

Chair's Annual Report
Community Research Ethics Board
2011 – 2012

Let me begin by thanking a number of people and organizations for their enthusiastic support for the Community Research Ethics Office (CREO) and the Community Research Ethics Board (CREB) over the last year and in many cases even longer. People are the backbone of the CREO and the CREB. First of all, I want to thank the members of the CREB, namely Paul Davock, Beth Dempster, Ed Hughes, Theron Kramer, Norah Love, Laura Mastronardi, Joanna Ochocka, Randy Penney, Helen Song, Natalie Forde, and Linda Terry. Your support has been invaluable for our work in the inaugural year of the CREO and the CREB. I especially want to thank Norah Love and Natalie Forde, who have been the two Coordinators of the CREO this year; I enjoy working with both of you; your efficiency and hard work have moved forward the mandate of both the CREO and the CREB. I also want to thank Kathleen Worton for her help during the transition period between Coordinators and for her input into our planning for future workshops. I have thoroughly enjoyed working with all of you and can write that I looked forward to all of our engagements, including the meetings.

With respect to organizations, the CREO and the CREB would not be here today without the financial and in-kind support from the Centre for Community Based Research and the Trillium Foundation of Ontario; we needed, especially in this first year in operation, a physical base from which to work and financial support for the Coordinator's position and for day to day operations; thank you to those two organizations for providing that support.

This has been a year of firsts for the CREO and the CREB. For the first time people in the Region of Waterloo people and organizations have a place to go if they want advice on how to treat people ethically in human participatory research, or in fact want to discuss any ethical aspect of their research. Anyone can use our services in the sense that they do not need to be associated with an institution or organization with a built-in ethics review body. In fact, requests for our services have spread beyond the Region of Waterloo to other parts of Ontario; for example, workshops and discussions have taken place in Orillia and Ingersoll, and the CREB has reviewed ethics application from researchers who are located in Toronto and Orangeville. This year CREO has undertaken its first consultations. The goal here is to provide advice to researchers who are in any stage of their projects with respect to how they may ethically collect information from people within the context of generally accepted ethical norms and of generally accepted tenants of community based research. This year the CREB has undertaken its first formal reviews of research projects. It became apparent that some researchers wanted and/or needed a formal review and approval of their projects; a consultation was not enough. They want or need the letter that states that their projects are ethically sound. For the first time in the Region of Waterloo an organization, CREO, approached different stakeholders with the offer to aid them in carrying out their

human participant research projects; over 20 stakeholders were contacted in person in order to make them better aware of the services of the CREO and the CREB. The response to these meetings was positive. The CREO also held its first community forum since its formal establishment; we called this the Community Public Launch, but it is in essence a community forum. As well as enabling us to inform the community and stakeholders of the CREO's services, we were able to gain some appreciation for the value that the community may place on those services and for the challenges that CREO will have as it moves forward.

The establishment of an ongoing tracking and evaluation system for both consultations and ethics reviews was accomplished this year. This is important because it enables us to obtain and receive feedback from the people who use the services of the CREO and the CREB. We gain an appreciation for how we are viewed by stakeholders in the Region of Waterloo and beyond.

The Community Research Ethics Network was also successfully developed this year. Besides providing consultations services and formal ethics reviews, the CREO committed to providing an on-line network where researchers could find information about human participant and community based research, and, if they wanted, engage in some on-line dialogue about ethical issues around research.

On the purely statistical side of the CREO and the CREB, the CREO organized 4 or 5 consultations and the CREB reviewed 8 ethics applications. As well, three workshops and two presentations were held for different groups. The CREB met 15 times over the year.

The CREB made two decisions that on the surface may not seem that controversial but have wider implications for the work of the CREO and the CREB. It was decided first that we could review non-community based research ethics applications, and second that we could review ethics application from people and organizations outside of the Region of Waterloo. By implication, those decisions also apply to consultations and to workshops (i.e., they can be non-community based research and outside of the Region). Those decisions mean that the potential audience and thus work of the CREO and the CREB expand greatly.

The CREO and the CREB have made a good start with a focused approach to workshops and presentations. The CREB set out some possible general topics for workshops and good progress has been made towards creating a set of modules that could be used in workshops that cover ethical issues around research in several settings. This development will likely be on-going.

There are challenges as I think about the next year or two. There will likely always be what I will call a personnel challenge. This past year the Coordinators (Norah and Natalie) and the members of the CREB have done all of the work (well, almost all of the work); will that be possible as the number of consultations, reviews, and workshops increases? There is also a demand challenge, in other words demand for the services of the CREO and the CREB. Can we generate enough demand for our services so that the CREO is viable? There is a related supply challenge too. Can our supply of services for consultations, reviews, and workshops generate enough revenue to enable the CREO to continue? At least three challenges, at least three questions.

Thank you again to all of the people and organizations who contributed to the success of the CREO and the CREB during the past year. I apologise for no doubt omitting important people and points, but this report is meant to be simply my own thoughts.

Respectively submitted,

Bill Marr

Chair, Community Research Ethics Board

February 1, 2012