RESEARCH ETHICS HANDBOOK

Office of Research Services MacEwan University



Version Date Fall 2024

Preamble

This document was created compile all REB guidelines into one place, in order to address commonly asked questions related to research ethics.

As the research ethics landscape is constantly evolving, this document will continually be reviewed and updated. Should there be any discrepancies between this document and the most recent version of the <u>Tri-Council Policy Statement on the Ethical</u> <u>Conduct of Research Involving Humans</u> (TCPS2), the TCPS2 will always be considered correct.

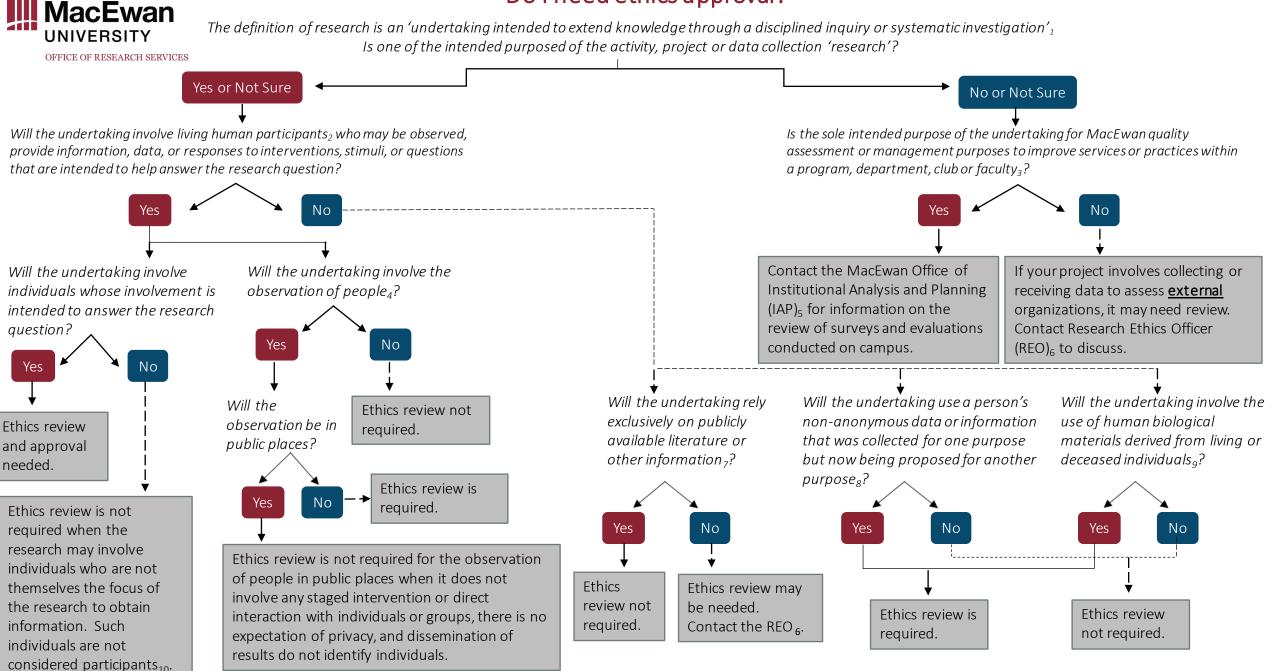
The area of research ethics is not black and white, and it's not possible to cover all types of projects in one document. If you are still unsure of the requirements of your specific project, please reach out to the Research Ethics Board, <u>REB@macewan.ca</u>.



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Do I need ethics approval?



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- 4. TCPS2: Research Exempt from Research Ethics Board Review, Article 2.3 and Application
- 5. MacEwan University Institutional Analysis and Planning, IAP@macewan.ca
- 6. Research Ethics Officer, <u>REB@macewan.ca</u>
- 7. TCPS2: Research Exempt from Research Ethics Board Review, Article 2.2 and Application
- 8. TPCS2: Secondary use of anonymous datasets does not require Research Ethics Board Review, <u>Article 2.4 and Application</u>.

Secondary use of datasets that include identifiable information, or were originally collected with identifiable information and have since been anonymized, see <u>Chapter 5D: Consent and Secondary Use of Information for Research Purposes</u>.

- TCPS2: Research Requiring Research Ethics Board Review, <u>Article 2.1 and Application</u>
 Also see <u>Chapter 12: Human Biological Materials Including Materials Related to Human Reproduction</u>
- 8. TCPS2: Research Requiring Research Ethics Board Review, <u>Article 2.1 and Application</u>

Click here for the full Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2022)

Getting started...

MacEwan's Research Ethics Board (REB) uses an online platform called ROMEO to review and process all submissions for ethics review.

For MacEwan Faculty & Staff:

If you are a MacEwan faculty or staff member, and it is your first time submitting an application, please register for ROMEO by completing the <u>registration form</u>. Once your registration has been processed, you can log in to the <u>Research Portal</u> using your MacEwan ID and password.

Your registration will be processed internally, and you should receive an email notifying you that your account has been created in approximately 1 – 2 business days.

For MacEwan Faculty & Staff, your log in page will look like this:

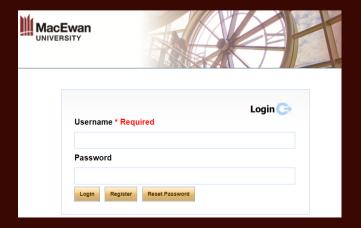
Ensure you are selecting 'Research Portal' to log in.

For MacEwan Students & External Researchers:

If you are a student or external researcher, you need to <u>register</u> for a ROMEO account before logging in.

After you receive a confirmation email, you will be able to log back in to the same website and begin your application.

For students and external researchers, your registration & log in page should look like this:





Requesting REB Exemption

There are two scenarios where research ethics exemption can be requested from the REB:

- 1. **Exemption for Dissemination Purposes,** in situations where a journal or conference requires formal REB documentation, and where the project itself was not research involving humans;
- 2. Exemption for Release of Funds, in situations where funding for research involving humans has been awarded to a faculty member, an REB approval is typically required in order to have the funds released to the researcher. However, the REB acknowledges that sometimes funds are needed to facilitate project activities other than those involving participants (ex. the researcher needs to hire a research assistant to fill out the ethics application, community engagement efforts).

Applying for REB Exemption

- Log in to ROMEO's Research Portal, and complete and submit the 'Request for REB Exemption' form. Ensure the appropriate section of the form is completed (Dissemination vs Funding Release), and clearly describe how the activity(s) do not fall under the purview of the REB.
- 2. The request is reviewed in-office, and should take 1 2 business days.
- 3. In the case of exemption for funding release, a 90-day exemption will be issued, so that the researcher can access funds for research activities that do not involve human (or animal) participants.
- 4. Note that the exemption letter does not mean funding will be released, as the decision ultimately lies with the Associate Vice-President, Research (AVPR).
- 5. The AVPR will confirm, in writing, whether or not the release of funds will be approved; if it is approved, the grant officer will open the grant.
- 6. It is the responsibility of the researcher to ensure full ethics approval is obtained before the 90-day exemption period is over. Failure to do so may result in the grant being suspended. If the researcher does conduct research involving humans prior to receiving ethics approval, the grant may be terminated.

Externally approved studies: Do I need approval from MacEwan?

As a post-secondary institution, we get many requests to distribute recruitment materials from external researchers. While we work to foster a collegial and collaborative space for all types of research, there are instances where ethics review from MacEwan University is required, even if the project has ethics approval elsewhere. Note that this policy was developed after consulting similar policies at other Alberta post-secondary institutions.

You are an external researcher, and you want to:

a. compare responses from MacEwan to other institutions. If your research will be using responses that are identified as being from participants at MacEwan as a variable in your analysis, and/or identifying MacEwan in the dissemination of results, then MacEwan REB approval is required.

b. ask MacEwan faculty, staff, or administration (e.g., a Dean or Department Chair) to distribute recruitment materials, using a listserv, newsletter or faculty contacts. Using MacEwan resources and formal channels of communication in this manner for the purposes of recruiting research participants requires MacEwan REB review as you are directly using MacEwan as a recruitment site for your study^{*}.

c. ask a member of the MacEwan faculty, staff, or administration, to share your recruitment materials using their personal social media accounts. Faculty or staff members are free to share study recruitment information on their personal social media accounts; this does not require MacEwan REB review.

d. email individuals (e.g., faculty, students, staff, administrators) you have identified on MacEwan's website using publicly available information to ask if they would be interested in participating in your study. Using publicly available information to contact individuals at MacEwan does not require MacEwan REB approval if you are only asking the person you are directly contacting to participate in your research, and are not asking them to forward the request to colleagues (see b above).

e. ask instructors to forward your recruitment materials to their students. Accessing students as research participants through an instructor requires MacEwan REB approval*.

^{*}Please note that in situations where MacEwan REB approval is required, obtaining ethics approval from MacEwan does not obligate MacEwan faculty or staff to distribute your recruitment information. It only allows the researcher to request this.

Externally approved studies: Do I need approval from MacEwan?

Obtaining MacEwan REB approval if you already have approval elsewhere is simple and straight forward. We have developed a streamlined process for obtaining approval from MacEwan if ethics approval has already been obtained elsewhere:

- a. <u>Register for our online system</u>, ROMEO, as an external researcher.
- b. Select 'Application for Externally Approved Studies'.
- c. Complete the short form and attach a PDF of the approved application from your home institution, the approval letter, and any additional study-related materials (ie. consent form, recruitment material, study instruments)
- d. Once received, the study is sent to the REB Chair for review, and a response should be issued within 2-3 business days.

If you are an internal researcher, and will be a coinvestigator on a project that is being administered through another post-secondary institution, primary ethics approval should be held at the host institution. However, as a MacEwan faculty member, you must also ensure you have sought secondary approval from MacEwan's REB.

Follow the steps outlined above to obtain ethics approval. Note that even though you may be a coinvestigator on the project itself, for the purposes of this review, you will be listed as the primary investigator within ROMEO. Once received by MacEwan's REB, it will be clear who the project principal investigator is, and how the rest of the study team is made up.

Please contact <u>REB@macewan.ca</u> with any questions or concerns.

Does my case study need ethics review?

To determine if your case study needs ethics review, consider the intent of the document; is it being developed for teaching or research purposes? Keep in mind the definition of research as determined by the <u>TCPS2</u> (2022), "*Research is an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation*.".

Criteria for Teaching* vs Research-based Case Studies

Teaching* does not require ethics review	Research requires ethics review
Would be written as a "story"	Would have research objectives and question(s) (e.g., What, How, or Why)
Would be written to support problem-based learning	Would have case study method recognized as research method to collect empirical data
Would have learning objectives	Makes a conceptual or theoretical contribution to discipline, generates knowledge
Would require teaching notes	Could include development of a research instrumen
Would value practical implications more than theoretical knowledge	Could have theoretical propositions in addition to practical implications

*Please note that a 'teaching case study' should not be confused with SoTL work, which is considered research and requires ethics review.



The following pages provide information and examples for situations where ethics review is not needed, and for when ethics review is needed.

If you are ever unsure about your case study, please contact <u>REB@macewan.ca</u> for help.

Does my case study need ethics review?

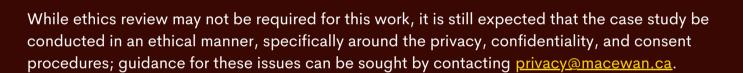
Case Studies Not Requiring Ethics Review

Writing a report on a unique or interesting business or clinical case would not fall within the definition of research and would simply be considered accounts of individual cases. These cases are typically not generalizable, and information may be considered educational by sharing. It is expected that individuals are made aware of plans to create a report about their case, which may be published. Where appropriate, the reports should be de-identified.

Per the TCPS2 (2022) <u>Articles 2.2-2.4</u>, case studies do not require REB review

- if the author is relying exclusively on information that is:
- a. publicly available;
- b. is in the public domain with no reasonable expectation of privacy;
- c. relies on the natural observation of people in public spaces, or;

d. secondary use of anonymous information, so long as the process of data linking does not generate identifiable information.



Examples of case studies where ethics is not required:

i. If you are anecdotally writing about a client receiving therapy or treatment, and the client is anonymous, then you do not need REB approval. However, you should ensure that individuals will be made aware of plans to create a report about their case which may be published, and consultation with the <u>Information & Privacy Office</u> may be needed.

ii. If you are writing about an organization facing a challenge / decision point, with the objective of using the case in class to provide students with a real-life scenario to apply business concepts, then you do not need REB approval. Such cases put students "in the shoes of the protagonist" to discuss solutions and approaches to the challenge. While REB approval is not needed, you should ensure that individuals / organizations will be made aware of plans to create a report about their case which may be published.

Does my case study need ethics review?

Cases Requiring Ethics Review

When the author seeks to use data collected to answer a research question to generate knowledge, and the information being used to answer the research question does not fall under TCPS2 <u>Articles</u> 2.2 - 2.4, above, it is now considered research. This includes data initially collected for non-research purposes. This requires REB review.

Examples of case studies where ethics is required:

i. You are analyzing a case report(s) to answer a specific research question, or are comparing two clients and their reactions to receiving treatment.

ii. You are using the case study method to answer a research question. This may include one or more cases, and may focus on theory building, theory testing, or description. Typically, this method follows a well-defined process including defining a research question, selecting case(s), deciding on research protocols and data collection methods, data analysis, and integration with the literature, in order to contribute new knowledge to the discipline.

External Ethics Requirements

It is possible that journals or grant applications require formal documentation from the REB, even though the work itself does not require ethics review. Authors may apply to the REB for an exemption letter to be issued regarding their work.

Contact:

Please contact the REB with any questions regarding the ethics requirements for your case study, at <u>REB@macewan.ca</u>.

Guidance regarding privacy and confidentiality for non-research studies can be sought by contacting <u>privacy@macewan.ca</u>.



The Secondary Use of Data in Research

Secondary use refers to the use of information originally collected for a purpose other than the current research purpose. This can include student work, educational materials, course and/or instructor evaluations, school records, public or private datasets from other researchers, your own previous datasets, and other identifiable data.

Educational and administrative evaluations and assessment procedures are used to gain insight into student perceptions, curricular revisions, and instructor accountability and efficacy; this information is typically collected without formal consent, as collection is not associated with a research project (TCPS2 Article 2.5). However, to use this information in a research project, ethical guidance should be sought.

It is important to note that the secondary use of data only applies to data that was collected prior to conception of the current study. If researchers know in advance that they will want to extract data from student records or feedback for research purposes before it is collected, then this is not considered secondary use of data, and the instructor/researcher is required to seek ethical approval in advance.

Prior to examining secondary data, it is the researcher's responsibility to determine, to the best of their ability, whether the data was collected anonymously, was anonymized/de-identified after the data was collected or is identifiable data. This responsibility also applies when examining data from an online research data depository. These three types of data are distinct and have different implications for REB Review and collection of participant consent, as explained below.

Secondary Use of Anonymous Information

Anonymous information has **never had identifiers associated with it** and the risk of identification of individuals is low or very low.

REB review is not required for research that relies exclusively on **secondary use of anonymous information**, if the process of data linkage, recording, or dissemination of results does not generate identifiable information (Article 2.4).

Example: You are using anonymous course evaluations, which were originally collected for course improvement purposes.

Example: You are accessing data from a repository that clearly indicates that initial data collection was anonymous.

Example: You had conducted an anonymous survey for a research project, and you would now like to use that data to address a new research question.

Secondary Use of Non-Identifiable (Anonymized & De-Identified) Information

For REB review purposes, non-identifiable data covers both anonymized and deidentified data.

Anonymized data is data that at a previous point in time was identifiable, but the data held by the data custodian has now been stripped of identifiers and any links to identifying information.

De-identified data is when the data custodian retains data that is identifiable or linked to identifying information but is providing researchers with a de-identified dataset for secondary use in research, with no access to the key to re-identify.

If you are using information that was identifiable when it was collected, but has now been stripped of identifiers (i.e., the data is anonymized or de-identified), you must seek REB review, but are not required to seek participant consent (Article 5.5B).

Example: You are provided with a spreadsheet of assignments and grades that no longer has student names or numbers associated with it, for the purpose of answering a research question.

Example: A researcher conducted interviews with a study population that you are also interested in researching, and is providing you with the coded dataset, with identifying information removed.

Example: Your previous research project involved focus groups. You have already coded the data and destroyed transcription records after that project was completed. You now want to use the coded data to address a new research question.

Secondary Use of Non-Identifiable information Stored in a Research Data Repository

Generally, secondary use of de-identified or anonymized information stored in research data repositories for future research purposes would **not** qualify for the exemption from REB review outlined in Articles <u>2.2</u> and <u>2.4</u>.

Example: You are interested in re-analyzing a dataset posted on a data repository (e.g., Open Science Framework, MacEwan University Data Repository).

Example: You are conducting a secondary study based on an existing dataset stored in a research data repository (e.g. MacEwan University Data Repository)

It is the responsibility of the researcher to determine if the data was collected anonymously or if it has been de-identified. Although any direct identifiers may be removed from the posted datasets, you may not know for certain if the data was originally collected anonymously. If you are not sure, seek advice from the REB.

Secondary Use of Identifiable Information

In the case of secondary use of **identifiable** information (e.g., you are accessing individual assignments to analyze common themes), researchers must obtain REB approval. Consent from participants/students is required, unless the researcher satisfies all the requirements set in TCPS2 Article 5.5A.

Researchers who have not obtained consent from participants for secondary use of identifiable information shall only use such information for these purposes if they have satisfied the REB that:

- identifiable information is essential to the research;
- the use of identifiable information without the participants' consent is unlikely to adversely affect the welfare of individuals to whom the information relates;
- the researchers will take appropriate measures to protect the privacy of individuals and to safeguard the identifiable information;
- the researchers will comply with any known preferences previously expressed by individuals to whom the information relates;
- it is impossible or impractical to seek consent from individuals to whom the information relates; and
- the researchers have obtained any other necessary permission for secondary use of information for research purposes.

If a researcher satisfies all the conditions in Article 5.5A (a) - (f), the REB may approve the research without requiring consent from the individuals to whom the information relates.

Note that 'impractical' refers to undue hardship or onerousness that jeopardizes the conduct of the research; it does not mean mere inconvenience.

Ethics Approvals

You can apply for ethics approval using the form in ROMEO 'Secondary Use of Data for Research Purposes'.

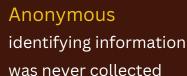
At MacEwan, accessing student information for reasons other than the initial purpose of collection requires permission from the Information and Privacy Office.

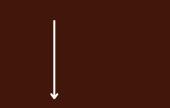
Email <u>privacy@macewan.ca</u> for more information.

Quick Reference: Secondary Use of Data

Secondary use refers to the use of information originally collected for a purpose other than the current research purpose, and only applies to data that was collected PRIOR to the conception of the current study. If you know in advance that you want to access data for research purposes before it has been collected, you will need to seek standard ethics review for the project.







Ethics review not required

Anonymized completely stripped of identifiers

or De-identified

you are being provided with data that has identifiers removed, but the custodian retains a link to re-identify

Ethics review required, but consent is not required Identifiable

data contains personally identifying information

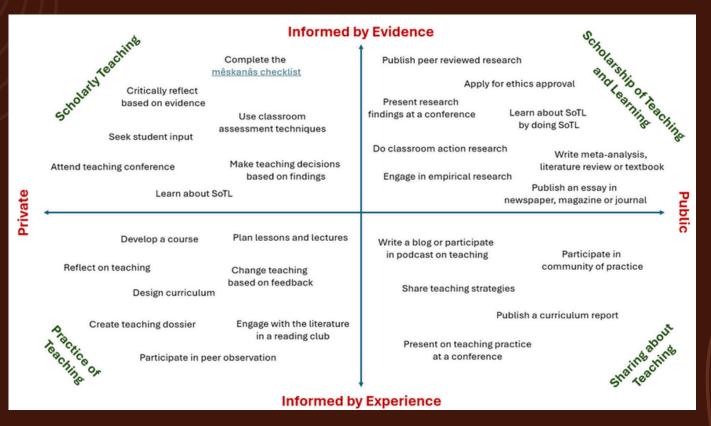
Ethics review required, and consent must be obtained UNLESS researcher satisfies requirements of TCPS2 Article 5.5A

To seek ethics review, complete and submit the application ' Secondary Use of Data for Research Purposes' in ROMEO.

The Scholarship of Teaching and Learning

There is an emerging interest in Canadian universities to move towards evidencebased teaching practices (MacLean & Poole, 2010), that is, consulting the literature on teaching and learning to make informed decisions about teaching and engaging in some level of classroom research to uncover how students learn best. While most professors reflect on their practices as a way to guide their teaching, a smaller number of faculty engage in the Scholarship of Teaching and Learning (SoTL); a methodologically rigorous and scholarly inquiry into teaching practices, attitudes, and values in higher education. It has the dual purpose of enhancing student learning and disseminating research findings.

How do I know if my work is SoTL?



Dimensions of activities related to teaching (Adapted from Maheaux-Pelletier & Rush, 2019; Original diagram by Kern et al., 2015)

Practice of Teaching is mainly informed by experience or the modeling of observed practice. It includes teaching and learning activities that are implemented in the classroom or the curriculum and can be shared within an institution (e.g., curriculum development, documenting teaching practice in a teaching portfolio). Changes in the practice of teaching are grounded in reflection and based on one's teaching experience, their disciplinary lens, and discussions with colleagues. They may also result from incidental changes that occur upon engaging with the literature on teaching and learning. These are activities discussed privately and generally are not subject to assessment beyond end-of-course student evaluations or a suggestion stemming from a private consultation or conversation. Sharing about Teaching is mainly informed by experience but moves from the private to the public. It includes teaching and learning activities that are implemented in the classroom or the curriculum with the explicit sharing of findings with others through informal and semi-formal means. The focus is on teaching itself with some informal evidence of student learning rather than a formal method of investigation. The sharing happens in various ways, including blogs, a presentation at an internal teaching and learning conference, teaching articles, and workshops, and aims to provide ideas for teaching, opportunities for community building, and a space for others to reflect on their own teaching.

Scholarly Teaching is informed by evidence. It includes teaching and learning activities implemented in the classroom or the curriculum based on best practices and critically reflected upon through evidence (e.g., literature, workshops, conferences), with some assessment of the approach implemented. For example, a teaching activity may be informed by the literature, and following its implementation the strategy may be assessed via classroom assessment techniques or a survey about the student experience. It may also be shared at the local level (at a departmental meeting, learning workshop, etc.).

The Scholarship of Teaching and Learning is, at its foundation, the process of exploring, researching, developing, refining, reflecting upon, and communicating better ways and means of producing, promoting, and enhancing scholarly learning and teaching. 'Going public' is the key factor that distinguishes SoTL from scholarly teaching. Being systematic in how to go about observing learning, gathering evidence of it and disseminating findings in peer-reviewed venues is another important characteristic of SoTL research.

Examples of SoTL research questions include:

- a. What factors influence student engagement in online, asynchronous courses?
- b. How do different assessment methods influence the approaches students take to studying in math courses?
- c. Do group contracts improve the outcomes of group project assignments?
- d. How can the language of a course syllabus impact students' perceptions and motivations for a course?

A. Undue Influence and Coercion

Context: The TCPS2 defines the potential risks of undue influence as "the impact of an unequal power relationship on the voluntariness of consent. This may occur when prospective participants are recruited by individuals in a position of authority over them (e.g. teacher/student)".

Coercion is defined as a more extreme form of undue influence that further undermines the ability for participants to offer full and free consent to participate in research. The issue of unequal power relationships is particularly relevant within SoTL as student participants engage in instructor-led research constitute a captive population that is dependent on their instructor for their grades and their broader educational goals. As a result, students may feel pressured to participate to avoid real or perceived repercussions or to please their instructors.

Recommendations:

The researcher/instructor should aim to remove themselves completely from the process of research in the classroom and delegate all functions related to recruitment, seeking informed consent and data collection a neutral third-party (such as a research assistant, co-investigator or colleague) who has no formal role with the course.

Students who are recruited to participate in research during class time might feel compelled to participate based on the decisions made by his or her peers. To mitigate this risk, researchers should consider including a consent form separate from the research instrument, in order to allow students the option to complete the research instrument while still withholding their consent to participate in the study.

Students should not be significantly advantaged or disadvantaged by participating in SoTL research projects. As such, incentives given by course instructors to encourage participation in the research project are generally discouraged. However, if you are offering a small token of appreciation to students for participating in your research activity (1 - 2% bonus mark), there should also be an alternate assignment for students who choose not to participate, to also receive the bonus marks. The alternate assignment should be equal in terms of effort and time to complete as the research activity, and should not be marked for content; if the alternate assignment is handed in, it should receive full bonus marks.

B. Dual-Role Research

Context: Section 7 of the TCPS2 introduces researcher/student conflict of interest and addresses the dual-role researchers have in the context of SoTL as both researcher and teacher (Article 7.4).

The TCPS2 emphasizes that researchers are responsible for ensuring that this trust is not abused, by recognizing and mitigating the conflict of interest that arises from their dual roles, and ensuring it does not affect the decision-making procedures of participants. This dual-role issue is particularly pronounced within SoTL, where the role of the instructor is to act in the best interests of their students, while the role of the researcher is to move the research project forward.

Recommendations

Researchers are responsible for distinguishing their role as instructors from their role as researchers. This distinction needs to be clear to students/participants. Recommended measures include:

1) ensuring that a third-party undertakes recruitment and consent,

2) holding off on accessing any research-related data until after final course grades have been submitted.

The research project should be described in the syllabus and introduced in the first week of the semester. The description of the research project to be included in the syllabus should also be included in the REB application.

C. Confidentiality in the Use of Participant Data

Context: Chapter 5 of the TCPS2 outlines the responsibility of researchers to ensure the privacy and confidentiality of their participants and their data, and states that researchers shall safeguard information entrusted to them and not misuse or wrongfully disclose it. Institutions shall support their researchers in maintaining promises of confidentiality (TCPS2 Article 5.1). The TCPS2 requires that researchers safeguard this information throughout the full life cycle of information: its collection, use, dissemination, retention and/or disposal (TCPS2 Article 5.3). Concerns around privacy and confidentiality are heightened when collecting and using student data and can lead to the reluctance of students to participate in the event that a violation of confidentiality impacts their outcome in the course.

Recommendations

Researchers have a responsibility to ensure that their collection and analysis of research data remains secondary to their responsibility for safeguarding student data. This can be done by:

- i. not viewing or accessing any identifiable research data until after the final course grades have been submitted;
- ii. having a neutral third-party de-identify data before it is viewed by the researcher to preserve participant confidentiality between the student/participant and the instructor/researcher.

Researchers who wish to make use of identifiable student data (i.e. comparing project or course grades with research variables) need to:

- i. ensure free and informed consent, and
- ii. ensure that no course or research data is viewed until after final course grades are submitted.

If researchers wish to access student data or information originally collected for non-research purposes, this is considered the secondary use of data, and must comply with the requirements described in the Section 5D of the TCPS2, and MacEwan REB guidance, 'Secondary Use of Data'.

D. Use of Class Time for Research Purposes

Context: A unique challenge with SoTL research can be the intrusion of research into class time. Students are an accessible, captive participant population and experience a greater research burden due to the power imbalance between them and the researcher/instructor.

Recommendations

Whenever possible, online research is preferred to in-class research, as the former allows students to make decisions about whether to participate in the research in private, without fear of these decisions being visible to others.

Researchers who propose to conduct research during class time must:

- i. provide strong justification for why class time is the most appropriate venue for undertaking the research, and
- ii. ensure a suitable alternative is provided for students who choose not to participate in the research process.

Researchers will need to justify using class time for research purposes in their REB application. Where possible, researchers are encouraged to tie in the research project with the learning objectives of the course, to ensure that time devoted to the research project enhances the learning experience for students.

Researchers should be aware of the burden that might be placed on students across multiple classes and make every effort to minimize the amount of class time devoted to the research process.

Researchers are encouraged to supply a letter of support from the academic head of the program of study demonstrating the value of the research activity (for the risk/benefit assessment), as well as the academic program's awareness of the potential research burden on students.

Other Approvals

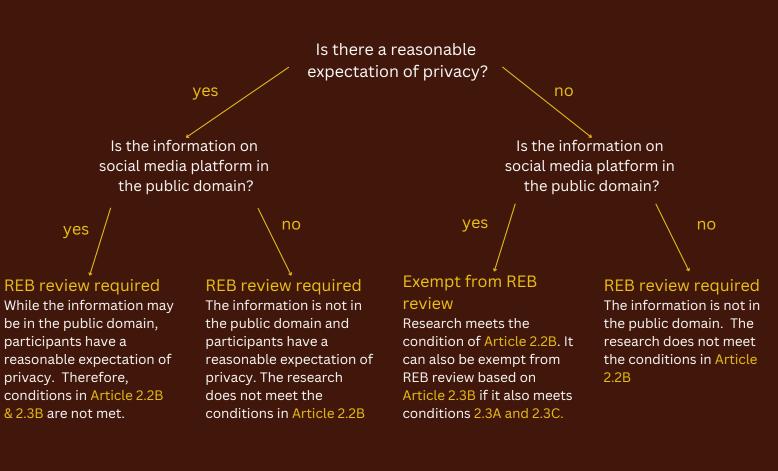
At MacEwan, accessing student information in mêskanâs for reasons other than the initial purpose of collection requires permission from the Information and Privacy Office. Email <u>privacy@macewan.ca</u> for more information.

Does Research Using Social Media Platforms Require Research Ethics Board Review?

The use of social media (SM) platforms provides new avenues and extended opportunities for researchers to access information created by social media users, to expand the scope and breadth of the pool of prospective participants globally, to understand and assess human behaviour in new contexts, and to facilitate collecting information from sources that may otherwise have been difficult to access. However, the use of social media platforms for the purpose of collecting research data also raises some ethical issues, questions, and considerations that apply to its context, and may involve varying levels of risk.

Researchers can refer to guidance recently published by the Panel on Research Ethics on the topic of using social media in research, which supports the implementation of the Tri-Council Policy Statement (TCPS2).

Quick Reference Guide : Research Using Social Media Platforms



Conducting Health Research at MacEwan

Research Using Health Information Governed by the Health Information Act

Health information in Alberta that is in the custody or under the control of a custodian or health information repository is governed and protected by the <u>Health Information Act</u> (HIA).

Researchers who propose to access/use health information, as defined in the HIA (diagnostic, treatment and care information, or, registration information), in their research must gain ethical approval for the project from a HIA Designated Research Ethics Board (under Part 5, Division 3 of HIA).

There are only three Research Ethics Boards (REBs) in Alberta that have been identified in the HIA as being able to review research involving health information;

i. <u>Conjoint Health Research Ethics Board</u> – University of Calgary

ii. Health Research Ethics Board - University of Alberta

iii. Health Research Ethics Board of Alberta – Alberta Innovates

MacEwan University has formally delegated the ethics review of HIA-designated research to the University of Alberta. The intent of this agreement is to streamline the ethics review process research involving health information (as defined above), while still ensuring all appropriate and necessary ethical standards and participant protections are upheld.

MacEwan University researchers who are conducting HIA reviewable research will now only have to apply for ethics review through the University of Alberta using the <u>Alberta Research</u> <u>Information Services</u> (ARISE) system. Researchers will no longer be required to also apply for ethics approval here at MacEwan. The MacEwan Research Ethics Board will accept the review conducted by the University of Alberta HREB without further scrutiny.



If you are planning on conducting research that involves health information that falls under the Health Information Act, you will need access to the University of Alberta ARISE system.

Please follow the steps outlined on the following pages.

Conducting health research, page 1/3

Conducting Health Research at MacEwan

Accessing the University of Alberta ARISE System

If you already have a University of Alberta CCID:

1. <u>Log in</u> to the ARISE System, click on your name in the top right-hand corner, and edit your profile by changing the Department to MacEwan University.

If you do NOT have a University of Alberta CCID:

1. You will need to <u>request a guest CCID</u> from their Research Ethics Office by completing the CCID Request Form. It may take 1-2 business days after you change the temporary password assigned to your CCID before you can log in to the online system. If you are not able to log in to the online system after 7 business days, please contact <u>reoffice@ualberta.ca</u>. Guest CCIDs must be renewed every twelve months.

2. Once you have your CCID, log in to the ARISE System, and select 'Request a Role'.

3. Scroll down to the bottom and select the "REB Principal/Co-Investigator" role, then click Continue to move to the second page.

4. On the second page, answer the four questions. For 3.0, set the Department/Employer to "MacEwan University (Department)". Leave 4.0 blank.

5. Click Continue and you will exit the form. Click on the left, then click OK to complete the request. You will receive a message right away that the role has been granted. If not, see Troubleshooting.



Conducting Health Research at MacEwan

Accessing the University of Alberta ARISE System

Receiving Notifications

The ARISE system sends system-generated notifications to inform applicants when an application moves through the review process (ie. when it is sent back to you for changes, when it is approved, when a renewal is due, etc).

The notifications will go to the @ualberta.ca email address associated with your UofA CCID but you can (and should) redirect them to your preferred email address.

To change your preferred email address:

- a) Log into the ARISE System.
- b) Click on your name (top right corner of the screen).
- c) Click on 'My Profile'.
- d) Click on 'Edit My Info' (on the left side of the screen).
- e) Enter your preferred email address in the Email field.
- f) Click OK to submit the change and exit the form.

Starting an Application

To start your application, click the button from your Dashboard.

- a) In Section 1.1 (5.0), list yourself as the local Principal Investigator.
- b) In Section 1.1 (6.0), set the Type of research/study to "External Researcher".

When the application is complete, *Save* and *Exit* the application. Click *Submit Study* on the left when you are ready to submit your ethics application for review.

Your study will initially route through MacEwan's Research Ethics Officer, and then will be automatically forwarded to the UofA HREB. From there, the project takes the regular UofA review pathway, and all questions regarding the status of your study can be directed to <u>reoffice@ualberta.ca</u>.

Once you obtain approval from the HREB, forward the approval letter to <u>REB@macewan.ca</u>; there is no need to complete an application at MacEwan.

If you are conducting health research and you wish to discuss whether or not this new review process applies to you, please contact the Research Ethics Officer at (780) 497-4280 or by email at <u>REB@macewan.ca</u>.

Purpose:

This guidance document has been created to highlight potential ethical challenges in conducting autoethnographic research and assist researchers in understanding when an REB application is required.

Definition:

Autoethnography is an approach to research and writing that seeks to describe and systematically analyze personal experience to understand cultural experience (Ellis, 2004; Holman Jones, 2005).

Is REB Approval Needed?

There are some instances in which REB review may be required for autoethnographic projects.

Self-studies done for the purpose of research, as defined in the Policy, and involving human participants falls within the scope of TCPS 2 and requires REB review (<u>Application of Article 2.1</u>).

Retrospective observations/reflections (data) about other people reported by auto ethnographers may be considered **secondary use of previously collected information;** originally obtained for purposes other than research – such as normal interactions during one's daily life. If the data involves individuals other than the researcher, it is subject to TCPS2 <u>Articles 2.4</u> (the individual is not known by the researcher, and ethics is not required), <u>5.5A, and 5.5B</u> (the individual is known by the researcher, and ethics is required).

Prospective encounters/reflections for the purpose using an autoethnographic approach – intentionally going into an event with the awareness that observations will be contributing to research – the ethical implications are heightened.

In these cases, there is more opportunity for transparency with those who may be implicated in the research, and/or there is an increased possibility for a researcher to intervene and/or manipulate the environment and frame the resulting observations in a particular way to support the research objectives.



While the observation of people in public places generally does not require ethics review, if there is any intervention staged by the researcher, if there is a reasonable expectation of privacy, or if individuals will be identified in dissemination of research, then REB review may be required (<u>Article 2.3</u>).

If information is acquired in some **professional capacity** (lawyer, psychiatrist, journalist) then the researcher must abide by those professional standards before pursuing research and determining whether additional REB approval is required.

1. Ethical Considerations for Self-Studies

a. Self-studies: General

Self-study typically involves a scholarly reflection on one's own experiences in a particular context in order to answer a specific research question. Self-study may involve narratives, reflections and/or analyses of experiences based on the researcher's observations of, interactions with, or information about other individuals or communities. In self-study, at least the researcher is a research participant.

The REB must assess the ethical acceptability of self-study by considering its foreseeable risks, its potential benefits, and the ethical implications of the research. The researcher may be the sole participant, e.g. a researcher writing a self-study of his/her experience camping alone in the woods. REBs should assess the level of risk that the researcher is willing to assume to himself/herself.

b. Self-Study: Confidentiality Concerns

Researchers should be mindful of the possible negative consequences that may arise because of conducting autoethnographic research. For example, once researchers reveal their autobiographical experiences, their data may become irretrievable depending on their dissemination and data retention plans. Thus, it is important for researchers to think carefully about not disclosing things about themselves that they would not want others to know. This typically includes embarrassing items, intimate information, and stories that may have legal and/or professional implications. In cases where researchers wish to reveal sensitive information about themselves, they should consider implementing safeguards to protect their own confidentiality (e.g., publishing the document using a pseudonym, incorporating pseudonyms for all participants, changing the names of towns, schools, and so on).

c. Self Study: Consent Considerations

Given the dual roles that researchers play with respect to autoethnographic research – i.e., as both researcher and participant – they do not need to obtain explicit consent for their own participation. In virtue of researchers voluntarily deciding to conduct autoethnographic research projects, their consent to participate in research-related activities is tacitly implied.

However, researchers must convey to the REB that they are aware and appreciate what their participation in their project involves. This includes all the necessary information required for fully informed consent, such as the potential benefits of the research, the dissemination plan, the privacy and confidentiality safeguards in place, the potential risks involved in their participation, and so on.

2. Ethical Considerations for Autoethnography Involving Others

a. Autoethnography Involving Others: General

While researchers may be conducting research on themselves, individuals outside the research may be identified through these stories, and specifically through references to the communities they inhabit. The researcher must consider these potentialities when determining whether others are identified.

b. Autoethnography Involving Others: Confidentiality Concerns

Since participants (other than the researcher) may be featured in an autoethnographic project without the researcher actively engaging with participants – e.g., by conducting interviews, focus groups, etc. – it is important for researchers to be especially careful of the way participants are represented in their research. The same precautions that researchers take toward protecting their own privacy and confidentiality typically applies to protecting the privacy and confidentiality of those participants that feature in the story/study. Researchers should not disclose things about other participants in their autoethnographic project that one would not reasonably want others to know. This includes embarrassing items, revealing/intimate information, and stories that may have legal and/or professional implications.

Confidentiality Concerns, continued

Out of concern for welfare, regardless of whether they meet the definition of research participants, others mentioned in the study have a right to privacy protections. Individuals and/or groups mentioned in the study may not be aware that their interactions with the researcher would be included in a research project. The REB should assess whether the dissemination of the research could lead to the identification of individuals and/or communities and may pose additional risks to participants' and non-participants' privacy and confidentiality. This assessment should also consider the research context, and the level and relevance of privacy protections to others mentioned in the self-study. For example, participants, or other individuals implicated in the research, who seek or expect public acknowledgement of their contributions may not have the same expectations or needs for privacy protections.

c. Autoethnography Involving Others: Consent Considerations

If others are involved as research participants, the REB must assess how the researcher plans to manage the consent process. In general, researchers must seek participants' consent to participate in their project. If the material on which autoethnography is based (e.g., journal entries, recollections) was not originally intended for research, but is later proposed for research purposes, then the consent of the individual(s) and/or communities involved, if any, must be sought.

In some exceptional circumstances, the researcher may request an alteration to consent requirements if they satisfy the REB that the provisions of <u>Article 3.7A</u> are met.

If in doubt, ask us!

Feel free to contact the REB at <u>REB@macewan.ca</u>. if you have any questions or concerns about your autoethnography study!



When children participate in research, researchers must secure the assent of the potential participant, and in most cases, also obtain the permission of the parent or guardian.

The assent process should involve taking the time to explain to the participant what will happen in the study, why the study is being done, what will be done to the participants, and that, if they object, that the research will be terminated and they will not be punished or scolded. Researchers must respect the decision of children who are capable of verbally or physically assenting to, or dissenting from, participation in research, even if the authorized third party has consented on their behalf (see <u>Article 3.10</u>).

The assent must be provided in a language that the participants can understand, while communicating the essential elements of consent without obscuring the important information in a lot of detail. The greater the cognitive capacity of the participant, the greater the amount of information that should be shared.

For children that are very young (younger than 7), it is not expected that they sign an assent form in order to participate in a study. Instead, an oral consent script using very simple language should be used to explain the research to the child, who can then indicate if they want to participate in research activities.

For children who are 7 to 14 years of age, an assent form is typically used, and younger children will need to have the assent read to them. For these reasons, the biggest challenge in writing assent forms is keeping the language and concepts appropriately simple.

Children 15 years of age and older are generally expected to give assent by signing the consent form used by their parents. However, if an investigator believes an assent form using simpler language is a better fit for a potential participant in this age group because of the complexity of the study or the nature of the study population, one may be used.

Although there are very formal requirements for the elements that must be present in a consent form, no such requirements exist for assent forms. This means that the investigator can propose assent content that he/she believes will best inform the potential participants about the study.

Below are recommendations for methods to be used when obtaining assent from different age groups. Please note that the TCPS2 advocates for an approach based on the decision-making capacity of the individual (as long as it does not conflict with any laws governing research participation) rather than an age-based approach to consent; it is up to the researcher to ultimately determine what method will best inform each of their participants about the study, and to rationalize this to the REB.

Generally speaking, however, the length and details provided in the assent form should be proportional to the complexity of the study and the age of the participants.

Age	Method of Obtaining Assent
younger than 7	oral assent for very young children, with parental consent see appendix A
7-10	written assent for younger children, with parental consent see appendix B
11-14	written assent for older children, with parental consent see appendix C
14+	signed consent form with parent/guardian see regular consent form template

The following documents (Appendices A - C) are examples of assent form templates that researchers can use to develop their own study documents. Word versions of the templates are available on the <u>MacEwan REB website</u>.

Appendix A: Oral assent for very young children (ages 7 and under)

Hi. My name is [insert name]. I am here today because I want to find out why/how kids with [describe inclusion criteria in simple terms and a short description of the purpose of the study].

Your Mom/Dad/Guardian has said yes to let me ask you some questions.

If you are willing to answer my questions, [Insert a few (1-3) sentences explaining what is involved in participation] (e.g., we are going to play a bunch of quick computer games/do some puzzles/read some stories/I'm going to ask you some questions). Some kids who answer these questions find them interesting, but sometimes they find them a bit hard/boring, but that's ok, just try your best.

[If the research is personal/sensitive] I am going to keep everything you say/do here private. Only you and I will know what you do/say here today. I'm not going to tell your parents/teachers.

If you don't want to answer my questions, that's ok. I won't mind. Even if you say yes, but change your mind later, just let me know and we can take a break or stop for good and it isn't a problem.

Do you have any questions?

Do you want to try to answer some questions?

Researcher attestation:

I have explained this research study with _____ using understandable and appropriate language. They agreed to participate in the study.

Researcher Signature

Date

Appendix B: Younger child assent (approximately ages 7-10)

Title of Study:

Principal Investigator(s):	Phone Number(s):
Study Coordinator:	Phone Number(s):

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about [insert topic and describe goals in simple language]. You are being asked to join the study because [insert name of condition or other reason(s) for inclusion].

If you agree to join this study, you will be asked to [describe procedures, (e.g., questionnaires, activities) in words a child would know and understand. Also include number of visits and time frame in words easily understood by a child].

Describe possible risks (e.g., discomforts) in simple language.

Will any part of the study hurt? (describe risks and discomforts using terms a child would know and understand; take into account a child's fears)

Use any of the following statements that are appropriate: We do not know if being in this study will help you. We expect that the study will help you by [describe how]. We may learn something that will help other children with [insert name of condition or topic under investigation] some day. This study will help us learn more about [topic under investigation].

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop.

Appendix B: Younger child assent (approximately ages 7-10)

Before you say yes or no to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Just tell the researcher that you have a question.

If you have any questions about this study please feel free to contact [Insert Study Contact name and contact #]

- Yes, I will be in this research study.
- No, I don't want to do this.

Child's name	 Signature	Date
Person obtaining Assent	 Signature	 Date

If oral assent was obtained:

I have discussed this research study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed them of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assent to participate in this study.

Researcher Signature

Date

Appendix C – Older Child Assent (approximately ages 11 – 14)

Title of Study:

Principal Investigator(s):	Phone Number(s):
Study Coordinator:	Phone Number(s):

What is a research study?

A research study is a way to find out new information about something. Children do not need to be in a research study if they don't want to.

Why are you being asked to be part of this research study?

You are being asked to take part in this research study because we are trying to learn more about (Insert name of what is studied here). We are asking you to be in the study because (state why the child is being asked to participate). About (enter #) children will be in this study.

If you join the study what will happen to you?

Describe what takes place from the child's point of view.

We want to tell you about some things that will happen to you if you are in this study.

- You will be in the study for (insert duration of participation).
- We will use a needle to take some blood from your arm (#) times.
- We will need you to take (name of procedure) that will last (duration). This is (a simple explanation of what will happen). Your (mother/father/other) can be (location).
- We will ask you to sit with us and (talk about some things/look at some pictures). It will take about 1 hour to do this
- We will ask you to answer some questions about X.

Will any part of the study hurt?

Describe risks and discomforts using terms a child would know and understand; take into account a child's fears.

Obtaining assent from children to participate in research

Appendix C – Older Child Assent (approximately ages 11 – 14)

Will the study help you?

Describe any benefits to the child from participation in the research or if there are none omit this section.

Will the study help others?

Describe any benefits to society from the research. This study might find out things that will help other children with (insert name of condition being studied) some day.

What do you get for being in the study?

You (and your parents) will get (enter amount or item) for (each visit/entire study).

Do you have to be in the study?

You do not have to be in the study. It's up to you. No one will be upset if you don't want to do this study. If you join the study, you can change your mind and stop being part of it at any time. All you have to do is tell us. It's okay, the researchers and your parents won't be upset.

What choices do you have if you say no to this study?

There are other ways to help your (insert name of condition being studied) if you don't want to be in this study. Provide examples.

This study is voluntary, so if you don't want to do it (nothing else will change)(there are no other choices).

Do your parents know about this study?

This study was explained to your parents and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about you?

The information collected about you during this study will be kept safely locked up. Nobody will know it except the people doing the research.

The study information about you (will, will not) be given to your parents (or teachers). The researchers will not tell your friends or anyone else.

Obtaining assent from children to participate in research

Appendix C – Older Child Assent (approximately ages 11 – 14)

What if you have any questions?

You can ask any questions that you may have about the study. If you have a question later that you didn't think of now, either you can call or have your parents call (insert study telephone number).

Other information about the study.

- If you decide to be in the study, please write your name below.
- You will be given a copy of this paper to keep.
- Yes, I will be in this research study.
- No, I don't want to do this.

Child's name	 Signature	Date
Person obtaining Assent	 Signature	 Date

If oral assent was obtained:

I have discussed this research study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed them of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assent to participate in this study.

Researcher Signature	Date



Guidelines for Research Involving Indigenous Peoples of Canada

1. Purpose

The purpose of this guideline is to provide information on engaging and conducting research involving First Nations, Inuit, and Métis Peoples in Canada. Note that this document is a general guideline meant to bring awareness to potential considerations and is not a checklist; each research project is unique and not all items will apply to every situation. It is the responsibility of the researcher to develop an understanding of how to best conduct their project in an ethical manner, given the considerations provided below. Please contact the Research Ethics Board if you have any questions about the items in this document.

2. Definitions

The following <u>definitions</u> are from the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (2022).

Community: A group of people with a shared identity or interest that has the capacity to act or express itself as a collective. A community may be territorial, organizational, or a community of interest.

Community-based research: research conducted at a community site that focuses not only on individuals, but on the community itself. Community-based research may be initiated by the community independently or in collaboration with a researcher.

Community engagement: a process that establishes an interaction between a researcher (or a research team) and a community with regard to a research project. It signifies the intent of forming a collaborative relationship between researchers and communities, although the degree of collaboration may vary depending on the community context and nature of the research.

Cultural heritage: a dynamic concept that includes, but is not limited to, First Nations, Inuit and Métis peoples' relations with particular territories, material objects, traditional knowledge and skills, and intangibles that are transmitted from one generation to the next, such as sacred narratives, customs, representations or practices. Identifiable information: information that may be reasonably expected to identify an individual, alone or in combination with other available information.

Indigenous Peoples: In Canada, this term refers to persons of First Nations, Inuit or Métis descent, regardless of where they reside and whether their names appear on an official register.

Research agreement: a document that serves as a primary means of clarifying and confirming mutual expectations and, where appropriate, commitments between researchers and communities.

Traditional knowledge: the knowledge held by First Nations, Inuit and Métis peoples, the Indigenous peoples of Canada. Traditional knowledge is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined by an Indigenous community's land, environment, region, culture, and language. It may also be new knowledge transmitted to subsequent generations.

3. Background

In accordance with the Canadian Constitution Act, 1982 Section 35 and the Tri-Council Policy Statement (TCPS 2), the Research Ethics Board (REB) acknowledges the unique status and affirms the rights of Indigenous Peoples in Canada. Indigenous rights have been interpreted to include a range of cultural, social, political, and economic rights including the right to land, as well as to fish, to hunt, to practice one's own culture, and to establish treaties.

Indigenous Peoples, include persons who self-identify as being of First Nation, Inuit, or Métis descent, regardless of where they reside or whether their names appear on an official register. The REB recognizes the uniqueness and richness of the over 600 distinct Indigenous communities across Canada.



^{1.} Asch, Michael. Home and Native Land: Aboriginal Rights and the Canadian Constitution. Agincourt: Methuen, 1984. 30.

4. The Scope of Indigenous Research

As emphasized in the <u>TCPS 2 Chapter 9</u>, Indigenous research is research that includes a major Indigenous component. This includes the following:

- i. Research conducted on First Nations, Inuit, or Métis lands;
- ii. Projects where Indigenous identity is a criterion for research participation;
- iii. Research that seeks input from participants regarding Indigenous culture, heritage, artifacts, traditional knowledge or unique characteristics of Indigenous Peoples;
- iv. Research in which Indigenous identity or membership in an Indigenous community is used as a variable for the purpose of data collection and primary data analysis;
- v. Projects where interpretation of data results refers directly to Indigenous communities, peoples, language, history or culture;
- vi. Research that is likely to affect the welfare of Indigenous Peoples;
- vii. Research that involves secondary use of data or human biological material identifiable as originating from an Indigenous community or Indigenous peoples;
- viii. Research that involves linking two or more anonymous data sets or data associated with human biological materials, and there is a reasonable prospect that it will generate information identifiable as originating from a specific Indigenous community or segment of the Indigenous community at large.

Below are three examples of research involving Indigenous Peoples:

- a. A researcher is planning to visit a school located on First Nation land to explore a particular community's views with respect to the content of a piece of federal legislation. Since this project will be conducted on First Nation lands, it is considered research involving Indigenous Peoples.
- b. An investigator is seeking to explore the challenges faced by young adults entering the job market and is conducting a comparative study looking at the diverse challenges that members of different cultural and ethnic groups face, including Indigenous Peoples. Given that the research design of this project includes Indigenous identity as both part of the inclusion criteria, and as a variable for the purpose of data analysis, it is considered research involving Indigenous Peoples.
- c. A researcher wishes to explore the benefits and challenges of transmitting traditional knowledge, or Indigenous knowledge, orally. This project is considered research involving Indigenous Peoples because the analysis and interpretation of data is on or about Indigenous culture.

5. Conducting Indigenous Research

All research involving Indigenous Peoples of Canada must be conducted in a manner that is (I) respectful of Indigenous communities and individuals, (II) demonstrates concern for the collective and individual welfare of Indigenous peoples, and (III) is collaborative in nature; that is, the research should typically consult and engage the relevant Indigenous community/communities. The researcher will be given the opportunity describe to the REB, in the REB application, how each of these conditions are/will be met, prior to the initiation of any research activity.

I. Respect

Respecting Indigenous Peoples entails, among other things, respecting their unique history and culture, their forms of knowledge, and their structures of governance.

History & Culture

Investigators conducting research involving Indigenous Peoples should demonstrate to the REB a solid understanding of the particular community's history and culture that it seeks to engage with. This is especially important given the differences that may exist between the researcher's own culture and that of the community they plan to work with. A lack of understanding of an Indigenous community's history and culture can lead to the misappropriating or devaluing of Indigenous art, music, symbols, narratives, forms of knowledge, etc., and to violating existing norms regarding the proper handling of human tissue and remains.

Traditional Knowledge

Investigators conducting research involving Indigenous Peoples should be aware as to how their possible contribution to "Western knowledge" fits with the particular form of knowledge held by the Indigenous community that they are engaging with, and, more generally, with traditional knowledge.

If disagreement about interpretation arises between researchers and the community and it cannot be resolved, researchers may consider the following options;

- (a) providing the community with an opportunity to make its views known, or
- (b) accurately reporting any disagreement about the interpretation of the data in their reports or publications.

This should not be construed as giving the community the right to block the publication of findings. Rather, it gives the community the opportunity to contextualize the findings (p. 128). The data remains the property of the Indigenous community and should not be incorporated into other research activities – the secondary use of data – without the prior informed consent.

Self-Governance

Investigators conducting research involving Indigenous Peoples should consider how best to seek the necessary permissions from all appropriate bodies. In some cases, and depending on the community, this may include not only a formal leader, but also an elder, an elder's circle, a knowledge keeper, or a specific council or association, in addition to individual research participants, but in other cases, it's possible that none of this would be needed. Regardless, investigators conducting research involving Indigenous Peoples should demonstrate respect and understanding toward the particular community's authority structure it seeks to engage with, irrespective of how complex or different it may seem. This includes respecting the most vulnerable individuals in a community, including sub-groups who may not have a voice in formal leadership.

II. Individual & Collective Welfare

Research involving Indigenous Peoples in Canada has typically been conducted by non-Indigenous researchers, and in a manner that has not benefited – and sometimes harmed – both Indigenous communities and individuals. Given this troubling history, it is imperative that all investigators conducting research involving Indigenous Peoples demonstrate to both the REB and the relevant Indigenous community that the potential harms that may arise because of the research being conducted are outweighed by the potential benefits. This is necessary in order to ensure that the welfare of Indigenous individuals and communities are taken seriously.

For research involving Indigenous Peoples, the potential benefits are to be understood as beneficial not only by the researcher, but also by the relevant Indigenous community. The onus is on the researcher to describe what the direct benefits to the individual/community are and how they outweigh the risks associated with the study.

Possible benefits to Indigenous communities include:

- (a) local hiring/training of members of the Indigenous community as research assistants, data analysts, translators, etc.;
- (b) recognition of Indigenous peoples' contribution to the project (if desired by the community);
- (c) sharing the results of the research with the community (if desired by the community); and
- (d) **adjusting** the research design so as to better fit the particular community's needs and priorities.

III. Collaboration & Engagement

Researchers engaging with Indigenous Peoples should consider the authority and important role that communities play with respect to this type of research. Researchers are encouraged to (a) familiarize themselves with any ethical guidelines that the particular Indigenous community it seeks to engage with holds (such as OCAP- Ownership, Control, Access, and Possession), and (b) create a community engagement plan laying out how they intend to respect and acknowledge the community that they seek to engage with.

OCAP (Ownership, Control, Access, and Possession)

Many Indigenous communities across Canada have adopted an ethical guideline called <u>OCAP</u> to govern the ethical conduct of research that takes place on their own lands. OCAP is a set of principles aimed at protecting Indigenous ownership, Indigenous jurisdiction, and Indigenous information.

Researchers working and engaging with communities that have adopted their own ethical codes (such as OCAP) are encouraged to familiarize themselves with such codes. They are also advised to consult the REB with respect to certain rules or guidelines that might be inconsistent or in tension with the ethical guidelines laid out in the TCPS 2. Inconsistencies or tensions between a community's ethical code and the TCPS 2 should be identified and addressed in advance of initiating any research.

Community Engagement Plan

Typically, investigators conducting research involving Indigenous Peoples will provide the REB with a formal community engagement plan. This plan should outline how the researcher has engaged, or intends to engage, the relevant Indigenous community, and the nature of this engagement. In accordance with the TCPS 2 "the nature and extent of community engagement in a project shall be determined jointly by the researcher and the relevant community and shall be appropriate to the community characteristics and nature of the research" (p. 154). Alternatively, researchers may provide relevant information detailing their relationship with the community, and how the community has already been engaged prior to the initiation of the research project. Note ethics approval is not needed in order to begin the engagement process.



Investigators conducting research in/with Indigenous communities should 'ensure, to the extent possible, that they take into consideration the views of all relevant sectors – including individuals and subgroups who may not have a voice in the formal leadership. Groups or individuals whose circumstances may make them vulnerable may need or desire special measures to ensure their safety in the context of a specific research project. Those who have been excluded from participation in the past may need special measures to ensure their inclusion in research' (p.117).

For examples of different types of research projects involving Indigenous Peoples, along with appropriate community engagement plans, see Article 9.2 of the TCPS 2 entitled "Nature and Extent of Community Engagement".

Two Possible Exemptions:

Investigators conducting research involving Indigenous Peoples may be exempted from providing the REB with a community engagement plan if:

- i. the research participants are not identifiable as part of a particular community, or
- ii. the welfare of the relevant community is not likely to be affected by the research project.

If a project involving Indigenous Peoples is exempt from a community engagement plan, individual consent still must be sought.

The onus is on researchers to demonstrate to the REB that their project involving Indigenous Peoples falls under one of the two exemptions, otherwise, typically, research involving Indigenous Peoples should include a community engagement plan.

6. Research Agreements

It is recommended that research involving Indigenous Peoples where a community has formally engaged with a researcher or research team through a designated representative shall set out, in a research agreement, the terms and undertakings of both the researcher and the community before participants are recruited. A research agreement may address the following questions:

- What is the nature of community participation?
- How will individual consent be obtained?
- What is the process by which amendments will be made to the agreement?
- How will potential benefits be distributed?
- Who is responsible for what part of the project design?
- How will data be collected, managed, and stored?
- What is the process for data analysis and data interpretation?
- How will credits pertaining to the research project be assigned?
- How will authorship be determined?
- Who will have the intellectual property rights or how will these be shared?
- How will possible benefits or royalties flowing from intellectual property be distributed?
- How will the data be disseminated?
- In the event that a dispute arises, what is the conflict resolution process?
- How will secondary materials or any other anticipated secondary use be managed?

The exact content of a research agreement will vary based on the nature of the research project, as well as the values and priorities of the community that the researcher or research team plans to engage with. Above are just some of the more common items that research agreements typically address, but the document itself can be as informal or as formal, as deemed appropriate for the situation.

For specific guidance on what to include in your research agreement or steps on how to construct a research agreement, please consult the <u>Office of Research Services</u>.

Alternatively, if the researcher believes that a research agreement is not necessary, then the researcher will have the opportunity to describe to the REB in the ethics application why an agreement is not needed.

All page number references refer to the online version of the TCPS 2 (2022).

Ethics Review for Course-Based Research

Background and Determining Eligibility

Frequently, undergraduate courses incorporate class projects and other activities for the purposes of developing research skills. These projects may be carried out by individual students, small groups or as a single class project. Research activities included within a course for pedagogical purposes (i.e. the objective is to provide students with exposure to research methods in their field of study) are defined as research and are therefore governed by ethics review policies.

To qualify for approval under course-based ethics student research assignments must be:

- 1. no more than minimal risk;
- 2. the participants must be drawn from the general population, and;
- 3. be capable of giving free and informed consent.

In addition, the student projects must not involve major deception, sensitive topics, physically invasive contact with the participants, or require ethics approval from another institution.

Examples of research activities that **could be approved** under course-based review include:

Having students conduct interviews, administer standard tests, or distribute questionnaires to individuals recruited from outside of class to help develop interview or questionnaire design skills.

Conduct "mini" research projects where students pose general questions while gathering responses from participants recruited from outside of class and using those responses for presentation.

Example of a research activity that **would not be approved** course-based ethics approval:

Children recruited through public elementary schools will be shown an educational video to see if it enhances their learning of that topic. This project **would not be approved** under course-based ethics because it would require ethics review from Edmonton Public Schools. This study would require regular REB approval. Example of a research activity that **would not require** course-based ethics approval:

Students distributing questionnaires to classmates, or students collecting data from computer administered tests from classmates; where data will be analyzed and presented only to classmates. **Ethics would not be required.** Course based ethics approval is only required if participants are being recruited from outside of class.

Determining Eligibility

Note that the following questions should be used as a general guide to determine if the research assignment(s) within your course can be covered by a course-based ethics review. Please use this guide prior to completing and submitting the ethics application. If you are unsure of the answer to a question, contact the Ethics Officer to discuss further.

Part I

In order for your course to be considered appropriate for course-based ethics review, the following questions should be answered **YES**:

- Do the projects potentially involve human subjects (beyond classmates) who are 18 years or older and are not considered part of a special or vulnerable population(children, Indigenous or minority groups, those with mental illness, etc)?
- 2. Is the primary purpose of the research to teach students about research or how to conduct research?
- 3. Will the research only be disseminated within the classroom/agency involved, or within the MacEwan University community (e.g. in a university poster session)?
- 4. Is the application for a set of minimal risk research projects occurring within the scope of a course at MacEwan University?
- If the answer to any of the above is **NO**, please contact the Ethics Officer at (<u>REB@macewan.ca</u>) to discuss your project further.



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Part II

In order for your course to be considered appropriate for course-based ethics review, the following questions should be answered **NO**:

- 1. Is this an Honour's Thesis or Independent Study research project?
- 2. Is this an undertaking that can potentially extend knowledge through a disciplined inquiry or systematic investigation? In other words, is there a possibility that any of these projects will further knowledge in the field and may be published or disseminated outside the university (i.e. by disseminating at conferences outside of MacEwan University, publishing in peer-reviewed journals, reports to the media)?
- 3. Will the projects be health-related (i.e. obtaining biomedical samples, collecting health information)?
- 4. Will any of the projects involve physically invasive contact with the participants?
- 5. Will projects involve any sensitive or incriminating topics/questions or information that could place participants at risk (e.g. participation in an illegal activity)?
- 6. Will any of the research projects involve major element(s) of deception for the participants?
- 7. Are any of the projects a direct extension of the course instructor's research?

If the answer to any of the above is **YES**, please contact the Ethics Officer (<u>REB@macewan.ca</u>) to discuss your project further.

Applying for Course-Based Ethics Review

To see if your project meets the requirements for a course-based review, and to submit your application to the Research Ethics Board, simply <u>sign in to ROMEO's Research Portal</u> using your regular log in, and complete the form entitled, '*Course-Based Research Ethics Board (REB) Application*'.

These applications are reviewed by the REB Chair, and will take up to 3 business days for initial processing.

CONTACT US with any questions



VISIT OUR WEBSITE

EMAIL US

CALL US 780-497-4280