RESEARCH PROTOCOL

Inter Tribal Health Authority

Working Together for Healthy Nations

December 23nd , 2005

ITHA

RESEARCH PROTOCOL

1. Introduction

Inter Tribal Health Authority is committed to the generation and dissemination of knowledge. Research is defined as the development of new knowledge. The ITHA recognizes the importance of research as a tool for improving the health status of it Member Nations, for improving health services and health policy.

Properly conducted research will help First Nations and their health organizations to:

- Better understand their health
- Better understand the causes of certain health conditions, including the environmental and personal causes
- Create data to support negotiations for needed resources to develop programs and policies
- Better understand how ITHA and its member First Nations can work toward improving their health and wellness.

National Aboriginal Health Organization (NAHO) summarizes issues relating to health accordingly:

> "Indigenous cultures throughout the world have always approached health in a holistic way. Holistic approaches to health mean the whole person is considered in the maintenance of wellness and any treatment of disease. The inter-relationship of the mental, physical, spiritual, emotional, and social aspects of health and well-being of individuals and communities are considered in order to treat a person or maintain health. This view also takes into account the many and varied inter-relationships of other segments of society when discussing health. The impacts of housing, poverty, economic status, and culture, among others, must also be considered when discussing the health of our communities and Nations."[1]

2. Research

The purpose of research is to create new knowledge, and with that knowledge, find solutions to issues that affect us. For example, heart disease, cancer, and diabetes all have centres of research devoted to finding a cure or finding ways of improving the lives of people living with these diseases. There are also centres of research devoted to the health of specific populations, such as women or aboriginal people.

Research to date has found that First Nations people in most communities have higher rates of illness and shorter lives than other Canadians. The purpose of research conducted amongst the people of ITHA's member First Nations, or on their lands, should be to improve the health of its people and First Nations people in general while ensuring the First Nations are full partners in research.

The purposes of ITHA's research protocol are:

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[1] National Aboriginal Health Organization (NAHO). Document accessed March 23, 2005 at http://www.naho.ca/english/pdf/health_sectoral_intro.pdf.

- To ensure research conducted in ITHA member communities will be of benefit to these communities, as well as Aboriginal people in general;

- To promote well-designed and First Nation controlled research. That research is seen as an important tool needed, to better understand the health of the people, and to better understand how ITHA and its member communities can improve the health of Aboriginal people;

- To build research partnerships with university and independent researchers, government and funding agencies and other First Nation and Aboriginal research bodies;

- To ensure that research is conducted ethically and reflective of First Nations cultural values; and

- To build research capacity within First Nations and their organizations.

3. Principles of research and of research ethics

3.1 Cultural values of Coast Salish and Kwakwakw'wakw

The implementation of this Protocol, through the Research Review Committee, will be guided in accordance to the values and protocols of the Coast Salish and Kwakwakw'wakw cultures.

3.2 General research principles

The general principles for research within our First Nations and with our people are that any research activities must demonstrate the following:

a. Cultural respect is demonstrated toward First Nations cultures and communities by valuing their diverse knowledge of health matters and environment, as well as their unique world views and value systems, and the contribution these make toward health science knowledge and community and individual wellness health.[2]
b. Relevance to cultural and community is critical for the First Nations health training and research.[2]
c. Reciprocity is accomplished through a two-way process of learning and research exchange. Both community and university benefit from effective training and research relationships.[2]
d. Responsibility is empowerment and is fostered through active and rigorous engagement and participation.[2]
e. Ownership respects and acknowledges that communities and groups own information collectively, in the same way as individuals own personal information. Ownership is distinct from stewardship of data.[3]

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[2] Kirkness, V.J. and Barnhardt, R. (1991). First nations and higher education: The four R's - respect, relevance, reciprocity and responsibility. *Journal of American Indian Education* 30(3):1-15. Adopted as principles by BC ACADRE. http://www.health-disciplines.ubc.ca/iah/acadre/site_files/research/4_r_s.htm

[3] Schnarch, B. (2004). Ownership, Control, Access and Possession (OCAP) or Self-determination applied to research. *Journal of Aboriginal Health* 1(1):80-95.

f. Control respects First Nations' rights and aspirations to maintain or regain control in all aspects of their lives, including research data. Control can include, all stages of a research project, research policy, ethics review processes, etc.[3]
g. Access recognizes that First Nations must have access to information, data about themselves and their communities, wherever it is held. First Nations have the right to manage and make decisions regarding access to their collective information.[3]
h. Possession is the mechanism with which to assert and protect ownership and control.[3]
i. Respect for human dignity[4]
j. Regarding individual research participants, ensure:[4]
    - free and informed consent for all research participants
    - protection of <u>all</u> participants
    - privacy and confidentiality
    - justice and inclusion
    - a clear understanding of the harms and benefits to individual participants,
    - avoidance, prevention and minimization of harm while maximizing benefits of research.

3.3 Guidelines for conducting research in ITHA member communities:

3.3.1 Respect for human dignity;

3.3.2 Respect for both individual and community interests;

3.3.3 Research must do no harm; or at a minimum, the benefit must outweigh the risk; Protecting individual research participants, by:
- free and informed consent for all research participants
- protection all participants, especially vulnerable person
- privacy and confidentiality
- justice and inclusion
- a clear understanding of the harms and benefits to individual participants, avoiding, preventing and minimizing harm while maximizing benefits of research;

3.3.4 Respect for Coast Salish and Kwakwaka'wakw culture, values, knowledge, and ways of doing things. Research methods must be culturally appropriate and acceptable to the community;

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[4] The Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (1998). Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. Ottawa: Public Works Canada. <u>Note</u>: The Tri-Council Guidelines that pertain to Aboriginal communities are currently under review by the Canadian Institute of Health Research, Institute of Aboriginal Peoples' Health.

3.3.5 Respect for First Nations' jurisdiction and decision making processes by following the OCAP principles: OCAP principles:

3.3.5.1 *Ownership* respects and acknowledges that communities and groups own information collectively, in the same way as individuals own personal information. Ownership is distinct from stewardship or possession of research.[5]

3.3.5.2 *Control* respects First Nations' rights and aspirations to maintain or regain control in all aspects of their lives, including research data. Control can include, all stages of a research project, research policy, ethics review processes, etc.[3]

3.3.5.3 *Access* recognizes that First Nations must have access to information, data about themselves and their communities, wherever it is held. First Nations have the right to manage and make decisions regarding access to their collective information.[3]

3.3.5.4 *Possession* is the mechanism with which to assert and protect ownership and control. [3]

3.3.6 ITHA respects the right of each member First Nation to decide whether they will consent to having research in their community;

3.3.6 Research must be relevant to the community and must benefit any or all ITHA First Nations;

3.3.7 Research partnerships must be based on mutual respect and responsibility; Community participation in research will encompass all aspects of the research processes, including data collection, analysis, and report writing, wherever practical. The aim is to increase understanding about data collection (how, why and what data) and to increase skills and capacity within the community;

3.3.8 Research processes should be reciprocal in the learning processes. There should be an implicit understanding about the value of indigenous knowledge, and that of research skills, with all partners willing to learn from and teach others in the partnership;

3.3.9 All researchers must report back to the community, in either written and/or oral presentation, in language understandable to community member;

3.3.10 Each research project must negotiate a research partnership agreement between ITHA, or its member First Nations, and the external research partners.

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[5] Schnarch, B. (2004). Ownership, Control, Access and Possession (OCAP) or Self-determination applied to research. *Journal of Aboriginal Health* 1(1):80-95.

4. ITHA RESEARCH REVIEW COMMITTEE

TERMS OF REFERENCE

MEMBERSHIP

The Research Review Committee will be made up of 8 to 10 members consisting of, but not limited to:

- Member of the ITHA Board of Directors
- Member of the ITHA Management Committee
- Someone who understands, or who has experience with, research processes
- Someone who understands research ethics
- Salish and Kwakwal Elders (2)
- Two other selected members from Member Nations (1 northern, 1 southern)
- A youth
- Representation from Coast Salish and from Kwakwakw'wakw
- Ad hoc members who know about the specific research project

Both males and females will be well represented on the Committee.

MANDATE

The research review committee is an advisory body to Inter Tribal Health Authority and its member First Nations. The committee has three main functions:

1. **Training and education**
    - Participate in training and educational opportunities for the committee
    - Assist in training and education for the local and project-specific advisory committees who will monitor the research process in their community,
    - Advise and assist with capacity building for research processes with ITHA Board and member First Nations.

2. **Actively seek research**
    - Set priorities in consultation with First Nations, ITHA, and the ITHA management committee,
    - Report on research opportunities (request for proposals) from outside agencies,
    - Seek funding sources for ITHA research priorities or projects,
    - Keep informed about, and meet with, wherever possible, other First Nations health research agencies, organizations and people.

3. **To review and monitor all health research**
    - Review all research inquiries and protocols to ensure they fit with ITHA's research guidelines,
    - Make recommendations to the Board or First Nation, using ITHA's research guidelines,
    - Monitor the progress of the research in conjunction with local or project-specific research advisory committees.

MEETING SCHEDULE

The research review committee will meet four times per year to review or monitor proposals and projects. In the event that there are no research projects to deal with, the committee will use the time together to take training or to train others. Ad hoc conference call meetings can be arranged as needed.

COMPENSATION

Members will be compensated with $150 per meeting. Travel and accommodations will be paid or arrangement made by ITHA.

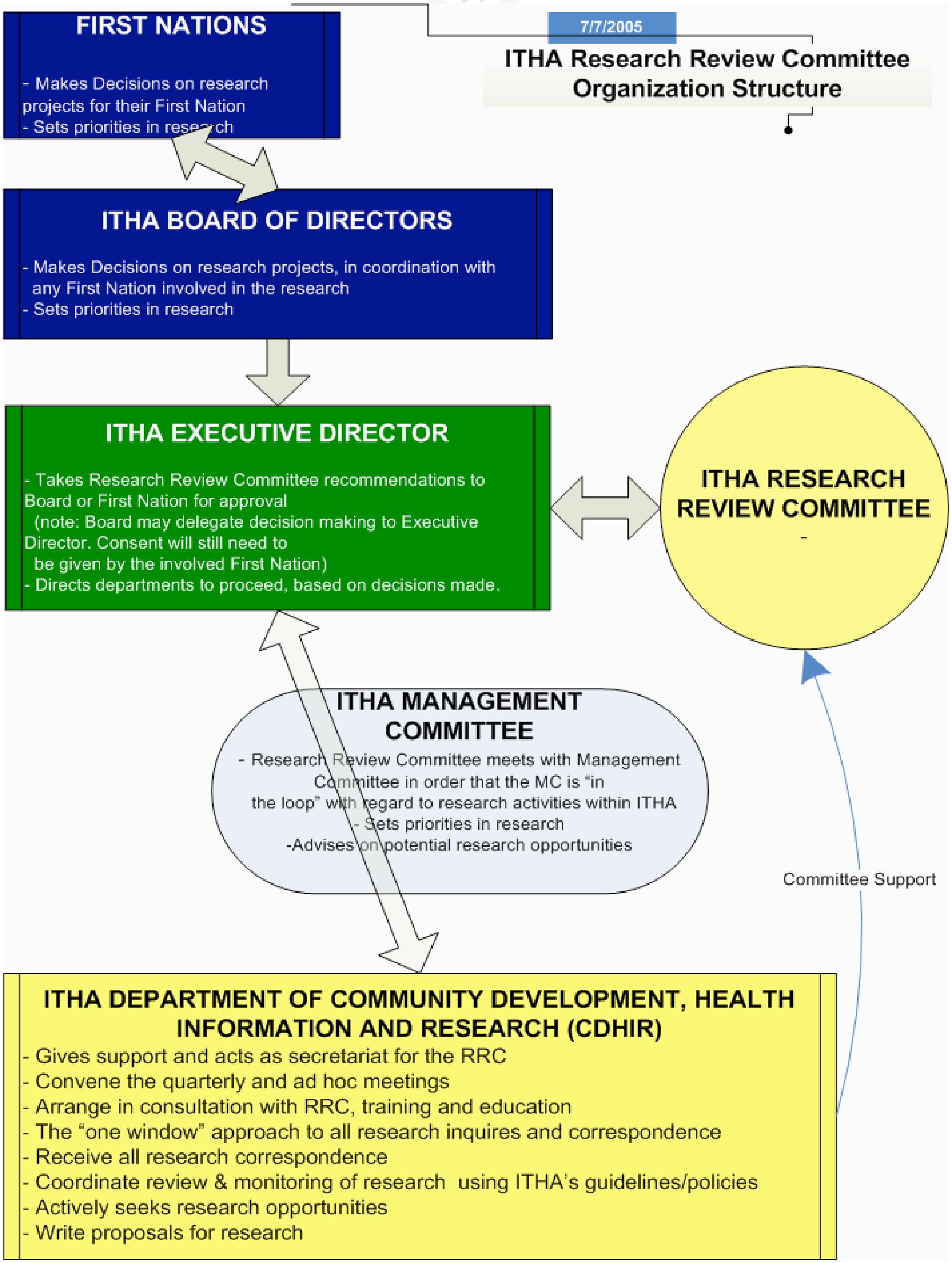
DISPUTE RESOLUTION

ITHA’s estasblished procedures will be used in cases requiring dispute resolution.

CONFLICT OF INTEREST

ITHA’s established procedures will be used in cases of conflict of interest.

5. ORGANIZATION CHART



ITHA Research Review Committee Organization Structure

FIRST NATIONS

- Makes Decisions on research projects for their First Nation
- Sets priorities in research

ITHA BOARD OF DIRECTORS

- Makes Decisions on research projects, in coordination with any First Nation involved in the research
- Sets priorities in research

ITHA EXECUTIVE DIRECTOR

- Takes Research Review Committee recommendations to Board or First Nation for approval
  (note: Board may delegate decision making to Executive Director. Consent will still need to be given by the involved First Nation)
- Directs departments to proceed, based on decisions made.

ITHA RESEARCH REVIEW COMMITTEE

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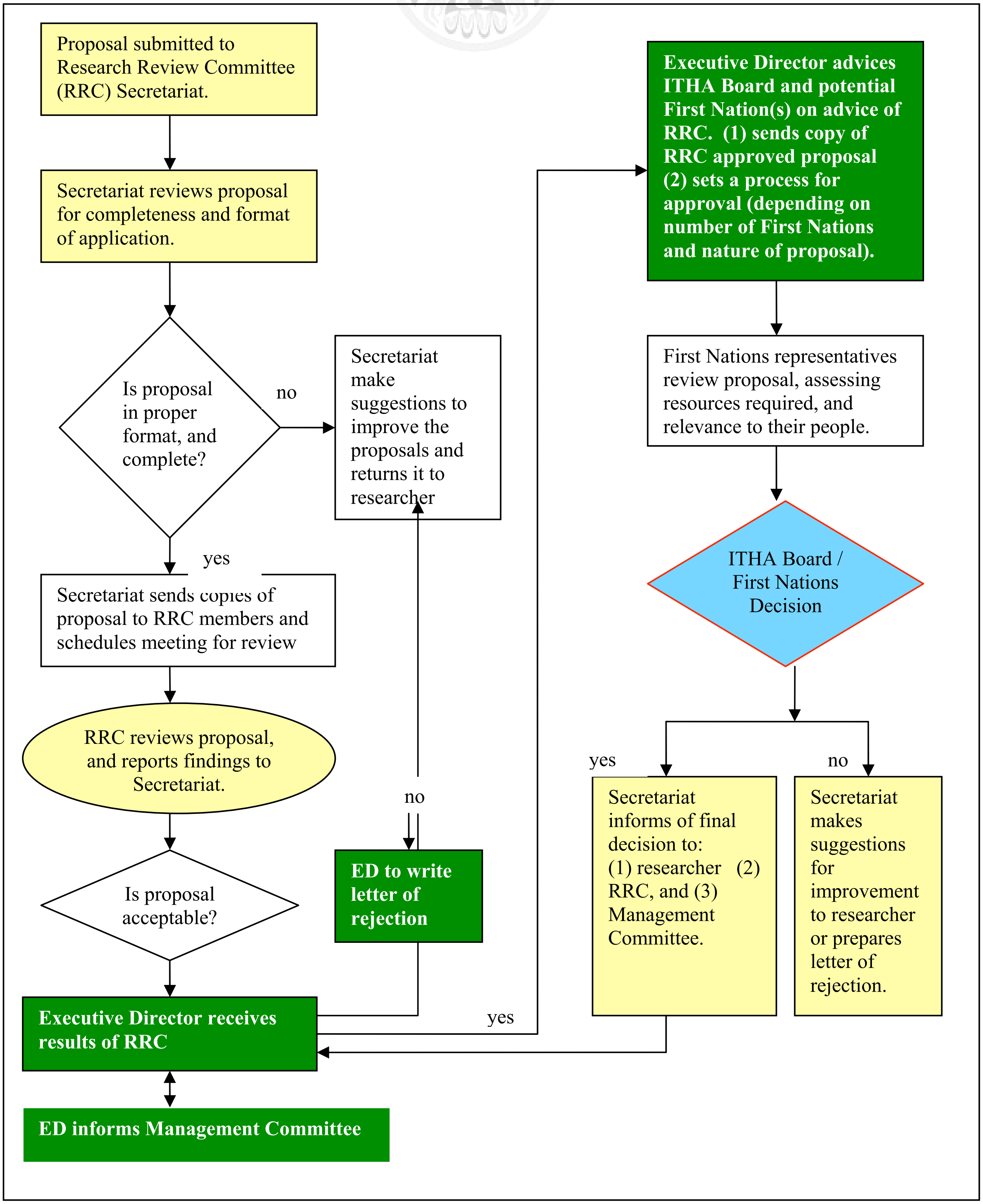
ITHA MANAGEMENT COMMITTEE

- Research Review Committee meets with Management Committee in order that the MC is “in the loop” with regard to research activities within ITHA
- Sets priorities in research
-Advises on potential research opportunities

ITHA DEPARTMENT OF COMMUNITY DEVELOPMENT, HEALTH INFORMATION AND RESEARCH (CDHIR)

- Gives support and acts as secretariat for the RRC
- Convene the quarterly and ad hoc meetings
- Arrange in consultation with RRC, training and education
- The “one window” approach to all research inquires and correspondence
- Receive all research correspondence
- Coordinate review & monitoring of research using ITHA’s guidelines/policies
- Actively seeks research opportunities
- Write proposals for research

6.FLOWCHART



🟨 Refers to Secretariat 🟩 Refers to E.D. 🟦 Refers to Board or First Nations

Appendix A:

FORM TO BE COMPLETED BY RESEARCHERS

Research project

1. Project title ____

2. Topic of project: ____

3. Dates: When will this research begin? _______________
   When is the anticipated end date? _______________

4. Description of project

____
____
____
____
____
____
____
____

Researchers

5. Who are the researchers? Please list all the researchers, their addresses, and their qualifications or experience.

Name	Address	Qualifications and experience

6. Do you, or anyone in your research team, have any of the following qualifications: (check all that apply):
    - ☐ Knowledge of community
    - ☐ Knowledge of culture and traditions
    - ☐ Knowledge of Kwakuitl culture and traditions of Kwakuitl
    - ☐ Knowledge of Coast Salish culture and traditions of
    - ☐ Training in research skills
    - ☐ Experience in research
    - ☐ College or university degrees or diplomas. Highest level ________________
    - ☐ Other qualifications important to this research _________________________
      ____

Research Methods

7. How are you collecting data? [water samples, surveys, traditional knowledge?]

____
____

8. Where will the research take place? Which communities? List each community within ITHA and elsewhere.

______________________________   ______________________________
______________________________   ______________________________
______________________________   ______________________________
______________________________   ______________________________

9. Who are the research participants? ____________________________________

10. How many research participants will you need for this research? ______________

11. Please describe any progress you have made regarding communicating with any of the First Nations Members, or other people or organizations within ITHA regarding this research. Who did you talk to or write to? What is their response?

____
____
____
____

External partners or partners

12. Is this coursework? If so, please describe (including college or university, course).

____

13. Funding
    11a. Is there funding for this project? ☐ Yes ☐ No
    11b. Where is the funding coming from? ________________________________
    11c. What obligations to the funders, or expectations of the funders exist with respect to this research? ____
    ____

14. Are you working on the same project with other communities, other than ITHA communities? ☐ Yes ☐ No
    If yes, please describe: ____

15. Are there agreements with any organizations – corporations, governments?
    ☐ Yes ☐ No
    If yes, please describe: ____

Results

16. Describe fully your plans for informing ITHA and any of its First Nations communities and research participants. For examples, will this be an ongoing process, what plans to you have at the end of the research for reporting back, and will this reporting be done in oral presentation or lay-language written reports?

    ____
    ____
    ____
    ____
    ____

Other

Please use this space to describe the research further, or to explain the importance of doing this research.

The following checklist is to understand or appraise the extent to which research projects follow the principles of community-based participatory research. There is no total score, but we are interested in the responses to each question. Please check the most appropriate rating from 1 to 5 (very much to very little). For each item, check only one box.

	1 Very much	2	3	4	5 Very little
A. Community and its involvement					
1. Is the community clearly described or defined? (For example, all people belonging to one First Nation; or all people within a certain age group or who have a certain condition.)	☐	☐	☐	☐	☐
2. Do members of the defined community participating in the research have concern or experience with the issue?	☐	☐	☐	☐	☐
3. Are interested members of the defined community provided opportunities to participate in the research process?	☐	☐	☐	☐	☐
4. Is attention given to barriers to participation, with consideration of those who have been under-represented in the past?	☐	☐	☐	☐	☐
5. Has attention been given to establishing within the community an understanding of the researchers' commitment to the issue?	☐	☐	☐	☐	☐
6. Are community participants enabled to contribute their physical and/or intellectual resources to the research process?	☐	☐	☐	☐	☐
B. Origin of the research question					
7. Did the impetus for the research come from the community?	☐	☐	☐	☐	☐
8. Are efforts to research this issue or topic supported by members of the community?	☐	☐	☐	☐	☐
C. Purpose of the research					
9. Can the research facilitate learning among community participants about individual & collective resources for self-determination?	☐	☐	☐	☐	☐
10. Can the research facilitate collaboration between community participants and resources external to the community?	☐	☐	☐	☐	☐
11. Is the purpose of the research to empower the community to address determinants of health?	☐	☐	☐	☐	☐
12. Does the scope of the research encompass some combination of political, social and economic determinants of health?	☐	☐	☐	☐	☐

D. Process and context — methodological implications					
13. Does the research process apply the knowledge of community participants in the phases of planning, implementation & evaluation?	☐	☐	☐	☐	☐
14. For community participants, does the process allow for learning about research methods?	☐	☐	☐	☐	☐
15. For researchers, does the process allow for learning about the community health issue?	☐	☐	☐	☐	☐
16. Does the process allow for flexibility or change in research methods and focus, as necessary?	☐	☐	☐	☐	☐
17. Are procedures in place for appraising experiences during implementation of the research?	☐	☐	☐	☐	☐
18. Are community participants involved in analytic issues: interpretation, synthesis and the verification of conclusions?	☐	☐	☐	☐	☐
E. Opportunities to address the issue of interest					
19. Is the potential of the defined community for individual and collective learning reflected by the research process?	☐	☐	☐	☐	☐
20. Is the potential of the community for action (social or political or other) reflected by the research process?	☐	☐	☐	☐	☐
21. Does the process reflect a commitment by researchers and community participants to social, individual or cultural actions consequent to the learning acquired through research?	☐	☐	☐	☐	☐
F. Research Outcomes					
22. Do community participants benefit from the research outcomes?	☐	☐	☐	☐	☐
23. Is there attention to or an explicit agreement for acknowledging and resolving in a fair and open way any differences between researchers and community participants in the interpretation of the results?	☐	☐	☐	☐	☐
24. Is there attention to or an explicit agreement between researchers and community participants with respect to ownership of the research data?	☐	☐	☐	☐	☐
25. Is there attention to or an explicit agreement between researchers and community participants with respect to the dissemination of the research results?	☐	☐	☐	☐	☐

These guidelines are adapted from: Green LW, George A, Daniel M, Frankish CJ, Herbert CP, Bowie WR, O'Neill M: Study of Participatory Research in Health Promotion: Review and Recommendations for the Development of Participatory Research in Health Promotion in Canada. Ottawa: Royal Society of Canada, 1995