



CAREB | ACCER

CANADIAN ASSOCIATION OF RESEARCH ETHICS BOARDS  
L'ASSOCIATION CANADIENNE DES COMITES D'ETHIQUE DE LA RECHERCHE

## **President's Report: Strategic Direction 2016-2020**

This report represents a summary of the strategic planning discussion undertaken by the CAREB-ACCER Board of Directors in 2015-2016. The Board gratefully acknowledges input derived from consultation with three former CAREB-ACCER presidents: Laurel Evans, Sharon Freitag and Alex Karabanow. Discussions are ongoing and the full strategic plan is anticipated by June, 2017.

### **Mission**

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CAREB-ACCER is a national organization dedicated to supporting and promoting the work of Research Ethics Boards (REB) members and administrators across Canada.

### **Vision**

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CAREB-ACCER's vision is to realize excellence in human research ethics review, administration and oversight. This is accomplished through:

- Supporting and promoting knowledge exchange, professional development and education within the CAREB-ACCER community;
- Fostering dialogue regarding local, national and international issues relevant to CAREB-ACCER members;
- Enhancing awareness of REB members' and administrators' contributions to the research enterprise in Canada;
- Representing the interests of REB professionals on national and international initiatives;
- Partnering with organizations to advocate for the recognition of adequate resources needed for REBs to fulfill their mandate; and
- Creating and providing educational opportunities and resources needed to successfully promote ethical research.

## Background

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CAREB-ACCER was established in 2000 as a community of Research Ethics Board (REB) professionals, namely REB chairs, members and administrators. Working in relative isolation from one another in a challenging environment and facing increasing responsibilities, it became apparent to REB professionals that they needed to work together to share best practices and to improve the visibility and credibility of their professional roles within their own organizations, the research community, and the larger public realm. With major government policy discussions underway, it was clear that there was an urgent need for a strong representative voice in national discussions to ensure that the issues and concerns of REB professionals would be heard and considered in policy development.

Since 2000, CAREB-ACCER has grown both its membership and available services. CAREB-ACCER is now an incorporated, not-for-profit association. Our active membership as of April 2017 stands at 220 and is representative of the diversity in REBs across Canada. With over 1200 registered users on our website and 300-350 delegates attending our annual national conference and professional workshop day, we know that there is a strong need for research ethics education, resources, information and networking. While there remains room for growth in advocacy activities, CAREB-ACCER has earned recognition as a stakeholder and advisor on various national and international initiatives and tables.

The successful growth of CAREB-ACCER is to be applauded; however, 17 years in, we are at a crossroad. In a sense, we have out-grown ourselves.

CAREB-ACCER is currently structured under three “arms” or areas of service: Conference Planning; Professional Development; and Membership Services and Communication. Each arm is run by a Vice President. The President oversees organizational direction and operation with the advice and support of the Past President. The Treasurer and Secretary must ensure that the Association meets its fiduciary and financial obligations as a legally incorporated entity and the remainder of the Board is comprised of up to five Members at Large.

Over the last two years, it has become clear that CAREB-ACCER has reached its maximum capacity in terms of what is realistically achievable under this structure. The majority of the CAREB-ACCER activity and workload is carried out by the Directors who are continually stretched to accommodate their volunteer commitments to CAREB-ACCER on top of the demands of their full-time jobs. Institutional support for our Directors is varied; while some are able to carve time out of their workday to conduct CAREB-ACCER activities, others are not. These dedicated individuals must conduct Association-related work on their own time; evenings, weekends and vacation time. Increasing demands on the Executive in particular, have made succession planning difficult.

Apart from an administrative coordinator who is employed for 12 hours per week (.33 FTE), all CAREB-ACCER work is done on a volunteer basis. The revenue under which CAREB operates is predominately generated from the annual National Conference. Should CAREB-ACCER's financial situation improve with income generated from planned educational, training and certification activities, we may be in a better position to hire an Executive Director. This would most certainly alleviate some of the burden on the Executive. Until that time, if CAREB-ACCER is to continue as an organization, our choices are to either scale back activities or to revise our current board and committee structures. As such, the overarching goal for CAREB-ACCER in the next five years is to create a robust organizational structure sufficient to support the national scope of the CAREB-ACCER mandate and in doing so, find a manageable way to ensure not only the quality of products and services but the continuity of the association over the long term.

The following sections describe the products and services CAREB-ACCER is in the process of creating, and the rationale for a new structure to allow better service delivery.

## **Professional Development and Education**

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### **REB Professional Certification**

Following implementation of the first edition of the Tri-Council Policy Statement (1998), the field of research ethics administration became informally recognized. Positions created in Research Ethics Offices included REB directors, managers, officers, coordinators, analysts and others. Administrators were tasked with not only managing the office and the ethics review process, but also training and orienting REB members, educating researchers, students and department heads. As regulatory requirements have evolved, the roles of REB professionals have become more robust—expanding to encompass quality assurance, auditing, monitoring functions and the responsible conduct of research.

While professionalization of REB administration has been discussed within the research ethics community for a while, serious discussion about CAREB as the provider of a certification program has amplified over the past five years. Factors responsible for this direction include the 2010 loss of funding from Health Canada and the Canadian Institutes of Health Research (CIHR) for the National Council on Ethics in Human Research (NCEHR) which led to its dissolution; increasing focus on REB harmonization initiatives provincially and nationally; the creation of standards for REBs reviewing regulated clinical trials; and the realization that professionalization of the research ethics system is fundamental to Canada reversing the downward trend in industry-funded clinical trials. As recommended by the Standing Senate Committee on Social Affairs, Science and Technology in its 2012 report, *Canada's Clinical Trials Infrastructure: A Prescription for Improved Access to New Medicines*, there needs to be an “accreditation program for research ethics review which assesses and awards accreditation to

research ethics boards that review, approve and oversee clinical trials of unapproved drugs” (p. 34).

In 2013, CAREB proposed to establish a recognized and sustainable formal certification program in human research ethics practice and administration. This program would serve to advance CAREB’s professional goals and to provide practical education for persons working in the research ethics field, setting a standard for knowledge of Canadian policy on the review of research with human participants. It is anticipated that those who meet the standard for certification will benefit from formal recognition of their skills, expertise and knowledge of Canadian policy on the review of research with human participants. Further, institutions will benefit from an increase in the quality of their research ethics programs with an associated reduction in risk for the institution

The program, designed for and offered to REB administrators, practitioners and those with an interest in the research ethics field, will be delivered on a modular basis beginning in 2017.

### **Conference, Workshops and Webinars**

The CAREB-ACCER national conference, inclusive of the pre-conference professional development workshop day, is currently the only education and professional networking event of its kind for research ethics professionals in Canada. We have been successful in building up a strong event that attracts the national and international attention of speakers and delegates. However, as a growing organization, we cannot simply rest on our laurels. Diverse and geographically disparate membership combined with financial constraints means that we need to be more creative and flexible in terms of content, frequency and mode of delivery if we are to support the education and professional development of our members. As such, CAREB-ACCER has committed to the design and delivery of a series of professional development webinars

Plans for the series include 15 webinars; 11 will focus on foundational skills while the remaining 4 will address special and emerging issues in research ethics. The webinars will dovetail with the CAREB-ACCER professional certification program, qualifying as continuing education in both core competency and advanced activities required for the ongoing maintenance of certification. The webinars will also function as stand-alone resource for members of CAREB-ACCER and the broader research community who may not desire to take the certification route. A team of content designers has been secured and the first webinar is tentatively set to launch in May, 2017.

We have also launched the Virtual REB (vREB), a professional development initiative designed to facilitate discussion on a series of case studies. These cases have been chosen to highlight a range of common ethical issues typically found in human research applications. Each study will result in a collaborative product to be archived as a resource available for members to use at their own institutions, to support the orientation and training of REB members and professionals.

## **Knowledge Exchange**

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In 2015-2016, CAREB embarked on a project to improve the form, structure and appearance of our communication tools to increase our capacity for knowledge exchange. In doing so, we were also able to clean-up our membership lists, streamline our mailing lists and ensure compliance with accessibility laws and anti-spam legislation.

While the National Conference and AGM is widely recognized as hub for research ethics networking and knowledge exchange, we recognize that this opportunity comes but once a year and not all members can attend. It is important that CAREB-ACCER has efficient platforms to disseminate information and allow members from different geographical areas to engage with one another. Therefore; we have enhanced our website with features such as the Newsroom and the CAREB-ACCER Forum—a modern symposium for members to post issues, ask questions and engage in dialogue on relevant issues concerning professional practice, administration and regulatory and policy matters related to human participant research. We intend to continue to develop and enhance our communication tools including the launch of a Canadian REB Directory. As part of this initiative, we have had preliminary discussions with the Canadian Clinical Trials Coordinating Centre (CCTCC) REB Accreditation Working Group to determine how CAREB-ACCER plans for a directory may align with and be enhanced by collaboration, given that recent recommendations released by that group include the creation of a National REB Registry.

## **Advocating, Promoting and Enhancing Awareness**

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Historically, advocacy and public affairs has been an important component of CAREB-ACCER. At one point, the Association had a Public Affairs Committee. In order to promote the interests of REB professionals, CAREB-ACCER must remain relevant by fostering and engaging in dialogue about local, national and international issues that affect our members. In addition to developing internal communication tools, it is important that we periodically step out of our own organization and onto the external stage.

In the last 2-3 years, we have been looking inward, concentrating on developing the CAREB-ACCER brand strategy, products and services; and transitioning to an incorporated association with all of the legal responsibilities that entails. While this was deemed necessary, it did detract focus somewhat from our involvement in public affairs. We recognize that activities related to strategic partnerships with organizations like Public Responsibility in Medicine and Research (PRIM&R), Alliance for Clinical Research Excellence and Safety (ACRES), Network of Networks (N2), Canadian Clinical Trials Coordinating Centre (CCTCC), Canadian Association of Research Librarians (CARL), Research Data Canada (RDC) and others need to be encouraged and fostered. As such, we will be revising our organizational model to once more include a Public Affairs Committee with a mandate including but not limited to, advising

on advocacy activities, drafting CAREB-ACCER position statements and responses (e.g. to relevant government and regulatory bodies) and representing CAREB-ACCER's interests on external committees and working groups.

## **Ensuring Productivity and Continuity**

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In order to ensure the continuity of CAREB-ACCER as a productive association, three main goals must be achieved.

1. The current structure of the CAREB-ACCER Board of Directors must be revised. The current workload borne, in particular by the Executive, is unsustainable. Models must be examined to decentralize responsibilities where possible and better delineate the various functions of the board. This will allow the creation of volunteer positions that are more focused and support efforts for skills-based recruitment.
2. The organization must induce the membership to become more involved. As a member-driven organization, member engagement is the cornerstone of CAREB-ACCER's success. It is through the generosity and expertise of our members that we can offer the services that we do and we encourage members to become involved with the Association by participating at the committee and Board of Director's levels. Plans to restructure the current Board include a decentralization of initiatives that will better employ the membership on working committees and task groups opening up new leadership roles. Successful restructuring is dependent on the membership's commitment to participate but we are confident that we have an enthusiastic and skilled membership base.
3. Currently most of the revenue under which CAREB operates is generated from the Annual National Conference. The cost of the conference itself is often offset by a generous grant from the Interagency Advisory Panel on Research Ethics (PRE) on behalf of Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council (NSERC), and Social Sciences and Humanities Research Council (SSHRC). CAREB-ACCER needs to find additional sustainable funding sources if we are to hire an Executive Director to support the organizational workload. Additional grants should be explored as well as income-generating products (i.e., educational, training and certification activities), and ways to increase membership.

## **Conclusion**

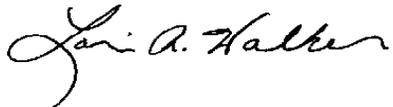
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A considerable amount of concerted effort from current and past members, be it at the board of directors, committee or participant level, has made CAREB-ACCER the success it is today. In the last 17 years, we have made incredible strides—planning, developing and executing CAREB-ACCER's vision. However, it is important that we be

realistic and recognize that success, under the current system, is somewhat precarious. Rather than scale back, we believe we must forge ahead or risk a dearth of professional training and education for research ethics professionals in Canada. As such, the CAREB-ACCER Board of Directors will be taking the next two months to reflect on how best to create a robust organizational structure sufficient to support the national scope of the CAREB-ACCER mandate. In doing so, we hope to find a manageable way to capitalize our resource base; meet our goals in terms of products and services; and ensure the continuity of CAREB-ACCER. The result will be a more fulsome strategic plan, circulated to the membership in June, 2017

My sincere thanks to the CAREB-ACCER Board of Directors and membership for their ongoing support of CAREB-ACCER's effort to advance the ethical conduct of human participant research in Canada.

Respectfully submitted,

A handwritten signature in cursive script that reads "Lori A. Walker". The signature is written in black ink and is positioned to the left of the typed name.

Lori A. Walker  
President, CAREB-ACCER