

# CANADIAN BRAIN RESEARCH STRATEGY

## Lived Experience Sessions Report

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## BACKGROUND

The Canadian Brain Research Strategy ([CBRS](#)) is building a collective national strategy to inspire and guide the Canadian government to invest in a major brain research initiative. As CBRS engages various groups of experts to inform the strategy, input from people who live with or have experienced a brain condition and those who support them is of particular importance.

To this end, CBRS held a series of Lived Experience Sessions in May-June 2022 with people with lived experience of brain conditions, family and caregivers, patient representatives, and advocates to discuss emerging themes on how to advance brain research in Canada. From more than 150 applications from across Canada, we selected forty participants aged 16 to 84 years to reflect a balance of diversity across neurological, mental health, and brain injury, geography (rural and urban centres), gender, race, Indigenous identity, socioeconomic status, education level, and familiarity with research. Additionally, representatives from our earlier Researcher Roundtable consultations joined the sessions to share preliminary findings and to learn about how people with lived experience envision the future of brain research.

Over the course of two introductory workshops and six focus groups, lived experience participants were asked to discuss the successes, challenges, and opportunities for brain research in Canada and to assess the current and future potential to impact on the lives of people living with brain conditions. They were also asked to provide feedback on the [Strategic Focus Areas](#) outlined in the emerging national strategy. This report has been condensed for ease of clarity and focus from a [summary document](#) produced by Amplify Engagement, who carried out the engagement.

## CHALLENGES IN BRAIN RESEARCH

### 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, that is made worse by there being a lot of duplication of research efforts. There is a lack of access to appropriate technologies. Communication of information, for example on ineffective treatment methods or research, should be greater.

Researchers are not accustomed to engaging people with lived experience and there is a lack of recognition of what people with brain conditions are experiencing - that can be overcome with education and training. Governments and politics influence the way research is conducted and funded; change would have to start at the policy level.

### Health and pharmaceutical environment

Some people with lived experience undergo medical gaslighting when more research is needed to generate knowledge for medical professionals to understand, diagnose and manage neurological and mental health conditions. There is a lack of access to research-informed healthcare providers, especially in isolated areas.

There is a lack of continuity of care - communications are limited to physician-patient interactions and doctors are overworked. 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 finding innovative treatments, such as incorporating alternative therapies in addition to traditional pharmaceuticals.

### **Research is not representative**

Research is not representative of everyone, and participant numbers are limited without enough funding. A lot of research previously focused on males, and left out other groups such as minorities, young people, and people with more complex conditions. There is a lack of awareness of research opportunities for people with lived experience. Patients are not in contact with researchers when they could provide unique perspectives and help with recruitment and outreach.

## **OPPORTUNITIES FOR BRAIN RESEARCH**

The following themes were brought up by participants in multiple focus groups on how the Strategic Focus Areas can advance brain research in Canada and support people with lived experience of brain conditions.

### **1. Collaboration with diverse perspectives**

The Strategic Focus Areas create transdisciplinary 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 other's expertise can increase research efficiency and lead to better solutions for people living with brain disorders.

### **2. Efficiency of research**

The Strategic Focus Areas 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. Impact on care and service delivery**

The Strategic Focus Areas 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 Strategic Focus Areas 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 Strategic Focus Areas 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.

## RECOMMENDATIONS TO GOVERNMENT

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? [Responses below are anonymized but not aggregated.]

- People with brain conditions deserve to be heard, they want to be heard.
- 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.
- 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.
- 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.
- The cost of not acting NOW is going to be huge.
- 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.
- 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).
- Brain research has become increasingly urgent but requires the patience of scientists and researchers to perfect treatment development.