

This Agreement dated for reference the 20th day of April, 2010.

COMMUNITY RESEARCH AGREEMENT



First Nations Food, Nutrition, and Environment Study (FNFNES)

BETWEEN:

*******FIRST NATION**

(the "First Nation")

AND:

**UNIVERSITY OF NORTHERN BRITISH COLUMBIA,
COMMUNITY HEALTH SCIENCES PROGRAM, AS REPRESENTED BY
LAURIE CHAN, PRINCIPAL INVESTIGATOR**

- and -

**UNIVERSITÉ DE MONTRÉAL,
DÉPARTEMENT DE NUTRITION, FACULTÉ DE MÉDECINE, AS REPRESENTED BY
OLIVIER RECEVEUR, PRINCIPAL INVESTIGATOR**

- and -

**ASSEMBLY OF FIRST NATIONS / NATIONAL
INDIAN BROTHERHOOD, (AFN), AS REPRESENTED BY
DONALD SHARP, PRINCIPAL INVESTIGATOR**

(Collectively referred to as the "**Lead
Researcher**")

WHEREAS the Lead Researcher has applied to the First Nation to do research, and agrees to the conditions placed upon the Lead Researcher in this agreement and to comply with the intent of the principles set forth herein;

WHEREAS the research study contemplated by this Agreement is of mutual interest and benefit to the Researcher and the First Nation, will further the integration and synthesis of research information to better understand, investigate, and document First Nations traditional and market food consumption, estimates of exposure to contaminants in both water and in food, and intake of nutrients; self-reported health status and lifestyle habits across communities; and food security concerns;

WHEREAS the research study contemplated by this Agreement will also help to address First Nations environmental health concerns regarding their traditional food sources and water supply, and will result in knowledge that could be used for the development of plans to protect traditional food systems, and to promote well-being and healthy lifestyles in communities;

WHEREAS the Lead Researcher and the First Nation agree to conduct the named community research project in accordance with the guidelines and conditions described in this document.

NOW THEREFORE, in consideration of the mutual covenants and conditions contained herein, the parties hereto understand and agree as follows:

1. SCOPE OF THE PROJECT

- 1.1 The overall objective of the study is to investigate traditional and market food consumption patterns and to identify background levels of nutrients and contaminants in the daily food and water intake of First Nations peoples living on reserves below the 60th parallel across Canada. As well, the study will collect information on health, lifestyle, social and economic factors that may affect the quality of nutrition or increase risk of exposure to environmental contaminants.
- 1.2 The FNFNES will assess the diets of First Nations peoples living on reserves south of the 60th parallel across Canada, who rely on a combination of traditionally-harvested and store-bought foods.
- 1.3 There are five general components to the study:
 - a. household interview (one-year traditional food frequency questionnaire, 24-hour food recall, and social, health and lifestyle questionnaire);
 - b. drinking water sampling for trace metals
 - c. surface water sampling for pharmaceuticals;
 - d. hair sampling for mercury; and
 - e. sampling of traditional foods for nutrient and contaminant analyses.
- 1.4 The study will develop a portrait of nutritional benefits and environmental contaminant

challenges that are intrinsic to the modern diets of First Nations people living on reserves through obtaining baseline data for food use patterns among First Nations Peoples. The data will be used to:

- a. Determine consumption patterns of traditional and market foods on reserve within each AFN region;
- b. determine dietary intake of selected contaminants within each AFN region;
- c. estimate intake of macronutrients and selected micronutrients for each participating First Nation region;
- d. determine availability, and accessibility of traditional and market foods on reserve within each AFN region;
- e. characterise current mercury exposure on First Nations reserves; and,
- f. characterise contamination from pharmaceutical products in the aquatic environment.

2. METHODS AND PROCEDURES

2.1 Data will be gathered using the following methods or procedures:

- a) Conduct personal interviews on dietary information using a questionnaire.
- b) Collect water samples used for drinking and in the preparation of food.
- c) Collect surface water samples from water bodies around the First Nation communities where fish are harvested.
- d) Collect traditional food samples from members of the participating communities for analyses of nutrients and contaminants.
- e) Collect hair samples for mercury determination.

2.2 Members of the First Nation will be recruited and trained on survey interview techniques by the project as community researchers to assist with the data-gathering phase in the following ways:

- a) Obtain individual consent from all participants prior to completing the dietary interview questionnaire using the FNFNES Study Consent Form.
- b) Conduct dietary interviews with one adult man or one adult woman in a maximum of 100 randomly selected households. The dietary interview takes approximately one hour and a half (1½), is confidential and voluntary. Questions are asked about the frequency of traditional food consumption, the dietary intake in the day preceding the interview, and a short series of social, health and lifestyle questions.
- c) If consent is given, measure height and weight of participant, and collect a small sample of hair for mercury determination.
- d) Where and when appropriate, collect samples of tap water, and traditional foods for analyses of nutrients and/or contaminants.

2.3 Once the survey data is collected, it will be reviewed and verified by a Nutrition Research Coordinator who will then input the data into a secure computer database.

3. RESPONSIBILITIES OF THE LEAD RESEARCHER

- 3.1 The Lead Researcher shall provide copies of the proposed research protocol to the participating First Nation.
- 3.2 The Lead Researcher, in undertaking research, shall:
- a) Recognize the rights of First Nation members participating in the project, including the rights not to participate, to privacy, to anonymity, to confidentiality, and to fully informed consent;
 - b) recognize the primary right of informants and suppliers of data and materials to the knowledge and use of that information and material;
 - c) respect First Nation requirements for ensuring protection of the data
 - d) respect local First Nation protocols, customs and values, and carry out research in a manner consistent with this Agreement;
 - e) assume responsibility to ensure that the subjects in the research are fully aware of their rights and the nature of the research and their involvement in it;
 - f) contribute to the interests of the First Nation in whatever ways possible so as to maximize the return to the First Nation for their cooperation in the research work; and,
 - g) recognize their continuing obligations to the local First Nation after the completion of the fieldwork, including returning research materials, reporting results and providing support and continuing concern for the well-being of the local First Nation;
- 3.3 The Lead Researcher, and the Lead Researcher's employees, students, partners and agents, shall maintain confidentiality of any and all records (except for drinking water – see clause 3.4.), data, and information gathered relating to the First Nation which is in the Lead Researcher's possession and control. Such data shall only be released or disseminated pursuant to the strictest policies of confidentiality and with the written consent of the First Nation.
- 3.4 While the Lead Researcher shall maintain confidentiality of the results, the Lead Researcher is also responsible to ensure that results of public health concern be communicated to responsible authorities. In the event of detection of any trace metal in drinking water at a higher concentration than that listed in the most recent *Guidelines for Canadian Drinking Water Quality*, the Lead Researcher will inform the Chief and Council

of the exceedance, as well as the Regional Environmental Health Manager who will take appropriate steps. If corrective action is needed, the Lead Researcher will assist the First Nation by facilitating proper referrals and follow-up action.

4. RESPONSIBILITIES OF THE FIRST NATION

4.1 The participating First Nation is the owner of the communal, cultural, natural, and biogenetic resources, and retains ultimate discretionary authority and final authority and responsibility for the approved research.

5. NON-COMMERCIAL PURPOSE

5.1 The Lead Researcher hereby warrants that no research performed under this Agreement, no research products, and no traditional or indigenous knowledge will be used for commercial purposes.

6. FIRST NATION INVOLVEMENT AND TRAINING

6.1 The Community Research Assistants will learn techniques common to most survey's as well as techniques specific to this particular project including administration of an extensive interview, and food, water, and hair sampling.

6.2 It is also within the goals of this project to develop First Nation capacity to conduct and analyze their own data. To aid in this process, the software package (EpiInfo) will be made available to First Nation members and additional training on the use of this software will be offered.

6.3 The development of this project is based on sincere communication between First Nation members and the Lead Researchers. All efforts will be made to incorporate and address local concerns and recommendations at each step of the project including data collection, data analysis, and return of the results.

6.4 At the end of the project, the Lead Researcher will participate in community meetings to present and discuss the research findings and results of the analysis with the First Nation both orally and in writing.

7. INFORMED CONSENT

7.1 Informed consent of individual participants is to be obtained in these agreed ways:

- a) An individual consent form will be read by the community researcher to the participant prior to conducting the dietary interview. The consent form will include

the contact information of the Principal Investigator, Dr Laurie Chan at the UNBC, and the National Project Coordinator, and a copy will be left with the participant should they require additional information.

- b) Participants have the right to withdraw from the project at any time for any reason. If a participant decides to drop out of the study, that participant's personal data will be destroyed.

8. CONFIDENTIALITY

8.1 The names of participants and the First Nation are to be protected in these agreed ways:

- a) As mentioned on the consent form, the interviews are confidential. In no instance will the name of a participant be attached to a record. No questions or samples will be collected without the informed consent of the participant.
- b) The written consent of the First Nation is required prior to the dissemination of data, whether it be by publication or contact with the media. Substantial or material changes to approved data require the consent of the First Nation prior to dissemination.

8.2 The Lead Researcher and the Lead Researcher's employees, students, and agents will maintain in confidence except as permitted in this document all personal and proprietary information or Aboriginal Traditional Knowledge disclosed or obtained from participants ("Confidential Information"). No genetic information (DNA) of any kind is being collected, stored or used in this study.

8.3 The Lead Researcher, and the Lead Researcher's employees, students, partners and agents, shall maintain confidentiality of any and all records, data, and information gathered relating to the First Nation which is in the Lead Researcher's possession and control except as permitted in this document.

8.4 The obligations of confidentiality under this section shall survive and continue in perpetuity after the termination of this Agreement.

9. EXPECTED OUTCOMES, BENEFITS AND RISKS

9.1 This research study will benefit the First Nation collectively in the following ways:

- a) Educational: The community researcher(s), who will work as interviewer, will be trained in conducting and interpreting surveys, and in tap water and food sampling techniques.
- b) Informational: The proposed study will develop a baseline of First Nations Peoples'

exposure to environmental chemical hazards through their food, drinking water, and results of hair sample analysis for mercury. This information is essential for the development of First Nation-level dietary advice and food guidance for First Nations at a national level aimed at lowering contaminant intake. The information on background exposures to persistent organic pollutants (POPs), heavy metals and pharmaceutical products is also essential for First Nations as an enabling foundation for any future food or water monitoring at the First Nation level.

- c) Financial: The University of Northern British Columbia will enter into a separate agreement with the First Nation to provide financial compensation for research project assistance, including interviews, collection of samples, and related administration.

9.2 The Lead Researcher will benefit by this research study in the following ways:

- a) With the consent of First Nations participants, scientific publications will be developed and published in peer-reviewed media at different times throughout the 10-year study period.
- b) First Nation-level results will be disseminated both orally and in reports through meetings with each participating First Nation. Regional and national-level reports will be developed as well, on the basis of aggregated information and provided to regional and national First Nations organizations.
- c) Results of the study will be maintained in a secure database, without any personal identifiers and will be utilized for probabilistic risk-benefit assessment on an ongoing basis and when requested by a First Nation. The custodian of the archived data will be the Assembly of First Nations.

9.3 Potential risks: The study may pose the following risks to the First Nation: i.e. excessive anxiety/stress, loss of collective privacy, misperception of traditional foods as negative, interference with other important First Nation projects or policy issues.

9.4 The Lead Researcher shall provide the First Nation with information to minimize these risks identified in section 9.3.

10. DATA MANAGEMENT AND OWNERSHIP

10.1 In this section “Data” includes anything that is collected from or provided by the First Nation, or individual member thereof, participating in the project for the purposes of the project including all social, health, diet and lifestyle information, and test results from water samples, hair samples, and traditional food samples.

10.2 The Data collected is confidential and no name is attached to a record. Copies will be kept at the offices of the principal investigators Dr. Laurie Chan (UNBC), Dr. Olivier Receveur (Université de Montréal), and Dr Donald Sharp (AFN), where the Data will be stored in electronic form. Each First Nation will have a copy of its own Data, and AFN will have a full

copy of all the communities Data. After termination of the project, the only holder of Data will be AFN (the Data custodian) where it will be safely archived for access by First Nations. The principal investigators will be available to answer questions and assist First Nation members should First Nation members decide to use the Data for different purposes beyond the objectives of this particular project.

- 10.3 An annual report summarising all FNFNES work done during each year including copies of all collected Data, reports, presentation materials and accompanying data dictionaries (with names of the communities removed, but with ecozone location information and regional identifiers intact), will be submitted by the Lead Researcher to Health Canada, the project funder, at the end of each fiscal year. A final report will be distributed after approval from the First Nation community. See sections 9.2b, 10.5, 12.1 and 12.4.
- 10.4 All Data shall vest in and remain the property of the First Nation, or individual member thereof who provided it.
- 10.5 The Lead Researcher will be able to use the Data for purposes set out in this Agreement. The First Nation understands that the Lead Researcher's participation in the First Nations Food, Nutrition and Environment Study is conducted under a broader scope of scientific research and the Lead Researcher intends to present the research findings by a variety of means including conference presentations, teaching, publishing in academic journals, and reports to the funding agency, Health Canada. Once published, copyright will vest in the publisher. For example, a graduate student will hold the copyright to his/her thesis, and an academic journal will hold the copyright to an article published in that journal. Distribution of copyrighted material will be in accordance with the Copyright Act. In all circumstances, any published material will be made freely available to any First Nation (individual or organization) that requests such materials.

11. HEALTH CANADA'S ROLE IN THE RESEARCH

Health Canada is the funder of the FNFNES and provides in-kind support to the project in the following ways:

- 11.1 Dr. Constantine Tikhonov will be responsible for ensuring laboratory analysis of mercury concentrations in anonymized hair samples collected in the course of the project, synthesize the data and report the results to the Lead Researcher for dissemination in accordance with the terms of this Agreement.
- 11.2 Dr. Harold M. Schwartz will be responsible for ensuring surface water sample collection for laboratory identification and quantification of pharmaceutical products, in the context of this project, synthesize and analyze the data, and report the results to the Lead Researcher for dissemination in accordance with the terms of this Agreement.
- 11.3 Dr. Harold M. Schwartz will be responsible for ensuring data analysis of trace metals in drinking water samples in the context of this project, synthesize the data, and report the

results to the Lead Researcher for dissemination in accordance with the terms of this Agreement.

12. DISSEMINATION OF RESULTS

- 12.1 Any future publication or dissemination of research results, beyond what is described in this agreement shall not be undertaken without an agreement between the Lead Researcher and consultation/accommodation with the First Nation community.
- 12.2 The First Nation Community will be the first to receive community research results and the first invited to provide input and feedback on the results, except in the event of a drinking water sample containing trace metals at concentrations higher than the Maximum Acceptable Concentration, as noted in the most recent version of the *Guidelines for Canadian Drinking Water Quality*. Community results should be presented in a format and language appropriate and accessible to the First Nation community. Results will not be released without prior presentation and consultation with the First Nation Community.
- 12.3 In compliance with section 9.2, the Lead Researcher agrees to participate in community meetings to discuss the results and their implications.
- 12.4 In compliance with section 9.2, the Lead Researcher shall release the findings of the study to the public at large in a joint research report, scientific journal or other publication. Participating First Nations will be acknowledged.

13. TERM AND TERMINATION

- 13.1 This agreement shall have an effective date of _____ and shall terminate on _____.
- 13.2 The Lead Researcher agrees to stop the research project under the following conditions:
- a) If First Nation leaders decide to withdraw participation.
 - b) If the Lead Researcher believes that the project will no-longer benefit the First Nation Community.

Signed by:

The First Nation

Date:

University of Northern British Columbia

Date:

Université de Montréal

Date:

Assembly of First Nations

Date:

