Date: Wednesday, July 03, 2013 9:04:38 AM

UBC BC Cancer Agency Research Ethics Board
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Vancouver, BC V5Z 1H5
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RISe: http://rise.ubc.ca

H07-01532 **Cancer support group study (Version 4.0)**

Principal Investigator: Kirsten Bell

1. Principal Investigator & Study Team - Human Ethics Application [View Form]

1.1. Principal Investigator Please select the Principal Investigator (PI) for the study. Once you hit Select, you can enter the PI's name, or enter the first few letters of his or her name and hit Go. You can sort the returned list alphabetically by First name, Last name, or Organization by clicking the appropriate heading.

Last Name	First Name	Employer.Name	Email
Bell	Kirsten	Anthropology	kibell@interchange.ubc.ca

Enter Principal Investigator Primary Department and also the primary location of the PI's Institution:

1.2. Primary Contact Provide the name of ONE primary contact person in addition to the PI who will receive ALL correspondence, certificates of approval and notifications from the REB for this study. This primary contact will have online access to read, amend, and track the application.

Last Name	First Name	Rank
Bell	Kirsten	Research Associate

1.3. Co-Investigators List all the Co-Investigators of the study. These members WILL have online access which will allow them to read, amend and track the application. These members will be listed on the certificate of approval (except BC Cancer Agency Research Ethics Board certificates). If this research application is for a graduate degree, enter the graduate student's name in this section.

Last Name	First Name	Institution/Department	Rank

1.4. Additional Study Team Members - Online Access List the additional study team members who WILL have online access to read, amend, and track the application but WILL NOT be listed on the certificate of approval.

Last Name	First Name	Institution/Department	Rank
[redacted]	[redacted]	[redacted]	[redacted]
[redacted]	[redacted]	[redacted]	[redacted]
[redacted]	[redacted]	[redacted]	[redacted]
[redacted]	[redacted]	[redacted]	[redacted]

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1.5. Additional Study Team Members - No Online Access Click Add to list study team members who WILL NOT have online access to the application and will NOT be listed on the certificate of approval.	Last Name / First Name / Institution / Department / Rank / Job Title / Email Address
Tri Council Policy Statement2 (TCPS2) Tutorial All undergraduate and graduate students and medical residents are required to complete the TCPS2 Tutorial (CORE) before submission. This tutorial provides an essential orientation to Canadian human research ethics guidelines. The Principal Investigator and all Co-Investigators must be familiar with the TCPS2. Indicate completion of the TCPS2 (CORE) tutorial below: 1.6.A. All Undergraduate/Graduate Students:	N/A (no undergraduate/graduate students participating in this study)
1.6.B. All Medical Residents:	N/A (no medical residents participating in this study)
Comments:	
1.7. Project Title Enter the title of this research study as it will appear on the certificate. If applicable, include the protocol number in brackets at the end of the title. If this is a class-based project, see guidance on the right.	Culturally Situating Cancer Experiences: a Pilot Study of Cancer Support Groups
1.8. Project Nickname Enter a nickname for this study. What would you like this study to be known as to the Principal Investigator and study team?	Cancer support group study
2 Study Dates and Funding Information - Human Ethics Application [View Form]	
You plan to start collecting data immediately after obtaining ethics and any other required approvals (the start date on the ethics certificate will reflect the approval date),	
You plan to start data collection at a later date i.e., 2 months or more after approvals are obtained. Click the calendar icon below to select the dates (Internet Explorer) or enter the dates manually using the format yyyy-mm-dd. Estimated start date:	August 6, 2007
2.1. B. Estimated end date:	July 31, 2008
2.2.A. Types of Funds Please select the applicable box(es) below to indicate the type(s) of funding you are receiving to conduct this research. You must then complete section 2.3 and/or section 2.4 for the name of the source of the funds to be listed on the certificate of approval.	Internal Funds
2.2.B. For Industry Sponsored studies, please provide a sponsor contact.	
2.3. Research Funding Application/Award Associated with the Study that was Submitted to the UBC Office of Research Services Please click Add to identify the research funding application/award associated with this study. Selecting Add will list the sources of all research funding applications that have been submitted by	

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the PI (and the person completing this application if different from the PI). If the research funding application/award associated with this study is not listed below, please enter those details in question 2.4.	
2.4. Research Funding Application/Award Associated with the Study not listed in question 2.3. Please click Add to enter the details for the research funding application/award associated with this study that is not listed in question 2.3. When you press Add you can do a search for your funding award by doing a search in the Sponsor box - over 7000 options are listed	UBC Number Title Sponsor British Columbia Cancer Agency
2.5.A. Is this a DHHS grant? (To view a list of DHHS funding agencies click on add in 2.5.B below)	
2.5.B. If yes, please select the appropriate DHHS funding agency from the selection box, and attach the grant to box 9.8. of the application.	
Attach DHHS Grant Application for each sponsor listed above	
2.6. Conflict of Interest Do any of the following statements apply to the Principal Investigator, Co-Investigators and/or their partners/immediate family members? Receive personal benefits in connection with this study over and above the direct cost of conducting this study. For example, being paid by the funder for consulting. (Reminder: receiving a finders fee for each participant enrolled is not allowed). Have a non-financial relationship with the sponsor (such as unpaid consultant, advisor, board member or other non-financial interest). Have direct financial involvement with the sponsor (source of funds) via ownership of stock, stock options, or membership on a Board. Hold patent rights or intellectual property rights linked in any way to this study or its sponsor (source of funds).	no
4. Study Review Type - Human Ethics Application [View Form]	
4.1. UBC Research Ethics Board Indicate which UBC Research Ethics Board you are applying to and the type of study you are applying for:	BC Cancer Agency Research Ethics Board - Behavioural
4.2. Institutions and Sites for Study A. Enter the locations for the institutions and sites where the research will be carried out under this Research Ethics Board approval (including specimens processed by pathology, special radiological procedures, specimens obtained in the operating room, or tissue requested from pathology). Click Add and enter the appropriate letter to see the locations for the institutions and sites where the research will be carried out under this Research Ethics Board approval: B for BC Cancer Agency C for Children's and Women's Health Centre of BC P for Providence Health Care U for UBC Campus V	Institution Site BC Cancer Agency Vancouver BCCA

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for Vancouver Coastal Health (VCHRI/VCHA). If you are NOT using any of these sites select N/A from the list.	
B. Please enter any other locations where the research will be conducted under this Research Ethics Approval (e.g. private physician's office, community centre, school, classroom, subject's home, in the field - provide details).	
4.3. A. If this proposal is closely linked to any other proposal previously/simultaneously submitted, enter the Research Ethics Board number of that proposal.	
B. If applicable, please describe the relationship between this proposal and the previously/simultaneously submitted proposal listed above.	
C. Have you received any information or are you aware of any rejection of this study by any Research Ethics Board? If yes, please provide known details and attach any available relevant documentation in question 9.8.	
4.4. If this research proposal has received any independent scientific/methodological peer review, please include the names of committees or individuals involved in the review. State whether the peer review process is ongoing or completed. A. External peer review details:	
B. Internal (UBC or hospital) peer review details:	[redacted]
C. If this research proposal has NOT received any independent scientific/methodological peer review, explain why no review has taken place.	
4.5. After reviewing the minimal risk criteria on the right, does your application fall under minimal risk (and therefore is eligible to be considered for Delegated Review, executive review or review by an Undergraduate Research Review Committee)?	no
4.6.A. Pandemic Research Does this study involve research concerning H1N1 or any other urgent public health event such that it requires urgent review and approval? [if no, move on to 5, if yes, answer 4.6B]	
4.6.B. Does this pandemic study require review and approval by multiple Canadian Research Boards (i.e. more than those covered under the certificate of approval for this application) [If no, move on to 5, if yes, answer 4.6.C]	

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4.6.C. Are you the Lead Investigator for this pandemic study? (i.e. the pandemic study involves numerous co-investigators from various sites external to UBC and you have been selected as the lead investigator for the entire project) [If YES, move on to 5, if NO move on to 4.7]	
4.7. Pandemic Research Lead PI REB Please review the guidance note on the right and then answer the following question: If the study has NOT been approved by the Lead PI's REB, UBC's REBs will not proceed to review the study independently. They will be participating in the Lead REB approval process and accordingly, your application is premature. Please discontinue this application and submit a new application as soon as the study approval by the Lead PI REB has been obtained. If the study HAS been approved by the Lead PI's REB, UBC's REBs will make every effort to review your study as quickly as possible. In order to ensure that the required documentation is incorporated into the RISe system, you will be directed to respond to Question 9. For more information please see the accompanying guidance note. Has this study been reviewed and approved by the Lead Principal Investigator's REB?	
5. Summary of Study and Recruitment - Human Ethics Application for Clinical Study [View Form]	
5.1. Study Summary 5.1.A Provide a short summary of the project written in lay language suitable for non-scientific REB members. DO NOT exceed 100 words and do not cut and paste directly from the study protocol.	
5.1.B Summarize the research proposal:	1) PURPOSE The purpose of this project is to obtain a better understanding of cancer support groups in terms of: a) what they reveal about the cultural and social factors that mediate people's experiences of cancer and b) what they reveal about the dynamics and functions of support groups themselves. 2) AIM/RESEARCH QUESTIONS • What cultural models of cancer are created and manifested at support groups and how do they cohere with and challenge biomedical views, as well as alternative ethnomedical models? • How are the experiences of people living with cancer (including understandings of treatment, recovery, suffering and death) situated on the basis of factors such as gender, ethnicity, and social class? • What functions do support groups serve for those who take part in them? • What factors are integral to a 'successful' support group? • How can support groups be made more attractive to people of diverse social and cultural backgrounds? 3) JUSTIFICATION

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There is near universal agreement amongst researchers that cancer support groups positively affect the psychosocial adjustment of cancer survivors, although anecdotal reports indicate that only about 5% of newly diagnosed cancer patients attend such groups (Herron 2005). Despite the beneficial role that support groups play for people living with cancer, little research has focused on support groups themselves as objects of study. The few available studies (Oliffe 2005; Mathews 2000; Moore 1997; Coreil, Wilke & Pintado 2004; Cope 1995; Fitch et al. 1996; Ussher et al. 2006; Yaskowich & Stam 2003), which focus primarily on breast cancer and prostate support groups, have provided invaluable insights into the gendered ways in which cancer survivors deal with the psychosocial impact of diagnosis, treatment and their differing support needs, and the perceived functions of support groups in relation to their individual efficacy. However, to date little attention has been paid to "…the cultural assumptions that underlie and give meaning to the information communicated in these groups or to the cultural work that the members often perform as they attempt to arrive at some shared understandings about cancer and its impact on their lives" (Mathews 2000: 394-395).

Through its comparative focus on support groups aimed at diverse audiences (e.g. men, women, the Chinese community, people with advanced cancer) this project will provide important insights into the cultural models of cancer that are created at cancer support groups and the ways in which people's experiences of cancer (including understandings of treatment, recovery, suffering and death) are situated on the basis of factors such as gender, ethnicity, and social class. It will also lead to an enhanced understanding of the functions of support groups as perceived by their participants and will add to our knowledge of the elements that constitute 'successful' support groups. Through this focus, the project will provide a deeper understanding of how support groups might be tailored to more fully support the needs of a diverse and multi-cultural population, and insights into how community outreach may be improved.

4) OBJECTIVES

- To identify the dominant cultural models of cancer that are created and manifested at support groups
- To explore the ways in which the experiences of people living with cancer are situated on the basis of factors such as gender, ethnicity, and social class
- To provide insights into the role that support groups play in the lives of cancer survivors
- To enhance our understanding of the elements that constitute 'successful' support groups and how they are maintained over time
- To develop insights into how support groups might be tailored to support the needs of an increasingly diverse and multi-cultural population
- To develop insights into how support groups might be

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	marketed and made more attractive to people living with cancer from diverse social and cultural backgrounds 5) RESEARCH METHOD The proposed pilot project will entail ethnographic research at four Vancouver-based cancer support groups over a six-month period, including: 1) [redacted] Ethnography is a qualitative research technique that uses a range of data collection methods, including participant observation and key informant interviews, to generate "thick description" of settings and contexts, and entails analytic processes that involve the explicit interpretation of the meanings and functions of human action. Two types of data collection are planned: 1) Unobtrusive participant observation: this established method will be used to collect observational data in the form of field notes at each support group session. Aside from collecting details on participants' narratives, observations will focus on behaviours, activities and segments of dialogue between actors. 2) Key informant interviews: semi-structured, qualitative interviews will be conducted with key informants during the six-month period. These interviews will be tape recorded. It is estimated that between 5-10 key informant interviews will take place in each support group. 6) STATISTICAL ANALYSIS No statistical analysis will occur. All fieldnotes and interviews will be transcribed in full. After transcription, the interviews and fieldntoes will be independently read by three members of the research team in order to ascertain the major emergent themes and to develop a coding frame. Content analysis of fieldnotes and interview transcripts will take place using the qualitative data software program Nvivo.
5.2. Inclusion Criteria Inclusion Criteria. Describe the participants being selected for this study, and list the criteria for their inclusion. For research involving human pluripotent stem cells, provide a detailed description of the stem cells being used in the research.	Inclusion Criteria (Support Groups) - Cancer support groups [redacted] Inclusion Criteria (Individual Interviews) - members of support groups who have received a cancer diagnosis at some point in their lives or who are the family member/caregiver of someone with cancer
5.3. Exclusion Criteria Exclusion Criteria. Describe which potential participants will be excluded from participation, and list the criteria for their exclusion.	Exclusion Criteria (Support Groups) [redacted] Exclusion Criteria (Individual Interviews) - no exclusion criteria for individual interviews within the support groups
5.4. Recruitment Provide a detailed description of	Colorectal Cancer Support Group

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the method of recruitment. For example, describe who will contact prospective participants and by what means this will be done. Ensure that any letters of initial contact or other recruitment materials are attached to this submission on Page 9.	The [redacted] Cancer Support Group is a small, support-oriented group with approximately 10 members held at the [redacted]. Although the number of participants in the group tends to fluctuate slightly from month to month, a regular 'core' group attend each month. [redacted], the facilitator of the [redacted] Cancer Support Group, provided permission for Kirsten Bell to present the project to the members of the group at the monthly meeting on 20 June 2007, to ascertain the group's level of interest in being part of the study. Kirsten Bell provided a short overview of the project (see attached summary of the content of the presentation) and answered questions about the project. Following Kirsten's departure from the meeting, [redacted] ascertained the group's interest in taking part. The group expressed their enthusiastic support for the project at this stage. Although 9 members were present at this meeting, it is recognized that not all members attended. Thus, verbal consent for the study will be renewed at the beginning of each meeting, with [redacted] explaining Kirsten's presence (making it clear that the research is separate from the meeting itself) based on a written summary (attached) and asking whether everyone feels comfortable with her being there. Copies of the research summary will also be distributed to support group attendees. If any member expresses discomfort with the study, Kirsten will leave the meeting and go through the same process the following month. [redacted] Support Group The [redacted] Cancer Support Group is a small support-oriented group with approximately 10 members held at [redacted] each fortnight. Although the number of participants in the group tends to fluctuate from month to month, a regular 'core' group attend each fortnight. [redacted], the facilitator of the [redacted] Cancer Support Group, provided permission for Kirsten Bell to present the project to the members of the group at the monthly meeting on 20 June, to ascertain the group's level of interest in being part of the study. Kirsten Bell provided a short overview of the project (see attached summary of the content of the presentation) and answered questions about the project. Following Kirsten's departure from the meeting, [redacted] ascertained the group's interest in taking part. Although the members present (6 women) were supportive of the project, three of the women who attended were first-time participants and several of the regular members were not at the meeting. Thus, Kirsten will also attend the group meeting on July 18 to repeat her explanation of the project - as this meeting is the last before the summer break it is expected that most of the regular members will show up. She will repeat the process from 20 June to ensure that the support for the project is widespread. Once fieldwork begins, verbal consent for the study will be renewed at the beginning of each meeting, with [redacted] explaining Kirsten's presence (making it clear that the research is separate from the meeting itself) based on a

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	written summary (attached) and asking whether everyone feels comfortable with her being there. Copies of the research summary will also be disseminated to support group attendees. If any member expresses discomfort, Kirsten will leave the meeting and go through the same process the following fortnight. The [redacted] Group The [redacted] Group is open to members of the public and has a large and fluctuating membership (40 plus participants per month). This support group, held on [redacted], takes the form of an information session and support activities are not formally integrated into the meeting format. Researchers are welcome to attend the meetings and the group has been the focus of previous ethnographic research [redacted] and is familiar with this research method. Permission to conduct the research has been provided by [redacted], the chairman of the group, and Kirsten Bell has attended one meeting where her potential research project was discussed and she was introduced to members – who all seemed supportive of the research. Prior to the initiation of the project, Kirsten will conduct a short presentation to present the goals of the project to the members of the group and answer any questions they may have. Following the initiation of her research, her presence at each of the subsequent support meetings will be announced in the 'Information and Announcement' section that kicks off each meeting.
5.5. Recruitment of Normal/Control Participants Describe how prospective normal/control participants will be identified, contacted, and recruited, if the method differs from the above.	N/A
5.6. Use of Records If existing records (e.g. health records, clinical lists or other records/databases) will be used to IDENTIFY potential participants, please describe how permission to access this information, and to collect and use this information will be obtained.	
5.7. Summary of Procedures	This project entails an ethnographic research design and will utilise two principal research methods: participant observation and interviews. Ethnographic research has been conducted at a number of cancer support groups and the procedures used in this study follow established procedures for this setting - a study using a similar research method by Ussher et al. (2006) is attached. Participant Observation The researcher (Kirsten Bell) will attend each support group meeting held over a 6-9 month period. The researcher/s will interact with members of the group before, during and after each regular meeting, where they will observe interactions and take part in any activities. In the large support group meetings ([redacted]) she

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	will take detailed notes during the meeting; in the smaller support group meetings findings will be recorded in detailed fieldnotes immediately after each meeting. Observations will focus on group activities, member interactions, reaction to guest speakers (especially questions asked of guest speakers) along with general observations of the meeting room, set up and number of attendees. Fieldnotes will be typed up, identifying markers removed, and disseminated to the full research team. As the data collection progresses, the research team will meet to discuss interpretations and to develop coding schemes and emergent themes. The fieldnote data will be analysed using the qualitative software program Nvivo. Interviews Those support group members who express an interest in being interviewed later in the course of fieldwork will have the opportunity to take part in a qualitative, semi-structured interview. Sample consent forms will be circulated early in the fieldwork process so that participants develop an understanding of what they are 'signing up for'. Once a participant approaches the researcher expressing an interest in being interviewed, an interview time and place will be determined and a consent form will be provided. Kirsten will run through the consent form with the participant and emphasise that if they change their mind about being interviewed over the course of the next week, the interview can be cancelled. The interview will be held in a location specified as convenient for the participant and with the participant's consent it will be tape recorded. (If the interviewee expresses discomfort with the interview being tape recorded, detailed notes alone will be taken). Depending on how much the interviewee has to say, the interview could last anywhere from 30 minutes to two hours. Following the completion of the interview, the recording will be given to a professional transcriber and will be transcribed. A copy of the transcription will be given to each interviewee, who will be able to clarify or modify the transcript to ensure that it accurately represents their views and opinions. As ethnographic research is a hermeneutic process and the interview questions will be determined as a result of the themes that emerge in the fieldwork process, it is impossible to provide a definitive interview guide at this point. However, a sample list of likely interview questions is attached.
6. Participant Information and Consent Process - Human Ethics Application for Clinical Study [View Form]	
6.1. Time to Participate How much time will a participant be asked to dedicate to the project beyond that needed for normal care?	No research participant will be required to dedicate any time to the project as the research will be carried out at support groups that participants are already attending. However, if participants are interested in being

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	interviewed, this would take between 30 minutes-2 hours of their time, depending on how much they have to say and how long they wish to talk.
6.2. Time to Participate – Normal/Control Participants If applicable, how much time will a normal/control volunteer be asked to dedicate to the project?	N/A
6.3. Risks/Harms Describe what is known about the risks (harms) of the proposed research.	Although the individual interviews will deal with issues that are readily discussed in the context of the support group meetings, they may touch upon topics that hold strong emotional significance for the interviewee. If participants become distressed during the interview, the process will be stopped until they feel ready to continue. Alternatively, if the participant prefers, the interview can be rescheduled for another day. Participants will also be provided with the details of patient and family counseling services in the event that they require further counseling and support. If participants become tired during the course of the interview, the interview will be stopped and rescheduled at their convenience. As the research is explicitly concerned with the cultural and social factors that mediate peoples' experiences with cancer, their birthplace, ethnicity, gender and social class are of direct relevance to this project. However, the goal of this research is to understand the complex ways in which people experience cancer and to move beyond taken-for-granted stereotypes and assumptions.
6.4. Benefits Describe any potential benefits to the participant that could arise from his or her participation in the proposed research.	It is hoped that participants will indirectly benefit from this study - although benefits cannot be assured. As this study will lead to a better understanding of people's experiences with cancer it is expected that its results will feed into the creation of better support services for cancer patients (which may include the participants themselves). Moreover, as the majority of research conducted to date on people's experiences with cancer has focused on women with breast cancer, the members of the support groups visited to date have emphasised that they believe the research will increase the profile of other forms of cancer (e.g. [redacted] cancer).
6.5. Reimbursement Describe any reimbursement for expenses (e.g. meals, parking, medications) or payments/incentives/gifts-in-kind (e.g. honoraria, gifts, prizes, credits) to be offered to the participants. Provide full details of the amounts, payment schedules, and value of gifts-in-kind.	Any participant who is interested in being interviewed will be provided with a $20 honorarium in recognition of the time they have taken out of their normal schedule to support the research project. The $20 honorarium will take the form of a gift card (appropriate gift cards will be determined in consultation with the support group leaders).
6.6. Obtaining Consent Specify who will explain the consent form and consent participants. Include details of where the consent will be obtained and under what circumstances.	From the outset of the project Kirsten will informally let the support group members know (i.e. in casual conversation before and after the meetings) that they will have the opportunity to take part in an individual interview. It is therefore expected that members who are interested in this prospect will approach the researcher during the course of the project. This approach, grounded in a context of longer term interaction between the researcher and participants, will also serve the purpose of

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	reducing participants' anxiety about being interviewed. Those participants who express an interest in being interviewed will be provided with a consent form by the researcher, who will also verbally explain the interview content and process. The consent form will be collected at the beginning of the interview by the researcher. The interview itself will take place in a location that is convenient for the interviewee (e.g. coffee shop, premises of [redacted] Agency, researcher's office or home of cancer patient).
6.7.A. Waiver/Alteration of Consent If you are asking for a waiver or an alteration of the requirement for participant informed consent, please justify the waiver or alteration and explain how the study meets all the criteria on the right. Please address each criterion on the right individually.	
6.7.B. Waiver of Consent in Individual Medical Emergencies If you are asking for a waiver or an alteration of the requirement for participant informed consent in individual medical emergencies, please justify the waiver or alteration and explain how the study meets all the criteria on the right. Please address each criterion on the right individually.	
6.8. Time to Consent How long after being provided with detailed information/consent form about the study will the participant have to decide whether or not to participate? Provide your rationale for the amount of time given.	As the interview will be scheduled at least one week following the participants' expression of interest in being interviewed and the provision of the consent form, they will have at least seven days to decide whether to participate in the interview.
6.9. Capacity to Consent Will every participant have the capacity to give fully informed consent on his/her own behalf? Please click Select to complete the question and view further details.	Will the participant have the capacity to give fully informed consent? / Details of the nature of the incapacity / If not, who will consent on his/her behalf? / If not, will he/she be able to give assent to participate? / If Yes, explain how assent will be sought. Yes [Details]
6.10. Renewal of Consent Describe any situation in which the renewal of consent for this research might be appropriate, and how this would take place.	If the interview is not completed or if the interviewee discloses further personal information following the completion of the interview (at subsequent support group meetings for example), renewal of consent may be appropriate. This renewal of consent will take place verbally (and will be recorded in the researcher's notebook) and the researcher will inquire whether the information being provided is can be used as research data or not.
6.11. Provisions for Consent What provisions are planned for participants, or those consenting on a participant's behalf, to have special assistance, if needed, during the consent process (e.g. consent forms in Braille, or in languages other than English).	All interviewees will be proficient in English.

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6.12. Restrictions on Disclosure Describe any restrictions regarding the disclosure of information to research participants (during or at the end of the study) that the sponsor has placed on investigators, including those related to the publication of results. Also, indicate any plans for communicating study results to participants.	No restrictions have been placed on the disclosure of information to research participants.
7. Number of Participants - Human Ethics Application for Behavioural Study [View Form]	
7.1. External Approvals External approvals for research involving other institutions and other jurisdictions: Provide written proof of agency approval for projects carried out at other institutions and, when applicable, other jurisdictions. Indicate external approvals below: A. Other Institutions:	no
B. Please select Add to enter the name of the institution and if you have already received approval attach the approval letter.	Name of Institution
C. Other Jurisdiction or Country (if answer is No go to 7.1.G):	no
D. Please select Add to enter the name of the jurisdiction or country and if you have already received approval attach the approval letter.	Name of Jurisdiction or Country
E. Has a Request for Ethics Approval been submitted to the institution or responsible authority in the other jurisdiction or country? (Send a copy to the Research Ethics Office when approval is obtained).	
F. If a Request for Approval has not been submitted, provide the reasons below:	
G. Does this research focus on aboriginal peoples, communities or organizations?	
If Yes, ensure that you are familiar with the guidance documents linked on the right. Also attach a copy of the research agreement with the community (if available) in question 9.7. Please describe the community consent process. If no community consent is being sought, please justify.	
H. Registration for Publication of Clinical Trials. Does this study fall within the clinical/intervention trial definition stated on the right (in the guidelines)?	
If 'Yes', click 'Add' to enter the following information. (Please note that registration by UBC ORS administration requires the prior ethical approval of the study. In that case, registration information should be added when it becomes available).	
7.2. Number of Participants A. How many participants will take part in the entire study (i.e., the entire study, world-wide)?	Support groups contain approximately 95 members. Approximately 20-30 people will be interviewed.
B. How many participants will take part at	

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institutions covered by this Research Ethics Approval (i.e., only at the institutions covered by this approval)?	
7.3. Researcher Qualifications Who will actually conduct the study and what are their qualifications to conduct this kind of research? (e.g., describe relevant training, experience, degrees, and/or courses).	Dr Kirsten Bell will conduct the fieldwork at the support groups [redacted]. Dr Bell is an experienced ethnographic researcher. Aside from her own fieldwork experience (15 months in South Korea, 1 month in Australia, 2 months in the USA), she has also taught numerous courses at both the undergraduate and graduate levels in anthropological research methods (including Ethnographic Field Studies, Field Methods in Cultural Anthropology, and Methodology in Local and Community Studies). She will provide the research assistant with training in ethnographic fieldwork. The research assistant employed to conduct the fieldwork in the Chinese cancer support group will also have previous training in interviewing and will have well developed interview skills.
8. Confidentiality - Human Ethics Application for Behavioural Study [View Form]	
8.1. Security of Data During the Course of the Study How will data be stored? (E.g., computerized files, hard copy, videotape, audio recordings, personal electronic communications device, other.) How will security of the data be maintained? (For example, study documents must be kept in a secure locked location and computer files should be password protected and encrypted, data should not be stored or downloaded onto an unsecured computer, back up files should be stored appropriately.) If any data or images are to be kept on the Web, what precautions have been taken to prevent them being copied?	Hard copies of the data (including minidisks containing interviews) will be kept in a locked filing cabinet in Kirsten Bell's office and electronic copies of the raw data will be kept in a password protected computer hard drive.
8.2. Access to Data Who will have access to the data (e.g., co-investigators, students or translators)? How will all of those who have access to the data be made aware of their responsibilities concerning privacy and confidentiality issues?	Kirsten Bell only.
8.3. Protection of Personal Information Describe how the identity of research participants will be protected both during and after the research study, including how participants will be identified on data collection forms.	
8.4. Transfer of Data Will any data that identify individuals be transferred (available) to persons or agencies outside of the University?	no
If YES, describe in detail what identifiable information is released, to whom, how the data will be transferred, how and where it will be stored and what safeguards will be used to protect the identity of participants and the privacy of their data. Attach the data transfer agreement if applicable.	
8.5. Retention and Destruction of Data UBC	The data will be stored for at least a 5-year period by

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policy requires that data be kept for at least 5 years within a UBC facility. If you intend to destroy the data at the end of the storage period describe how this will be done to ensure confidentiality (e.g., tapes should be demagnetized, paper copies shredded). UBC has no explicit requirement for shredding of data at the end of this period and it may be kept indefinitely. Please note that the responsibility for the security of the data rests with the Principal Investigator.	Kirsten Bell in a password-protected computer and a lockable filing cabinet.
8.6. Future Use of Data Are there any plans for future use of either data or audio/video recordings? Provide details, including who will have access and for what purposes, below.	As this is an ethnographic study, Kirsten cannot be expected to know all the uses she plans to make of the data, which will depend on the outcomes of the study. However, possible future uses of the data will be outlined in the consent form.
8.7. Feedback to Participants Are there any plans for feedback on the findings or results of the research to the participant? Provide details below.	Upon the completion of the study, Kirsten will present the research findings to each of the four support groups. At this meeting feedback will be sought on how well the findings reflect the participants' experiences and whether anything is missing from the findings. Kirsten will also facilitate feedback from the research participants on how to best disseminate the research findings and the most appropriate mediums and contexts in which to a) enhance awareness of the experiences and challenges of living with cancer and b) to improve the attractiveness of support groups for people living with cancer.
9. Documentation - Human Ethics Application for Behavioural Study [View Form]	
9.1. Research Proposal Examples of types of proposals are listed on the right. Click Add to enter the required information and attach the documents.	Name / Version / Date Research Proposal / / May 14, 2007 [View]
9.2. Documentation of Consent Examples of types of consent documents are listed on the right. Click Add to enter the required information and attach the documents.	Name / Version / Date Clean revised consent form / V2 / July 31, 2007 [View] Clean Consent Form / V3 / November 27, 2007 [View]
9.3. Documentation of Assent Examples of types of assent documents are listed on the right. Click Add to enter the required information and attach the documents.	Name / Version / Date
9.4. Advertisement to Recruit Participants Examples are listed on the right. Click Add to enter the required information and attach the documents.	Name / Version / Date Introductions at Cancer Support Groups / / July 3, 2007 [View]
9.5. Questionnaire, Questionnaire Consent Cover Letter, Tests, Interview Scripts, etc. Please click Add to enter the required information and attach the documents.	Name / Version / Date Sample Interview Questions / / June 29, 2007 [View]
9.6. Letter of Initial Contact Please click Add to enter the required information and attach the	Name / Version / Date

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forms.	
9.7. Other Documents A. Other documents: Examples of other types of documents are listed on the right. Click Add to enter the required information and attach the documents.	Name / Version Date Sample study using ethnographic methods — January 1, 2006 [View] Research Summary Blurb — June 29, 2007 [View]
B. If a Web site is part of this study, enter the URL below. Since URL's may change over time or become non-existent, you must also attach a copy of the documentation contained on the web site to one of the sections above or provide an explanation.	
10. Fee for Service - Human Ethics Application for BC Cancer [View Form]	
A. Please select one of the following:	Fee N/A as per above criteria
B. Explanation of fee waiver due to circumstances other than those listed above.	
C. Internal transfer of funds. Funds can only be transferred from another BCCA account. Please hit Select to complete the information.	
11. BC Cancer Agency Centre PI [View Form]	
A. Lead PI for Vancouver Centre:	Last Name / First Name / Rank Bell / Kirsten / Research Associate
B. Lead PI for Vancouver Island Centre:	
C. Lead PI for Fraser Valley Centre:	
D. Lead PI for the Centre for Southern Interior:	
E. Lead PI for the Centre for Abbotsford Centre:	
F. Lead PI for the Centre for the North:	
11.2. If this application requries a Clinical Trial Agreement, what is the status of the Agreement?	N/A
12. Save Application - Human Ethics Application [View Form]	

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Introduction at [redacted] Cancer Support Group Meeting (20 June 2007)

Hi, I'm an anthropologist at Sociobehavioural Research Centre in BC Cancer Agency. I'm interested in conducting study of cancer support groups – goal to learn more about experiences of people living with cancer and also more about support groups themselves – why they are so beneficial. I'm particularly interested in [redacted] support group because we know very little about experiences of people with this form of cancer. Most research on breast cancer and prostate cancer, but your experiences are probably very different.

The research method used by anthropologists is called "participant observation" – I learn more about experiences by observing and participating in support group. Basically would entail me coming along to your support group over 6-9 month period and learning more about your experiences through this context. The key benefit of this approach is learning about your experiences in natural setting, rather than an artificial research setting. I would get to know you far better than just through one off interview. Later in the 6 month period, if you were interested in interview we could arrange that. Study would be used to raise awareness of health professionals and public about experience of [redacted] and hopefully will lead to better understanding of support groups – how they can be made more attractive to people with cancer. Thus, at the end of the study I would present the research findings to the support group and get your feedback on these findings – whether I have missed anything, whether the findings fit with your experience. I would also use this opportunity to get your feedback on how these findings should be disseminated.

Introduction at [redacted] Cancer Group Meeting (20 June 2007)

Hi, I'm an anthropologist at the Sociobehavioural Research Centre in BC Cancer Agency. I'm in process of setting up study of cancer support groups – to learn more about experiences of people living with cancer and also more about support groups themselves – why they are so beneficial. The research method used by anthropologists called "participant observation" – we learn more about people's experiences by observing and participating in their communities for extended period of time. In the context of support group study would entail me coming along to support groups over 6-9 month period and learning more about experiences of people living with cancer through this context. The key benefit of this approach is that learn about people's experiences in natural setting rather than artificial research setting. You get a far deeper understanding of people's experiences than just through one off interview – although interviews are often part of process later on – if people interested in that possibility.

I am interested in the [redacted] cancer support group – to learn more about your experiences and what it is like to live with [redacted] cancer – the issues you face quite different from someone with stage 1 breast cancer for example. To date most studies of support groups with breast cancer and prostate cancer support groups. But we know very little about collective experiences of people living with [redacted] cancer. I think the research would be valuable in helping to increase understanding of [redacted] cancer amongst both health professionals and public. Hopefully it will also lead to better understanding of support groups – how they can be made more attractive to people with cancer. However, although there are good reasons for conducting this research, there are also good reasons for not conducting it. I recognize that for some of you, idea of researcher coming to group may seem intrusion on space. Thus, the research would only go ahead if this was something you were interested

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in. Thus, at the end of the study I would present the research findings to the support group and get your feedback on these findings – whether I have missed anything, whether the findings fit with your experience. I would also use this opportunity to get your feedback on how these findings should be disseminated.

Introduction at [redacted] Cancer Support [redacted] Meeting (3 May 2007)

Introduction by [redacted]

We have Kirsten Bell here today, who is a researcher at the Sociobehavioural Research Centre at the BC Cancer Agency. Kirsten is interested in conducting research at cancer support groups and would like to come along to observe the [redacted] Cancer support groups over the next couple of months. Prior to starting the research she has indicated that should would like to do a presentation on the specific goals of her study and give you the opportunity to ask questions about the project.

Cancer Support Group Study

Principal Investigator: Kirsten Bell, Sociobehavioural Research Centre, BC Cancer Agency

Ph: (604) 877 6000 ext. 2160

Email: kbell@bccancer.bc.ca

Kirsten Bell is conducting an ethnographic study of three cancer support groups affiliated with [redacted]. Ethnographic research is a qualitative research technique that focuses on gaining an insider's perspective on people's experience through prolonged engagement with a particular setting, which the researcher *participates in* and *observes* over an extended period of time (6-9 months). Aside from attending the support group meetings, Kirsten is also interested in interviewing you about your experiences. The primary goal of this comparative study is to learn more about the experiences of people living with cancer and how their experiences vary based on factors such as gender, cultural background, cancer site and stage. A second key goal of this study is to learn more about the dynamics of support groups and what makes them 'successful' in helping people living with cancer.

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Consent Form
Culturally Situating Cancer Experiences:
A Pilot Study of Cancer Support Groups

Principal Investigator: Dr Kirsten Bell, Sociobehavioural Research Centre, BC Cancer Agency. Ph: (604) 877 6000 ext. 2160.

Purpose:
The goal of this project is to gain a better understanding of cancer support groups in terms of: a) what they reveal about the cultural and social factors (e.g. gender, cultural background, cancer site, cancer stage, etc) that impact people's experiences of cancer and b) what they reveal about the functions of cancer support groups.

Project Funding:
This project has been funded by "Palliative Care in a Cross-Cultural Context: A New and Emerging Team (NET) for equitable and quality cancer care for culturally diverse populations", a CIHR-funded five year grant. NET researchers are from the University of BC in Vancouver, the University of Saskatchewan in Saskatoon, Dalhousie University in Nova Scotia, Cancer Care Nova Scotia, and the BC Cancer Agency.

Study Procedures:
You are invited to take part in a single interview of between 30 minutes and 2 hours. The length of the interview will depend entirely on how much you would like to say. The interview will cover topics including your cancer diagnosis, your experience of living with cancer, and why you attend the support group. With your permission, the interview will be audio-taped to accurately record your views and opinions. Written notes will also be taken during the interview in the event that there are problems with the recording. If you would prefer the interview not to be audio-taped, written notes alone will be taken. Hard copies of the interview notes and transcript will be stored in a locked filing cabinet in the office of the Principal Investigator and electronic copies will be stored on a password-protected computer.

Project Outcomes:
The research findings will be represented in a variety of formats to be determined in conjunction with the support group participants. Possible research products include: journal articles, a book, newspaper articles, magazine articles, brochures for people newly diagnosed with cancer, plain language summaries for health care providers.

Potential Risks:
The interview will largely deal with topics you will have discussed in the context of the support group. However, as you will be asked about your experience of living with cancer, you may find that the interview raises issues or feelings that you would like support in dealing with. If you would like counseling or support following the interview, please contact Patient and Family Counseling Services at the BC Cancer Agency on (604) 877 6000 ext. 2194 or 1800 663 3333 ext. 2194.

Potential Benefits:
Although there are no direct benefits to you by taking part in this study, it is hoped your participation will entail some indirect benefits. The interview will provide you with the

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opportunity to voice your opinion on your experiences, and will hopefully raise awareness of the issues that people with cancer face, as well as lead to the improvement of support programs and services.

You will be provided with a copy of the interview transcript, and you will have the opportunity to check the accuracy of this transcript and make modifications to ensure that it accurately represents your views. The results of the full study will also be presented at a support group meeting and you will be able to provide input into these findings and suggestions as to how the results should be disseminated.

Confidentiality:
Your identity will be kept strictly confidential and only the Principal Investigator will have access to this information. All interview transcripts will be identified only by code number and kept in a locked filing cabinet; electronic copies will also be stored on a password-protected computer. Participants will not be identified by name in any reports of the completed study.

Your rights to privacy are legally protected and guaranteed by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor or the UBC BCCA Research Ethics Board.

Remuneration/Compensation:
In order to acknowledge the time you have taken out of your normal schedule to support the project, you *will receive an honorarium* in the form of a $20 gift card.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact Kirsten Bell at (604) 877 6000 ext. 2160 or email: kbell@bccancer.bc.ca.

Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your continued participation in the support group.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

_____	_____
Interviewee Signature	Date
_____	_____
Witness Signature	Date

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