

**First Nations, Inuit, and Métis Women’s Experiences of Cancer Survivorship:
Protocol for the National Picture Project**

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Abstract

Little is known about First Nations, Inuit, and Métis (FNIM) women's experiences with cancer, including how they relate to cultural and social factors such as geography, history, racism, identity, traditional values/practices, and spirituality. Research into FNIM women's strengths and challenges in relation to cancer is much needed. Our team, in partnership with Saint Elizabeth Health, is documenting the experiences and needs of 60 FNIM cancer survivors across Canada, using sharing sessions, photography (photovoice), journaling, and film. We will evaluate the impact of photography and journaling on the participants to assist with the future development of supportive programs and health-care delivery. This innovative research will result in a video, which will address gaps in knowledge and care. The video will then be screened in several communities and will be publicly available. In future projects, the findings and video will be used in supportive programs for cancer survivors and in educational initiatives for health professionals.

Keywords: First Nations, Inuit, and Métis health, cancer survivorship, quality of life, qualitative methods, photovoice

Background

Psychosocial survivorship issues are an increasing concern in cancer research (Miedema, Tatemichi, & MacDonald, 2004; Tomich & Helgeson, 2002) as reflected in the growing body of high quality research examining the experience of urban, middle-class, White, and heterosexual women (Bettencourt, Schlegel, Talley, & Molix, 2007; Nelson, Gould, & Keller-Olaman, 2009). Although psychosocial research has resulted in evidence-based interventions known to enhance well-being (e.g., peer-modeling videotapes, journaling), researchers and policy makers acknowledge many gaps remain in the existing knowledge base (Bettencourt et al., 2007; Hewitt, Greenfield, & Stovall, 2006; Miedema et al., 2004; Nelson et al., 2009; Ristovski-Slijepcevic, 2008; Stanton, 2006; Tomich & Helgeson, 2002). Research examining the intersection of ethnicity, marginalization, and cancer survivorship, although scant, recognizes that the interplay of these dimensions invites attention (Bettencourt et al., 2007; Gotay, Holup, & Pagano, 2002).

In response to these gaps, marginalized populations are receiving increased attention within studies of cancer survivorship (Aziz & Rowland, 2002; Schutt, Cruz, & Woodford, 2008). However, much of the health disparity research tends to focus on examining associations between particular social locations and health outcomes (Anderson, Yeates, Cunningham, Devitt, & Cass, 2009; Benoit, Carroll, & Chaudhry, 2003; Tarlier, Browne, & Johnson, 2007; Warin, Baum, Kalucy, Murray, & Veale, 2000; Wilson, 2003), as opposed to exploring cancer survivorship experiences and quality of life in terms of the intersection of multiple social locations (e.g., gender, age, culture). Researchers concerned with satisfaction of medical care are unanimous in pointing out the lack of attention to FNIM experiences in this regard (Aziz et al., 2002; Garrouette, Kunovich, Jacobsen, & Goldberg, 2004; Gould, Sinding, Mitchell, & Fitch, 2009; Mitchell & Maracle, 2005; Schutt et al., 2008). More specifically, First Nations, Inuit, and Métis (FNIM) women living with cancer often “fall through the cracks” (Poudrier & Thomas, 2009) within survivorship research and support. As health-care providers increasingly recognize cancer survivorship as complex (Hewitt et al., 2006; Ristovski-Slijepcevic, 2008), it will be critical to incorporate diverse perspectives and identify similarities and differences across geographical, cultural, and, sociohistorical locations.

The few studies that do research within a paradigm of intersectionality report that women in marginalized populations may not receive the care they need because they do not fit the model of patient for which the health-care system is designed (Aziz et al., 2002). Reasons for the lack of fit are twofold: (a) health-care professionals may overlook the distinctive needs of these patients, lacking the tools and resources to identify and respond appropriately; and (b) women’s experiences of marginalization (e.g., racism, sexism, ageism, and poverty) may also increase their vulnerability, thereby hindering communication of their needs. FNIM health and healing must be viewed within a complex web of factors that range from physiological, psychological, and spiritual, to historical, sociological, cultural, economic, and environmental (Brant Castellano, 2004; Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000; Waldram, Herring, & Young, 2006). The Royal Commission on Aboriginal Peoples (1996) has indicated that for many FNIM cultures, “good health is a state of balance and harmony involving the body, mind, emotions, and spirit.” Yet, FNIM people are the least healthy population in Canada, with FNIM women experiencing an unequal burden of illness compared to FNIM men and other Canadian women (Browne & Fiske, 2001; Browne, Smye, & Varcoe, 2007; Gionet, 2009).

FNIM people in Canada disproportionately experience the types of health problems associated with a context marked by poverty and heavily influenced by their historical treatment within society (Waldram et al., 2006). FNIM peoples’ health has been linked to the effect of colonization, including a history characterized by wardship, displacement, and continued discrimination and racism (Browne, 2007). Colonization and neocolonialism have affected all FNIM people, but FNIM women are considered to have experienced the greatest effects (Browne,

2007). Structural barriers and the burden of colonial histories must therefore be carefully considered when addressing health-care needs of FNIM women who experience cancer. Unfortunately, epidemiological studies conducted within the Western scientific tradition have reinforced unequal power relations by depicting FNIM peoples and their communities as “sick, powerless and lacking in capacity” (Mitchell & Baker, 2009, p. 59), rather than integrating awareness of the impacts of structural inequality. Identifying and documenting FNIM women’s perspectives by using decolonizing approaches to research is essential to developing practices, programs, and policies sensitive to gender, culture, and sociohistorical context within cancer survivorship. It is important to note that research and programs geared toward empowering marginalized groups are effective in improving health and communities, particularly when centered on women (Wallerstein, 2006).

Our current research focuses on the above significant research gaps regarding cancer survivorship and the marginalization of FNIM women’s experiences with cancer by addressing psychosocial issues in relation to ethnicity, culture, and sociohistorical positioning (Ashing, Padilla, Tejero, & Kagawa-Singer, 2003; Garrouette et al., 2004; Gotay et al., 2002).

Pilot Work

Our research with FNIM women living with cancer began with a successfully completed photovoice pilot study in which 12 First Nations and Métis women in Saskatchewan described the meaning of breast cancer and survivorship via photography, interviews, and focus groups (Brooks et al., 2008; Thomas-MacLean et al., 2008; Poudrier & Thomas-MacLean, 2009). The Visualizing Breast Cancer (VBC) study was the first opportunity many First Nations and Métis women had to voice and image their experiences, identifying a pressing need for further research into their social location (e.g., class, geography) and role of identity (e.g., traditional beliefs and values). The pilot was also richly suggestive of the capacity for expressive methods (e.g., photography) based on models of empowerment (Duffy, 2011; Pulvirenti, Mcmillan, & Lawn, 2014; Van Uden-Kraan et al., 2008) to function in tandem with psychosocial and knowledge translation (KT) interventions for FNIM cancer survivors (Pulvirenti et al., 2014; Van Uden-Kraan et al., 2008).

The VBC project is one of few studies completed with First Nations and Métis breast cancer survivors and the first photovoice project used to understand the meaning of breast cancer for Aboriginal women. Of several themes from the VBC study that require additional research, we identified three of the most pressing: (a) the intersection of multiple marginalizations (e.g., geography, racism, class) bears significantly on the needs and experiences of cancer survivors; (b) cultural silence about cancer is a significant barrier to health communication; and (c) the vital role of identity, traditional values/beliefs, and spirituality (Brooks, Poudrier, & Thomas-MacLean, 2008; Thomas-MacLean, Poudrier, & Brooks, 2008; Poudrier & Thomas-MacLean, 2009). Our pilot study shows that Aboriginal women draw on resources associated with their local traditions (e.g., healing sweat lodges) and rely on the strength of community attachments. This is not to suggest that FNIM women are a homogenous group, but rather that they might experience cancer, from detection to survivorship, in ways not currently recognized or addressed by the health-care system.

The findings of the VBC project led to the development of the current National Picture project, funded by a Quality of Life Grant from the Canadian Cancer Society in memory of Edna Goebel (#701822). As a national, multi-site study, the National Picture project was designed to identify and describe on a larger scale the community-specific needs of FNIM women, and draw cross-community comparisons to explore similarities and differences via a qualitative, participatory research design using arts-based approaches.

Study Objectives

Following a similar approach to the VBC study, the National Picture three-year study is utilizing sharing sessions, journaling, photography, interviews, and video to address our main goal: to create and disseminate knowledge of cancer survivorship from the perspectives of FNIM women in diverse Canadian communities in order to establish a strong foundation for culturally responsive psychosocial and KT interventions. Our specific objectives include the following: (a) document the experiences and needs of FNIM women with cancer, with specific attention to cultural and sociohistorical factors that may influence their cancer care and survivorship experiences; (b) qualitatively evaluate the impact of photovoice and journaling as interventions to inform future intervention development and health-care delivery; and (c) increase knowledge concerning the effects of cancer on the lives of FNIM women through the production and screening of a video resulting from our data. Our research will contribute to the development of creative interventions and culturally meaningful ways to communicate with diverse audiences to increase uptake of findings relevant to psychosocial well-being.

Partnership

Our interdisciplinary team includes members of Saint Elizabeth, a community-based health care delivery organization with an established knowledge exchange program with FNIM care professionals. The Saint Elizabeth FNIM Program is comprised of a national team of Engagement Liaisons, and through their knowledge exchange portal and related activities the program currently reaches more than 2,000 community health care providers in over 420 FNIM organizations and communities across Canada. From action-based research to KT, the FNIM Program supports communities to understand and solve complex health care issues, improve access, and address barriers to care.

Explanation and Justification of Method

Qualitative methodologies are useful when little is known about a topic and drawing on participants' personal and collective experiences will contribute to understanding its complexity (Berg, 2004; Creswell, 1998; Liamputtong & Ezzy, 2005). Comparative analysis of personal and collective experiences across multiple research sites extends the power of such methodologies to explore the intersection of health services with social determinants of health such as income and FNIM identity (Gould et al., 2009). Qualitative methods have also been cited as foundational to the theoretical basis of complex interventions, determining their acceptability and confirming their "active ingredients" to tailor them to participants' needs (Craig et al., 2008; Sandelowski & Leeman, 2012).

Within qualitative methodologies, participatory research (PR) is considered a culturally appropriate approach that is increasingly recognized as essential for research with FNIM peoples (Castleden, Garvin, & Huu-ay-aht First Nation, 2008; Keller-Olaman & Austin, 2009; Mitchell & Baker, 2009; Moffitt & Vollman, 2004; Salmon, 2007; Smith, 2006). PR is collaborative, facilitating capacity building that enhances a community's ability to improve health (Crisp, Swerissen, & Duckett, 2000; Labonte & Laverack, 2001). Such strategies involve forging dynamic relationships between individuals/groups, health and human service practitioners, and service providing organizations (Hawe, Noort, King, & Jordens, 1997; Labonte & Laverack, 2001; Smith, Littlejohns, & Thompson, 2001).

Within PR focused on empowerment, visual methods have emerged as innovative approaches toward better understanding of health experiences (Foster-Fishman, Nowell, Deacon, Nievar, & McCann, 2005; Liamputtong, 2007; Villagran, 2011). Photovoice, now a widely used methodological tool (Catalani & Minkler, 2010; Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009; Lal, Jarus, & Suto, 2012), is designed to empower research participants to share

stories and assess their needs visually (Harrison, 2002; Liamputtong, 2007; Wang, 1999). The beneficial outcomes include the following: (a) psychosocial, through the validation of participants' expertise; and (b) transformative KT that will deepen understanding and improve practice among care providers (Wang & Burris, 1997). Photos create knowledge grounded in experience and, in our study, are accompanied by a process journal that promotes reflection on the arts-based processes. A culturally relevant journal guide was designed by an advisory group of FNIM community leaders. Participants' photos and journals are used to initiate a dynamic loop of critical-creative production, reflection, and discussion.

Process

Each of our 3 specific objectives corresponds to a phase of the research, with some overlap between them (see Appendix A, Data Collection Schedule). As the study evolves, the planned methods of data collection are adapted according to context and participants' input.

Phase I

To document the experiences, needs, and intersecting factors of cancer survivorship among FNIM women (Objective A), our interdisciplinary team is conducting sharing session discussions with 60 FNIM women in British Columbia, Ontario, and New Brunswick. These discussions are often opened with a ceremony and cofacilitation by trusted members of the community, followed by an overview of the study and signing of consent forms (Appendix B) and filling out demographic forms (Appendix C). The sharing sessions provide data about the women's experiences (e.g., when diagnosed, impact of cancer, use of cultural resources), but also familiarize them with the project and subsequent phases (e.g., walkthrough of photography and journaling guidelines). The sharing sessions usually last around 90 minutes.

Each participant is then loaned a digital camera for about a month and provided with a journal. Participants are asked to complete a minimum of two journal entries per week. Photography and journaling activities completed by each participant assist with the documentation of their experiences and needs. As in Thomas' prior research involving journals, participants will also be informed that they may include drawings, beadwork, clippings, or other creative materials if they wish, and that they do not need to be concerned about spelling or grammar. After the month period, each participant is interviewed individually for approximately an hour, where they talk at length about three to five photos of their choice and about the experience of doing the activities (i.e., benefits and challenges of journaling and photography).

Phase II

Participants come together again for a second sharing session after the interviews. The second sharing session is intended to assist with meeting Objective A, but its primary focus is to receive FNIM women's evaluations of the project and how their stories and creative materials might be disseminated to affect a broader impact (Objective B). In particular, participants are invited to talk about if and how their stories and creative practices might be used to benefit their communities, support other FNIM women with cancer, and/or address limitations and provide solutions within health care services.

Phase III

To increase knowledge concerning the effects of cancer on the lives of FNIM women (Objective C), we will engage in KT strategies using the data from Phases I and II. Most notably, we intend to produce a video out of participants' audio recordings and photos. A video production company will work with the research team to create an educational video to be screened at our research sites. Local participants will be invited to introduce the video. The screenings will be open to the public, but specifically marketed toward patients and health professionals.

At each screening, research assistants will facilitate discussion of the video as both a KT initiative and an intervention component, following the model of one of Thomas' earlier studies on lymphedema, using ethnodrama performances to facilitate a dialogue. Research assistants will take notes of the audience responses, a process that will not identify audience members, which will then be synthesized and shared with the team. The screenings will also provide direction for wider dissemination, for which a KT grant will be subsequently sought. Initially, however, the video will be disseminated to all research participants for use in their communities (via DVD's, an interactive website, and YouTube), and to key cancer organizations such as the Canadian Cancer Society and the Canadian Breast Cancer Foundation.

Sampling

FNIM women may participate regardless of when they experienced cancer. Inclusion criteria are FNIM women who have had cancer, are 19 years of age or older and able to provide informed consent. Women in acute care will be eligible to participate and will assess whether or not they themselves feel that they are able to assume the tasks associated with data collection.

Sites were chosen to allow for integration of diverse perspectives, the inclusion of Inuit women, and national representation. Our sample has been determined through consultation with Saint Elizabeth, as well as principles of theoretical sampling. It will allow for the generation of sufficient data (Mason, 2002), even with attrition (~10%, based on our pilot). In order to engage with a "meaningful range" of experiences (e.g., age, time since diagnosis, considerations of place), and to allow for comparisons across research sites, we have determined that a sample size of 60 women will allow for the generation of such comparisons, as well as saturation (Mason, 2002).

Recruitment

We first approach local First Nations, Inuit, and Métis health leadership and community champions to request support in the distribution of information. Promotional materials are then disseminated in First Nations, Inuit, and Métis community centers and organizations, along with other local media (e.g., newspapers, mailing lists, radio). The Saint Elizabeth FNIM Program is also very well positioned to provide recruitment information to community health care providers and leadership who in turn will ensure community members are informed and invited to participate. This method of engagement and recruitment has proven effective for the Saint Elizabeth FNIM Program in past projects and has been essential to accrual for the National Picture project.

Potential participants contact either the research assistant or community champion to find out more about the project. When between 4 and 10 participants in a specific geographic area (i.e., within a 100 km radius) have been located, data collection for the site proceeds.

Each participant receives a \$25 honorarium for completing each of the three phases (\$75 total per participant, Appendix D). Their travel costs for attending the sharing sessions are covered up to 100 km and they are provided food and refreshments at the venue. We also provide honoraria to community leaders who have supported us in accrual and in opening the sessions.

Data Handling

Within Phases I and II both sets of sharing sessions and the photovoice interviews are digitally recorded and transcribed verbatim. Digital copies of journal entries and photos are collected during the individual interviews and the originals are left with participants; if that is not possible, the hard copies are taken to be digitized elsewhere and promptly returned to participants at the second sharing session or confidentially by mail. Journal entries are all typed for analysis. Participants must also submit third-party photo release forms filled out by those within the

photographs; without permission given by participants and all third parties, all personally identifying information will be blurred on the photos (Appendix E).

The women's selection of three to five photos especially meaningful to them initiates thematic analysis of the data, which is then triangulated with the journal entries. Guided by each woman's selection and discussion of meaningful photos, transcripts and journal entries are read holistically and line by line to extract significant statements following established guidelines for thematic data analysis to generate a preliminary report (Charmaz, 2000; Charmaz, 2005; van den Hoonaard, 1997).

Once each site completes their preliminary coding of their data, the project coordinator (Hammond) compiles and further analyzes it. This synthesis of the sites' data is then shared with the whole team, enabling members to compare experiences among participants as well as across sites to provide a "national picture" of FNIM women's experiences with cancer. Analysis of data across geographical and social locations provides vital information about health-care barriers and opportunities that influence the cancer survivorship experience of FNIM women. Our samples and sites will allow for the emergence of "cross-contextual generalities" based on "rich understandings of specific contexts" (Mason, 2002, p. 125). Significant statements are used to generate specific codes for the project coordinator to create a coding tree, or schema, within the analysis program NVivo 10. Team members review the coding tree and provide feedback to the coordinator. It is then modified and used to code transcripts line by line by the coordinator. Resulting thematic categories and their contents are collapsed into thematic clusters (i.e., via the modeling feature of NVivo 10) to capture relationships between and across themes, as well as to examine characteristics of the data that do not fit within the themes. This process of examining absent or contradictory data is well established in qualitative analysis (Mason, 2002).

Rigor

Rigor regarding the development of themes is ensured by independent coding done by each of the researchers, by extensive team discussions surrounding the development of the themes via conference calls at various points of the data collection, and by facilitating further discussion of themes with the FNIM women in the second sharing sessions (Phase II). In selecting what data is to be highlighted, the participants themselves contribute to the interpretation of the data.

The above steps will also guide in-depth interpretation of the photographic data into thematic clusters. Photographs can be categorized and compared holistically, or interpreted with the assistance of the software's capability for isolating specific segments of photos. Reports or papers generated by the assessment of resources, interviews, and group discussions will be evaluated according to established qualitative criteria, such as credibility, patterning, saturation, and transferability (Munhall & Oiler-Boyd, 1993).

Ethics

Principles guiding research with FNIM peoples state that methodological protocols should empower participants and benefit communities. This includes participation in the production and dissemination of knowledge. Saint Elizabeth and the research team have strong commitments to meeting those principles. Our main KT strategy (i.e., video production and screening) is intended to give back to FNIM communities the knowledge they shared and to facilitate discussion within the communities on how best to support FNIM women with cancer. Thus, our research will deliver culturally meaningful ways of communicating what is at stake in FNIM cancer survivorship, with a focus toward improving the psychosocial well-being of cancer survivors and their communities.

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Appendix A

Data Collection Schedule

PHASE I: INITIAL SHARING SESSION/INTERVIEW GUIDE

Prior to arrival: Identify a *community champion* to support and help arrange for a meeting room, healthy refreshments.

Purchase and ship or travel with supplies (journals, pens, markers, stickers, craft supplies, and name tags); photocopies of ethics forms; projector/laptop; audio recorder (charged).

Preparation on location: Refreshments and food; welcome women individually; set up craft items for free usage; distribute forms; prepare to show sample photovoice project.

Give overview of study, and information about **consent forms, demographic forms**, confidentiality + **third party release forms** for people who appear in photos (take about 10 copies for each participant).

Fill out **consent forms**. Emphasize that consent is an *ongoing process* and at any point they may ask to discuss the terms of their consent or to withdraw their consent.

Beginning the sharing session: Explain sharing session is intended to be a safe place to talk, and will be used to *share their stories* with others involved in cancer care. Then, ask for input as to how the group should work – sharing, respect, one person speaking at a time, etc.

Round-robin introductions. Together, *come up with an activity* to build trust and intimacy within the group prior to the discussion (e.g., use the crafts to express something about themselves, their families, or their communities). Facilitators should be involved as well.

Throughout the discussions, facilitators could invite the women to *use and translate words from their first languages* that they think particularly relate to their experiences.

Questions for Discussion:

1. I would like you each to begin with a brief summary of your experiences with cancer, sharing with us when you were diagnosed and what types of treatments you received.
2. I'd like everyone to think about who supported them during cancer or during other difficult times and to write that person's name down. If you become upset or you need someone to talk to during this project, please turn to that person.
3. What does healing mean to you and to your families?
 - a. What has facilitated healing or provided you with strength (physical, mental, emotional, and spiritual) through your cancer experience?
 - b. What has disrupted healing or tested your strength?
4. What does cancer mean to you and to your families?
5. How do people in your community talk about cancer? How does that compare to how your health care providers talk about cancer?

What impact has cancer had upon your life and daily routines?
Where did you get information about cancer? What information do you think should be available to FNIM women with cancer?
6. Follow up questions: *Have you drawn upon traditional knowledge or culture since having cancer? Have you had the support of your community? Can you please describe your interactions with health professionals?*
7. Is there something concerning cancer that you would like to share with us and we have not discussed?

Introduction to Digital Photography & Journaling (set aside 30 minutes):

Research Assistant (RA) will inquire about familiarity with digital cameras, then explain/review how to use the digital cameras. (S)He will provide an example of this data collection technique and discuss the sample photos with participants.

Provide **overview of journaling** and **handout**. Emphasize that the women may record their journals in several different ways (e.g., written entries, scribed speech, visual expressions, sharing/writing circles, etc.). Use the **journal guide** for examples of how to begin.

Request that the women *date their journal entries* and record in the journals *at least two times per week* for three weeks (photography data collection period).

PHASE II: FOLLOW-UP INDIVIDUAL INTERVIEW GUIDE

Prior to Interview: When arranging the interview, a) work out *where/how* the interview will take place, and b) ask the participant to *select 3-5 photos* and journal entries that are most significant to them. Confirm interview a couple days before.

Preparation: Copy interview **consent forms**; bring laptop to view photos; audio-recorder; bring camera for journal entries (may not be needed).

Review study protocol, interview **consent forms** and sign interview **consent forms**.

Collect **third party consents** for non-participants appearing in photos (or let participant know that images of people will be blurred if consents have not been obtained).

Interview: Start with a *review* of the person's cancer story. Then discuss each *photo*, beginning with the 3-5 selected, before discussing the collection as a whole.

If the participant hasn't already, ask her to talk about what she recorded in her *journal*. The RA may wish to ask the participant if she is comfortable reading out loud (being recorded) some of her journal entries. Or, they can be summarized during the interview.

Questions will depend upon the photos and journal entries shared, but could use the following:

- Why did you choose to share this particular photo/journal entry?
- Can you please provide me with an example of...?
- Could you tell me more about...?
- Can you please tell me more about the people in the photos/journal entries?
- Were there photos you wanted to take but couldn't (e.g., because of season)? How are these important to understanding your experiences?
- Was there something you were unable to put in your journal?
- What would you like others to know about cancer? What did you wish you had known?

Invite comments on the research process, such as:

- What did you like about the photography/journal? Dislike?
- Was photography meaningful? Please explain.
- Did you experience it as empowering? Please explain.
- Was the journal a meaningful exercise? Please explain.
- Did you experience it as empowering? Please explain.
- Would you recommend these activities to other cancer survivors? Why/why not?
- What would improve them?

With participant's permission, the RA will then upload or gather a **copy** (e.g., take photo) of their photos and drawings or other items included in journals. *Participant keeps originals* (if they need to be borrowed to be copied, make sure they are returned).

PHASE III: FOLLOW-UP SHARING SESSION GUIDE

Preparation: Review study protocol, follow-up focus group **consent forms**, sign forms.

Return **journals** and other **borrowed materials** to participants.

Each participant will be asked to (re)introduce herself and, if comfortable, briefly share 2-3 photos with the group (via laptop and projector).

Discussion: State that the main goal of the follow-up sharing session is to understand *if/how photography and journaling can be used to support other FNIM women with cancer*. Ask them what they enjoyed about the project and how it might be improved.

1. We would like to develop a supportive program for FNIM women who have had cancer. This program could include photography and journaling, and other forms of expression. Do you have any suggestions for this program, based on your experiences?

Follow up questions:

What did you like about the photography? Dislike?

What did you like about the journaling? Dislike?

Have you been involved with other supportive programs (e.g., support groups, exercise programs)? Likes? Dislikes?

What, if anything, is missing in cancer care for FNIM women?

How might that gap be filled?

2. We will be creating a video using some photos and interview material. What should we include in the video and what should be kept out?
3. What are some important messages for the people who will view the video? What would you like people to know about FNIM women's experiences with cancer?
4. The video we develop from this project will be publicly screened and we will produce DVDs and a YouTube channel. Who should receive the DVDs/link to video?
5. Do you have any additional thoughts or ideas to share?

Concluding comments (e.g., explain next steps of research process)

Appendix B

Consent Form

Title of Study: A National Picture: First Nations, Inuit & Métis Women's Experiences of Cancer Survivorship

Principal Investigators:

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Purpose: The purpose of this research study is to explore from the perspective of First Nations, Inuit and Métis women their experiences of cancer. It is hoped that this research study will contribute to a better understanding of how the lives of these women are affected and what supportive services are needed.

Study Procedures: This study will take place over the course of 3 years. The study will collect stories of First Nation, Inuit and Métis women's cancer experiences

First Nation, Inuit and Métis women are being invited to participate in taking photographs that highlight significant aspects of their illness experience. Participation in the study begins with a sharing session, in which women will come together to talk about their experiences with each other and attend a short demonstration of a sample photovoice project. The sharing session will be audio-recorded.

You will then be given 3 weeks to take the pictures and will be asked to keep a journal during this time. You will then have the opportunity to talk about your experiences, the photographs you have taken, and your journal entries in an audio-recorded interview. Interviews will last approximately 60 to 90 minutes.

A second focus discussion will occur after all interviews have been completed, and will be audio recorded. Total time commitment from participants will be approximately 12-18 hours, but may depend on how much time participants spend on the photography and journaling portion of the study. You will be asked to confirm whether or not you would like to share the photographs you have taken and your journal with the researchers for their use in publications and presentations. You do not have to share your work. If you consent to share your work, it will be photocopied or photographed and the original will be returned to you. A video will be produced as part of the study. The research team will create a video from the photographs you have taken, your journal entries, your interview audio files and focus group participation, if you have consented to share your work.

Potential Risks and Benefits: This study poses no known risks to participants. You may find that participating in this research study helps you with the emotional aspects of your cancer experiences. As a participant you will receive \$25 for each phase of the study completed (focus group 1, interview, focus group 2). The personal and sensitive nature of the research introduces the possibility that participants may experience an emotional response as a result of talking about their illness. Participants have the right to refuse to answer any questions that they do not wish to and can request that the recording device be turned off at any time. If participants have strong emotional responses to participation in the study, the researcher will provide participants with the contact information for appropriate services available within the province. Participants may also be subject to a potential loss of anonymity and confidentiality because of the use of photography in the study. Participants who wish for their identities to remain confidential will be able to do so by choosing to use a pseudonym and by not appearing in any of their photographs.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You

may withdraw from the research project for any reason, at any time, without penalty of any sort. Withdrawal will not affect your medical care or access to health services. If you choose to withdraw from the study, any data you have contributed will be destroyed beyond recovery at your request.

Confidentiality: Your personal information will be kept confidential unless you choose for it to be associated with your contributions to the study.

1- Anonymity and pseudonyms: If you wish to remain anonymous, your identity will be protected (i.e., you will be assigned a pseudonym, identifying information in photographs will be blurred, identifying information will not be used in quotations, and the audio portion of the video will not use your audioclips/voice). Personal information such as phone numbers, addresses, and organizational affiliations will be kept confidential and any information that may identify third parties associated with participants will be deleted or altered (i.e., names of doctors, family members, etc.).

2- Photographs: Photographs must be taken in an ethical manner. This means that identifiable items such as license plates, realty signs, and addresses should not be photographed. If such items are included, the researchers will blur or crop the identifying information from the photographs before publications or presentations are prepared. Photographs may be taken during the focus groups. You may be identifiable in these photographs. Please let the researchers know if you prefer not to have your photograph taken.

3- Limits to confidentiality in focus groups: Despite all of these efforts to keep information confidential, and given the nature of group work, absolute confidentiality can never be guaranteed.

Ownership of Photographs: The researchers of the study retain publication rights of the photographs participants take and the journaling document produced, if you indicate you wish to share them. Public use (i.e., in presentations or publications) is limited to the researchers. However, as a participant in this study, you retain personal use of these items, which means you may print or otherwise share these items with family members or friends. You may not share these items in other studies, presentations or publications. This includes social network websites such as Facebook and Twitter.

Storage of Data: All information collected for this study, including audio-recordings and transcripts of interviews, photographs, and contact information, will only be available to the researcher and the research associates working on the study. The data will be stored in a locked filing cabinet and all records, including interview sound files, will be kept on password protected computers in a locked and secured area at the research office, for a minimum of five years after the study is completed. After five years, if the data is chosen to be destroyed, it will be destroyed beyond recovery.

Dissemination of Findings: The findings of this research study will appear in reports to support groups, conference presentations or academic journal articles, as well as the video. We are also committed to ensuring participants are involved throughout the research process, will have a say in how your stories are presented, and will receive the benefits and products of your participation (e.g., video screenings and discussions within their communities).

If you have any questions concerning the study, please feel free to ask at any point; please do not hesitate to contact the researchers with any questions about the research or findings. You can contact:

Dr. Roanne Thomas, School of Rehabilitation Sciences, University of Ottawa, telephone: (613) 562-5800 ext. 8645, e-mail: Roanne.Thomas@uottawa.ca.

Dr. Wendy Gifford, School of Nursing, University of Ottawa, telephone: (613) 562-5800 ext.8975, email: wgifford@uottawa.ca

Questions

You are free to ask any questions that you may have about your rights as a research participant. If any questions come up during or after the study, please feel free to contact the principal investigator at your convenience.

Do not sign this consent form unless you feel that all your questions have been answered.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss this research study. I have had my questions answered in language I understand. I understand the risks and benefits of the study. I believe that I have not been unduly influenced by any study team member to participate in the research study or by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. ***I will participate in this research study.***

I understand that information regarding my identity will be kept confidential, but that complete confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by the University of Ottawa Research Ethics Board, for quality assurance purposes. This study has been approved by the Research Ethics Board.

I, _____, agree to participate in the above described research study conducted by Drs. Roanne Thomas and Wendy Gifford.

There are two copies of the consent form, one of which is mine to keep

_____ (Participant's Name) _____ (Date)
_____ (Signature of Participant)

_____ (Researcher's Name) _____ (Date)
_____ (Signature of Researcher)

Verbal Consent Obtained: _____ (Date)

DATA RELEASE FORM

The researchers realize that some participants would like to be identified with their stories and/or photos. This consent form lets you choose to be identified or to remain anonymous because some participants may prefer to be credited for the contributions made to this project. Through this form you may choose whether your name will OR will not appear in any reports, conference presentations, publications, videos and/or websites about this study. We are also asking about your choice for identification in photos. You can choose to be anonymous, to have only your name used, or to have both your name and your identity revealed in the photos.

I have been offered the opportunity to reveal my identity or de-identify myself in the study: A National Picture: First Nations, Inuit and Métis Women's Experiences of Cancer Survivorship.

I have chosen to _____ reveal my identity in all my data to be used. My data may consist of:

- the photographs I have taken for this study.
- the photographs taken of me during the focus groups.
- quotes from my interview.
- audiofiles/clips from my interview and focus group participation.
- my journal produced during the study.

_____ only reveal my identity in the following data to be used:

(please check)

- the photographs I have taken for this study.
- the photographs taken of me during the focus groups.
- quotes from my interview.
- audiofiles/clips from my interview and focus group participation.
- my journal produced during the study.

_____ remain anonymous using a pseudonym

I HAVE RECEIVED A COPY OF THIS FORM FOR MY RECORDS.

_____ (Participant's Name) _____ (Date)

_____ (Signature of Participant)

_____ (Researcher' Name) _____ (Date)

_____ (Signature of Researcher)

Appendix C
Demographic Form

Name: _____

Date of Birth: ____/____/____
Year Month Day

1. **Do you live in a community with more than 10,000 people?**
 1. Yes, More than 10,000 - Urban
 2. No, less than 10,000 - Rural

2. **Are there any children** (e.g., immediate family, grandchildren, nieces) **living with you at your home?**
 0. Does not apply
 1. No
 2. Yes How many? _____ Ages? _____

3. **Are you working for pay?**
 1. No
 2. On paid sick leave
 3. Part-time
 4. Full-time
 5. Retired (year) _____

4. **What is your occupation?** 0. Does not apply
(List) _____

5. **What is your highest level of education?**
 1. Finished primary or elementary school
 2. Finished junior high school or middle school
 3. Finished high school
 4. Finished community college
 5. Finished undergraduate degree at university
 6. Finished a graduate degree at university

6. **Current Marital Status**
 1. Single
 2. Married
 3. Divorced
 4. Separated
 5. Widowed
 6. Common law relationship

7. **What do you estimate your current annual family income to be?**
 1. Less than \$20,000
 2. Between \$20,001 and \$30,000
 3. Between \$30,001 and \$40,000
 4. Between \$40,001 and \$50,000
 5. Between \$50,001 and \$60,000
 6. Between \$60,001 and \$70,000
 7. Between \$70,001 and \$80,000
 8. \$80,001 or over
 9. Do not wish to answer

8. **When was your cancer diagnosed (year)?** _____

- 9. Are you in active treatment?**
1. No
 2. Yes
- 10. Did you receive surgery for cancer treatment?**
1. No
 2. Yes
 3. Do not wish to answer
- 11. Did you receive chemotherapy?**
1. No
 2. Yes
 3. Do not know
 4. Do not wish to answer
- 12. Did you receive hormonal therapy?** (e.g., Tamoxifen, letrozole (Femara), anastrozole (Arimidex), and exemestane (Aromasin))
1. No
 2. Yes years? (e.g., from 2005 to 2010) _____
 3. Do not know
 4. Do not wish to answer
- 13. Have you used any traditional or complementary approaches to healing?** (e.g., traditional medicines, yoga, massage)
1. No
 2. Yes please list/describe them, IF this is culturally permissible

 3. Do not know
 4. Do not wish to answer
- 14. What other types of support did you receive that helped you with your healing from cancer?**
1. Talking with an elder
 2. Support group
 3. Mental health professional (e.g., social worker, psychologist)
 4. Healing ceremonies (e.g., sweat lodge)
 5. Do not know
 6. Do not wish to answer
- Additional Notes:

- 15. Besides cancer, do you have any other health concerns or illnesses** (circle all that apply)?
1. None
 2. Asthma
 3. Diabetes
 4. Heart disease
 5. High blood pressure
 6. Tuberculosis
 7. Do not know
 8. Do not wish to answer

Appendix D
Honorarium Receipt

I, _____, hereby confirm that I have participated in the study entitled “*A National Picture: First Nations, Inuit and Métis Women’s Experiences of Cancer Survivorship*” that is being conducted by Drs. Roanne Thomas and Wendy Gifford. As an expression of appreciation for my participation, the research team has provided me with an honorarium of \$25.00 for this phase of the research, as stipulated in the consent agreement of this study.

As of _____ (date), I have completed Phase 1 of 3
As of _____ (date), I have completed Phase 2 of 3
As of _____ (date), I have completed Phase 3 of 3

Researcher’s signature: _____ Date: _____

Participant’s signature: _____ Date: _____

Participant mailing address:

Appendix E

Third Party Release Form

Researchers: (author details removed for review).

Information about the study: We are doing a research study to document the experiences and needs of First Nation, Inuit and Métis women whom have cancer experiences. We are hoping to learn about how aspects of their lives are affected by illness and the impact it has on their activities of daily living. It is hoped that this research study will help health professionals and others to better understand the experiences of First Nation, Inuit and Métis women who have cancer experiences.

Participants are taking pictures to capture their responses to these questions. This form asks your permission to use the photograph(s) that you appear in as part of this study.

Information about dissemination of research findings: The findings will be used in conference presentations, publications, study reports, videos, and/or websites about this study. Data will be included only after participants have given consent for its use.

I, _____, have reviewed the photograph(s) that I am in as part of the study entitled: **A National Picture: First Nations, Inuit & Métis Women's Experiences of Cancer Survivorship**

_____ I would like **photographs of myself to be used** in the study and in publications and presentations.

_____ I would like **my face to be de-identified** in the pictures that I am in for the study and in publications and presentations.

I hereby authorize the release of the photographs that I appear in to be used in the manner indicated above. I have received a copy of this Photograph Release Form for my own records

_____ (Name of Person in Photo)	_____ (Date)
_____ (Signature of Person in Photo)	
_____ (Signature of Participant)	_____ (Date)