



**CBRS Leadership & NHCC Governing Council
Patient Engagement Strategy Planning**
Monday, August 24, 2020
1:30 pm (ET), 11:30 am (MT), 10:30 am (PT)

INTERNAL MEETING NOTES

CBRS Leadership participants

Dr. Yves de Koninck, CBRS Chair
Dr. Judy Illes, CBRS co-chair (first 30 minutes)
Dr. Caroline Menard

NHCC Governing Council participants

Michelle McDonald, NHCC chair,
Kent Bassett-Spiers, NHCC treasurer
Bev Heim-Myers
Stefanie Ince
Susan Marshall, NHCC vice-chair
Deanna Groetzinger, Staff

Legend:

YDK: Yves de Koninck
CM: Caroline Menard
MB: Marianne Bacani
DG: Deanna Groetzinger
Michelle: Michelle McDonald
Kent: Kent Bassett-Spiers
Bev: Bev Heim-Myers
Susan: Susan Marshall

Overview (YDK)

Canadian Brain Research Strategy (CBRS) is an initiative that has emerged in the last 5 years, which in line with other global initiatives to better understand the brain and how to move forward with this information.

There is also the International Brain Initiative (IBI) that brings together different initiatives from Canada, the US, Europe, China, Australia, Japan and South Korea to establish a platform where these groups can synergize and work together. In the IBI, different members identified certain focus areas for discussion, called Working Groups. In the CBRS, we are also trying to create a similar system (e.g., Stakeholder Collective, Research Leaders Collective, and ECR Collective).

CBRS' structure will be very similar to IBI's structure. Partnership with constituents is really important for CBRS.

Neuroscience research in Canada:



Canada has a long tradition of strong research in brain science, coast to coast, especially in topics like in memory, basis of cognitive neuroscience, cross-cutting neurotechnology and expertise, neuroinformatics. All of these strengths we need to capitalize to move the field forward.

CBRS is a grassroots initiative in a sense that scientists and NHCC participate in the thinking process. It brings together leader scientists across the country. It's a collective effort.

MISSION: Build on Canada's strengths and current investments in neuroscience to transform neurological and mental health for Canadians.

VISION: Innovative and collaborative brain science driving policy, social, health and economic advancement for Canada and the world.

CBRS' Enabling Principles: Collaborative, Transdisciplinary, Open.

Pillars of the Strategy: Moving from Understanding (how the brain works), to Addressing (health challenges through prevention and treatment), to Building (better artificial intelligence), and to Applying (brain research to improve individual brain health, education, and societal and cultural well-being).

Central Organizing Question: How does the brain learn, remember, and adapt?

CBRS sees neuroethics as an important pillar for making sure that the Strategy benefits the society as well.

At the Halifax meeting, we asked Scientists to list major priorities to see if we can work as a consortium, across the country, to move forward towards an open-science approach.

CBRS is not trying to be one-stop-shop, a funding agency, or an entity that attracts funding for itself. CBRS is there to inspire decision makers to invest in brain research through new channels. CBRS tries to be a hub between major projects and funding agencies.

CBRS recently received a grant of 1.5M (for 5 years) to fund the networking aspect of the Initiative: to hire a Secretariat, to host networking activities, and to build a coalition.

MISSION: Raising Awareness, Raising Issues, Raising Engagement.

NHCC role in building CBRS patient engagement

Kent: How do you differentiate between other strategies (for example, Alzheimer's strategy) and the CBRS?

YDK: CBRS focuses on fundamental issues and aims to gather a broader context across multiple disciplines, hoping that we can make a bigger impact this way.

Kent: "Bigger bang when making it broader"

DG: Moving forward, would you see CBRS as a process of identifying where Canada can best contribute to the IBI, in terms of “(only) in Canada, we can do this thing better than anywhere else?”

YDK: Absolutely. We have to identify where we can make a difference and that’s very important. Personally, I would like Canada to be a role model of “how are we going to do this” research-wise. We need to do this in a collaborative, transdisciplinary fashion. We need to inspire decision makers in supporting research that will be conducted differently from other countries.

Bev: For clarity, this initiative is not necessarily to fund discovery science in specific diseases, but it’s looking at “how do we collaborate, share it, and therefore expedite discovery in different disease disciplines so that all disease/professional disciplines can learn?”. Is this correct?

YDK: On discovery research, we need to put more funding as a nation into this. But in addition to that, then comes in “we want to find ways on multiplying on this enormous resource in the country to bring it to another level, and more efficient at advancing research and guide the outcomes of the research”.

Bev: When you talk about new generation of scientists, do you want to encourage scientists to focus not just on one disease, but to find answers that might be common in all of them? You’re hoping to develop a new group of scientists that has a broader perspective at brain disease or trauma?

YDK: Yes. It’s not to speak against “Expertise”, but YDK believes that we need specialists to properly apply their expertise into the research. A big effort is breaking language barriers, and opening horizons to other problems they wouldn’t have focused on otherwise. Unless you understand the real problems in the other discipline, you can’t really apply your expertise to actually help. That’s where we need people to be transparent. When you work in silos, if you only speak to colleagues in the same field, you’re missing other valuable information.

Re: CBRS and the NHCC

Ideas from the Governing Council how stakeholder involvement may take place, how they can assist CBRS moving forward, others ways how the NHCC can contribute to the Strategy.

Kent: We work with stakeholders to communicate how we go forward by discussing research and how to apply the research. Knowledge translation and informing the community is valuable. Bringing the community’s perspective in the dialogue is important.

Michelle: Will CBRS run through the Secretariat, will it be centralized through that, or will CBRS run through the 30+ institutions? How will each of the organizations work with CBRS?

YDK: The Secretariat will focus mainly on operations/administrative matters. We will have a Stakeholders Collective. We can envisage levels of interaction within Collectives. With IBI, we have a regular meeting will all Collectives to participate in global discussion, and then each group has their own meetings to identify their own priorities. CBRS will follow a similar system. The objective is to not just reach out to the community, but is there to also help build the vision of the CBRS. Scientists need to understand from the patients and caregivers’ perspectives, and guide their research from this.

DG: We want to avoid tokenism. There were meetings where there are people from the community saying they were overwhelmed with what they were hearing, and has led them to feel unable to contribute to the discussion.

YDK: The dynamics between collectives is important. When you gather everyone there will be various levels of understanding, so it's helpful when people regroup in collectives first, identify priorities themselves, and then come back together as a bigger group to discuss.

Bev: To avoid making the patient/caregiver community overwhelmed, educating them prior to the meeting with scientists is key. Bringing the patient/caregiver community (lived-experience experts) first, and then together with scientists, can make a difference. This eliminates intimidation and allows lived-experience experts to actually contribute to the general discussion.

YDK: Agrees with Bev, as the CBRS is here to engage different stakeholders and identify priorities.

Susan: Agrees with Bev, that for many patients, they would need to have a certain level of understanding before they can participate in the discussion, but if its more about understanding their lived experience, then that's a difference conversation as well. Our medical community understands the needs of the patients very well because they get a lot of opportunities to hear people's stories and understand their challenges, and often that's the basis of a research project.

Susan: Is there an effort to encourage research into the causes of the disease?

YDK: This will be in symbiosis of understanding the brain. We are understanding how we adapt to the environment. Humans are social beings and we cannot be dissociated from our environment. We need to understand how we interact with the environment and how it affect us.

Re: Communication:

YDK: It's important to note that we need to learn how to speak to people who are not expert on other fields and in a way where one can help the other. We need to remember that we should bring people to the right level of understanding, engage in a dialogue, and learn to speak in a way that it sparks ideas. The conversation is an effort that goes both ways for patients and scientists.

Next steps:

Re: Early Career Researchers (ECR) workshops, Retreat, and Personnel Hiring

YDK: Most of the funds in the grant was to cover travel. We hope we can go back to face to face meetings soon. In the meantime, we are moving forward with a Retreat this Fall via Zoom. This change in expense projection has allowed us to reallocate funds towards hiring staff instead.

YDK emphasizes how DG is invaluable to help us connect to more people and the guidance on this. Perhaps we need to host preparatory meeting sessions to educate patients leading up to Retreat/main meeting.

YDK: Notes that the NHCC's help is invaluable, and that we'll do this step by step. We want to gather ideas of who else should be in the table, how should we shape the next couple of meetings to help build up the CBRS.

DG: Do you like NHCC to spearhead the development of Stakeholders Collective?

YDK: If you can help us build up stakeholders collective, that would be most appreciated!

YDK: Within IBI, we want Canadians to be part of the Stakeholders Collective as well.

Michelle: Is there funding for the Stakeholders Collective? Is there going to be compensation for the work DG/Stakeholders will be putting in this?

YDK: We can discuss that. If we have to organize/invite to meetings, definitely CBRS can support that. There is funding allocated within the CBRS to support individuals to participate in IBI activities. There is also a small funding from IBI to support CBRS individuals to participate in their activities.

Re: ECRs and Stakeholders Perspective

CM: Will host two upcoming workshops (via Zoom) with ECRs (appointed within the last 5 to 10 years). One of the discussion topics will include transdisciplinarity. We also talk about how researchers in different fields can work together, and how important it is to also include the stakeholders' perspectives in their research. Hosting conversations via Zoom also brings good opportunity to host online public seminars for the community. This brings an opportunity for ECRs to talk about their science and for the public to learn about the latest in science. Further details can be discussed later.

YDK: Agrees on using social media as a tool to engage people in the dialogue.

Michelle: Shares an idea on hosting a panel where the community representatives discuss and educate researchers how to collaborate effectively with the community to make sure the benefits are towards community as well as the researchers. The community wants to become more meaningful participants. Educating ECRs is a great way forward!

NHCC Governing Council action items:

- Forward recommendations for the Secretariat position
- Browse through recommended readings available at the www.canadianbrain.ca website

Program Leaders action items:

- YDK to coordinate with DG to organize a meeting with IBI re: comparison of IBI's Stakeholders Collective and CBRS'
- DG to send out YDK's presentation (the final version will be sent by YDK to DG)