

CANADIAN ASSOCIATION OF RESEARCH ETHICS BOARDS L'ASSOCIATION CANADIENNE DES COMITES D'ETHIQUE DE LA RECHERCHE

VIRTUAL REB (VREB) DEBRIEF

Preface: The Virtual REB (vREB) is a CAREB-ACCER professional development initiative that facilitates discussion on a series of research ethics case studies. While the cases presented are study overviews rather than full protocols, they are designed to include enough information for a fulsome discussion of the ethical issues entailed.

Case Studies are posted for CAREB-ACCER members across Canada to contribute their thoughts on relevant ethical issues as if conducting a research ethics review. The case debrief that follows is a collaborative product of vREB review. Where applicable, comments are supported by relevant legal and regulatory references, in particular the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2).

This debrief is archived in the professional development section of the CAREB-ACCER website as a resource which can be used by CAREB-ACCER members to support the orientation and training of REB members and professionals within their own institutions. The vREB Advisory Working group acknowledges that research ethics opinions are often seen through the lens of context and are open to interpretation. As such, opinions may vary; however, these variations may be the seeds of professional discussion, learning, and development which are the goals of this exercise.

Case Study #2: <u>Survey to Determine Culturally Different Patterns of Emotional Growth</u> and Stability Among Young Adults

The CAREB-ACCER virtual REB (vREB) determined that the proposed research as described involves Minimal Risk.

CAREB-ACCER members: Only 8 survey respondents answered this question: 4 yes, 2 no, 2 unclear.

As per TCPS2, Chapter 2, section B, "minimal risk" research is defined as research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in those aspects of their everyday life that relate to the research.

Ethical analysis of research should consider both the foreseeable risk and the available methods of eliminating or mitigating the risk. The REB must consider the magnitude or

seriousness of the harm (social, behavioural, psychological, physical, or economic) and the probability of occurrence of the harm.

Ethical issues identified relating to Participants:

The researcher proposes to recruit participants aged 16 years and older. Some jurisdictions (within and beyond Canada) require consent from a parent or guardian for participation of minors. TCPS2 Articles 4.4 and 4.6 must be considered.

One CAREB-ACCER member argued that guardian consent should not be required because young people in this age range could normally be considered capable to decide whether or not to participate in the research. The complexity in the proposed study is the need to consider different interpretations in different jurisdictions across the country and around the world about the capacity of youth to provide consent.

The researcher may wish to set an upper limit for age of participants to focus on the target population of young adults. Chatroom membership requirements should be reviewed to determine if the demographics of chatroom participants meet the inclusion criteria.

Criteria for which countries will have access to the survey should be indicated. Internet accessibility varies between countries and in some countries there may be surveillance by government authorities. In an international chatroom, more than one language might be used, and it is not clear if the intention is to provide information in all languages. Consider TCPS2 Article 4.1 for fairness and equity in inclusion criteria.

The research is conducted online, so the researcher will have no way of knowing who has responded, which is a limitation of the research method, but does not raise ethical concerns. The survey respondent population is largely unknown and not verifiable, which will affect the validity of the research findings. How will the researcher determine if potential participants live with their parents? There may be gender differences in the propensity to participate in these kinds of chatrooms, which could introduce gender bias into the study. As per *TCPS2* Article 2.7, scholarly review of the research is important when the research involves more than minimal risk but has little bearing on the ethical acceptability of minimal risk research.

It is not clear how recruitment via purposive sampling will be conducted or how contact information will be obtained in order to send specific invitations to target individuals. As a small student study, the snowball sampling poses an ethical issue, given the possible small n from this approach, and the possible personal nature of the questions the researcher is asking of friends. Therefore, snowball recruiting may not be voluntary as per TCPS2 Article 3.1a Undue Influence. If the snowball sample includes individuals who do not participate in chatrooms, they may have different parental values, culture, and emotional growth stability, which could affect the generalizable of findings as per TCPS2 Article 4.1.

Ethical issues identified relating to Method:

Questions about nationality do not address cultural background; the REB would need to see the survey to understand how the research question is addressed. Data collection includes nationality but the study is trying to tease out information about cultural differences. The study is also to address regional differences but it does not appear to capture this personal information.

No information is provided about the chatroom policies or requirements that could shape research possibilities and limitations. The researcher would be expected to provide such policies as part of the application for ethics review and explain how the research fits with these policies.

The research involves the chatroom as well as a questionnaire. It would therefore be appropriate to post results of the study to the chatroom and not rely upon participants reaching out to the researcher to request results.

As parents' values are a big component to this study, the researcher might want to gather some data from parents directly; however, such an extension of the study may be too much for an undergraduate research project.

It is not clear if researcher's presence and intentions will be disclosed in the chatroom. The REB may need to consider TCPS2 Article 3.7A, and the potential impact the researcher's presence could have on the function of the chatroom if it is disclosed.

It is not specified if the research is quantitative or qualitative in design, therefore it is not possible to ensure that the anticipated number of participants is appropriate. There is no information about proposed data analysis.

Ethical issues identified relating to Privacy and Confidentiality:

Chatrooms generally have controlled access and are associated with a reasonable expectation of privacy. It would be unethical for the researcher to join this chatroom under false pretenses. Privacy expectation of chatroom users should be indicated by inclusion of site membership requirements.

It is unclear whether the researcher intends to incorporate quotations or other potentially identifiable information from the chatroom in research reports and therefore it is unclear the extent to which confidentiality can be maintained from chatroom participants or from the general population. Participants should be informed if they could be identifiable through their chatroom posts or IP addresses associated with a completed survey.

Due to the snowball recruitment method, the peer group may be able to identify research participants. This limitation would need to be addressed. The researcher is proposing to collect personal information that could be easily linked to create identifiable information. If more friends of friends participate in the study, the risk of being identified will be greater. Measures to ensure confidentiality in that context are not clear.

It is unclear how the researcher will collect and store participant email addresses to disseminate study findings. When and how will this identifiable information be separated from participant data? How will confidentiality of the email addresses be maintained per *TCPS2* Articles 5.1 and 5.3? Posting results to the chatroom could reduce the need to rely upon storing confidential information.

Ethical issues identified relating to Risk:

Psychological risk could be associated with questions about emotional growth, cultural identity, and parental relationships, so it will be important to review the questionnaire items to assess risk. The age of participants could heighten this risk. It may be possible for participants to

compare their responses with others in the study via chatroom posts and become embarrassed, worried, or upset.

There could be social risks for cultural groups depending upon the ways different cultural groups are represented in the research findings. Outside researchers may not be able to fully anticipate the level of sensitivity for all cultural groups who may participate. The well-being of some participants might be at risk in countries where access to the Internet is under surveillance by government authorities.

If parents or guardians monitor computer use, this could affect confidentially and associated social risks to participants; provisions for consent from a parent or guardian could heighten this risk. In addition, a family member might become aware of, but not agree with, a person's participation in the research and respond with repercussions for the participant. There are no proposed measures to help participants if they experience that risk.

There may be a social risk to the researcher for a change in her relationships with her friends.

The research is conducted online so the researcher has limited opportunity to provide supports to mitigate risks to participants at a distance or to know what supports might be available locally.

Ethical issues identified relating to the Consent Process:

The researcher proposes to use a tacit consent process whereby participants indicate consent by submitting the questionnaire. Clarity is required to ensure full information is available to all participants (whether recruited through chatroom, snowball sampling, or direct invitation) prior to completion of the questionnaire. *TCPS2* Article 3.2 specifies the information generally required for informed consent.

Direct recruitment through specific invitations or snowball sampling could be considered undue influence that could undermine voluntary consent as per TCPS2 Article 3.1.

The researcher plans to track ongoing discussions in the chatroom. Since the researcher intends to join the chatroom and post information, there is an element of researcher intervention in the setting and therefore this component of the study requires REB review as per *TCPS2* Article 2.3. The REB would need to consider *TCPS2* Article 3.7A in deciding whether consent could be waived for participants in this component of the study. It may be possible to consider the analysis of the chatroom discussions to be secondary use of data collected for a non-research purpose, in which case *TCPS2* Article 5.5A would apply.

Participants should be able to print a copy of the consent form from the survey website.

The researcher indicates that all collected data will be "delinked" upon submission, but clarity is required about what this statement means. The software company provides the option to exclude identifying information, but it is not clear the researcher intends to select this option. It is possible that this information relates to the chatroom data.

Ethical issues identified relating to Data Security:

Data will be stored with a cloud-based company on servers outside North America. The researcher must secure permission from their institution to comply with institutional standards and safeguards. See *TCPS2* Article 5.3 and 5.4 relating to institutional standards and

safeguarding of information throughout the full life cycle of the data. In some countries, laws enable access to data in certain circumstances. Participants should be informed that their survey data will be transferred across national boundaries and may be subject to other privacy regulations.

The consent process would be expected to include a description of these data storage plans as per *TCPS2* Article 3.2 (i) and 5.2.

Employment of a third-party data destruction service requires a confidentiality agreement based on Chapter 5 Privacy and Confidentiality.

The intended plan is to retain the data for 7 years. Assurances would need to be provided that the supervisor has agreed to be data steward and be responsible for data storage and destruction after the thesis student graduates.