Application

00283 - Human Ethics Application

09801 - From Research to Action on Clean Water and Sanitation in First Nations Communities in Canada

Human Ethics

Status:	Correcting
Submitted Date:	06/26/2017 11:41 AM

Primary Investigator

Last Name*	O'Gorman		Melanie
	Last Name	Middle Name	First Name
Primary Email:	m.ogorman@uwinnipeg.ca		
Secondary Email:			
Primary Phone Number:	204-786-9966		
Secondary Phone Number:			
Address:	515 Portage Ave.		
	Winnipeg		
Country:*	Canada	Manitoba	R3B2E9
		State/Province	Postal Code/Zip

UW Academic Information

Appointment:*	Tenured and Continuing Appointment	07/01/2006	
		Session Start Date	Session End Date
UW Academic Rank:	Associate Professor		

Faculty: Business and Economics

Department: Economics

Organization Information

1.0 Project Details

1.1 Project Dates:* 07/03/2017 (Start Date) 12/29/2017 (End Date)

1.2 Project Title: From Research to Action on Clean Water and Sanitation in First Nations Communities in Canada

1.3 Researcher Type:* Faculty/Staff

Indicate the affiliation of the principal researcher to the University of Winnipeg

If Other, please specify

Is the proposed research funded?

1.4 Project Funding: No

Researcher's Supervisor (if applicable)Select from the following drop down list:

1.5 Supervisor:

If the person is not in this list, enter the name and institutional affiliation in the fields below:

Last Name

First Name

Institutional Affiliation:

Project Objectives and Design

Provide a summary of the proposed research project.

The summary of your research project should clearly indicate the problem or issue to be addressed, the potential contribution of the research to the advancement of knowledge and (where relevant) the wider social benefit. Use language that is understandable to the general public.

1.6 Project Summary:

Community and university-based researchers, most of whom were based in Manitoba, Canada, worked together on projects designed to encourage thinking about how to improve drinking water and sanitation in First Nation communities. Legal experts examined frameworks to assert violations of the right to clean drinking water. Social scientists and community members evaluated the effectiveness of different messages describing the problem. Economists considered how to make plain the financial and human costs of failing to deal with this problem. In this project we are interviewing experts in advocacy to gain insight into how these research results suggest a way forward for bringing about real change in the water/sanitation situation in First Nations communities.

For Biomedical research, indicate the type of study.

1.7 Type of Study:

Provide a description of the proposed research project including study objectives, context, methodology, procedures, etc.

Footnotes and references are not required and best not included here.

1.8 Objectives:

We aim to speak to approximately 10 experts on the issue of water/sanitation on reserve regarding their views of the ideal advocacy/legal strategies for bringing about an improvement in the water/sanitation systems on reserve.

1.9 Context/Literature:

A now oft-cited statistic is the number of drinking water advisories (DWAs) in First Nations communities across Canada. As of October 31, 2016 there were 133 DWAs in 90 First Nations (Health Canada (2016)). While DWAs are in the news right now ? often caused by contaminated source water or faulty water treatment plants ? other concerning conditions regarding water systems persist. In Manitoba in 2002, 14.2% of individuals participating in the First Nations Regional Health Survey (RHS) reported not having running water (FNIGC (2002)). That same year, 30% of individuals reported not having either a flush toilet or a septic system for their home. This project aims to shed light on practical ways that these statistics can be improved.

1.10 Methods:

We and/or student research assistants will interview experts or key informants including First Nations leaders, NGO staff, lawyers and other advocates and public servants to get their expert opinions on the pros and cons of various advocacy strategies in order to realize the goal of clean water and sanitation.

1.11 Knowledge Mobilization/Dissemination:

We will send the report we prepare with Manitoba Keewatinowi Okimakinak (MKO) and the Assembly of Manitoba Chiefs - the two main First Nations political organizations in Manitoba. These organizations may share our findings with First Nations across the province if they feel the results would be helpful in their efforts to secure improved water/sanitation infrastructure. We will also incorporate the insights from these interviews into an academic paper for the Journal of Human Rights Practice. We will also aim to publish these results in an outlet such as the Winnipeg Free Press and will summarize the results for the Centre for Human Rights Research (CHRR) website.

Review

Indicate the type of review you are requesting.

Note: 1 Year Expedited and 2-2-1 Expedited reviews are available only for minimal risk projects. Full review is required for moderate risk projects.
See Policies and Procedures for definitions and criteria.

Review Type: 1 Year Expedited Review

If selecting a 2-2-1 review, indicate why this type of ethics review is necessary for your research.

2-2-1 Review Justification: We view this research as very low risk given that we are asking impersonal questions to individuals that deal with the issue of water/sanitation on reserve in their professional lives. At the same time we view this information as valuable given that advocacy on the issue is essential, but methods for effective advocacy are unknown.

Other Approvals

Indicate if all or part of the proposed research has or will receive ethics approval from other Canadian Research Ethics Boards or Canadian institutions.

Additional Ethics Approval: No

If yes to the above, specify and attach letters of institutional approval (pdf format) in the attachment section at the end of this application. Project Details Attachments or confirm that these will be submitted to the Research Office prior to initiating your research.

Is this study being conducted under a publicly declared emergency?

Please refer to Chapter 6 Section D - Research Ethics Review during Publicly Declared Emergencies of the TCPS-2 document for further information.

No

If Yes, are you the lead investigator for this study?

Will any part of the research take place outside of Canada?

If Yes, please provide location details in the section below.

No

Research Locations Outside of Canada

Institution:	Country:	City:	Province/State:

Research Team

Role:	Associate:	Name:		Organization:	Position:
Co-Investigator		Busby	Karen	University of Manitoba	Co-Investigator
Co-Investigator		Starzyk	Katherine	University of Manitoba	Co-Investigator
Community Partner		Star	Leona	Nanaandawewigamig	Co-Investigator
Community Partner		Fallding	Helen	Centre for Human Rights Research	Co-Investigator

Funding

Funding Source:	Funding Source Category:	Application or Grant Number:	Funding Status:	Date of Award:	Peer Review:

2.0 Conflict of Interest

2.1 Are any of the investigators or their family receiving any personal remuneration from the funding of this study that is not accounted for in the study budget?

Personal Remuneration: No

2.2 Do any of the investigators or their immediate family have any proprietary interests in the product under study or the outcome of the research?

Proprietary Interest: No

2.3 Is there any compensation for this study that is affected by the study outcome?

Compensation: No

2.4 Do any of the investigators or their immediate family have equity interest in the sponsoring company?

Equity Interest: No

2.5 Do any of the investigators or their immediate family receive payments of other sorts, from this sponsor ?

Other Payment: No

2.6 Are any of the investigators or their immediate family, members of the sponsor's board of Directors, Scientific Advisory Panel or comparable body?

Governance: No

2.7 Is there any other relationship, financial or non-financial, that could be construed as a conflict of interest?

Other Relationship: No

2.8 If the answer to any of the above questions is Yes, provide further explanation and evidence of ethical acceptability.

Summary:

3.0 Participant Information

3.1 Does your research involve contact with a living person or persons?

Participant Indicator: Yes

3.2 Describe the participant(s) to be recruited or population about whom personally identifiable information will be collected.

Description: Those knowledgeable about the issue of inadequate water/sanitation on reserve.

3.3 Describe and justify the inclusion criteria for participants.

Inclusion Criteria: The main criterion for inclusion in the study is the individual's knowledge of the issue of water/sanitation on reserve.

3.4 Describe and justify the exclusion criteria for participants.

Exclusion Criteria: There is no exclusion criterion with the exception that we may not have time to speak to all individuals in the group of those considered knowledgeable about water/sanitation on reserve.

3.5 Will this study involve any group(s) where non-participants are present?

Non-participant: No

If Yes, answer the following:

3.6 What measures will be taken to ensure that non-participants and their data are not included in the study?

Non-participant Exclusion:

3.7 Describe how appropriate activities for non-participants will be provided.

Non-participant Activities:

3.8 What measures will be taken to address discomfort or disadvantage, if any, arising out of non-participation?

Non-participant Mitigation:

4.0 Aboriginal Community

4.1 Does this research project specifically focus on Aboriginal people?

Aboriginal Community: Yes

4.2 Is there a formal research agreement with the community?

Research Agreement: No

4.3 Provide details about the agreement or why an agreement is not in place or not required, etc.

Please attach any supporting documentation in the attachment section at the end of this application.

Agreement Details: This research project aims to put to use research that was conducted in partnership with First Nations communities in a previous project. That project was entitled "The Most Precious Gift: The Right to Clean Water and Sanitation in First Nations Communities". We will be interviewing individuals - including First Nations leaders - about how to impact this issue, but we will not be focussing on a specific community.

4.4 Does this research project involve obtaining consent from elders, leaders, or other community representatives?

Yes

If yes, provide details explaining how consent will be obtained and from whom. If no, explain why consent will not be sought.

Leadership Consent:

The First Nations leaders who we will be interviewing will be given consent forms (as all research participants will).

4.5 If leaders of the group will be involved in the identification of potential participants, provide details.

Leadership Involvement:

Not applicable.

4.6 If property or private information belonging to the group as a whole is studied or used, provide details.

Group Data:

Not applicable.

4.7 If the research is designed to analyze or describe characteristics of Aboriginal people, provide details.

Group Analysis:

The research will not analyze or describe characteristics of Aboriginal people. We will be analyzing and describing the characteristics of the system of financing water/sanitation infrastructure.

4.8 If individuals are selected to speak on behalf of, or otherwise represent the group, provide details.

Group Representation:

All individuals that we speak with will be providing their own personal opinions, rather than those of the organization or group of individuals that they may work with.

4.9 Provide information regarding compliance with relevant frameworks for research involving Aboriginal groups or communities (e.g., OCAP)

Framework:

The original research project noted above was guided by OCAP principles. As the Principal Investigators on that project, we are now investigating how to use those research results to have a practical impact on the issue that was studied.

4.10 Provide information on how final results of the study will be shared with the participating community.

Sharing Results:

The results of the study will be summarized and shared with the Assembly of Manitoba Chiefs and Manitoba Keewatinowi Okimakinak (MKO) membership for distribution to all interested First Nations.

5.0 Other Communities

5.1 Does this research involve other self-governed communities or groups?

Community Indicator: No

5.2 Is there a formal research agreement with the community?

Research Agreement:

5.3 Provide details about the agreement or why an agreement is not in place, not required, etc.

Please attach any supporting documentation in the attachment section at the end of this application.

Agreement Details:

5.4 Does this research project involve obtaining consent from leaders or other community representatives?

Provide details:

Leadership Consent:

5.5 If leaders of the group will be involved in the identification of potential participants, provide details.

Leadership Involvement:

5.6 If property or private information belonging to the group as a whole is studied or used, provide details.

Group Data:

5.7 If the research is designed to analyze or describe characteristics of the group, provide details.

Group Analysis:

5.8 If individuals are selected to speak on behalf of, or otherwise represent the group, provide details.

Group Representation:

5.9 Provide information on how final results of the study will be shared with the participating community.

Sharing Results:

6.0 Risk/Benefit Analysis

Risk Analysis

6.1 Indicate the level of risk associated with this research.

Level: Minimal Risk

6.2 Does the research involve any potential risks or discomforts listed below?

No

If Yes, complete the section below:

Potential Physical Risks and Discomforts:

Fatigue:

Stress:

Injury:

Potential Psychological, Emotional, Social and Other Risks and Discomforts:

Stress:

Fatigue:

Social:

Economic:

6.3 Provide details of the risks and discomforts associated with the research.

Risk Description: We will be interviewing individuals in their professional capacity as experts on the issue of water/sanitation on reserve. We do not think the questions we are asking are stressful or uncomfortable whatsoever.

6.4 Describe how you will manage and minimize risks and discomforts, as well as mitigate harm.

Risk Management: Not applicable.

6.5 If your study has the potential to incidentally identify conditions warranting medical attention, describe the arrangements made to try to assist these individuals. Explain if no arrangements have been made.

Risk Mitigation: Not applicable.

6.6 If any data were released, could it reasonably place participants at risk of criminal or civil law suits?

No

If Yes, provide details:

Benefit Analysis

6.7 Describe the benefits (direct or indirect) to the participants and/or the participant's community, from their involvement in the project. If using human biomaterials, describe the benefit to society.

Benefit Description:

The methods of advocacy and/or litigation for improving water/sanitation conditions on reserve has never been studied. Through the interviews we propose to conduct, we will be able to assess which advocacy/litigation strategies would be most effective and we will disseminate this analysis to First Nations for their use. We view this as the main benefit to our study.

6.8 Describe the benefits to the scientific/scholarly community or society that would justify involvement of participants or human research models in this study.

Academic Benefit:

The academic benefits are similar to the practical benefits listed above. The academic paper that will bring together the insights gleaned from our interviews will be of interest to scholars of Human Rights research and we hope to publish our findings in the Journal of Human Rights Practice.

6.9 Benefits/risks analysis: Describe the relationship of benefits to risk of participation in the research.

Benefit/Risk Analysis:

Given that we don't foresee any risks to our participants in this research, the benefit/risk ratio for this project is very high.

7.0 Recruitment

7.1 Are there any recruitment activities for this study?

Recruitment Indicator: No

If Yes, describe the activities that will be used when recruiting individuals for this study.

Recruitment Method

7.2 How will potential participants be identified?

Identification:

We have already identified the individuals we would like to interview. They are: Sheila North Wilson (Grand Chief, MKO), Derek Nepinak (Grand Chief, AMC), Amanda Klasing (Human Rights Watch), Craig Benjamin (Amnesty International), Irving Leblanc (Assembly of First Nations), Russ Anthony (retired, ex-Vice Principal of Stantec), Merrell-Ann Phare (Centre for Indigenous Environmental Resources) and Kathy Kinew (Nanaandawegimig).

7.3 Outline how individuals will be approached for participation or screened for eligibility.

Approach:

Our student research assistant on this project, Courtney Bear, a student currently completing the Indigenous Summer Scholars program, will contact the potential interviewee by email.

7.4 Indicate the method by which individuals will obtain details about the research in order to make a decision about participating.

Method: Researchers will contact potential participants

Describe the above in more detail.

We will provide the potential interviewee with the questions we will ask and with summaries of our prior research results.

7.5 If contact will be made through an intermediary (including snowball sampling), select one or more of the following:

Note: Selecting answer #3 is not normally an accepted form of contact for an Ethics protocol. It would be accepted only in minimal risk applications and should never compromise informed consent.

Third Party Contact Method:

7.6 Explain why the intermediary is appropriate and describe what steps will be taken to ensure participation is voluntary.

Third Party Justification:

7.7 Provide the locations where recruitment will occur, if applicable.

Location:

7.8 If recruitment will take place in a group situation, describe what measures will be taken to guard against peer pressure influencing an individual's decision to participate or not.

Peer Pressure:

7.9 How many participants do you hope to recruit?

Recruitment Number:

7.10 If this is a multi-site study, how many participants are expected to be enrolled by all investigators at all sites in the entire study?

Total Number:

7.11 Provide justification for your choice of sample size.

Justification:

We view these 8 individuals as experts on the topic in question. We expect that those 8 individuals may refer us to other individuals and thus predict that we'll interview up to 15 people.

Pre-Existing Relationships

7.12 Will potential participants be recruited through pre-existing relationships with researchers ?

Relationship Indicator: Yes

7.13 If yes, identify any relationship between the researchers and participants that could compromise the freedom to decline, e.g., professor-student.
Describe the measures that will be taken to ensure that there is no undue pressure on the potential participants to agree to the study.

Relationship Description:

We have worked with most of the potential interviewees before on prior research. However this has always been on a peer-to-peer basis. In other words, we and the potential interviewees share a common stake in this research and they are likely as motivated to analyse the issue at hand as we are. The potential interviewee will be asked to participate by email, and if there is no response, we will follow up with a maximum of 2 more emails. However no pressure will be applied - the interview is completely voluntary.

7.14 For biomedical research involving therapies, procedures and interventions, describe the standard of care in Manitoba for this patient population.

Standard of Care:

Secondary Use of Data

8.1 Does this study involve secondary use of data?

No

8.2 List all original sources.

Source:

9.0 Informed Consent Determination

9.1 Indicate who will provide informed consent for this study (select all that apply).

Depending on the research topic, some categories of participant may lack the capacity to give informed consent, e.g., children or individuals with cognitive impairments.
Additional information on the informed consent process is available at website link- link to the policy and procedure on the RO website

Consent Determination:

1. All participants have capacity to give free and informed consent

9.2 If prior consent is not required or has been obtained by a third party, provide justification.

Justification:

9.3 If a participant wishes to withdraw, end, or modify their participation in the research or certain aspects of the research,
describe how their participation would be ended or changed.

Termination:

The interviewee can end the interview at any time.

9.4 Describe the circumstances and limitations of data withdrawal from the study, including the last point at which it can be done.

Data Withdrawal:

Regarding the use of their views in the study, interviewees will have multiple opportunities to express limitations on the use of the opinions they express including making a statement expressing the expectation of confidentiality (either generally or on a specific matter) when signing the consent form, at any point during the interview itself, on a review of the transcript or by contacting the Principal Investigator at any time after the transcript has been approved but prior to publication, presentation or any other form of dissemination.

9.5 Indicate how participants or their authorized representatives may follow up with researchers and/or UHREB to ask questions or obtain information about the study.

Followup:

All participants will have the email addresses and phone number of the Principal Investigator (Melanie O'Gorman) plus the email addresses of the other four project participants (Karen Busby, Katherine Starzyk, Leona Star and Helen Fallding). Participants may contact us any time after the interview for information or to adjust their confidentiality in the study. We will let them know when we plan to present or publish the study and ensure that they have time (2 weeks) so that they have a chance to ponder their confidentiality prior to the last point that they may make a decision on this.

For Authorized Representative, Third Party Consent, Assent answer the following:

9.6 Explain why participants lack capacity to give informed consent.

Consent Capacity:

9.7 Will participants who lack capacity to give full informed consent be asked to give assent?

If applicable, please ensure that a copy of assent form is attached in the attachment section at the end of this application.

Assent:

If Yes, provide details:

9.8 In cases where participants (re)gain capacity to give informed consent during the study, how will they be asked to provide consent on their own behalf?

Method:

9.9 What assistance will be provided to participants, or those consenting on their behalf, who have special needs?

Special Needs:

9.10 Explain how the study information will be communicated and participant consent/assent will be documented.

Consent Documentation:

The participants will sign a paper consent form and this form will be photocopied for their records.

9.11 How is participant consent to be indicated and documented. Select all that apply.

Informed Consent Method:

Signed Consent Form (please attach a copy printed on UW letterhead)

10.0 Deception or Partial Disclosure

10.1 Does this research project include the use of deception or partial disclosure?

No

10.2 Describe the information that will be withheld from, or the misinformation that will be provided to, the participants.

Description:

10.3 Provide a rationale for withholding information or misinforming the participants.

Rationale:

10.4 Indicate how and when participants will be informed of the concealment and/or deception. Describe the extent of debriefing.

Disclosure:

10.5 Describe the procedure for giving the participants an opportunity to provide fully informed consent after debriefing. Explain if debriefing and re-consent are not viable.

Consent:

10.6 If applicable, indicate how participants may follow up with researchers for further debriefing.

Follow-up:

11.0 Reimbursements and Incentives

11.1 Will any participant in this study receive reimbursement or incentive for their participation?

A reimbursement includes any reimbursement for costs associated with participating in this study, e.g., meals or parking. An incentive would include prize draw, gift card, cash payment etc.

No

11.2 Describe in detail the expenses for which participants will be reimbursed, the value of the reimbursements and the process, if applicable.

Reimbursement Description:

11.3 If personal information will be collected to reimburse or pay participants, describe the information to be collected and how privacy will be maintained.

Reimbursement Personal Details:

11.4 Select the incentive types that participants may receive. Select all that apply.

Incentive Type:

11.5 Excluding prize draws, what is the maximum value of the incentives offered to an individual throughout the research?

Incentive Value:

11.6 Provide details of the value, including the likelihood (odds) of winning for prize draws and lotteries.

Incentive Details:

11.7 Justify the value of the incentives offered.

If incentives are offered to participants, they should not be so large or attractive as to constitute coercion.

Justification:

12.0 Anonymity and Confidentiality

12.1 Will the identify of participants or human biomaterials be protected both during and after research?

Identity Protection: Yes

12.2 Indicate how privacy will be maintained.

Data Privacy Method: **None of the Above**

12.3 Will the researcher or study team be able to identify any of the participants at any stage of the study?

Participant Identification: Yes

12.4 If applicable, describe the extent of your confidentiality obligations, e.g., limits on what can and can not be disclosed.

Confidentiality: Participants will have the option of being identified in the outputs of this study or not. This decision is completely up to the participant. As noted in an earlier section, the interviewee can make the decision to be anonymous or not during the interview and afterward up until the point that the results are being presented or submitted for dissemination/publication. If an interviewee wishes to be identified, their name, institutional affiliation and a brief biography may be included in publications and presentations associated with this research. It will be explicit that all interviewees' views are not be attributed to the organization of the interviewee.

12.5 How will the principal investigator ensure that all study personnel are aware of their responsibilities concerning participants' privacy and the confidentiality of their information?

Confidentiality Awareness: This entire ethics protocol will be shared with all members of our research team and the research assistant.

12.6 What measures will be taken to protect the anonymity and/or confidentiality of your participants? Explain how participants will be informed about any limits on your ability to protect this information.

Protection Measures:

The only limit to a participant's involvement in the study will be that if they wish to remain anonymous, the project team (the 5 researchers plus the research assistant) will know that they were interviewed. The individuals interviewing them (Melanie O'Gorman and Courtney Bear) will also know their opinions. However the participant will be completely aware of these limitations. Otherwise an individual that wishes to remain anonymous will never be named in any documents arising from their interview.

13.0 Interviews, Focus Groups, and Surveys

13.1 Does this research involve an interview, focus group, and/or survey?

Yes

13.2 Are any of the questions potentially of a sensitive nature?

No

If yes, provide details:

13.3 Will you be using audio/video recording equipment and/or capture of sound or images for the study?

Yes

If yes, provide details:

We may audio and video record all interviews, and we may take pictures of each interviewee.

14.0 Use or Production of Creative Works

14.1 Does this research involve the use or creation of media or other works?

Yes

14.2 If Yes, who will have access to this material?

Access:

Footage of interviews and photos/audio recordings arising from them will be available only the research team (Leona, Helen, Karen, Katherine, Courtney and Melanie). Pictures and videos may be used in publications and on the CHRR website afterwards, but as noted above, participants will only appear in these photos or videos if they consent.

14.3 In cases where you will be sharing materials for verification or feedback, what steps will you take to protect the dignity of those who may be represented or identified?

Interim Feedback:

Each interviewee will only receive their interview transcript, photos or video for review. The materials from others interviews will never be shared among the interviewees.

14.4 When publicly reporting data or disseminating results of your study that include materials you have collected, what steps will you take to protect the dignity of those who may be represented or identified?

Public Reporting:

As noted above, each individual will be able to consent to the public use of their opinions, photos and video of their interview.

14.5 Does this research project involve the use of materials created by participants?

No

14.6 Explain if consent obtained at the beginning of the study will be sufficient, or if it will be necessary to obtain consent at different times, for different stages of the study or for different types of data.

Consent:

Consent at the beginning of the study will not be sufficient. After the interview, participants will be sent any video clips, photos and quotations that we would like to use in the outputs from this study, and they may reject to their use at any time until we publish or present the results.

14.7 At what stage, if any, can a participant withdraw his/her material?

Withdrawal:

Please see last response.

14.8 What opportunities are provided to participants to choose to be identified as the author/creator of the materials created in situations where it makes sense to do so?

Identification:

Participants in this study may co-author outputs from this study however given that each participant has an occupation that does not incentivize the type of outputs we'll be creating, it's unlikely that they would desire this. If they do we will update the research team list in this application.

14.9 If necessary, what arrangements will you make to return original materials to participants?

Return:

If the interviewee wanted to keep the video or audio tape of their interview or if they wanted to keep photos of the interview, we would simply provide them.

15.0 Internet-based Interaction

15.1 Does this research project involve interaction with participants via the Internet?

No

15.2 Will your interaction with participants occur in private spaces where there is a reasonable expectation of privacy?

Yes

15.3 Will these interactions occur in public spaces(s) where you will post questions initiating and/or maintaining interaction with participants?

No

15.4 Describe how permission to use the site(s) as a research site will be obtained, if applicable.

Site Permission:

15.5 If you are using a third-party research tool, website survey software, transaction log tools, screen capturing software, or masked survey sites, how will you ensure the security of data gathered at the site?

Data Security:

15.6 If you do not plan to identify yourself and your position as a researcher to the participants from the onset of the research study, explain why you are not doing so and at what point you will disclose that you are a researcher. Provide details of debriefing procedures, if any, and indicate if participants will be given a way to opt out, if applicable.

Disclosure:

15.7 How will you protect the privacy and confidentiality of participants who may be identified by email addresses, IP addresses, and other identifying information that may be captured by the system during your interactions with these participants?

Privacy:

16.0 Safeguarding Information

Personal Identifying Information

16.1 Indicate which if any of the following Personal Identifiers will be collected during the course of this study, including recruitment. Select all that apply:

Personal Identifiers: Email Address, First and/or Last Name, Photograph, Recorded Image

16.2 If collecting personal identifiers, explain why it is necessary to collect this information.

Rationale: We'll be interviewing individuals widely considered to be experts in the area of the provision of water/sanitation infrastructure on reserve. It will lend credibility to the study if we can describe how/why these individuals are experts.

16.3 If applicable, explain when and how identifying information will be removed.

Removal: Identifying information will be removed for those participants that do not want to be identified.

16.4 If applicable, specify what identifiable information will be retained once data collection is complete, and explain why retention is necessary. Include the retention of master lists that link participant identifiers with anonymized data.

Retention:

We will prepare a biography for each participant containing information on their occupation and how they became an expert on the issue of water/sanitation in First Nations in Canada. The participant may edit this bio as they see fit. The bio will then be used in any outputs from this study. If the participant wishes to remain anonymous then the transcript of their interview will be assigned a number, and quotations may be used from this transcript however the participant would only be identified as "Study Participant".

16.5 If applicable, describe if the data in this study will be linked with data associated with other studies or with data belonging to another organization.

Data Association:

Not applicable.

17.0 Data Storage

17.1 Describe how research data will be stored, e.g., digital files, hard copies, audio recordings. Specify the physical location and how it will be secured to protect confidentiality and privacy.

Data Storage:

Hard copies of the transcripts of the interviews will be kept in a locked filing cabinet in Melanie O'Gorman's office. Digital files (transcripts, videos, audio recordings) will be password-protected and kept on Melanie's laptop or in a cloud that only the research project members will have access to.

17.2 If you plan to destroy your data, describe when and how this will be done.

Data Disposal:

All raw data will destroyed 5 years after the interviews have taken place. Any videos that are produced with the footage of the interviews will never be destroyed.

17.3 If the research data will become part of a data repository or if this research involves the creation of a research database or registry for future research use, provide details.

Data Usage:

Not applicable.

17.4 How long will the research data be retained?

University policy requires that you keep your data for a minimum of 5 years following completion of the study but there is no limit on data retention.

Data Retention: 5 years

17.5 Specify where the database(s) will be located.

Specify if the database will be under Canadian or foreign jurisdiction. Note that data housed on US servers fall under the US Patriot Act. At a minimum, participants should be informed of this potential Breach in confidentiality.

Location: Canada (University of Winnipeg)

17.6 Describe who will have access to the database and how that access is determined.

Access: Only research team members that use the data will have the password that allows the data to be accessed.

17.7 Will identifying information be stored within the database?

Yes

17.8 If the database is to be maintained locally, what steps have been taken to ensure the security of the database is upheld?

Security: Password protection and restricted access to team members only.

17.9 Indicate who is responsible for the database(s).

Responsibility: Melanie O'Gorman

17.10 Are there standard operating procedures for the database management, use and access? If Yes, attach in the attachment section at the end of this application.

No

18.0 Human Biological Material

18.1 Does this research project involve Human Biological Material?

Human Biological Material: No

18.2 Indicate if this study will involve any one of the following:

Material Sample Type: Not Applicable

18.3 Indicate the biological material that will be studied.

Description:

18.4 Describe how the material will be collected.

Collection Method:

18.5 Identify the person(s) or institution that collected the biological materials.

Collector:

18.6 Describe how the material will be stored.

Storage Method:

18.7 Indicate how long the material will be stored.

Length of Storage:

18.8 Describe where the material will be stored.

Storage Location:

18.9 Specify all intended uses of collected material.

Biological Material Use:

18.10 Indicate if there will be a code that allows linkage of the specimens back to the original study and/or the patient's clinical records.

Specimen Linkage:

If yes, specify how specimens will be coded to protect confidentiality and indicate who will maintain the link to identifying information.

19.0 BioHazard Safety

19.1 Does this research project involve Biohazard Safety?

No

19.2 Indicate if your research will involve the use of one or more of the following. If you answer Yes to any of these, provide details below.a) Risk group 2,3 or 4 viruses, bacteria, fungi, parasites or eukaryotic cell lines

b) Environmental specimens suspected to contain risk group 2, 3 or 4 microbes

c) Large-scale single volume culture in excess of 10 litres for any microbe or eukaryotic cell line

d) Microbial toxins

e) Human clinical specimens, including blood or other body fluids or primary culture of human cells

f) Xenotransplant studies involving vertebrate donors and/or recipients

g) Genetic manipulation involving virulence genes from risk group 2, 3 or 4 microbes, mammalian oncogenes, mammalian cytokine or interleukin genes or microcide resistance genes

h) Genetic manipulations involving the use of recombinant vector systems base on lentivirus, adenovirus, retovirus or herpese virus backbones

19.3 If you answered YES to any of the above, describe in more detail

Description:

20.0 Application Attachments

Attachment	Description	File Name	File Size	Type
Letter of institutional Approval			11.8 MB	
Conflict of Interest			11.8 MB	
Aboriginal Community Agreement Details			11.8 MB	
Other Communities Agreement Details			11.8 MB	
Recruitment Materials			11.8 MB	
Informed Consent Documents	Consent form for Interviewees	Research to Action Consent Form.pdf	11.8 MB	pdf
Interviews, Focus Groups, and Surveys - Protocols			11.8 MB	
Interviews, Focus Groups, and Surveys - Question Frameworks			11.8 MB	
Interviews, Focus Groups, and Surveys - Survey Questions	Interview questions	Interview Questions.pdf	11.8 MB	pdf
Biohazard Safety Approval			11.8 MB	
Other Attachment 1	DEC evaluation	Ethics_Review_Melanie_2017.pdf	11.8 MB	pdf
Other Attachment 2			11.8 MB	
Other Attachment 3			11.8 MB	
Other Attachment 4			11.8 MB	
Other Attachment 5			11.8 MB	

Declaration

*By checking **I Agree** below, I (the applicant/Principal Investigator):*

- *certify that the information provided in my ethics application and related documents is true, complete and accurate;*
- *attest that others listed on the application have agreed to be included;*
- *am familiar with and accept the terms and conditions set out in the University of Winnipeg's Research Manual: Policies and Procedures;*
- *am familiar with and accept the terms and conditions set out in the University of Winnipeg Senate Committee on Ethics in Human Research and Scholarship (UHREB) Policies and Procedures;*
- *am familiar with and agree to comply with the policies described in the TCPS 2 - 2nd edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans;*
- *will follow guidelines and procedures which ensure compliance with all relevant professional, University, provincial, national or international policies and regulations governing research involving human participants;*
- *understand that if there is any deviation from the project as originally approved, I must submit an amendment or reapply to the UHREB for approval before implementing any such changes;*
- *will report to the Research Office, without delay, all adverse participant responses that exceed the levels anticipated and provided for in this application;*
- *have read and agree to comply with the Policy and Procedures on Integrity in Research and Scholarship.*

I Agree: Yes

THE UNIVERSITY OF WINNIPEG
DEPARTMENT OF ECONOMICS

From Research to Action on Clean Water and Sanitation in First Nations Communities in Canada

Consent form for Research Project Participation

The project "From Research to Action on Clean Water and Sanitation in First Nations Communities in Canada" is a multi-disciplinary and multi-university project which seeks to learn about the advocacy strategies that may be most effective for improving the safety of drinking water/sanitation conditions in First Nations in Canada. The interview you are being asked to be a part of will be a face-to-face, 1-hour session. Information gained though our discussions will be used to write a policy-focused paper, a paper for an academic journal, blog entries and videos that may be posted online. The information collected in this interview may provide important new insights for designing policies and/or practices regarding the provision and financing of drinking water/sanitation systems in First Nations in Canada.

Your participation in this interview is very important, but voluntary. You may cease your participation at any time, and withdrawal will not adversely affect you in any way.

Notes will be taken on discussions and the discussion may be video/audio recorded. Photographs will be taken for use in published reports for this study, however you may decline to be photographed below. Notes will be stored in locked filing cabinets in the research project member's office for 4 years after the conclusion of the research, at which point they will be destroyed. Each participant may choose if they would like to remain anonymous or if they would like to be identified with their comments/insights in documents resulting this study. If an individual chooses to remain anonymous, they will be assigned a number/pseudonym and will only be identified by that number/pseudonym in the transcripts of the interview to ensure confidentiality.

If you choose to remain anonymous, the video recording will only be used for transcription. If you choose to be identified, the you can choose to allow us to share portions of the video publicly or not. You will always retain the right to preview the section of video being shown.

We are collecting names and contact information in case we can do a follow-up study sometime in the next three years. If you would not like to be contacted in the future please indicate so below.

You will be given a copy of this consent form. If you have any questions regarding the research project and/or if you wish to receive a summary of the study's results contact the researcher at the contacts below:

- Melanie O'Gorman, Principal Investigator, University of Winnipeg m.ogorman@uwinnipeg.ca (204) 786-9966 - If you have any concerns about the way this focus group is conducted, you can contact the Senate Committee on Ethics in Human Research and Scholarship Program Officer by email at ethics@uwinnipeg.ca or at (204)786-9058.
- Leona Star, Community Partner, Nanaandawewigamig - lstar@fnhssm.com.
- Helen Fallding, Community Partner, Centre for Human Rights Research - Helen.Fallding@umanitoba.ca.
- Karen Busby, Co-Investigator, University of Manitoba - Karen.Busby@umanitoba.ca.
- Katherine Starzyk, Co-Investigator, University of Manitoba - Katherine.Starzyk@umanitoba.ca.

THE UNIVERSITY OF WINNIPEG
DEPARTMENT OF ECONOMICS

Thank you for your consideration.

Consent for Interview Participation

I have been fully informed of the objectives of the project being conducted. I understand these objectives and consent to being interviewed for the project. I understand that steps will be undertaken to ensure that this interview will remain confidential. I understand that, if I wish to withdraw from the study, I may do so without any repercussions.

Regarding participation in this interview, please choose one option below:
_____ I do agree to participate in the interview described above.
_____ I do not agree to participate in the interview described above.

Regarding anonymity, please choose one option below:
_____ I wish to remain anonymous in any documents arising from my interview.
_____ I wish to be identified in any documents arising from my interview.

Regarding future contact with our research team, please choose one option below:
_____ I agree to be contacted in the future by the research team
_____ I do not want to be contacted in the future by the research team.

Regarding a video of my interview, please choose one option below:
_____ I agree to the video of my interview being disseminated for this study
_____ I do not agree to the video of my interview being disseminated for this study

Participant's Name (please print): _____ Participant's Signature: _____
Participant's email address: _____
Witness' signature: _____ Date of consent: _____
Principal Investigator's signature: _____ Date of consent: _____

Interview Questions for From Research to Action on Clean Water and Sanitation in First Nations Communities in Canada

Purpose: People living in many First Nations communities in Canada have inadequate water and wastewater systems. This problem has existed in some communities for decades and it has significant adverse effects on the quality of life in these communities. In this project, we are interviewing key informants, including First Nations leaders, NGO staff, lawyers and other advocates to get their expert opinions on the pros and cons of various advocacy strategies that realize the goal of clean water and sanitation.

Interview Questions: The interviews will be semi-structured using the list of questions below as a template.

1. In this study we are interviewing people who have insight into advocacy strategies that may or may not work to advance the objective of ensuring that First Nations communities have access to clean drinking water and sanitation. Would you describe yourself as someone with such insights?
2. How did you develop your expertise? (Probe re: volunteer and paid employment, training, offices held, specific projects (eg research, litigation).)
3. We want to ensure that Indigenous perspectives are well-represented in this study. How would you describe your ethnicity or nationality?
4. We have written a short bio to describe you. [Give a copy to interviewee. Read the bio into the recording.] Would you change anything in this bio?
5. In your opinion, why have we not succeed to date in ensuring that people living in all First Nations communities have access to clean drinking water and sanitation? What are the barriers to success? {repeat the question about reasons and barriers until the interviewee has no more to say.]
6. We want to get your opinions on the pros and cons of various strategies that could be pursued to move governments towards achieving clean water and sanitation in First Nations communities. Here is a list of some strategies. (Hand over the list.) Starting with whichever strategy you want to discuss first, can you tell us the pros and cons of each strategy/ whether you think it should be prioritized and ideas on how to implement it?
    - post card, letter writing and petition campaigns;
    - action toolkit
    - advocating for legislative or regulatory reform;
    - encourage adoption of a national plan
    - encourage and support litigation;
    - develop workshops and curricula on water issues;
    - findings ways to support water protectors (protest);
    - innovative data visualization;
    - address on the ground operations issues;
    - innovative governance,
    - new regulatory structures/joint water boards/ public private partnerships.
7. Would you add any strategies to the list?

8. Is there anything you would like to add?
9. Do you have any questions?
10. Can you recommend anyone else that we should interview?

DEPARTMENTAL ETHICS COMMITTEE (DEC) REVIEW
(For Committee use only)
Researchers – Please attach a PDF of the signed form to your WebGrants application

Review (Check all that apply)

PRINCIPAL INVESTIGATOR: _____

PROJECT TITLE: _____

___ The DEC has reviewed this submission to ensure completeness.

___ This submission appears to comply with *Policies and Procedures*, the Tri-Council Policy, and relevant disciplinary ethics guidelines.

___ All relevant ethical issues appear to have been addressed in this submission.

___ We recommend the following conditions of approval (regarding methods, monitoring, reporting, and/or ongoing review):

Approval Recommendations *Note: Unless otherwise recommended above, approval is in effect for one year only.*

___ We **approve of** the procedures proposed in this submission (subject to any conditions listed above).

___ We **do not approve of** the procedures proposed in this submission.

Type of Review Recommended – Please note, Delegated Review applies to minimal-risk applications only

___ The investigator has requested Delegated Review, and we **recommend Delegated Review**.

___ The investigator has requested Delegated Review, but we **do not recommend Delegated Review**.

___ We **recommend Full Review**.

Additional Comments (optional)

DEC Student Ethics Approval (DEC approval of student **Delegated Review** submission)

___ The student Delegated Review submission has been approved.

Print/type name Departmental Ethics Committee Chair:	**Department:**
Signature of Departmental Ethics Committee Chair:	**Date:**