BROCK UNIVERSITY RESEARCH ETHICS BOARD Thursday October 28, 2021 12:00 – 2:00 p.m.

Teams

Minutes of the HREB Meeting

Attendance

Stephen Cheung Alyssa Bax (non-voting) Jenalyn Yumol Megan Magier Shirin Ghoujalou (non-voting) Connie Schumacher Maureen Shantz Terrance Wade Lori Walker (non-voting) Kimberley Gammage Jennifer Matunin-Brown Regrets
Gail Frost
Nicole Chimera
Shawn Beaudette

MINUTES					
IT	TEM DISCUSSION		ACTION		
1	Motion to app • Approv		Motion to approve: TW Seconded: MM All in favour		
	Motion to approve September Minutes • Approved		Motion to approve: JB Seconded: TW All in favour		
	Motion to app • Approv	rove September Decision Report red	Motion to approve: MS Seconded: JY All in favour		
2	Discussion Reviewer tips & reminders				
	Items	 Please fill in your comments under the appropriate heading on the Standard Application Outline. Write as if you are addressing the researcher. Use the language "Please clarify" "Please revise" or "Please note" when appropriate. Q: Where should we request consent form changes/revisions? A: Under the "Consent form" heading whereas questions about the process of obtaining consent can be put under "The Consent Process" heading. Clearly distinguish comments and suggestions from requirements and requests for clarification. Explain the ethical reasoning behind any questions that are not obvious. Let the researcher know why this question is important so they don't become confused or think that we are just "picky". Not all items on the document checklist (the first page of the Application for Ethics Review) are required. This is an administration tool to ensure that the office has received all attachments. Review the decision letters to help familiarize yourself with the language used and to help ensure consistency across reviews Remember that reviews should be participant-centered and take a proportionate approach (according to risk). Feel free to ask the ORE questions at the top of the form – just make sure you clearly indicate that this is not part of your review. Remember to keep comments professional and relevant since they do remain part of the file. Researchers have the right to access their file(s). 			

- Remember to focus on ethical issues. Methodological issues are of concern if the research is more than minimal risk. Spelling and grammar are only relevant in participant materials where they could impact on clarity and therefore undermine informed consent. If there are issues with spelling and grammar a note is sufficient.
- Be sure to consider the entire application because sometimes researchers provide information in different sections of the application than expected.
- Discussion: Overall the reviews have been well done. We just would like to streamline the process. It is important to use language that is clear and will not lead to the office/chairs having to interpret what you mean. For example, use the wording "please revise/change" instead of "please consider revising/changing".
- Q: Should we put comments in multiple places if they are relevant for multiple headings?
- A: No, just include comments under the heading that is most relevant so as to not repeat. If the comment also requires a change to the consent form you can add "remember to include this change in the consent form as well".

Snowball sampling recruitment presentation & discussion

- Snowball sampling is a recruitment method that has historically been used for research purposes. The aim of the presentation today is to increase awareness of how snowball sampling can affect researchers vs. participants.
- What is snowball sampling?
- Snowball sampling is a recruitment technique that involves asking current research participants to help identify other potential participants (i.e., referrals).
- It is a non-probability sampling technique used where potential
 participants are difficult to find due to the specific traits sought. Because
 this method of recruitment raises ethical issues it should be justified and
 not used for convenience.
- Snowball sampling models:
- 1) <u>Direct referral (Active)</u>: Researcher contacts potential participants: Researchers can ask current participants to provide the names and contact information of people they think might be interested. Researchers then contact these people directly.
- 2) <u>Indirect referral (Passive)</u>: Potential participants contacted by previous participants not researcher: Researchers can ask current participants to tell other people about the study, pass on research information package etc. If interested, these people are instructed to contact the researcher directly.
- Snowball sampling "rules":
- Current participants cannot receive any compensation for providing referrals or be offered any incentives to provide referrals.
- Current participants <u>MUST NOT</u> be required to refer others or incur any penalty for not referring other participants.
- Issues with direct referrals (active snowball sampling):
- Having current participants provide referrals' names directly to the
 researcher <u>may violate referrals' privacy</u>. For example, if participants
 were to be recruited based on sensitive criteria, such as an illness,
 asking current participants to refer others may reveal confidential
 information about these people and leave the potential participant

- feeling unsure and concerned about contact from a researcher without any warning.
- Do people have the right to know who the referral came from? Does that further violate privacy?
- Issues with indirect referrals (passive snowball sampling):
- If current participants have some degree of power over referrals, such as an employer-employee relationship, then asking current participants to mention the research to others may raise issues of undue influence.
- Discussion:
- It is preferred that researchers use indirect sampling. However, it is
 often questioned whether or not potential participants have a right to
 know who referred them, which may result in privacy issues. Our main
 concern is if researchers are using snowball sampling simply for
 convenience. Thus, researchers must justify their use of snowball
 sampling in their application.
- If you are unsure whether or not active/passive snowball sampling is appropriate for an application, you are reviewing you can always ask the ORE or leave a comment at the top of your review or in the recruitment section and we will double check.

Data retention policy discussion

- Data retention policies are often mistaken to be recommended by the TCPS2. Researchers are left wondering how they are required to keep their data, what storage plans should be put in place, and what happens if the plans are not followed.
- The TCPS2 currently does not have any stance on data destruction, except to direct researchers to follow grant/funding agency requirements.
- The Tri-Council wants institutions to have Research Data Management (RDM) plans in place for researchers (e.g., data repositories, requirements for password protection, keys, timelines, and descriptions of secondary-use purposes).
- The recent TCPS2 public consultation outlined potential upcoming changes including allowing researchers to use broad consent to use data repositories if participants are properly informed.
- Q1: What about unfunded data? There is an ethical problem if only government funded data is kept.
- A1: Eventually all researchers at Brock will be required to have a data management plan. Researchers typically assume that they have to destroy data when they actually just need to outline their data storage plan. These changes will be coming up in the next two years.
- Q2: Could our application wording be the reason that researchers are confused (i.e., asks researchers to justify why they want to keep the data)? Could we change this wording?
- A2: Yes, our wording is currently not very clear. However, our new online application has been enhanced to eliminate this issue. The new application will ask researchers to outline their data management plan rather than justify why they want to keep the data.
- Q3: Can students/faculty keep their data at home?
- A3: This is not the best practice as data should be securely stored (e.g., locked filing cabinet /computer in locked office).
- Q4: Is data allowed to be stored on the cloud or is that forbidden?
- A4: In some situations, the REB considers storing data on a USB to be more secure than using the cloud. However, Brock's secure system should be fine for data storage (e.g., requires multi-factor authorization).

- Historically cloud storage was not known to be secure but the increased security measures and understanding has allowed for more flexible data storage options. Data storage plans should also be tailored to the level of risk and anonymity of the data.
- Q5: Are data storage plans based on what is stated in the consent forms (e.g., permission for secondary use/re-contact)?
- A5: We judge how reasonable a plan is and if participants are being correctly informed of and consent to the secondary use/retention of their data. This is especially relevant for child participants when they turn 18 and can request for their data to be deleted.
- Q6: Does data that is being combined for analysis need to go through the REB as secondary use?
- A6: Potentially. You should check that the consent form doesn't say the
 data won't be used elsewhere/for other purposes. Data that is
 anonymous doesn't require REB review for secondary use. However,
 anonymized data requires REB review. Non-anonymous data requires
 participants to be re-contacted to consent to the new use of their data.
- Q7: What should we advise for storage/retention?
- A7: We can create new guidelines for researchers until the new online form is active, and in the meantime, we can spread the word that data does not always have to be destroyed.
- Comment: Researchers used to write out very descriptive plans for how they would destroy their data that was collected on physical tapes (e.g., drive over them/burn them).
- Comment: We should work to communicate with our researchers so that data is not destroyed unnecessarily.

COVID-19 Update

- The ORE website links/FAQ/email templates have been updated to include the most recent COVID-19 information and requirements for Brock University.
- Vaccination exemptions are only provided through the Secretariat.
- The Brock legal team evaluates each case and provides information on how to access antigen testing at the pharmacy in East Academic.
- Exempt individuals are welcome to go to the Brock pharmacy and pickup a test (paid for by Brock). They could also get a test from another pharmacy and would be reimbursed for the cost, but the process would take longer.
- It is unclear how individual tests would be covered for longitudinal studies but so far, we have only approved research studies involving single sessions of in-person testing.
- Exemption issues: religious exemptions are unlikely as there have been meetings with religious leaders that have come out mostly in favour of the vaccination requirements. Required to be sworn in front of a Commissioner of Oaths (Notary). It is unclear who would pay for this.
- Children are aging into the vaccination requirements and the vaccine may soon be available to those under 12 years of age. Our vaccination requirements remain the same – two vaccines plus 14 days.
- Unsure of how to handle children who may turn 12 in the middle of a study. Potentially could use a grace period of 28 days and evaluate on a case-by-case basis.
- We have recently granted REB clearance for a file where participants did not have the correct information required for Brock COVID-19 contact tracing etc (i.e., no phone numbers or emails). We waived our

		procedures and allowed the researchers to use the procedures in place at the external institutions.	
3	Other Business	 Gail Frost is retiring. She is thanked on behalf of the HREB for all of her contributions for many years and numerous projects. The REB is greatly appreciative of Gail's guidance for many years in her role as acting chair. If anyone knows of potential new members for the HREB please contact us. New HREB Research Ethics Officer (Melissa) Hired – Starting November 1, 2021 	
4	Adjourn	Meeting adjourned at 1:18 p.m.	Motion to adjourn: TW Seconded: KG All in favour