

CAREB

Pre & Post



President's message

Dear CAREB members,

As I come to the half-way point of my term as CAREB President, I am proud and honoured to contribute to the inaugural CAREB Pre & Post Newsletter, a new tool to communicate with our members regarding CAREB's activities and recent happenings in the world of research ethics, from a Canadian perspective.

It has been a long, hard winter for most of us across the country, and we are thankful that spring has finally arrived. Along with the blooming flowers comes the CAREB 2014 National Conference and Annual General Meeting, to be held at the Fairmont Queen Elizabeth Hotel in beautiful Montreal, Quebec. Running from April 23rd through 26th, I am certain that you will reap many benefits from attending.

The Conference Planning Committee has been working diligently to develop an exceptional conference program for you on April 25th and 26th. The theme of this year's conference is "Plus ça change?", where we will be revisiting historical and recurring ethical issues as opportunities to find new and creative solutions. The keynote speakers include Professor Charles W. Lidz (University of Massachusetts Medical School), Professor Ian Mosby (University of Guelph), Professor Joseph J. Fins (Cornell University), Professor Ted Palys (Simon Fraser University) and Professor Jonathan Kimmelman (McGill University). We have expanded the number of breakout sessions to provide a wide range of topics to cover all areas of research ethics. Our pre-conference workshops, planned by the Professional Development Committee and

being held on April 24th, will provide educational opportunities for all levels of experience and includes topics such as administrator basics, biobanking, responsible conduct of research and emergency research.

On behalf of CAREB, I am pleased to welcome the Cana-

dian Animal Ethics Coordinators (CAEC) to CAREB, as they now have their own conference day on April 23rd. We hope this addition is a permanent one as we recognize the needs of our current and future CAREB members.

If you have already registered for the CAREB National Conference and AGM, thank you, and if not, we hope that you do so very soon.

In addition to planning for the conference and workshop, the CAREB board and its committees have been hard at work on a variety of projects, some of which will be profiled in the Newsletter. The goals of these projects are to broaden CAREB's offerings. Some of these will strengthen our back-end systems and infrastructure. Others will provide more educational and professional services to our members and provide better ways to communicate with you as well as to promote the CAREB brand. We are excited to be launching these initiatives in the coming months, so please stay tuned.

Finally, I would like to thank all of our board and committee members for their contributions over the year. Special shout-outs go to:

Lori Walker – Vice-President, Conference Planning Committee

Diane Martz – Vice-President, Professional Development Committee

Sandra Reid and Suzanne Richardson – Acting Co-Vice-Presidents, Membership and Communications Committee

I hope you enjoy our inaugural issue of the Pre and Post, and I look forward to seeing many of you in Montreal!

Rachel Zand
President



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ABOUT CAREB NEWSLETTER

CAREB Pre and Post is not a refereed journal and does not publish full length articles. The opinions expressed are those of the writers, and do not necessarily represent the views of CAREB. CAREB Pre and Post will be distributed via the CAREB listserv and can be read on the CAREB website: <https://www.careb-accer.org/>.

Contributions are welcome. If you have a suggestion for upcoming editions of the newsletter or if you would like to contribute an article, please email: post@careb-accer.org.

About CAREB

CAREB was established in 2000 as a community of research ethics board (REB) professionals, namely chairs, members and administrators of REBs. Faced with increasing responsibilities and working in a challenging research environment, a desire emerged for professionals to share best practices and to work together to improve visibility and credibility within their own organizations, the research community, and the public at large. With major policy discussions underway, there was a clear need for a strong representative voice in national discussions to ensure that the issues and concerns of the REB would be heard and considered in policy development. We respect our past while moving forward to embrace new challenges with new solutions. We seek to maintain our current membership while also increasing and evolving membership.

CAREB's membership is enthusiastic, highly motivated, generous of spirit, collaborative, action-oriented and shares a strong sense of community and purpose. As a volunteer supported organization, CAREB relies on the expertise and energy of its members to forward its mission and to conduct its business functions, including: organizing and running the annual national conference; creating timely and thoughtful responses to national initiatives; establishing position and guidance documents; and developing and facilitating education and outreach initiatives.

Over the past decade, a growing membership and positive feedback from CAREB members on its offerings have suggested that CAREB continues to be relevant to its

members. In its first ten years, CAREB has established a firm foundation upon which to build and has earned a "seat at the table" in many national policy setting discussions. CAREB's current focus is to continue its growth as a national organization dedicated to serving the pragmatic needs of its membership, and to consolidate and strengthen its ability to do this well and over the long term. In particular, CAREB is evolving from an organization driven by a few key members to a more broadly based organization by strengthening its ability to recruit experienced and talented individuals to lead and participate in its working groups and board and implement a more sophisticated succession plan. Collaboration with other research ethics organizations in Canada and internationally must also be forged.

Membership in CAREB ensures that you never work alone, that you have easy access to the experience and advice from colleagues at similar institutions who face similar challenges as you. Access through CAREB to your colleagues gives you a voice through which to speak.

One of the ways that CAREB proposes to give you this voice is through expanding its web offerings to include: sites for discussion, examples of prior decisions with examples as specific as possible considering the need to protect confidentiality; and case studies that have had an impact on an institution's application of the TCPS2. This shared experience will create a community of research ethics professionals who are both similar and different in their local needs. In addition, future services include online educational modules and an REB professional certification. The first stage is expected to begin in September 2014.

This will be in addition to CAREB's current initiatives as a national association dedicated to promoting the ethical conduct of human research and the protection of research participants, by facilitating research and supporting organizations in earning and maintaining public trust. CAREB provides information, education and advocacy for its members and continues to grow its services and roles.

CAREB's goals include: the protection of research participants; managing the risk inherent in research with human participants by ensuring compliant, consistent and principle-based REB review; providing ongoing professional development and advocacy; collaboration with various research and research ethics-related endeavors by serving on several harmonization initiatives and working groups in the development of standards and standard operating procedures; staying abreast of emerging issues, compliance re-

quirements provincially in Canada and internationally.

We hope to achieve recognition by research institutions in Canada of our leadership and expertise and what we can provide to their REB professionals and oversight programs; increasing membership and representation within institutions ; greater participation including: commitments to take online courses and webinars when they become available; funding from institutions to allow for staff to attend conferences or inviting CAREB to come into institutions to provide education and professional development; volunteering for CAREB committees and events; and an understanding, based on discussions with senior administrators, REOs and REBs of what they need and how CAREB can help them achieve their internal objectives for REB professionalism and compliance.

CAREB Board of Directors

<i>Name/Affiliation</i>	<i>Position</i>	<i>Term</i>
Rachel Zand University of Toronto	President	2013-2015
Ken Jenkins Capital District Health Authority	Past President	2013-2015
Lori Walker Brock University	Vice-President and Chair of Conference Planning Committee	2013-2015
Diane Martz University of Saskatchewan	Vice-President and Chair of Professional Development Committee	2011-2014
Catherine Paquet University of Ottawa	Vice-President and Chair of Membership and Communications Committee	2013-2015
Patrick Clifford Southlake Regional Health Centre	Treasurer	2011-2016
Susan Babcock University of Alberta	Secretary	2011-2016
Suzanne Richardson University of British Columbia	Member-at-Large and Acting Co-Chair of Membership and Communications Committee	2013-2016
Sandra Reid Newfoundland & Labrador Health Research Ethics Authority	Member-at-Large and Acting Co-Chair of Membership and Communications Committee	2013-2016
Tony Kerr OCAD University	Member-at-Large	2013-2015
Maureen Nummelin University of Waterloo	Member-at-Large	2013-2014

For a list of all CAREB Committee Members, please visit:
<http://www.careb-accr.org/content/careb-committees>

Researcher-participant confidentiality now a formal concept in Canadian law

February 3, 2014

Reprinted from CMAJ
DOI:10.1503/cmaj.109-4717
— Miriam Shuchman, Toronto, Ont.

The successful quashing of a search warrant for confidential research records has changed the landscape for protecting research participants in Canada, says a research confidentiality expert. John Lowman, a criminology professor at Simon Fraser University in Vancouver, British Columbia, says the court decision made researcher-participant confidentiality privilege a formal concept in Canadian law. However, the privilege won't apply automatically to all confidential data; the ruling from Quebec Superior Court underscores that it must be argued on a case-by-case basis. The pivotal case began in late May 2012, when an international manhunt was underway for Luka Magnotta, the Montréal porn actor suspected in the gruesome, videotaped murder of a Concordia University student in Montréal. With the web awash in photos of Magnotta, a man contacted police and told them that five years earlier, when he was a research assistant on a Social Sciences and Humanities Research Council-funded study of escorts, he had interviewed the alleged murderer, University of Ottawa criminologists Chris Bruckert and Colette Parent led that study, but when Montréal police asked Bruckert if Magnotta had been interviewed, she said she didn't know.

"In fact, there was no way I could have known," she told CMAJ. To protect the privacy of research subjects working in the sex trades, Bruckert and Parent used strict confidentiality protocols, including asking research participants to choose pseudonyms — Magnotta chose "Jimmy" — and

having their research assistants sign the pseudonyms to consent forms, to guard against anyone identifying participants based on handwriting. After an interview is taped, transcribed and stripped of obviously identifying information, they send it to the participant to delete other details that could identify them. Once the participant returns the transcript, the team destroys the participant's e-mail address, along with the connection between the name, e-mail address and pseudonym.

Undeterred, police told Bruckert they would take legal steps, including a search warrant, to obtain the interview.

Bruckert contacted the Canadian Association of University Teachers (CAUT) where Executive Director Jim Turk hired Peter Jacobsen, a lawyer known for defending journalists who are pressed to divulge their sources. Bruckert sent the digital audiotape of the interview and the 68-page transcript to Jacobsen's Toronto office. Police seized the materials there, but took them in a sealed package, because of the legal move to quash the search warrant on the grounds that it would violate the researchers' promise of confidentiality.

By then, Magnotta had been arrested in Europe. Later he wrote an affidavit stating that he gave an interview as "Jimmy" in a study at the University of Ottawa, that he was assured the interview would be private and confidential, and that he wanted it to remain so.

To Bruckert, the threat was clear: her research on sex workers would be impossible without confidentiality. But the issue had been tested only once before in Canada. In a 1994 Coroner's Inquest in Vancouver, a masters' student was subpoenaed to testify about confidential interviews with

MEMBERSHIP AND COMMUNICATIONS COMMITTEE

The Membership and Communications Committee (MCC) is responsible for developing and maintaining communications, programs and processes appropriate to the needs of the Membership. The committee's activities include developing and implementing communication tools and programs for CAREB members, managing CAREB's web presence, developing recruitment initiatives and extending CAREB's reach to others.

The MCC also identifies opportunities for CAREB involvement in regional groups and events, responds to concerns and queries of the membership, and provides consultation to other committees or projects on matters of membership services.

CONFERENCE PLANNING COMMITTEE

The Conference Planning Committee (CPC) is responsible for planning and promoting the annual general meeting and national conference, including setting the conference program, inviting presenters and arranging logistics.

PROFESSIONAL DEVELOPMENT COMMITTEE

The Professional Development Committee (PDC) serves to support CAREB members in their efforts to excel in their work through professional development activities and conferences focusing on the delivery of programs relating to the ethical review of research with humans.

The committee's activities include planning, publishing and implementing workshops on various aspects of the development, delivery and management of research ethics review to the CAREB membership, delivery of CAREB's workshops, and development of a web accessible resource centre for CAREB members.

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individuals who assisted suicides among people with HIV/AIDS, but after he refused to answer questions, the coroner ruled that the student's communications with his research subjects were privileged so his refusal to answer questions was not contempt of court.

As Bruckert and Parent worked to prepare their case, CAUT negotiated with the university seeking its support of the researchers, but University of Ottawa President Allan Rock wrote Turk that the university would not pay legal costs "in the context of criminal proceedings." Members of the university's Research Ethics Boards also pressed for support for the professors, writing Rock that a board had approved the research on condition of the participants' confidentiality, and months later, University administrators agreed to cover about half the CAUT's expense, or \$150,000.

The hearing took place in April 2013 before Justice Sophie Bourque of Quebec Superior Court. Her 37-page decision issued Jan. 21, follows a legal framework known as the Wigmore criteria, a four-step analysis to determine if a particular

communication should be protected against disclosure. The case hinged on whether the public interest in obtaining the "Jimmy" interview for the investigation and suppression of crime outweighed the interest in what Justice Bourque described as "the free flow of accurate and pertinent information," which could dry up without a reliable promise of confidentiality. She broke the seal and reviewed the interview transcript privately, but did not share its contents, writing that its relevancy to the charges against Magnotta or to a "not criminally responsible" defence was "minimal at most and marginal." Bourque quashed the search warrant, concluding that "the Confidential Interview is covered by the researcher-participant confidentiality privilege and...it should not be disclosed."

The Crown has until late February to appeal the decision but already, the case has prompted rethinking of researchers' duties. New guidelines at the University of Toronto, for example, list principles to be followed in "research where external pressure to disclose is reasonably foreseeable" and the federal Panel on Research Ethics told CMAJ it would issue a new interpretation of the duty of confidentiality in the next two months.

Update from the Panel on Research Ethics (PRE) SRCR: Interpretations 'R' Us

- Laura-Lee Balkwill, Policy Analyst
Secretariat on Responsible Conduct of Research

Interpretation Services offered by the Secretariat on Responsible Conduct of Research

If you have ever wondered what the people at the Secretariat on Responsible Conduct of Research do when they aren't giving workshops at CAREB conferences, chances are good on any given day that we are working on an interpretation of the 2nd edition of the Tri-Council Policy Statement: Ethical Conduct of Research (TCPS 2). At each conference we attend and during each webinar we deliver, we invite people to write to us with questions. Since the launch of TCPS 2, in December 2010, we've responded to over 400 interpretation requests. And yet, we have heard that there are a lot of people in the research community who are unaware of this service.

Typically, an interpretation request begins when someone

wonders if they (or others) are applying TCPS 2 guidance correctly to research design or research ethics review and decides to contact us. When an interpretation request is received at the Secretariat, it is assigned to a Policy Analyst for follow up. The requester can normally expect to hear from an analyst by phone or by email within the week. Our role is to identify the guidance in TCPS 2 that applies to the question and provide clarification. We seek to clear up misunderstandings and offer practical examples of how the guidance can be applied. We cannot act as arbitrators in a disagreement, and we cannot offer interpretations of other guidance (e.g., privacy legislation, ICH-GCP, Health Canada regulations).

Although most interpretation requests are answered directly by Secretariat staff, when we receive a question that raises an issue that is novel or complex or that points to a need for clarification of specific guidance, the response is developed further with the Panel on Research Ethics (PRE). The interpretation is then posted on our website. There are over 30 interpretations posted to date on topics like Consent, Conflict of Interest, Research



TCPS2 and the Future

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Ethics Governance and Scope. They are intended to help researchers and REBs apply similar considerations to their decisions about ethical issues in the context of research design and research ethics review. The next time you have a question, look at our posted interpretations and you may find your answer already posted.

Interpretations that point to a possible need for revision to the Policy become part of our ongoing Policy evolution. That is, PRE reviews the issue raised and determines whether a revision to the Policy is needed. Interpretations are often incorporated into our education opportunities such as the online Course on Research Ethics (CORE) or our webinars. We recently concluded a public consultation on proposed revisions to TCPS 2. Many items proposed in the consultation stemmed from interpretation requests.

The Secretariat and PRE are now reviewing the close to 70 sets of comments received in the course of the consultation and considering their impact on the proposed revisions. We will present a set of recommended revisions to the Presidents of CIHR, NSERC and SSHRC. Once the three Agencies approve the revisions, a revised version of TCPS 2 will be published on our website.

The Secretariat provides guidance on TCPS 2 in a variety of ways. For more information on the range of activities that we offer the research community, we invite you to visit our website where we have published our activities report.

Plus ça change, plus c'est la même chose National Conference 2014

The more things change, the more they stay the same.

So it would seem for the many of us who had no sooner managed to recite chapter and article from the TCPS when along came the TCPS 2, and recently the TCPS 2 with amendments.

While this may cause discomfort, as learning always does, it's important that we ignore the disillusionment that "plus ça change" suggests and embrace the positive difference change creates, that researchers undertake to make, and that we make in the delivery of our promise of Respect for Persons, Concern for Welfare, and Justice with every application we review.

With all change, no matter how much and as many times as we experience it, one thing remains the same. There will always be a need for our commitment to the people of Canada to promote the ethical conduct of research that involves them.

As a member of CAREB you can make certain that always stays the same.

CAREB CONTACT INFORMATION AND SOCIAL MEDIA

CAREB Contact Information:
Questions? Contact us!

CAREB homepage: <https://www.careb-accr.org/>

CAREB membership and web access:
memberservices@careb-accr.org

Conference registration and inquiries: registration@careb-accr.org

Listserv and web forum postings: post@careb-accr.org

Coming Soon: Connect with CAREB through social media!

CAREB will be launching new social media platforms through Twitter, Facebook, and Flickr in the coming months. Stay tuned!

LAUNCH OF THE CAREB FORUM

CAREB is pleased to announce the re-launch of the web forum! The web forum is a great tool for members across Canada to discuss various topics within the scope of research ethics. Members are encouraged to submit questions or comments requiring response to the web forum. All members have access to the forum and will be able to review and submit responses at any time.

If you have a topic you would like to discuss or obtain input on, please email post@careb-accr.org with the message you would like to relay to members. A notification will be sent out via the listserv advising there is a new topic on the forum to be discussed.

In order to access the forum, please log in to your CAREB account and go to the Member Resources > Forums & Discussion tab at the top of the page.