## BROCK UNIVERSITY RESEARCH ETHICS BOARD Wednesday, October 18, 2017 12:00 – 2:00 p.m. MC D350-L

## Minutes of the SREB Meeting

Attendance

Michael Ashton Lynn Dempsey Ann-Marie DiBiase James Foley Christina Garchinski Karen Julien Linda Morrice Catherine Nash Mary-Beth Raddon Robert Steinbauer Kendra Thomson Regrets

Sandra Bosacki Miya Narushima Esther Santos

Christine Tardif-Williams

M	MINUTES					
IT	EM	DISCUSSION	ACTION			
1	Motion to approve Agenda		Motion to approve: LM Seconded: CN All in favour  Motion to approve: MBR Seconded: LM All in favour  Motion to approve: LM			
	Approved		Seconded: JF Abstention: MA for conflict of interest			
2	New Business	<ul> <li>LW explained to new members of the Board that Decision Reports (documents outlining approved protocols, continuing reports, modifications, final reports) are posted publicly online, in keeping with the Tri-Council's goal to maintain public trust and accountability.</li> <li>We have also always posted the REB membership online. If any members are uncomfortable with this, they were encouraged to contact the Office.</li> <li>Decision reports can also be a tool for participants to look up studies to ensure files are legitimate.</li> <li>There is a statement in the REB Guideline for Confidentiality that states, "unless otherwise specified by the Principal Investigator, the file number and title of research projects that have received REB clearance will be posted on the Office of Research Services website. This list will be updated monthly." This is the information listed in the Decision Repots. The Office should consider sending out an announcement to researchers, reminding them that this information is public knowledge.</li> <li>The Office explained to new board members that although every Board member would not have seen</li> </ul>				

- every file on the Decision Report, the purpose of bringing them to the meeting is to ratify the decision. The Office encouraged members to ask any questions about any files before voting to approve the report.
- A Board member asked about a statement included on a recent clarification and revision request. The Board asked a researcher to justify a draw for \$500 for completing a 15-minute survey. Is this appropriate to ask if the study is less than minimal risk?
- The Office explained that a conversation was had with the researcher on this point (because incentives are a bit different than compensation). Per the TCPS2 Article 3.1, "the offer of incentives in some contexts may be perceived by prospective participants as a way for them to gain favour or improve their situation. This may amount to undue inducement and thus negate the voluntariness of participants' consent. This Policy neither recommends nor discourages the use of incentives. The onus is on the researcher to justify to the REB the use of a particular model and the level of incentives. In considering the possibility of undue influence in research involving financial or other incentives, researchers and REBs should be sensitive to issues such as the economic circumstances of those in the pool of prospective participants, the age and decision-making capacity of participants, the customs and practices of the community, and the magnitude and probability of harms." The REB has to consider these factors to ensure the decision to participate is made voluntarily (keeping with the principle of voluntary consent). When the incentive amount was considered in the context of the present study, it was determined that there was no risk to prospective participants and therefore, the decision would be up to the researchers to offer the incentive amount they are able to (per funding
- LW also explained that generally, incentives are not given to every participant (e.g., a gift card draw) and are instead a way to encourage participation. This is different from compensation which would be offered to every participant to recognize the time they invested in the research or to ensure they are not out of pocket any costs (e.g., parking; to ensure it does not cost participants anything to participate in research).
- Should the REB determine that the economic circumstances of those in the pool of prospective participants, the age and decision-making capacity of participants, the customs and practices of the community and the magnitude and probability of harm would not cause undue inducement (in relation to the incentive provided) or negate the voluntariness of participants' consent, we should not ask researchers to justify the amount of incentive provided.
- In the present example, the study was deemed less than minimal risk and therefore, participants would not be in a

- position where they would be assuming risk *because* of the monetary value or draw (i.e., assuming risk only for the purposes of money, draw etc.). In these cases, we do not have to ask researchers to justify the amount of incentive offered.
- LW gave an example of a time where we would ask for justification: if a large incentive or compensation amount was offered for muscle biopsies or risky clinical trials. People might decide to take on the risk just for the money.
- LW also noted that each faculty at Brock seems to have their own rate of compensation that is considered "standard." The REB needs to be aware of this too during our reviews. For example, social sciences might offer compensation rates of \$10/hour versus health sciences that offers \$15 as their norm.
- A Board member inquired about another comment included on a clarification and revision request pertaining to the REB discouraging researchers to conduct interviews in public places such as coffee shops (given the lack of privacy, confidentiality and the potential to inadvertently record third-party conversations on a recording device). Would there ever be a situation where there are not any privacy concerns for the participant and the REB could allow for interviews in these more public venues? E.g. interviewing a participant about fiscal policy or asking someone why they like a certain music band for example. For topics such as this, should the REB be worried about privacy concerns and dictate where researchers can/cannot conduct their interviews? Can we adapt our recommendations if there are no privacy concerns involved?
- The Office indicated we generally comment that coffee shops are "discouraged" as interview locations (versus demanding that researchers change their location).
- LW pointed out that if it is a project that requires privacy, we should be saying that researchers need to find another location (that a coffee shop would not be appropriate). The other thing to consider is third-party conversations that could end up on the tape in these more public venues. Our thought is that people should not be recorded if they are not aware of it (even in public). However, the REB should be making this comment in proportion to the risk associated with the project. Perhaps "discourages" is too strong of a word in our comment. Participants could very well be more comfortable having their interview in a place like a coffee shop and should be permitted to if there is no risk or privacy concerns involved. Perhaps we can ask researchers if it is possible to conduct the interview in an alternate setting, or for them to please consider confidentiality in their plan for example.
- The other thing researchers come back to us about is collecting data in people's homes. We must inform them

- that any research taking place in a participant's home presents opportunity for the researcher to witness (and therefore be under legal duty to report) risks related to abuse/harm. Participants should be informed that a researcher is under obligation to follow mandatory reporting laws, meaning if they disclose or a researcher views any child abuse, the researcher must by law report it to child protective services.
- These are standards in all ethics boards across Canada. Further, we are all mandated as Canadian citizens to report suspected child abuse or neglect (this is not something we are asking unique to the research context).
- This pertains to other people coming into the home as well what if someone else enters the home and you witness something between this person and a child for example? Possibilities to witness are increased by entering someone's home. We ask researchers to include in the consent form that this would be a limitation to the confidentiality they can guarantee a participant (they would have to break confidentiality to report). This is simply a precaution to ensure participants are aware of this limitation upfront, prior to participating.
- A Board member asked if this could be worded as a "suggestion" versus a requirement to have this statement in the consent form.
- LW clarified that this does not pertain to reporting crimes which researchers would have no responsibility to do in their role – child abuse/neglect is a mandatory reporting law for all Canadian citizens.
- Snowball sampling is the other comment that keeps coming up in reviews. LW explained that most REBs prefer that participants pass on the researcher's contact information to those believed to be suitable candidates for participation. It would then be up to these individuals to contact the researcher should they wish to participate. This ensures the decision to participate is completely voluntary and avoids sharing contact/personal information, which may appear as intrusive.
- Particularly if just being associated with the topic of the study could be risky to that individual (e.g., a study investigating women who have had an abortion). By passing on that person's information, it could infringe on their privacy or reveal something about them (that they might not otherwise be comfortable sharing).
- Sometimes traditional snowball sampling is fine if we think it is core to reaching the group of interest (assuming they want to be reached and their desire to be involved would override the intrusion of passing on contact information).
- LW gave the example of a group of historians in Niagara who have proposed transitional snowball sampling techniques in the past. Given this group does not have a head office or shared space where they could pass on

- contact information for the researchers, it makes most sense to allow them to utilize their own contacts. The REB has to consider, how else would these people be reached? What are the situations they are in that make them inaccessible to the public (therefore making it potentially unrealistic to ask researchers to adapt their methods)?
- The other comment that is coming up a lot in reviews is stating that a participant's decision to participate will not affect their employment. Reviewers have to consider each unique project and determine whether this comment is appropriate. For example, does the researcher actually have the ability to make this statement? (e.g., a manager asking employees to participate in a study).
- LW also clarified for the Board the difference between confidentiality of data versus confidentiality of participation (will people just be aware that someone participated in the study?). For example, a group testing session where responses are private but there are multiple people completing the study in the same room at the same time means that participation is not confidential, but responses are. When making this comment, reviewers should consider if there is a risk in just being associated with the project. If so, confidentiality measures should be put in place (e.g., quiet room and only testing one person at a time). Otherwise, this comment does not need to be included.
- For example, if there was a sign on a door indicating the study examining survivors of sexual abuse takes place "here." Anyone waiting outside the room or seen entering the room might be assumed to be associated with the project and therefore, a survivor of sexual assault. This could be risky if an individual did not wish to reveal that information about themselves to the public or outside of the study space.
- If it is innocuous data and we are not worried about other people knowing someone participated in the study/is associated with the study, then we do not need to include this comment. Reviewers should consider the context of each study.
- Then there is the confidentiality of, 1. the research site and 2. the data. For example, a study that interviews grade 2 teachers and in study reports, includes quotations or descriptors that could reveal the teachers' identities (e.g., if there are only two, grade 2 teachers in the DSBN and these characteristics are provided in results, readers might be able to attribute the comments to a specific person).
- Further, when participants are selected from the school board, it requires the Superintendent to provide suggestions to the principal, then the principal has to agree. Then if the researcher is accessing teachers, they may need to get a substitute teacher to come in if testing occurs during class time. This may also limit the

- confidentiality researchers can guarantee the participant.
- LW clarified that even if researchers cannot promise confidentiality, it does not mean they can't do the research. It just means researchers need to make explicit in the consent form the limitations to confidentiality they can guarantee participants.
- This is the same consideration reviewers need to look at if researchers are going in to an office to do research – depending on the topic, does it matter if a participant is associated with it and if others in their work space becoming aware of their involvement?
- Some descriptors are easily identifiable in the results.
- For example, at one point an individual was the only intervener in the DSBN. So, if the results indicated that data came from the intervener in the DSBN, they would be identified by default. Reviewers and researchers should consider this comment proportionate to the actual risk of the project.

The REB Sub-Committee on Guidelines, Practice, and Procedure (GPP)

- The new documents to be approved by SREB today were reviewed:
- 1. REB Guideline Multi-Jurisdictional Research:
  - The Board approved the guideline but asked for the formatting to be fixed, prior to distribution.
- REB Guideline Continuity During Unforeseen Circumstances:
  - Guideline approved by the Board.
- 3. REB Standard Minor and Substantive Changes:
  - The Board requested more examples be included under minor changes. One Board member volunteered to craft more examples of minor changes that can be included.
  - For example, just updating an instrument from one original version to an updated version – would this be considered a minor or substantive change?
  - Board members also discussed whether this system is setting up an unfair advantage to emergent research like grounded theory and ethnography. The Board allows those methodologies to be explained with a lot of space. Are we disadvantaging people with strict, structured measures saying you have to tell the Board and wait for approval for every single change but the emergent researchers do not need to?
  - This document also leaves the judgment of whether a change is minor or substantive up to the researchers.
     Will all researchers gauge and interpret the guideline equally to ensure we do not encounter cases of noncompliance?
  - The Board asked that this guideline go back to GPP to work out these final details.

		<ul> <li>4. REB Standard – Definition of a Research Team:         <ul> <li>Given this standard refers to a separate guideline regarding who can be a Principal Investigator, the SREB decided to wait until after this other guideline is completed to approve both of these together.</li> </ul> </li> </ul>	
3	Adjourn	Meeting adjourned at 2:03 p.m.	Motion to adjourn Seconded All in favour