|
| Very familiar | 1 |
| Somewhat familiar | 13 |
| Not familiar | 17 |
| Not sure | 3 |
| Total | 34 |

Introductory Workshop Attendees

- Angela King
- Anthony Ngayan
- Arlene Fellner
- Cassidy McCarthy
- Catherine Barker
- Cindy Norrad
- Claire Martisius
- Faraz Ahmad
- Ingrid Kovitch
- Jane O’Faherty
- Jason Morphy
- Jeannine Alain
- Jennifer Monaghan
- Jillian Philpott
- Justin Graham
- Karen Tang
- Katelyn Layland
- Katrina Breau
- Keri-Rose Tiessen
- Lou Sawaya
- Lynn Mendonza
- Maryam Abbaszadeh
- Prabin Dahal
- Raymond Malbeuf
- Rick Suvanto
- Rob Heighington
- Russell Levy
- Sheryl Boblin
- Sophie Lyne Zaretto
- Stacie Smith
- Susan McAlpine
- Tammy Karatchuk

Project Team

- Jennie Young (CBRS)
- Ashley Lawson (CBRS)
- Deanna Groetzinger (NHCC)
- Jenine Paul (Amplify)
- Saskia Kwan (Amplify)

Focus Group Attendees

Open Science

- Anthony Ngayan
- Jane O’Faherty
- Jeannine Alain
- Stone Peter
- Darya Sargin (researcher)
- Rachel Harding (researcher)

Platform Science

- Cassidy McCarthy
- Catherine Barker
- Mary Ellen Edwards
- Prabin Dahal
- Rick Suvanto
- Stacie Smith
- Arlette Kolta (researcher)
- Marie-Ève Paquet (researcher)

Diversity and Team Science

- Justin Graham
- Lynn Mendonza
- Russell Levy
- Susan McAlpine
- Keith Yeates (researcher)
- Melissa Perreault (researcher)

Transdisciplinary Training

- Angela King
- Claire Martisius
- Karen Tang
- Keri-Rose Tiessen
- Lou Sawaya
- Sophie Lyne Zaretto
- Susan Boehnke (researcher)
- Jackson Cone (researcher)

Neuroethics

- Jillian Philpott
- Sheryl Boblin
- Tammy Karatchuk
- Cindy Norrad
- Raymond Malbeuf
- Ben Gibbard (researcher)
- Ashley Lawson (researcher)

Neuroscience-AI

- Faraz Ahmad
- Jennifer Monaghan
- Maryam Abbaszadeh
- Rob Heighington
- Eilif Muller (researcher)