

# Widening the circle of care: An arts-based, participatory dialogue with stakeholders on cancer care for First Nations, Inuit, and Métis peoples in Ontario, Canada

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## Executive summary

Cancer incidence is growing within First Nations, Inuit, and Métis (FNIM) communities, yet research and supportive care is slow to respond to their unique needs and experiences. The proposed project will engage important stakeholders involved in FNIM cancer care within Ontario, including health care professionals, health administrators, and FNIM community leaders. This study builds upon a national study on FNIM cancer survivors. Three objectives drive this research: 1) To identify strengths and needs within FNIM cancer care in Ontario from multiple perspectives; 2) To exchange knowledge of FNIM cancer experiences between stakeholders through arts-based methods, especially photography; 3) To work collaboratively with stakeholders to establish recommendations for improving FNIM cancer care. The project involves early consultations with stakeholders on the most pressing questions and issues in the area. Then, 20 participants (10 health care professionals, 5 health administrators, and 5 FNIM community leaders) will be recruited to use and discuss photos that capture experiences of FNIM cancer care. A report will be generated and dispensed to participants, bringing together various experiences, themes, perspectives, and recommendations for improving the state of care.

## Keywords

Indigenous health; cancer; arts-based methods

## Participants

Participants will include the following: 10 health care professionals in Ontario who work with Indigenous cancer patients; 5 First Nation, Inuit, and/or Métis community leaders (e.g., elders, tribal chiefs); 5 health administrators in Ontario cancer centres.

## Third parties involved in the project

In the development phase of data collection materials, consultations will be held with major regional and provincial stakeholders in FNIM cancer care in Ontario. Representation will be sought from the following organizational bodies: Cancer Care Ontario, Aboriginal Health Access Centres, regional cancer programs, and Local Health Integration Networks. Stakeholder consultations have the purpose of revising research processes in order to ensure relevance of project objectives, data, and analyses to cancer care policy and practice, as study recommendations will be targeted to the above organizations (among others).

## Preliminary work

The proposed project is based upon findings from the *National Picture* project, a nationally-funded study (\$244,128) from the Canadian Cancer Society Research Institute on cancer survivorship experiences among FNIM peoples. The project is a national collaborative effort between University of Ottawa (Drs. Thomas and Gifford), University of Saskatchewan (Drs. Poudrier and Brooks), University of New Brunswick (Dr. Hamilton), and the FNIM program of Saint Elizabeth, a highly regarded community-based health care organization. This participatory research project uses arts-based methods (i.e., journaling and photography) and Indigenous protocols (i.e., Elder and tribal council consultations, sharing circles, and storytelling) to identify culturally distinct challenges and resources of FNIM cancer survivors. The *National Picture* study is an innovative and effective way to engage Indigenous communities in health research. The proposed project builds on this parent study, using arts-based, participatory methods to address challenges in FNIM cancer care within Ontario.

## Objectives, Concept and Approach

**Study Objectives:** **1)** To identify strengths and needs within FNIM cancer care in Ontario from multiple perspectives; **2)** To exchange knowledge of FNIM cancer care experiences between knowledge users through arts-based methods; and **3)** To collaboratively establish recommendations for improving the quality of FNIM cancer care in Ontario.

**Research Plan: Phase I** (May 2016 - Sept 2016): Third-party stakeholder consultations will begin in order to identify priorities in FNIM cancer research (Obj 1). Stakeholder input will inform Phases II and III, ensuring the research process and goals are relevant to stakeholders. **Phase II** (Oct 2016 – Sept 2017): 20 participants will be recruited (10 health care professionals, 5 health administrators, and 5 FNIM community leaders) through existing networks of knowledge users from the parent study and Phase I. Arts-based methods and interviews will be used to produce rich, accessible data. Data will be collected over 3 stages. First, a photovoice approach will be used with health care professionals to capture their experiences of providing care for FNIM cancer patients and their families (Oct 2016 - Mar 2017). Second, their photos (and photos from the parent *National Picture* project) will be the basis for interviews with health administrators and FNIM community leaders, a research process known as photo-elicitation (Obj 2, Apr 2017 – Aug 2017). Third, summaries from the photo-elicitation interviews will be taken back to the 10 participating health care professionals for follow-up discussions (Sept 2017 – Jan 2018). The creation of dialogue between participants is informed by Aboriginal concepts of “two-eyed seeing” and an ethical space of intercultural engagement. **Phase III** (Jan 2018 – Apr 2018): A report from Phases I and II (Obj 3) will be co-developed with all 20 participants, bringing together various experiences, themes, perspectives, and recommendations for improving FNIM cancer care in Ontario. This report will be distributed to the above consulted stakeholders, and serve as the basis for discussions with stakeholders around implementing the recommendations, for which additional funding opportunities will be sought.

## Impact

This research builds on a program of research in the field of interdisciplinary, inequities-based cancer research. In order to increase impact of the research, integrated and end-of-project knowledge translation activities have been built into the proposed project, including: (a) knowledge user engagement at all stages of research; (b) participatory methods of data collection and interpretation; and (c) the production of actionable recommendations for improving FNIM cancer care. The use of photography as data and for eliciting data marks an innovative and inclusive approach to studying challenges within FNIM cancer care, while extending the reach of established projects. Through strong partnerships and a stakeholder-driven agenda, this research promises to build timely knowledge exchange initiatives between professional stakeholders and to identify viable pathways toward improving cancer care for FNIM peoples in Ontario.

## Implementation

My intent to engage in community-based, interdisciplinary research continues to be supported by a dynamic research environment within uOttawa's Faculty of Health Sciences (FHS), which is situated within a large campus composed of the Children's Hospital of Eastern Ontario and The Ottawa General Hospital. My research is housed within the CFI-funded Creative Practices Centre (CPC), a collaborative space shared by local researchers and students, and the hub of several national and international teams. All equipment and infrastructure needed for completion of my research is available through the CPC, including videoconferencing access, photography equipment, and data analysis software (e.g., NVivo). The CPC is coordinated by FHS faculty with diverse backgrounds: Drs. Roanne Thomas (Sociology), Mary Egan (Occupational Therapy/Epidemiology) and Judy King (Physiotherapy). Dr. Thomas is uniquely positioned to strengthen my repertoire of research skills; with a Canada Research Chair (CRC) in Qualitative Health Research with Marginalized Populations, 75% of her time is protected for research. Her CRC will support administrative assistance for projects and my participation in at least 2 conferences per year. She is a highly accomplished researcher and model supervisor, holding over \$3 million in external funds as PI and \$3 million as Co-I, and authoring 60 peer-reviewed articles. She has a mature network of interdisciplinary cancer survivorship researchers and stakeholders who will also provide mentorship and support. Dr. Thomas has a valuable research background working with FNIM cancer survivors and holds community partnerships (e.g., the Ottawa Regional Cancer Foundation) through which I will develop capacity working with FNIM communities.

## Budget

### Salary

Postdoctoral Fellowship: \$40,000 x 2 years = \$80,000

Honoraria: \$1000

### Equipment

None: Provided by the Creative Practices Centre

### Knowledge Dissemination

Conference Attendance: \$1000

### TOTAL

\$82,000

## **Plans for data management and sharing of the products of research**

### **Data Management**

All data will be stored in the locked office of the Creative Practices Centre (CPC) and digitally backed up on a local, secure university server.

### **Knowledge Dissemination**

Knowledge dissemination is integrated into the research design throughout Phases I - III. Consultation with FNIM cancer care stakeholders in Phase I will inform a research process that is accessible and relevant to knowledge users. Phase II involves a dialogic and participatory research process (i.e., returning to participants multiple times and using photos as both data and data elicitation tool); the production of knowledge will be driven by participants' perspectives as well as an overarching ethic of engagement across different stakeholder groups (i.e., health care professionals, health administrators, and FNIM community leaders). Phase III is scheduled to deliver a tangible product to both participants and consultants, a report informed by a variety of stakeholder perspectives, insights, and concerns. Beyond this community-based focus to dissemination, traditional outlets will also be targeted with at least 2 research publications and 2 conference presentations.

## **Funding program**

This proposal was submitted to the annual Canadian Institutes of Health Research (CIHR) competition for postdoctoral fellowships. CIHR accepts a wide range of research proposals regarding health, including basic biomedical, health services/systems, psychosocial, and population-based health research. This proposal was favourably reviewed but not funded in the 2015 competition. The reviewers encouraged resubmission to the 2016 competition, for which the proposal is currently under review.

## **Hosting institution**

University of Ottawa

## **Conflicts of interest**

None.