



## COMMUNITY RESEARCH ETHICS OFFICE

*Strengthening and Supporting Community  
Research in Waterloo Region*

### **Public Launch of the Community Research Ethics Office**

#### **Summary of the Afternoon**

**Thursday, June 9<sup>th</sup>, 2011**

**Kitchener, City Hall, Rotunda**

**Purpose:** To share the story of a community coming together to facilitate ethical assessment and support processes for community-based research.

**Representation:** In total, 33 people attended the Public Launch of the Community Research Ethics Office (CREO). There was representation from within the Region, including Waterloo, Kitchener and Cambridge, as well as from outside of the Region, including Toronto, Mississauga, St. Catharines and Peterborough. There was also broad stakeholder representation, including community members, members from community organizations, academic institutions and government.

**Summary of Proceedings:** The afternoon began with a welcome and introductions. Joey Bell and Richard Garvey, from the Conrad Centre for Performing Arts, greeted us with beautiful music on the double bass and acoustic guitar. Norah Love, Coordinator of CREO, welcomed everyone to the launch and indicated how excited members of the Community Research Ethics Board were to unveil CREO. Bill Marr, Chair of the Community Research Ethics Board, echoed Norah's enthusiasm for the afternoon and provided a brief overview of the purpose and outline of the event. Bill Marr continued to facilitate the remaining of the afternoon.

Debbie Wang kicked off the event with a story-telling presentation, titled "The Feast". Her story highlighted the importance of community-based research and the crucial role that participation and inclusion play in creating healthy communities. She indicated how CREO, at the very core, hopes to ensure that those conducting research involving communities are supported and those participating in it are protected.

Following Debbie Wang's story-telling presentation, members of the Community Research Ethics Board collaboratively presented the story of CREO. The presentation included a brief overview of the research that led to its development, what CREO currently offers and who is involved.

After the presentation, the launch participants divided themselves into three groups. Each group worked on answering three questions: (1) Do you foresee yourself using the services offered by the Community Research Ethics Office? (2) What do you believe are the challenges associated with using the Community Research Ethics Office? (3) Does the Community Research Ethics Office meet the needs of stakeholders in your community or context?



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Participants were also encouraged to note any emerging questions that were identified by their group. Once each of the groups had answered each question, they were invited to share some key points from their discussions with members of the Community Research Ethics Board for comments and feedback.

### Summary of Discussions:

#### **Do you foresee yourself using the services offered by the Community Research Ethics Office? Why or why not?**

Launch participants indicated that yes, they can foresee themselves using the services offered by CREO. The way in which people envisioned using CREO varied by stakeholder group.

University and government stakeholders indicated being primarily interested in using the consultation and education service offered by CREO. It was noted that the consultation would be useful in the planning and development of ethics applications for review by university Research Ethics Boards, as it would help to ensure that the impact of research on communities is considered. University stakeholders also indicated an interest in the training and education component of CREO. In particular, they encouraged training for university REB's and faculty with an interest in community-based research.

Community researchers, members from community organizations and independent consultants indicated an interest in all components CREO (consultation and education, review of research projects, and the Community Research Ethics Network). There was a particular interest to receive review with the purpose to strengthen projects, build internal research capacity and support funding applications. It was noted that factors such as time, type of project and size of project would impact use and that review would not be requested for every project that is conducted. Overall, it was emphasized that although review is not mandated for research conducted independently in the community, it would be useful to receive review to ensure that key ethical issues are being considered and that research is being carried out with ethical integrity.

#### **What do you believe are the challenges associated with using the Community Research Ethics Office?**

There was agreement among launch participants with relation to challenges associated with using CREO. The most frequently noted challenge was lack of awareness. Launch participants indicated that CREO needs to ensure that people know what services are being offered and how to use them. Also, given that consultation and review are voluntary, launch participants cautioned that people may take time to incorporate CREO into workplans. It was emphasized that this is a particular challenge, given that CREO's credibility will stem from use by stakeholders and feedback from people who have used CREO.



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Another challenge noted was the lack of clarity regarding whether a review by CREO would be considered sufficient by granting agencies requiring ethical review.

There were other challenges identified that were not necessarily associated with using CREO specifically, but with the existence of a community-based ethical assessment and support process more generally. These challenges included:

- Funding and sustainability-the challenge of ensuring that a long-term presence in Waterloo Region will be established
- Liability-the challenge of handling misconduct and determining who will be responsible
- Subjectivity- the challenge of recognizing the subjective nature of ethics and in particular the subjectivity of ethical guidelines as they relate to community-based research
- Invalidation-the concern that a community-based ethical review process will indirectly invalidate projects that choose not to receive review

### **Does the Community Research Ethics Office meet the needs of stakeholders in your community or context?**

There was strong agreement that CREO is filling a major gap in Waterloo Region and offering an exceptionally valuable service to people conducting research in community contexts. Launch participants believed that it was too soon to answer with confidence whether CREO meets the needs of stakeholders, as more time is needed to utilize CREO and to reflect on how it is impacting the Region.

**Conclusion:** The Public Launch of CREO was a success and the feedback from the community was essential to ensuring that we have a seamless implementation in Waterloo Region. Thank you to everyone who came out and supported us. We truly enjoyed discussing who we are and what we do with people who share our interest in community. We valued the opportunity to meet you and we hope that you remain in touch with us. For those who were unable to attend, please do not hesitate to contact us if you have questions or want support. As community researchers, let's talk to one another as we strive to strengthen and support community research in Waterloo Region!