



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road
Vancouver, BC V6T 1Z3

H12-00967 Molecular screening technologies (Version 1.0)**Principal Investigator: Kirsten Bell****1. Principal Investigator & Study Team - Human Ethics Application [\[View Form\]](#)**

<p>1.1. <i>Principal Investigator</i> 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.</p>	<table border="1"> <thead> <tr> <th>Last Name</th> <th>First Name</th> <th>Employer.Name</th> <th>Email</th> </tr> </thead> <tbody> <tr> <td>Bell</td> <td>Kirsten</td> <td>Anthropology</td> <td>kibell@interchange.ubc.ca</td> </tr> </tbody> </table>	Last Name	First Name	Employer.Name	Email	Bell	Kirsten	Anthropology	kibell@interchange.ubc.ca
Last Name	First Name	Employer.Name	Email						
Bell	Kirsten	Anthropology	kibell@interchange.ubc.ca						
<p>Enter Principal Investigator Primary Department and also the primary location of the PI's Institution:</p>	<p>Anthropology</p>								
<p>1.2. <i>Primary Contact</i> 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.</p>	<table border="1"> <thead> <tr> <th>Last Name</th> <th>First Name</th> <th>Rank</th> </tr> </thead> <tbody> <tr> <td>Bell</td> <td>Kirsten</td> <td>Research Associate</td> </tr> </tbody> </table>	Last Name	First Name	Rank	Bell	Kirsten	Research Associate		
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Bell	Kirsten	Research Associate							
<p>1.3. <i>Co-Investigators</i> 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.</p>	<table border="1"> <thead> <tr> <th>Last Name</th> <th>First Name</th> <th>Institution/Department</th> <th>Rank</th> </tr> </thead> <tbody> </tbody> </table>	Last Name	First Name	Institution/Department	Rank				
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<p>1.4. <i>Additional Study Team Members - Online Access</i> 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.</p>	<table border="1"> <thead> <tr> <th>Last Name</th> <th>First Name</th> <th>Institution/Department</th> <th>Rank</th> </tr> </thead> <tbody> </tbody> </table>	Last Name	First Name	Institution/Department	Rank				
Last Name	First Name	Institution/Department	Rank						
<p>1.5. <i>Additional Study Team Members - No Online Access</i> 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.</p>	<table border="1"> <thead> <tr> <th>Last Name</th> <th>First Name</th> <th>Institution / Department</th> <th>Rank / Job Title</th> <th>Email Address</th> </tr> </thead> <tbody> </tbody> </table>	Last Name	First Name	Institution / Department	Rank / Job Title	Email Address			
Last Name	First Name	Institution / Department	Rank / Job Title	Email Address					
<p>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</p>	<p>N/A (no undergraduate/graduate students participating in this study)</p>								

Undergraduate/Graduate Students:							
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.	Molecular screening technologies and the transformation of cancer survivorship						
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?	Molecular screening technologies						
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:	May 14, 2012						
2.1. B. Estimated end date:	June 29, 2012						
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.	No Funding						
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 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.	<table border="1"> <thead> <tr> <th>UBC Number</th> <th>Title</th> <th>Sponsor</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	UBC Number	Title	Sponsor			
UBC Number	Title	Sponsor					
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	<table border="1"> <thead> <tr> <th>UBC Number</th> <th>Title</th> <th>Sponsor</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	UBC Number	Title	Sponsor			
UBC Number	Title	Sponsor					
2.5.A. Is this a DHHS grant? (To view a list of DHHS funding agencies click on add in 2.5.B)	no						

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.	DHHS Sponsor List: Order: Active:				
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:	UBC Behavioural Research Ethics Board				
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 for Vancouver Coastal Health (VCHRI/VCHA). If you are NOT using any of these sites select N/A from the list.	<table border="1"> <thead> <tr> <th>Institution</th> <th>Site</th> </tr> </thead> <tbody> <tr> <td>N/A</td> <td>N/A</td> </tr> </tbody> </table>	Institution	Site	N/A	N/A
Institution	Site				
N/A	N/A				
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).	Offices, cafes and other locations convenient for expert interviewees				
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.	H09-02526				
B. If applicable, please describe the relationship between this proposal and the	This project is connected with an ongoing study of the experiences of cancer survivors. I have been awarded a				

previously/simultaneously submitted proposal listed above.	Brocher Foundation visiting researcher fellowship in Geneva to conduct this small project, which will draw on data I've previously collected in my cancer survivorship study, along with new data collected under this sub-study.
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.	no
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:	The Brocher Foundation in Switzerland - completed.
B. Internal (UBC or hospital) peer review details:	N/A
C. If this research proposal has NOT received any independent scientific/methodological peer review, explain why no review has taken place.	N/A
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)?	yes
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]	no
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]	
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.	

<p><i>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?</i></p>	
<p>4A. Study Review Type - Undergraduate Behavioural Research [View Form]</p>	
<p>4. A1. Has this study been approved by another Canadian Research Ethics Board or is it a Class-Based Research Project?</p>	no
<p><i>If the study has been approved by another Canadian Research Ethics Board, provide the name of the Research Ethics Board (REB) and the REB contact information below and proceed to the next page. Attach all relevant documentation in Section 9 of the form, including all documents submitted to the other Canadian REB. The application and correspondence between the researcher and the REB must be attached in Question 9.8. If the study is a minimal risk Class-Based Research Project, and you will be using the Class-Based Research Project Form, you should click yes. The application will truncate and allow you to attach necessary documentation on page 9. See the class-based application form and instructions on the right. If there is a Departmental Ethics Officer (DEO) in your department, this application will be forwarded to them for review. If No complete question 4. A2.</i></p>	
<p>4. A2. Is this study being submitted to an established Undergraduate Student Research Review Committee (USRRC)? Note only departments who have established USRRCs should click yes to this box. All other class-based research projects should use the system outlined above in box 4.A1.</p>	no
<p><i>NOTE: Currently, the First Nation Studies Program has the only active USRRC</i></p>	
<p>5. Summary of Study and Recruitment - Human Ethics Application for Clinical Study [View Form]</p>	
<p>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.</p>	<p>The key goal of this project is to further our understanding of the ways that molecular technologies impact the experience of life with and 'after' cancer. This project is connected with my prior research into the experience of cancer survivorship, but I am applying for ethics approval to conduct expert interviews with officials within the Union on International Cancer Control in Geneva who are interested in talking to me about recent developments in cancer screening relating to the growing use of serum biomarkers to monitor for disease.</p>
<p>5.1.B Summarize the research proposal:</p>	<p>The primary objective of this project is to explore the rise of molecular technologies in cancer screening and monitoring and their impacts on the experience of cancer survivorship. I will draw on both primary and secondary data to accomplish this objective, including: 1) a scan of</p>

	<p>the published literature, 2) an analysis of prior qualitative interviews conducted with cancer survivors and 3) expert interviews with officials in Geneva (policy makers and researchers) who are interested in discussing the rise of molecular technologies in monitoring disease status. In this application I am applying for ethics approval for component 3 of the study (expert interviews) as I have a current ethics approval to cover component 2 of the study.</p> <p>The primary research method will be expert interviews conducted with approximately 5 experts interested in discussing the rise of molecular technologies. These will be analysed using ethnographic content analysis techniques.</p>
<p><i>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.</i></p>	<p>Experts in Geneva (primarily from the Union for International Cancer Control) who are interested in speaking about the shift from imaging to molecular technologies in primary and secondary cancer prevention.</p>
<p><i>5.3. Exclusion Criteria Exclusion Criteria. Describe which potential participants will be excluded from participation, and list the criteria for their exclusion.</i></p>	<p>N/A</p>
<p><i>5.4. Recruitment Provide a detailed description of 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.</i></p>	<p>I will scan the website of key cancer control organizations in Geneva to ascertain relevant experts to interview. I will then email them to inquire whether they are interested in being interviewed (see email invitation in section 9).</p>
<p><i>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.</i></p>	<p>N/A</p>
<p><i>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.</i></p>	<p>N/A</p>
<p><i>5.7. Summary of Procedures</i></p>	<p>Once participants respond indicating that they are interested in being interviewed, a time and place to meet will be arranged.</p> <p>At the beginning of the interview I will discuss their preferences regarding whether they want to be identified in the study publication or not, and let them know that if I end up quoting them in the paper, I'll send them a draft copy so they can see how they have been quoted and verify their preferences regarding being named (or not).</p> <p>With the participants' permission, interviews will be audio recorded and written notes will also be taken (in case of</p>

	recorder malfunction). The interviews will be relatively unstructured and will focus primarily on recent developments in the area of cancer screening technologies (especially the rise of serum biomarkers) and their views of these technologies. No personal information will be requested - except for their personal opinions on new developments in disease monitoring.
6. Participant Information and Consent Process - Human Ethics Application for Clinical Study [View Form]	
6.1. <i>Time to Participate How much time will a participant be asked to dedicate to the project beyond that needed for normal care?</i>	Approximately an hour.
6.2. <i>Time to Participate – Normal/Control Participants If applicable, how much time will a normal/control volunteer be asked to dedicate to the project?</i>	N/A
6.3. <i>Risks/Harms Describe what is known about the risks (harms) of the proposed research.</i>	There are no known harms associated with this research. Experts are being asked to discuss recent developments in their field and the topic itself is a non-sensitive one.
6.4. <i>Benefits Describe any potential benefits to the participant that could arise from his or her participation in the proposed research.</i>	There are no direct benefits through study participation. If experts wish to be named in the paper to result from this study, this may increase their profile as 'experts', but this is not a guaranteed benefit and would be limited to those who wish to be named.
6.5. <i>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.</i>	N/A
6.6. <i>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.</i>	As I am conducting expert interviews, no signed consent form will be obtained. I (Kirsten) will invite the prospective participant to take part in the study via email (see attachment in section 9), and agreement to take part in the interview will be taken as evidence of consent (the emails themselves will be kept as a means of documenting consent). As Article 10.2 of TCPS2 states: "In cases where the participant holds a position of power, or routinely engages in communicative interactions similar to those involved in the research by virtue of their position or profession, consent can be inferred by the participant's agreeing to interact with the researcher for the purpose of the research... In this type of research, where a prospective participant agrees to be interviewed on the basis of sufficient information provided by the researcher, it may be sufficient for the participant to signify consent to participate in the research."
6.7.A. <i>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.</i>	N/A

<p>6.7.B. <i>Waiver of Consent in Individual Medical Emergencies</i> 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.</p>											
<p>6.8. <i>Time to Consent</i> 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.</p>	<p>All the necessary information to consent to participate in the study will be provided in the initial email invitation. Participants have as long as they want after that to decide whether to participate or not. In some cases, this may be less than 24 hours (if they choose to respond quickly to the email). This is entirely at the prospective participant's discretion.</p>										
<p>6.9. <i>Capacity to Consent</i> 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.</p>	<table border="1"> <tr> <td data-bbox="820 661 950 892"> <p>Will the participant have the capacity to give fully informed consent?</p> </td> <td data-bbox="950 661 1079 892"> <p>Details of the nature of the incapacity</p> </td> <td data-bbox="1079 661 1177 892"> <p>If not, who will consent on his/her behalf?</p> </td> <td data-bbox="1177 661 1307 892"> <p>If not, will he/she be able to give assent to participate?</p> </td> <td data-bbox="1307 661 1515 892"> <p>If Yes, how will assent be sought.</p> </td> </tr> <tr> <td data-bbox="820 892 950 953"> <p>Yes</p> </td> <td colspan="3"></td> <td data-bbox="1307 892 1515 953"> <p>[Details]</p> </td> </tr> </table>	<p>Will the participant have the capacity to give fully informed consent?</p>	<p>Details of the nature of the incapacity</p>	<p>If not, who will consent on his/her behalf?</p>	<p>If not, will he/she be able to give assent to participate?</p>	<p>If Yes, how will assent be sought.</p>	<p>Yes</p>				<p>[Details]</p>
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<p>Yes</p>				<p>[Details]</p>							
<p>6.10. <i>Renewal of Consent</i> Describe any situation in which the renewal of consent for this research might be appropriate, and how this would take place.</p>	<p>N/A</p>										
<p>6.11. <i>Provisions for Consent</i> 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).</p>	<p>N/A - English is the lingua franca in Switzerland given the multi-lingual nature of the country (French, German and Italian speakers).</p>										
<p>6.12. <i>Restrictions on Disclosure</i> 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.</p>	<p>N/A</p>										
<p>7. Number of Participants - Human Ethics Application for Behavioural Study [View Form]</p>											
<p>7.1. <i>External Approvals</i> 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:</p>	<p>no</p>										
<p>B. Please select Add to enter the name of the institution and if you have already received approval attach the approval letter.</p>	<p>Name of Institution</p>										
<p>C. Other Jurisdiction or Country (if answer is No</p>	<p>no</p>										

go to 7.1.G):	
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).	no
F. If a Request for Approval has not been submitted, provide the reasons below:	I am interviewing experts in Geneva - no request for ethics approval is required from either Switzerland or the participants' organization. Participation in the interview is at their individual discretion.
G. Does this research focus on aboriginal peoples, communities or organizations?	no
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)?	Approximately 5
B. How many participants will take part at institutions covered by this Research Ethics Approval (i.e., only at the institutions covered by this approval)?	5
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).	Kirsten Bell - I am a cultural and medical anthropologist with 12 years of post-PhD research experience. I have conducted qualitative interviews with hundreds of people on a variety of research projects.
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 security is not really an issue in this study - experts will be interviewed about their topics of expertise (which are non-sensitive) and some of them may want to be named in the publication stemming from this study. However, data will be subject to basic security measures (i.e. stored on a password-protected laptop computer).

<p><i>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?</i></p>							
<p><i>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?</i></p>	<p>Kirsten only.</p>						
<p><i>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.</i></p>	<p>Participants can choose to be named or not - it is anticipated that some will prefer to be named. This will be discussed with them at the beginning of the interview, with participants' preferences audio-recorded and a note made on their resulting interview transcript (as per Article 10.4 of the TCPS2).</p>						
<p><i>8.4. Transfer of Data Will any data that identify individuals be transferred (available) to persons or agencies outside of the University?</i></p>	<p>no</p>						
<p><i>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.</i></p>							
<p><i>8.5. Retention and Destruction of Data UBC 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.</i></p>	<p>Data will be kept indefinitely on Kirsten's password-protected laptop computer.</p>						
<p><i>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.</i></p>	<p>No.</p>						
<p><i>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.</i></p>	<p>Once a draft of the paper is prepared, a copy will be sent to interviewees - to ensure that they are happy with the way they are being quoted before the paper is submitted. If they wish to withdraw their data at this time they can do so. The provision of the draft of the paper will also serve to provide them a copy of the study's findings.</p>						
<p>9. Documentation - Human Ethics Application for Behavioural Study [View Form]</p>							
<p><i>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.</i></p>	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td>Research Proposal</td> <td></td> <td>April 3, 2012 [View]</td> </tr> </tbody> </table>	Name	Version	Date	Research Proposal		April 3, 2012 [View]
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Research Proposal		April 3, 2012 [View]					
<p><i>9.2. Documentation of Consent Examples of types</i></p>	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> </table>	Name	Version	Date			
Name	Version	Date					

of consent documents are listed on the right. Click Add to enter the required information and attach the documents.							
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.	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Name	Version	Date			
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.	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Name	Version	Date			
Name	Version	Date					
9.5. Questionnaire, Questionnaire Consent Cover Letter, Tests, Interview Scripts, etc. Please click Add to enter the required information and attach the documents.	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Name	Version	Date			
Name	Version	Date					
9.6. Letter of Initial Contact Please click Add to enter the required information and attach the forms.	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td>Invitation letter</td> <td></td> <td>April 3, 2012 [View]</td> </tr> </tbody> </table>	Name	Version	Date	Invitation letter		April 3, 2012 [View]
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Invitation letter		April 3, 2012 [View]					
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.	<table border="1"> <thead> <tr> <th>Name</th> <th>Version</th> <th>Date</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> <td></td> </tr> </tbody> </table>	Name	Version	Date			
Name	Version	Date					
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 Behavioural Study [View Form]							
Mechanism for Submitting Fee. Please indicate which of the following method of payment will be used for this application:							
Contact information regarding where to send the invoice.							
12. Save Application - Human Ethics Application [View Form]							

Cover letter explaining consent document

This invitation will also act as the main consent document – as per article 10.4 of the TCPS2 – a response indicating interest in taking part in the study will be taken as evidence of consent.

I believe I have provided all of the necessary information that participants require to take part in the study in this email. Although some standard elements of consent are not provided in this email, Article 3.2 of the TCPS2 states clearly that not all standard elements are necessary – and should be dictated by the specifics of the study. Key missing standard elements are as follows with a justification for their absence:

1) A plain language description of all reasonably foreseeable risks and potential benefits, both to the participants and in general, that may arise from research participation.
In this study there are no risks or benefits and so this information seems unnecessary.

2) An assurance that prospective participants:

- are under no obligation to participate; are free to withdraw at any time without prejudice to pre-existing entitlements;
- will be given, in a timely manner throughout the course of the research project, information that is relevant to their decision to continue or withdraw from participation; and
- will be given information on the participant's right to request the withdrawal of data or human biological materials, including any limitations on the feasibility of that withdrawal;

It is obvious to participants that they are under no obligation to participate. Stating this is unnecessary. I have made it clear that they can withdraw their data from the study.

3) The identity and contact information of the appropriate individual(s) outside the research team whom participants may contact regarding possible ethical issues in the research.

This information seems unnecessary – the participants have total control over how they are represented. I think that providing the standard information about the complaints line makes the email unnecessarily officious. Considering things from the participants' point of view (something the TCPS2 asks researchers to do), I think participants would be bewildered by a barrage of legal-looking information about complaints lines, rights to withdraw etc., for what is an extremely innocuous expert interview. It is worth noting that Northern European researchers and policy makers are unused to North American research ethics requirements, as they have no equivalent frameworks in place beyond the context of medical research.

Email Invitation

Dear X,

I am a Research Associate in the Department of Anthropology at the University of British Columbia in Canada currently in Geneva on a Brocher Foundation Visiting Researcher Fellowship to examine the rise of molecular screening technologies in monitoring cancer survivorship.

Based on the information provided on your organization's website, it seems that this is an area you have some expertise in. I was therefore wondering whether you would be interested in talking to me for about an hour about new developments in cancer screening – especially the growing use of serum biomarkers to monitor disease recurrence and what you think of these developments.

The interview would last approximately one hour and would be audio recorded with your permission. My goal is to produce a paper on this topic that I plan to submit to the journal *BioSocieties* – the paper itself will discuss the implications of the rise of molecular screening technologies on cancer survivors.

If you are interested in being interviewed, you can choose to be identified – or not – it's entirely up to you. I will also send you a copy of the paper once a draft has been completed so you can confirm its final content and how you've been quoted before I send the paper to *BioSocieties*. At that point, you would be able to make changes – or withdraw your comments completely if you decide you'd prefer not to be quoted at all in the final paper.

I look forward to speaking with you soon!

Regards,

Dr Kirsten Bell

Research Associate
Department of Anthropology
University of British Columbia
Canada