



Brain Canada

**Report**  
on  
**Stakeholder Consultations**  
2013

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The Max Bell Foundation

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## Executive Summary

Brain Canada convened five invitational stakeholder consultations in Vancouver, Calgary, Toronto, Montreal and Halifax during the spring of 2013. These discussions were designed to help inform the research program of the Canada Brain Research Fund. A Consultation Planning Committee (page ii) supported the design and implementation of these meetings.

Participants expressed their appreciation for being consulted and spoke candidly about their hopes and concerns for the Canada Brain Research Fund and the future of Brain Canada. While the initial intent of the consultations was to focus on the fund, participants' comments often expanded to include opinions and suggestions related to the larger organization.

## Background

In 2011, The Government of Canada announced the establishment of the Canada Brain Research Fund, a \$100-million commitment to match funds raised by Brain Canada to support the very best neuroscience, fostering collaborative research and accelerating the pace of discovery, in order to improve the health and quality of life of Canadians who suffer from brain disorders. The fund is a public-private partnership designed to encourage Canadians to increase their support of brain research, and maximize the impact and efficiency of those investments.

The consultation process was to help ensure that the Canadian Brain Research Fund: (i) increases understanding of the brain; (ii) is relevant to and has the support of patients living with a neurological disorder or disease, mental illness or addiction, and (iii) will have the greatest potential for the development of new and better therapies, and eventually cures.

## Key Themes

An analysis of the consultation discussions resulted in two main themes. The first focused on strategic themes, suggesting that both Brain Canada and the Canada Brain Research Fund require a well communicated, over-arching strategy and clear strategic directions to achieve their full potential. The second involved organizational questions: participants were unclear about the purpose, objectives and priorities of both Brain Canada and its research fund and what makes this fund distinct from others currently in operation.

With respect to strategic themes, there was significant agreement throughout the consultations about the opportunity for Brain Canada to support high-risk, high-reward projects. Participants also agreed that Brain Canada senior leadership (board and staff) need to be clear about the types of research to be funded and the type and level of commitment to knowledge translation that the fund will support. The lack of a clear leadership entity within the neuroscience community was also identified as an opportunity that Brain Canada could address by: (i) creating opportunities to bring together the community; (ii) engaging funders and the public; and (iii) coordinating the work that is currently being done in order to maximize its impact.

With respect to organizational themes, there was agreement about the need to clarify the purpose, objectives and priorities of the fund. Participants were equally divided about whether greater awareness about Brain Canada and the fund would be a benefit or whether the current low profile served them well. There was general agreement that Brain Canada needed to define itself clearly and differentiate itself from others in neuroscience research. It also became clear throughout the consultations that the transition from Neuroscience Canada to

Brain Canada was not yet clear to participants and that this distinction should be made evident to researchers in the field.

## **Consultation Questions**

Participants responded to the same four questions in each consultation.

The most important question at these consultations was, “How can we as a brain research community support the translation of research results into new and better diagnostics, therapies and programs?” In addition to a plea for research that would result in prompt application, participants emphasized that Brain Canada needs to decide whether knowledge translation is a strategic priority for the organization, and therefore the research fund.

When asked “What are the most exciting/promising developments today in brain research in Canada and internationally?” several areas emerged: early diagnosis and prevention, stem cells, networks, neuroplasticity, the disappointments in clinical trials for Alzheimer’s, and epigenetics.

In response to the question: “What significant gaps/challenges do you see in brain research today in Canada and internationally?”, participants cited funding, lack of application of scientific knowledge, investments in training, addressing the current situation in the pharmaceutical industry, the roles of behavioural researchers, developing therapeutic and diagnostic products, the challenges faced by adults with disabilities, and the lack of a big picture synthesis in neuroscience.

Participants also reflected on current opportunities in neuroscience research. When asked, “Based on the purpose statement for these consultations, what opportunities are you aware of where Brain Canada would be ideally situated to work collaboratively with others in addressing the current situation?” participants recommended the development and sustained support for platforms, and seeing the changes in the pharmaceutical industry as an opportunity rather than a challenge. Other opportunities mentioned included streamlining the clinical trial process, drug repurposing and orphan molecules, and the social determinants of health.

Each consultation concluded with a discussion about potential partners and champions for the research fund, with participants providing several suggestions for each area.

## **Conclusion**

These consultations were held at a key point in the development of the Canada Brain Research Fund and Brain Canada as the steward of the fund. This is a transitional phase after sponsoring several successful programs through the fund and the organization is looking to the neuroscience and related stakeholder communities for input and engagement. As a result, the consultations were designed to welcome divergent opinions while also noting areas of agreement. Conversations were flowing and open, with the facilitator and participants directing the topics discussed in the context of the four basic questions that shaped the agenda.

Because of this flexibility, each consultation had its own flavour, with representatives building their conclusions based on demographic and geographic similarities and differences in the Canadian brain research community and related disciplines. The fact that common themes emerged from the diverse settings and range of consultation participants strengthens the messages that these themes bring to both the Canada Brain Research Fund and to Brain Canada as an organization.

## Introduction

This report summarizes the results of a Brain Canada invitational consultation held during the spring of 2013. Five in-person consultations were convened in Vancouver, Calgary, Toronto, Montreal, and Halifax.

The purpose of these half-day consultations was to help inform the research program of the Canada Brain Research Fund. Objectives were to:

1. Raise awareness of the importance of brain research, the Canada Brain Research Fund, and the effectiveness of Brain Canada's one system approach to the brain, i.e., the 'one brain' model;
2. Consult with stakeholders on underserved and underfunded areas of need where Brain Canada can complement existing research funding with minimal duplication or overlap;
3. Engage participants in thinking about how research can better inform best practice in patient care and what shifts in public policy may be required to support this.

This report is intended as a concise overview of the consultation results. While it was not an original intent of this work, as the consultations proceeded it became clear that the results could also be helpful to Brain Canada senior leadership who were entering a strategic planning process.

## About the Canada Brain Research Fund

In 2011, The Government of Canada announced the establishment of the Canada Brain Research Fund, a \$100-million commitment to match funds raised by Brain Canada to support the very best neuroscience, fostering collaborative research and accelerating the pace of discovery, in order to improve the health and quality of life of Canadians who suffer from brain disorders. The fund is a public-private partnership designed to encourage Canadians to increase their support of brain research, and maximize the impact and efficiency of those investments.

## About the Consultations

Consultations were held with researchers, clinicians, patients/families (directly and through stakeholder organizations), and philanthropists and decision makers, including policy advisors, representatives of governments, and private industry. Numbers of participants at consultations were small to encourage engagement and meaningful, focused discussion – a decision that was supported by attendees at all sessions. Preference was given to those who fulfilled more than one of the following criteria:

- Established researchers with a special interest in the brain and who come from a range of disciplines and perspectives
- Representatives of research organizations/key influencers
- Voluntary sector organizations
- Emerging researchers with a special interest in the brain
- Neuroscience policy advisors
- Informed lay public.

Participant observers included Brain Canada board members at two consultation workshops and a Max Bell Foundation representative who was present at the first two consultations.

The role of Strachan-Tomlinson (consultants) in this process was to be an objective listening post for participants' voices and to report faithfully a summary of what was heard. This involved preparing a synthesis report including key themes, opinions and suggestions of consultation participants.

These consultations were held at a key point in the development of the Canada Brain Research Fund and Brain Canada as the steward of the fund. This is a transitional phase after sponsoring several successful programs through the fund and the organization is looking to the neuroscience and related stakeholder communities for input and engagement. As a result, the consultations were designed to welcome divergent opinions while also noting areas of agreement. Conversations were flowing and open, with the facilitator and participants directing the topics discussed in the context of the four basic questions that shaped the agenda.

Because of this flexibility, each consultation had its own flavour, with representatives building their conclusions based on demographic and geographic similarities and differences in the Canadian brain research community and related disciplines. The fact that common themes emerged from the diverse settings and range of consultation participants strengthens the messages that these themes bring to both the Canada Brain Research Fund and to Brain Canada as an organization.

Four questions formed the basis of discussions:

1. What are the most exciting/promising developments today in brain research in Canada and internationally?
2. What significant gaps/challenges to you see in brain research today in Canada and Internationally?
3. Based on the purpose statement for these consultations, what opportunities are you aware of where Brain Canada would be ideally situated to work collaboratively with others in addressing the current situation?
4. How can we as a brain research community support the translation of research results into new and better diagnostics, therapies and programs? (e.g., through leadership, champions, partnerships etc.)

## **About this Report**

Participants' comments and suggestions are synthesized into three linked areas:

- A. Organizational Themes
- B. Strategic Themes
- C. Responses to Consultation Questions.

Participants' original words and phrases are used throughout the report to represent what a number of consultation responses indicated. Conflicting statements represent differences of opinion among consultation participants. In addition, in some cases participants may represent as factual, items that may not be entirely correct. In these cases, participants' understandings are included as they were initially provided.

Items provided under the headings “Key Questions” and “Considerations” serve a dual function: to summarize key points raised by participants and to support Brain Canada leadership in reflecting on current priorities and making decisions with respect to strategic planning.

One purpose of these consultations was to surface and describe underserved and underfunded areas of need in relation to brain research. Two important reflective questions for Brain Canada senior leadership are:

Consultation participants have identified needs based on their situations. To what extent are, or should these needs be part of Brain Canada’s core business?

What is Brain Canada’s position on priority topics in brain research such as knowledge translation, and relationships with other research organizations?



## A. Strategic Themes

Five strategic themes arose out of consultation discussions for consideration by board members and staff. While opinions varied regarding relative importance and suggested action among these themes, there was strong agreement regarding the need for clarity regarding an overall, high-level organizational strategy. Each of the themes in this section begins with a summary of the area followed by questions for consideration by Brain Canada leadership, and actions suggested by consultation participants.

### 1. Embrace Risk

There was significant agreement throughout the consultations about the opportunity for Brain Canada to differentiate itself and the Canada Brain Research Fund and by supporting high-risk, high-reward projects. Other funders were described as being too conservative, and not willing to fund innovative projects or anything that had the possibility of failure. In the words of several participants, *“If nothing is ventured, nothing is gained”*. For example:

*The Brain Canada focus on high-risk/high impact research is fantastic. That is where everyone wants to be. We don't have this in Canada and it's important. Has Brain Canada thought about a 'moon-shot' project focused on the brain? CIHR is much too conservative, e.g., requiring preliminary data before funding.*

*Incorporate in your philosophy something that is discouraged at every level in other organizations: the courage to take risks. It is an intangible that requires the support of your board, and it is the difference between doing a good job and greatness.*

#### Key Questions

- Have courage! How can Brain Canada become a remarkable organization?
- Brain Canada's approach is to slice the pie horizontally with generic programs (e.g., MIRI). Are you willing to take a vertical approach, (e.g., Brain Canada to focus on projects that work out the neuronal wiring in the brain)? This would differentiate Brain Canada from others.
- Brain Canada is unique – are you willing to take the chance to propose an innovative model, complementary to the field?

#### Suggested Actions

- Fund areas without predicted outcomes or preliminary data.
- Do something valuable and unique that won't happen without you.
- Avoid conservatism in research and push researchers to think differently. This is where everyone wants to be, but can't.
- One strategy: invest in a lot of small projects, expecting that 80-90% will die. The first investments are small investments, e.g., \$100 thousand for 12-18 months. People shouldn't need anything but an idea. The second phase would be \$1-2 million.

## 2. Clarify Research Types and Priorities

Participants agreed that Brain Canada senior leadership needs to be clear about the type of research to be funded through the Canada Brain Research Fund. There were two views on this, with one group saying:

*Brain Canada's focus is research, but Knowledge Translation (KT) is needed for impact. Families want improvements in daily life, not more basic research. Is the research being done out of curiosity, or to research solutions for patients experiencing these disorders? Something is lost when the focus is on generating research without generating improvements in the lives of Canadians.*

*There is a gap between fundamental research and early translational research. Families don't get access to programs that can help them. Go beyond the biomedical and focus on areas where there is a demonstrable impact.*

The second view called for less KT and translational research and focused on simply funding the best science possible:

*Stick to basic research, and believe in the collective wisdom of the research community – it wouldn't be research if we knew what we were doing. It is impossible to predict the impact of research, and there is currently a lack of KT capacity.*

*Don't ask researchers to use a skill set they don't possess. Asking Principal Investigators to do KT is like asking the engineer who designed the car to race it. The more people partner and leverage, the less they research.*

### Key Questions

- Does Brain Canada want to be in the business of KT? If so, how does it define this outcome in terms of its strategic directions?
- Does Brain Canada have the capacity to support KT initiatives? Don't spread money without research capacity – funding is limited in pillars 3 and 4. This will take a long time (e.g., 10-15 years) to develop.
- Is KT a way for Brain Canada to re-balance funding through the Canada Brain Research Fund away from basic science?
- Who are the KT 'experts' in brain research and brain health?

### Suggested Actions

- Create knowledge that can be applied immediately:
  - Ask the community: "What is the problem you see that needs to be solved?"
  - Ask researchers: "What could you do that would help the greatest number of people?"Use the results of these questions to inform policy.
- Provide funding for front-line educational programs that have the potential to demystify dementia.
- Don't make researchers write letters and do administration. Enable researchers to do what they are best at, i.e., research.

- Fund great teams and ‘big science’.

### 3. Build Community

Participants emphasized the importance of three strategies critical to the Canada Brain Research Fund and future success of Brain Canada: (i) creating opportunities to bring together the community, (ii) engaging funders and the public, and (iii) coordinating the work that is currently being done to maximize its impact.

While there wasn't agreement on the approach and style of coordination (e.g., high or low profile), there was no doubt about its importance in supporting a successful future for the organization. In the words of one participant:

*Kudos to Brain Canada for engaging with the community through consultations, and for taking a flexible approach: it will be a critical feature of any success.*

#### a. Engage Funders and the Public

There was strong support for and positive feedback on the consultation initiative in all five cities. Participants appreciated being asked for their opinions and supported future initiatives related to engaging stakeholders and understanding their hopes and concerns.

*Funding for research is about hopes for discoveries and change. Engaging stakeholders in these consultations is one way to surface these hopes.*

*Engage policy makers – they are facing horrendous challenges, and there is tremendous pressure to use research knowledge to make policy decisions.*

*The brain won't be understood in a five-year time frame, but funders will want to see tangible results so they can point to what they paid for. It is easier to go back for more funding with a demonstrated success in hand.*

*The public needs to be open to the idea that their money is being spent to support the organization's strategic directions – this will lead to policy makers being open to funding of brain research.*

#### Key Questions

- How can you integrate policy makers into the process from the very beginning?
- As part of strategic planning could you write the executive summary now for the next ask to government? In a 10-year window there is the opportunity to make investments based on your strategic plan.

#### Suggested Actions

- Engage the public and potential funders: find out what their relevant issues are.
- Involve patient foundations in the process as early as possible. They are becoming more sophisticated and are interested in impacting clinical outcomes.
- Lived experience is so important. You need people willing to go the microphone and talk about their issues. Stigma is still a factor, and story-telling is crucial to communities.

- Personalize the brain for ordinary people. Get them to think about what is inside their heads.

## **b. Coordinate and Collaborate with Others**

Brain Canada is in a unique position given it's the Canada Brain Research Fund and status in the brain research community. While partnerships are not a new idea, Brain Canada could innovate how it works with others in its domain:

*Success in the first five years will depend on partnerships.*

*Overcome siloes – what helps one patient can help another.*

*The Federal Government could have chosen to fund CIHR but did not. Given that, the onus is on all parties to figure out how to work together and be strategic.*

### **Key Questions**

- How does Brain Canada want to play with other brain research funders regionally, nationally and internationally?
- To what extent is coordination and collaboration with others a key approach to implementing the Brain Canada mission, vision and values?

### **Suggested Actions**

- Spend time with and learn from others who have gone through a start-up phase and/or who have experience in dealing with government partnerships.
- The pharmaceutical industry is eager to partner: facilitate connections between industry and academia.
- Avoid making mistakes that have been repeated elsewhere. Sit down with everyone involved and build on strengths.

## **4. Strengthen Leadership**

A common theme throughout the consultations was the need for a public face for the brain research community. Much as the Canadian Partnership Against Cancer (CPAC) acts as the public face of multiple diseases, so might Brain Canada act as an 'umbrella' organization for the Canadian brain research community. In participants' words:

*Brain Canada has the opportunity to synergize agendas and bring people and organizations together to accomplish what they can't do alone. A consortium of interests could direct resources collectively to address the common themes that cut across diseases. This would help organize funders around a few big themes in research.*

*Brain Canada's job is about more than just giving out money –there is a need to infuse optimism into the system. People are discouraged; there are cutbacks and institutional difficulties with fundraising. We need someone to support the community and tell them that there is a future in research.*

## **Key Questions**

- Is the timing right for Brain Canada to take on a leadership role with respect to brain research?
- What are the risks, costs and benefits of Brain Canada taking a leadership role in the brain research community?
- What strategic direction does Brain Canada want to take with respect to its public face and how it interfaces with other players in this research area? What resources are required to support this potential strategic direction?

## **Suggested Actions**

- Cohesiveness is lacking in this field. The confusing number of agencies and players makes it hard for researchers and the public. Brain Canada could be the voice to the public about brain research in Canada.
- It would be nice to have someone else in a leadership role, so that small organizations could say, "we are doing fundraising in conjunction with Brain Canada". This would help smaller organizations build scientific credibility.
- What if Brain Canada were to make a general offer with the match to everyone, e.g., all the private charities and foundations across the country?

## B. Organizational Themes

As the consultations proceeded, it became clear that participants wanted to focus on both the Canada Brain Research Fund and Brain Canada and their perceptions of current organizational challenges.

Most participants lacked a clear understanding of the purpose and objectives of Brain Canada. A majority felt the organization lacked focus and clarity about its strategic priorities, boundaries and intended impact within the larger research community in Canada.

### 1. Awareness

A majority of participants commented that their awareness about Brain Canada was low. However, two fairly balanced perspectives regarding what to do about awareness emerged during the consultations.

On the one hand, there was the view that increased awareness is a key to future success. On the other hand was the perspective that the current situation – where Brain Canada is not well known – is not a bad thing.

Each consultation featured a poll of participants, who were asked, “On a scale of one (low) to five (high), how would you rate the awareness of Brain Canada in your communities?” Responses ranged from 0 to 5, with the average being 2.2. Brain Canada was described as “not being on the radar”, and that “While there is some buzz about Brain Canada in the research community, not many people understand what the organization is about.”

Participants who thought that increased awareness of Brain Canada was a key to future success made comments such as:

*Awareness for its own sake isn't effective. But having the public understand that there are significant developments in brain research is a good thing. Resources have to be used effectively, but broadcast goals can't be achieved without public awareness. It is no surprise that people have heard the Obama announcement but not about Brain Canada.*

For those who disagreed, comments focused on the value of a low profile and a lean organization:

*Low ratings for how well we know Brain Canada should not be taken as criticism. The Brain Canada model works beautifully – a smaller organization is more responsive, and can talk to more people and make suggestions. You only need to be known by key stakeholders and parts of the research community – do you really need to be known to have your funding renewed?*

*You can't be all things to all people. The lean nature of Brain Canada is attractive to potential partners and donors: they know the money goes to research. Increased awareness will come with time.*

## Key Questions

- How might an increased profile affect relationships with other organizations in the neuroscience community?
- Who outside of the research community needs to know the overall intent of the organization?
- Would a strong brand and organizational profile resulting in increased professional and public recognition serve the mission, vision and values of Brain Canada?

## Suggested Actions<sup>1</sup>

Both groups of participants felt strongly that the first step in awareness and community building is for Brain Canada to more clearly define its strategy and goals as well as whom its research is meant to help. Examples of comments:

- Create a good strategic communications plan. Legacy goes back to the importance of communications and brand. Leverage your partners and create public awareness of your impact – that will build your legacy.
- Create a public relations plan. Most people who donate money like to be recognized for their contributions. They like to play with winners. Some work anonymously, but those people don't work in politics. It is important that people talk about the work of Brain Canada – public presence and image is of key importance.
- Keep the organization small. This gives ownership for the work to other involved parties.
- The visibility of Brain Canada isn't something to worry about. Don't spend resources on communication – it leads to diffusion and waste.
- There are ways to cost-effectively build awareness of Brain Canada. Look for partners to provide resources for this work.

## 2. Definition and Differentiation

Participants in all consultations commented on the potential for duplication and overlap in Canadian research funding. There was general agreement that it wasn't clear what Brain Canada's goals were, how they differed from other funders, and what types of research they were intended to fund. Without an organizational understanding or purpose, participants saw the potential for waste:

*100 million dollars is not as much as it sounds. If your programs are diffuse, it will be gone before you know it.*

## Key Questions

- How is Brain Canada any different from Neuroscience Canada? Will the same small group of basic or clinical scientists be funded?

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<sup>1</sup> Suggestions are included as provided by participants. They may/may not reflect the views of the authors.

- What is the difference between Brain Canada and the Canadian Institutes of Health Research (CIHR)? Avoid becoming another cog in the bureaucratic machine of science funding. You know what CIHR is doing. Don't do that.
- Is Brain Canada a start-up or is it building capacity or both?
- Willingness to take risks is a positive differentiator. Are you willing?
- Program boundaries are too broad, and partnership requirements aren't clear.
- Without clear organizational boundaries the money provided by partners/donors will speak too loudly.
- Researchers may not think that their 'wild ideas' are appropriate if the boundaries are unclear.

### **Suggested Actions**

- Differentiate Brain Canada from other funders.
- Clarify program boundaries and make partnership requirements more distinct.
- Clearly define what success looks like in 5- and 10-year time frames.

### **3. Related Issues**

Address the myths and realities about the Brain Canada organizational culture.

*Neuroscience Canada saw itself as an elite – too grand to even look at disease mechanisms. It would be good to see some people outside of the 'inner circle' get funded.*

*Ensure that the best science and approaches are funded. Make sure that there isn't a new 'old boys' network in charge.*



## C. Responses to Consultation Questions

Consultation participants were asked four main questions:

1. What are the most exciting/promising developments today in brain research in Canada and internationally?
2. What significant gaps/challenges to you see in brain research today in Canada and internationally?
3. Based on the purpose statement for these consultations, what opportunities are you aware of where Brain Canada would be ideally situated to work collaboratively with others in addressing the current situation?
4. How can we as a brain research community support the translation of research results into new and better diagnostics, therapies and programs? (e.g., through leadership, champions, partnerships etc.)

### 1. Exciting and Promising Developments in Brain Research

When asked “What are the most exciting/promising developments today in brain research in Canada and internationally?” four key areas emerged as outlined below.

- a. Early diagnosis and prevention:
  - Experimental therapies for treating Alzheimer’s before symptoms develop.
  - Early molecular changes that are harbingers of neurodegenerative diseases.
  - The neurodevelopmental view of disease.
- b. Stem cells, networks, neuroplasticity:
  - The science underlying brain wiring will inform brain research for the next 20 years.
  - Changes in the brain are reversible.
- c. The disappointments in clinical trials for Alzheimer’s. It’s time for a new approach.
- d. Epigenetics.

### Other Exciting Developments

- New Technologies, e.g., Optogenetics, Nanotechnology, Halifax Consciousness Scanner, Human Connectome Project, Brain Activity Map, Mind/machine interfaces.
- Perspective shifts, e.g., biological functions merging with psychiatry: the meaning of creativity in biological terms; resolution of the nature/nurture dichotomy; the shift in perspective that one single thing is the neurotransmitter, i.e., there is more than one and they work in combination; the increased involvement of engineers when historically the physical sciences have been shut out of neuroscience; taking into account the interactions between caregivers and babies during development is changing how international development programs are rolled out; systems biology; the “Tomorrow Project”, which looks at healthy people as they age

- New discoveries, e.g., discovering what newfound genes (e.g., in autism) really do; developments in gene transfer, stem cells, and prosthetics at the back of the eye; some human neurological diseases and dementias may be related to Creutzfeldt-Jakob Disease (CJD) – entirely new basic pathobiology area has opened as an opportunity to examine these diseases; certain musical rhythms enable Parkinson’s patients to react; progress is being made in the understanding of pain.
- New collaborations, e.g., between neurodevelopment (pediatric) and age related neurodegeneration (geriatric) researchers.

## 2. Gaps and Challenges

Following is a synthesis of participant responses to the question: “What significant gaps/challenges do you see in brain research today in Canada and internationally?”

### a. Challenge: Funding is a constant concern.

*The National Sciences and Engineering Research Council of Canada (NSERC) and CIHR won’t fund molecular neurobiology.*

*Maintenance and servicing of equipment is a big need – there are those who have purchased MRIs but can’t afford to turn them on. Operating funds are a challenge.*

*Small Non-Government Organizations (NGOs) don’t get their fair share of funding, and are like orphan diseases.*

*There is little funding for research related to neuroscience and the arts.*

#### Considerations

- We don’t fund enough clinician scientists, and we are losing them.
- Mid-sized Canadian labs will be challenged in the years to come.
- Funding agendas should be driven by the cost to the system and the public. Research on orphan diseases may not be the best return on investment.
- When new funding is made available for a new agency, our instinct is to be proprietary but we need to stay focused on the major goal – funding great research and supporting the benefits of that research. The goal is not to spend \$100 million. The goal is to support research.

### b. Challenge: Scientific information is not being applied.

*Implementing change in health care is easy with great research and a series of miracles. Some academics think that once their research has been published their job is complete, and that people will change their behaviour.*

*Policies are out of line with what we understand about the brain.*

*Researchers have learned to pay lip service to knowledge translation, while struggling to articulate the public impact of their work.*

### Considerations

- We need to get closer to the bedside, but if we get too far away from basic research the pipeline will dry up.
- New doctors and nurses can be trained, but in the nursing home it is difficult to change the practice of a nurse or doctor with 25 years of experience.

### c. Challenge: What is the best way to invest in training?

*Only 20-30% of researchers end up in academia – the rest are struggling to find a place for themselves. Institutional training is very technical and specific, and it is difficult to translate those skill sets.*

*Training more graduate students may not be the best value for money. There is already a lot of capacity in neuroscience.*

*We've built a successful scientific base with a core of researchers we can't afford.*

### Considerations

- A Canadian foundation studied productivity in research and found new investigator grants to be the most productive use of funds.
- Half of our Principle Investigators (PIs) are over 60 years old and still on the job.
- How can we keep attracting the brightest people into brain research?

### d. Challenge: The pharmaceutical industry is in transition.

*Drug companies have shut down their research portfolios.*

*Big companies want 40% of their target molecules from universities, but there is a huge valley of death between what you can do and what they want.*

### Considerations

- There is still the feeling that working with big drug companies means you've sold your soul to the devil. The corporate need for confidentiality crimps research.
- Universities have the research, but links between universities and pharmaceutical companies are limited.

### e. Challenge: Is there a role for behavioural researchers?

*Will a focus on the brain perpetuate the exclusivity of brain over behaviour research?*

*Some basic neuroscientists don't appreciate the value of behavioural research.*

### Key Considerations

- Many brain diseases are highly determined by behaviour - how do you understand behaviour as a determinant of all of the major diseases?
- Basic neuroscientists seem to make up the majority of the Brain Canada Science Advisory Council.

## **f. Challenge: Developing therapeutic and diagnostic products**

*There is a chasm between good ideas and commercialization.*

*Venture capital is moribund. We need strategies to get past 'death valley' in pharma and biotech.*

*The best thing to do if you want to commercialize is to invest in great science (e.g., Jeff Hinton was bought out by Google for his work on neuro-computation.)*

### **Key Considerations**

- There is a tolerance for risk in the US which we do not have in Canada.
- Getting beyond the blood-brain barrier more effectively could lead to entirely new ways of doing therapy.
- We can fund amazing research; we can get the people together to create an amazing device, but how do we get that device to the end user?
- Does Brain Canada really have the resources to get into this game? The initial grant will need to show government a return of investment.

## **g. Gap: Adults with disabilities**

*We are losing economic productivity and well-being to learning disabilities.*

*As much as neuroplasticity is cool, there is still a very strongly held belief that once you have something like Fragile X or Down syndrome, there is nothing more to do in terms of treatment.*

*Researchers love descriptive research, but it often doesn't lead to any changes. In the world of basic research, work can take 25 years to bear fruit.*

### **Key Considerations**

- There is an opportunity in better understanding the prevalence of autism. The estimates vary, and they are scaring governments into inaction.
- Current data on the cost of mental illness is poor. Better economic data on costs could determine priorities for research, as well as bring governments onside.

## **h. Challenge: A 'big picture' synthesis is lacking in neuroscience**

*We've come a fair way in drug discovery by working incrementally, but the reduction of a complex disease into simple parts has failed time and time again.*

*Looking for commonalities in different brain diseases is a tremendously powerful strategy that resonates with health charities and the public.*

*There is more over-promising and under-delivery in neuroscience than in other fields.*

*Neuroscience is held to a higher standard than other areas.*

## Considerations

- Taking the problem as expressed and translating it into either a researchable question or a systematic trial is not a common skill set.
- Managing information is a challenge. We are overwhelmed by a glut of data.

## 3. Opportunities

Below are participant responses to the question: “Based on the purpose statement for these consultations, what opportunities are you aware of where Brain Canada would be ideally situated to work collaboratively with others in addressing the current situation?” These opportunities are provided in order of frequency of mention, from most to least.

### a. Opportunity: Building and maintaining platforms

*There is a lack of support for linking brain banks, e.g., creating standardized procedures for accessing tissues.*

*With a significant amount of money a children’s brain bank could be established.*

*There is a need for a national brain bank.*

*The technology for creating platforms is one of the biggest challenges.*

## Considerations

- Platforms are very valuable, but they are a long-term commitment. Registries have been developed only to have their funding dry up and become unusable.
- Some major donors are only interested in funding platforms.
- Five years is not enough time for funding a brain bank.
- Build something focused on the brain into the Canadian Longitudinal Study on Aging.

### b. Opportunity: Transition in the pharmaceutical industry

*In-house research and development divisions are being cut and they are starting to look externally for innovation.*

*PIs used to think that companies were there to steal their ideas; now, taking on a pharmaceutical partner at an early stage is a very attractive option.*

## Considerations

- Neurological degeneration is a target of every pharmaceutical company.
- There is a willingness to partner in the industry right now.
- Biotech is looking for partnerships at the clinical level, and many of the new therapies are coming from biotech.

### **c. Opportunity: Streamlining the clinical trial process**

*The big companies are all doing trials in India and China. They like the streamlined process and the lower level of regulation.*

*There is a competitive advantage in holding clinical trials in Canada.*

#### **Considerations**

- Research ethics board clearance can be a barrier. Clinical Trials Ontario is trying to address this. Is there a role for advocacy in this area?
- Access to well categorized clinical databases and samples is also important.

### **d. Opportunity: Drug repurposing and orphan molecules**

*An antibiotic used for acne has turned out to have a very direct impact on the regrowth of dendrites, and is being tested for use with Fragile X.*

*Metformin is being studied in children who have had brain tumours removed.*

*For ten years people have screened compounds in the FDA roster for neurodegenerative impacts.*

#### **Considerations**

- Pharmaceutical companies need to release their orphan molecules. What will it take to get access to this intellectual property?
- Researchers and drug companies need to talk in a coherent and productive manner. The paradigm has changed.

### **e. Opportunity: The social determinants of health**

*There are large potential impacts on this area, e.g., aboriginal health, FASD, Addiction. We need to study the interaction between social context and the brain.*

*Child poverty is high in Canada. This is a political matter that is an opportunity to showcase that we are delivering better than the OECD average.*

#### **Considerations**

- A focus on 'at risk' populations would be a very good focal point for Brain Canada, as this is a deserted area, and there are a lot of gains to be made as opposed to simply putting more money into high cost, low effectiveness interventions.
- Sports and sports injuries receive a lot of attention, but there are many factors more relevant in terms of the development of neurological outcomes.

## f. Other Opportunities

- Once genes are identifiable for mental illness they are the road to understanding the molecular pathways in the brain. Whoever clones these genes will open up a whole new area of brain research.
- Devote all your resources to a 'non-marketable' disorder or orphan disease. The disorders may all be the same – we could learn a lot from that approach.
- We still don't understand what the beta amyloid precursor protein is there for. Should we have more of it or less?

## 4. Translation of Research Results

Below is a synthesis of participant responses to the question: "How can we as a brain research community support the translation of research results into new and better diagnostics, therapies and programs?"

Translating knowledge into results was a frequent topic of discussion at the consultations. In the words of one participant:

*A lot of money has been spent without any practical results. Don't make that mistake. People don't donate money anymore – they invest. This is an opportunity for Brain Canada to become a catalyst for accelerating research into practice.*

### a. KT Opportunities

- Engaging economists is another way to have an impact – they can help make the case for new investments.
- Ethics and knowledge translation are standalone areas meriting their own research.
- Use meetings and conferences to expose researchers and others to a wide variety of professionals so they can discuss meaningfully: this is low cost, effective, and the results are remarkable.
- Focus on prevention: Screening and diagnostics are an opportunity to have an impact in a measurable and pragmatic way.
- Fund training for students and scientists: not for research, but to use information to translate research into policy. These types of training programs can be done in a short time frame, and they create an informed population in society.
- There is an entire industry built on scaring the elderly into buying devices and playing games to prevent disease. Study the effectiveness of these games and devices.

### b. Examples of KT Successes

- A team at McGill consisting of a physician, an engineer, and a basic scientist found a way to map the brain for emergency surgeries in three seconds.

- Translating what we know into action takes money and feet on the ground. The stroke network put a trained volunteer to intercept people as they went into pharmacies. There was a nine percent reduction in heart attacks and stroke in one year. No government would scoff at that.
- We set up a way to train the new generation of social work researchers to do KT – they had to do an online KT course. It had very little impact. For our next iteration, we expected everyone to do the course, and to the greatest extent possible volunteer two afternoons a week at a clinic. The feedback from the researchers on seeing someone with Alzheimer's, from having to sit and feed someone for an hour wound up being more powerful than doing the online course.

### **Strategic Consideration**

- Should KT be a strategic priority for Brain Canada? If yes, what needs to happen to commit to the implementation of this priority?

### **c. Potential Partnerships**

Partnerships suggested during the consultations are listed below in alphabetical order.

- Calgary's Hotchkiss Brain Institute
- CanChild (at McMaster University)
- Celebrities and other high profile sports figures
- Graham Boekh Foundation
- IBRO, the International Brain Research Organization
- "Let's Talk Science"
- NeuroDevNet
- Pharmaceutical companies and Rx&D
- Provincial formularies
- Québec Consortium for Drug Discovery (CQDM)
- The Association of Fundraising Professionals (AFP)
- The Canadian Forces
- The Canadian Institute For Advanced Research (CIFAR)
- The Canadian Science Policy Centre
- The Centre for Neuroscience in Edmonton
- The Foundation Fighting Blindness
- The International Serious Adverse Events Consortium (iSAEC)
- The National and Canadian Football Leagues are interested in brain injury
- The School of Public Policy at the University of Calgary



#### **d. Potential Champions**

In addition to supported researchers, participants suggested the following potential champions for brain research and Brain Canada:

- Alexandre Bilodeau
- Roberta Bondar
- Etienne Boulay (football player)
- Sidney Crosby
- Stephen Fletcher
- Chris Hadfield
- Jay Ingram (host of Daily Planet)
- Michaëlle Jean
- Craig Oliver (CTV)
- Sarah Polley

## Appendix A: Participants

### Vancouver

Mr. Bill Barrable	CEO, Rick Hansen Institute
Dr. Lynn Beattie	President, Pacific Alzheimer's Research Foundation, University of British Columbia
Ms. Natalie Dakers	President and CEO, CDRD Ventures Inc. (Centre for Drug Research and Development)
Dr. Benedikt Fischer	CIHR/PHAC Chair in Applied Public Health, Faculty of Health Sciences, Simon Fraser University
Dr. Otto Forgacs	Chair, MIND Foundation of British Columbia
Dr. Gloria Gutman	WHO Expert Group on KT on Aging and Health, Simon Fraser University
Dr. Gabe Kalmar	Vice President, Sector Development, Genome BC
Dr. Michael Kobor	Scientist, Centre for Molecular Medicine and Therapeutics, University of British Columbia
Ms. Nicola Lewis	Executive Director, NeuroDevNet
Dr. Julie Robillard	Postdoctoral fellow and project lead, National Core for Neuroethics, University of British Columbia
Ms. Samantha Rogers	Corporate Development and Partnerships Coordinator, Michael Smith Foundation for Medical Research
Ms. Angela Webster	Executive Director, The Hecht Memorial Foundation
Dr. Max Cynader	Brain Canada Director
Dr. Ralph Strother	Chief Investment Officer, Max Bell Foundation

### Calgary

Mr. Pierre Berube	Executive Director, Psychologists Association of Alberta
Dr. Margaret Clarke	Senior VP of Policy and Programs, Sinneave Family Foundation
Ms. Teren Clarke	Executive Director, Canadian Paraplegic Association (Alberta)
Dr. Michelle Gagnon	Vice President, Norlien Foundation
Dr. Kevin Keough	Executive Director, Alberta Prion Research Institute
Dr. Ronald Kneebone	Professor, Department of Economics, University of Calgary
Dr. Bryan Kolb	Canadian Centre for Behavioural Neuroscience, University of Lethbridge
Dr. Glenda MacQueen	Vice Dean, Faculty of Medicine, University of Calgary

Dr. Grant McIntyre	Executive Director, Campus Alberta Neuroscience
Dr. Pamela Valentine	Vice President, Research and Innovation, Alberta Innovates Health Solutions
Dr. Jennifer Zwicker	School of Public Policy, University of Calgary
Dr. Ralph Strother	Chief Investment Officer, Max Bell Foundation

## **Toronto**

Ms. Brenda Agnew	Board Director, Three To Be
Dr. Naomi Azrieli	Chair and Executive Director, The Azrieli Foundation
Dr. Alan Bernstein	President and CEO, Canadian Institute for Advanced Research
Dr. Denise Figlewicz	Vice Dean, Research and Innovation, Schulich School of Medicine and Dentistry, Western University
Ms. Shirley Freek	Senior Development Officer, University Development, York University
Mr. Gary Goldberg	Director, The Barbara Turnbull Foundation
Ms. Mary James	Associate Director, Community Investment, Bell Canada
Mr. Brian Levine	Executive Director, The Glenn Gould Foundation
Dr. Karlee Silver	Program Leader, Grand Challenges Canada – Saving Brains
Dr. Martin Steinbach	Head, Division of Visual Science, Toronto Western Research Institute
Ms. Barbara Turnbull	Founder and President, The Barbara Turnbull Foundation.

## **Montreal**

Ms. Andrea Budgell	Senior Policy Analyst, Policies, Priorities and Analysis Division, Health Canada
Dr. Alain Gratton	Interim Scientific Director and researcher, Douglas Institute, McGill University
Dr. Antoine Hakim	Director, Neuroscience Research, Ottawa Hospital Research Institute
Ms. Vani Jain	Program Director, The J.W. McConnell Foundation
Ms. Janis Levine	Co-President, The Henry and Bernice Kaufmann Foundation
Dr. Helen Loughrey	Senior Director, Scientific Affairs, The Quebec Consortium for Drug Discovery
Ms. Kristina Ohrvall	Director of Research Planning and Special Projects, McGill University
Dr. Eric Racine	Director, Neuroethics Research Unit, Institut de recherches cliniques de Montréal

Mme Marie Robert	Founding President and CEO, NeuroTrauma Foundation
Dr. Laurel Young	Assistant professor, Music Therapy, Concordia University
Dr. Vincent Castellucci	Brain Canada Director
Dr. Lili de Grandpré	Brain Canada Director

## Halifax

Dr. Bruno Battistini	CEO, New Brunswick Health Research Foundation
Ms. Meredith Campbell	Director of Programs, Nova Scotia Health Research Foundation
Dr. Gerald Johnston	Associate Dean Research, Faculty of Medicine, Dalhousie University
Dr. Susan Kirkland	Professor, Departments of Community Health and Epidemiology and Medicine, Dalhousie University
Dr. Ken Rockwood	Director, Geriatric Medicine Research Unit, Dalhousie University/ Canadian Dementia Knowledge Translation Network
Dr. Darlene Skinner	Professor of Behavioural Neuroscience, Faculty of Science, Memorial University
Dr. Donald Weaver	Canada Research Chair in Clinical Neuroscience, Dalhousie University



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The partners have a special interest in health/health research and their experience with foundations and professional associations includes consultations on a wide range of issues where they are valued for their informed objectivity.

Examples of national/international work in the neurosciences area include projects with Canadian Blood Services, the World Health Organization, Health Canada, the Public Health Agency of Canada, Neurological Health Charities Canada, and the Institute of Neurosciences, Mental Health and Addiction at CIHR as well as other CIHR Institutes.

## Appendix B: Consultation Agenda

- 8:30 am **Welcome and Opening Remarks:** Astrid Eberhart, Director of Partnerships and Stakeholder Relations, Brain Canada
- 8:35 am Purpose, agenda, introductions, consultation guidelines  
Dorothy Strachan, Facilitator
- About Brain Canada: overview, commitments, a unique model  
Astrid Eberhart, Director of Partnerships and Stakeholder Relations  
Q and A
- 9:15 am **Current Situation**
1. What are the most exciting/promising developments today in brain research in Canada and internationally?
  2. What significant gaps/challenges to you see in brain research today in Canada and Internationally?
- 10:15 am Break
- 10:30 am **Opportunities**
3. Based on the purpose statement for these consultations, what opportunities are you aware of where Brain Canada would be ideally situated to work collaboratively with others in addressing the current situation?
  4. How can we as a brain research community support the translation of research results into new and better diagnostics, therapies and programs? (e.g., through leadership, champions, partnerships etc.)
- 12:20 pm **Concluding Remarks**
- 12:25 pm Feedback
- 12:30 pm Closing