### **BROCK UNIVERSITY RESEARCH ETHICS BOARD** Wednesday, July 11, 2018 12:00 - 2:00 p.m. MC D350-L

### Minutes of the SREB Meeting

**Attendance** 

Michael Ashton James Foley Christina Garchinski Carly MaGee (nonvoting) Linda Morrice

Miya Narushima Mary-Beth Raddon Robert Steinbauer Kendra Thomson Lori Walker (non-voting) Regrets

Robyn Bourgeois Lynn Dempsey Karen Julien Catherine Nash Christine Tardif-Williams

МІ	MINUTES			
ITEM		DISCUSSION	ACTION	
1	Motion to appro	ve April, May & June Decision Reports	Motion to approve: LM Seconded: CG All in favour  Motion to approve: KT Seconded: CG	
	Motion to approve April & May Minutes  • Approved		All in favour  Motion to approve: LM Seconded: MBR All in favour	
2	Business Item	<ul> <li>Discuss and compiled feedback on draft Tri-Agency</li> <li>Research Data Management Policy</li> <li>The three federal research funding agencies - CIHR, NSERC, and SSHRC - have developed a draft Tri-Agency Research Data Management Policy, which aims to support Canadian research excellence by fostering sound digital data management and data stewardship practices. The policy includes suggested requirements related to institutional data management strategies, researcher data management plans and data deposit.</li> <li>LAW clarified that as a Board, we need to decide if we want to submit a group response to the consultation or respond individually, or through academic departments.</li> <li>She gave Board members the option of sending in their comments to the Research Ethics Office (REO) and we can compile them to submit on behalf of both Boards and the Office.</li> <li>LAW summarized that the Tri-Council is moving towards requiring that all Tri-Agency funded projects follow this data management policy. But it will also suggest that all research – even non-Tri-Agency funded - abide by the policy as well (but this will be left to each institution to decide).</li> <li>From an ethics perspective, it means we will ask more questions about long-term data management practices,</li> </ul>		

- and move away from the assumption that data needs to be destroyed. The policy will outline the options such as retention, archiving, and ask who the custodian of the data during that time will be.
- When the new set of revisions to the TCPS2 are released, there will be a big focus on the dissemination of the data. Most of the drive around this has come from clinical trials (where negative results have not been reported).
- In terms of process, researchers will be asked to attach their data management plans with their grant application, and their data management plan will be assessed as part of the grant review.
- One of the challenges at this point is that different sectors seem to be speaking different languages. Because of this, Boards can ask to see contracts to ensure they are in line with the TCPS2. For example, a recent contract indicated that the researchers would anonymize the data. The REO encouraged the researchers to familiarize themselves with the definition of anonymize in the TCPS2 (irrevocably stripped of identifiers) versus de-identified (identifiers can still exist but not with the dataset that is passed on). It was believed that the researchers meant to agree to deidentify data, without understanding the definitions used in ethics.
- Board members were encouraged to read through the policy as it covers much more than just "open access."
- A detail that will need to be cleared up with the new TCPS2 pertains to the "public" nature of the data in databases such as open access. Currently, any data that are publicly available do not require REB approval to use. However, when the TCPS2 was written, they were referring to a different kind of "public" data (e.g., Statistics Canada). Will data in databanks require a secondary use of data application to access and use for future studies? This is unclear at this point.
- It was pointed out that we will need to modify our Brock consent form templates accordingly to ensure they meet the requirements of archiving data.
- LAW indicated that some of the Portage committee groups are looking at boiler plate language to give to other REBs to help out with this. This should ease the transition period for both REB administrators and researchers.
- The new TCPS2 will also indicate that researchers should not be agreeing to anything that limits how they use data. For example, Ministry of Education contracts all currently say that the Ministry has control of the data and the researcher can only publish what the Ministry agrees can be published. This is going to be very clear that REBs should not be approving projects if the researcher has signed such an agreement. In that regard, REBs will also need to look at these agreements

- as part of the review process. This will be much more enforced with the new data management policy.
- LAW clarified that if we decide the project represents fee for service or program evaluation then it can be exempt from REB review. But those projects that fall under the mandate of the REB will need to be closely considered to ensure these restrictions are not in place.
- This will be more complicated when working with industry partners – something that is currently being pushed by the Conservative Government to engage in more.
- A member asked what level of data needs to be included in these banks. LAW clarified that currently, this is left with the researchers to propose and justify. If there is a reason, for example, interview transcripts should be available for others, the onus will be on the researcher to provide justification.
- A member pointed out that as part of a researcher's "literature review," it would seem they will first have to make sure the data does not already exist.
- LAW reminded the Board that even if the data already exists, a researcher could argue that the results need to be replicated, so they require the existing data in the bank to compare their results. In the end, this will be a beneficial tool for new studies and add rigour to projects.

### 3 Education Items

# <u>Discussion on article: "Trauma and Sex Surveys Meet Minimal Risk Standards: Implications for Institutional Review Boards"</u>

A summary of the article was provided: Institutional review boards assume that questionnaires asking about "sensitive" topics (e.g., trauma and sex) pose more risk to respondents than seemingly innocuous measures (e.g., cognitive tests). The researchers in this study tested this assumption by asking 504 undergraduates to answer either surveys on trauma and sex or measures of cognitive ability, such as tests of vocabulary and abstract reasoning. Participants rated their positive and negative emotional reactions and the perceived benefits and mental costs of participating; they also compared their study-related distress with the distress arising from normal life stressors. Participants who completed trauma and sex surveys, relative to participants who completed cognitive measures, rated the study as resulting in higher positive affect and as having greater perceived benefits and fewer mental costs. Although participants who completed trauma and sex surveys reported slightly higher levels of negative emotion than did participants who completed cognitive measures, averages were very low for both groups, and outliers were rare. All participants rated each normal life stressor as more distressing than participating in the study. The article suggested that trauma and sex surveys pose minimal risk.

- The article illustrated how the standards for this generation are very different – the types of questions/topics that might be more normative for this generation, may have been more distressing/worrisome in the past.
- Board members felt however that it would still be fair to give participants a warning about the types of questions that will be asked in the study to allow them to exclude themselves if they thought it might be triggering.
- The focus of the article though was to stress that these types of studies should not be automatically lumped into the high-risk category.
- The new TCPS2 will hone down on the definition of risk to indicate that as REBs, we should be looking at research attributable risk (i.e., risk that is increasing or being introduced by the research itself). This does not account for the risk that people are in naturally, in their everyday life.
- For example, research on people with a spinal cord injury, we had to consider. Is the risk to participants part of their everyday life? Does the research add any additional risk or does the risk exist already as part of their everyday life?
- Board members acknowledged that some research projects on this topic can absolutely be treated as greater than minimal risk if it involves limited privacy, confidentiality, risk of sensitive information being revealed etc. These considerations are different from asking the question itself (which may not be particularly upsetting in and of itself).
- Members also agreed there is a difference between checking off in a questionnaire the number of traumatic things that have happened versus an in-depth interview where these are discussed one-on-one and in detail.
- Similarly, showing images to participants may elicit different degrees of emotion compared to a structure questionnaire.
- This study showed that structured questionnaires on this topic are not necessarily distressing to everyone. It would be interesting to conduct a similar study with political attitudes as well.
- As long as the researchers disclose in the consent form the types of questions that will be asked, it gives participants the opportunity to decide whether the study is a good fit for them. If the questions go too much into detail though, we as a REB can decide the risk level. The purpose of the article was to encourage REBs to assess risk proportionately, instead of saying these topics go automatically to full board.
- Members were reminded that if they get a delegated file and think it needs to be a full board (greater than minimal risk), it automatically goes back to the full board.

## Discussion on Student Voices on Sexual violence survey (Ontario-wide sexual violence survey)

- Students at Brock and all Ontario publicly-funded universities and colleges were asked to participate in a massive online survey about sexual violence or harassment. The survey was designed to provide a clearer sense of the prevalence of sexual violence in the province.
- This "climate survey" was a government initiative and part of new Ontario legislation that also requires universities and colleges to report on student experiences involving sexual violence. The anonymous survey inquired about sexual violence supports, services and reporting processes at campuses, as well as perceptions of consent and the experiences of survivors of sexual violence.
- The survey came to the REBs for approval all the universities and colleges were rather confused about how to handle it (i.e., exemption or approval). The Ministry was asking REBs to review it (with a short deadline) and provide approval.
- Some of the questions were very pointed and detailed (although anonymous). The Ministry had hired a company to do the research who had set dates out for when it needed to be reviewed and launched etc. A lot of REBs were asking for clarifications/changes to the survey, but the Ministry was not able to make any changes because then it would not be considered a provincial survey. In other words, they were looking for a rubber stamp approval from REBs which we felt uncomfortable giving. Since the government amended the Ministry of Training, Colleges and Universities Act and the Private Career Colleges Act to require institutions to have sexual violence policies and report to the Minister or the Superintendent on the effectiveness of those policies, it became mandatory for all postsecondary institutions to complete this survey.
- This became an interesting dilemma for REBs so at this point, CAREB got involved, and LAW met with the VPR and Provost where it was determined that the study represented a program evaluation (not research). Mandating a REB to accept a project would force them to conduct a review that was not meaningful (since changes could not be made anyways), or ethical. During communication as well, REBs found out that many of them were told all other universities had accepted the project and that they were the last one to approve it (which made them feel they had to decide quickly and rashly).
- LAW met with Brock senior administration and the REB Chairs, where they concluded that the project represented quality assurance versus a project to be reviewed within mandate of the REB. The REB office remained firm that we could not provide clearance to the project given it was not under our mandate, and the

- review would not be meaningful as no changes could be made.
- The survey has already gone out and in response, the heads of Applied Research are all writing a paper together to the government to express their concern about the way this process was handled – it caused breakdowns in institutions and put REBs in a difficult position, being used in an inappropriate way. In the future, a survey like this either needs to be mandated with no request for REB approval, or not mandated and subject to REB review and changes.
- Some Boards across Ontario expressed concern over the types of questions being asked. The Ministry had built-in some support services (locally for each institution) however, some REBs argued that the survey was being done online which made support proximal and perhaps less effective. Further, could they guarantee that the supports would be available during the time the participant was completing the survey? (i.e., after hours). When the REBs posed these questions, the Ministry was not prepared to answer them or make any changes.
- Two institutions told the Ministry they could not implement the survey – one of these institutions had two recent sexual assault incidents on campus, so it was agreed this was too sensitive of a time.
- Some institutions took their logo off the form so when it was sent out to the student body just appeared as on behalf of the Ministry (to remove the institution's "endorsement").
- It was also unclear what the government planned to do with the data which made it even more confusing why REB approval was being sought.

#### Discuss suggested changes to the ethics application

- The Board went through the proposed changes to the ethics application and revised/comments accordingly.
- Members asked for approximate timelines around when this new application might be implemented. LAW explained we are unsure given we do not yet have the specific system we are using (e.g., smart form, Enterprise system). Once those details are finalized, we can start to draft rough timelines.
- The plan after the REBs comment on the application is to pilot it with researchers and work out any kinks before it goes live.
- The Office of Research Services has hired a new Director and their number one priority when they arrive is to determine what online application system we will be getting. The new intake office for the REO (once hired) will also be a main contact for the system (e.g., running, administrating, troubleshooting).

Adjourn

Meeting adjourned at 2:00 p.m.

Motion to adjourn: MN Seconded: JF

All in favour