

## INFORMED CONSENT STATEMENT

**Project:** PROMISING PRACTICES IN THE ENGAGEMENT OF PEOPLE LIVING WITH OR AT-RISK FOR HIV/AIDS IN RURAL CANADA

**Principal Investigator:**

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## **DESCRIPTION OF THE STUDY**

### **INTRODUCTION**

The Canadian government has said that it is important for AIDS Service Organizations (ASOs) to find ways to involve people living with or at-risk for HIV/AIDS in decisions about ASO programs, practices and policies. It is difficult to do this in rural areas where the numbers of such people are small and where people worry about other people knowing that they go to an ASO. This study will help us to find ways of involving people living with or at-risk for HIV/AIDS in ASO decisions.

### **INVITATION TO TAKE PART IN STUDY**

We invite you to take part in this study about involving rural people living with or at-risk for HIV/AIDS in ASO decisions. We are asking you to join this study if you meet the following criteria: (1) you are HIV positive or you do things that place you at-risk for HIV/AIDS; (2) you are able and agree to take part in taking photographs and discussing their meaning with others in a group; and (3) you are at least one of the following: Aboriginal, an immigrant to Canada, a woman, or you use drugs, such as cocaine or crystal meth. You also are 18 years or over, you speak English, and you live in the Cape Breton region of Nova Scotia.

### **GOALS OF THE STUDY**

We are hoping to find out (1) how you understand meaningful involvement in an ASO; (2) your experience with being involved in making decisions about programs, practices and policies in ASOs in the Maritimes; (3) your thoughts about why some people such as yourself become involved or do not get involved in making decisions about programs, practices and policies in an ASO; and (4) your thoughts about what ASOs could do to help more people like yourself become involved in making decisions about programs, practices and policies.

### **THE STUDY METHODS**

We will ask 7 to 10 people who live with or are at-risk for HIV/AIDS to take pictures with a camera to show what they mean by being involved in ASO decision making. In the following year, we will be having a two day workshop to bring together all the people who took part in the study with government people and people who run AIDS organizations. We will invite you to take part in that workshop at a later date.

For now, we are asking you to learn how to take photographs about being meaningful involved and then to discuss your photographs with others in a group. If you agree to take part in the study, you will be expected to attend a 4-5 hour workshop. You will be given a digital camera and asked to take photos of what you and your group this is important to capture. At the

following monthly meetings (lasting about 3 hours) you will share your photos and their meanings with the group and a couple of the researchers. Together you will decide how to explain what the photos mean and which photos should be shared with people so that they understand issues around meaningful involvement. A total of about 14 hours of meetings, from February to May 2012, will be required if you decide to take part. If we take photographs at the meetings we will ask your permission first.

The workshop and group discussions will be tape recorded and the tapes will later be typed by a typist (transcriber). If we take photographs or videos of what is happening in these meetings, we will ask your permission first.

All photos you take in the project will be yours. You will decide which photographs to share with the group and later which of your photos will be enlarged to share at a strategy workshop and which photos can remain with the research project for use in articles or presentations.

### **COMPENSATION AND ADDITIONAL COSTS**

We will give you \$20 after you attend the beginning workshop and after each group discussion meeting (a total of \$80) to help cover your costs such as child care. As well, we will give you the digital camera to keep when the study is finished and we will provide you with an album of your photographs.

### **BENEFITS**

Your taking part in this study will help us to better understand the ways in which people who live with or are at-risk for HIV/AIDS could be better involved in making decisions in ASOs in the Maritimes.

### **RISKS AND DISCOMFORTS**

It is possible that you may have taken part in some behavior that is against the law, such as buying and selling illegal drugs. Sharing this information may put you at risk for being arrested.

We will not ask you to talk about anything you have done or are doing that is against the law.

**We ask that you do not talk about this kind of behavior in the workshop or group discussions.** If you accidentally let it slip that you have taken part in this kind of behavior, we will take out your answers about such behavior from the tape and typed copy of the discussions/workshop.

### **CONFIDENTIALITY**

It is most important for you to know that this study is fully private. Your name will not be noted on the typed records of the interviews or used in reports about the study. However, you need to know that there are unusual instances where we would have a duty to report certain types of information. Some examples are if you tell me that you are going to harm yourself or others, or

in a situation where child abuse is suspected, or where there is a court warrant to get the information.

The secretary who will type the transcripts of your interviews and the research assistant who will help the research team will sign an agreement saying that they will keep your identity and the information you give confidential. We will be assigning you a confidential code name, known only to Dr. Lynne Duffy and the research assistant. Your code will be kept in a computer that can only be entered through a password. The typed copies and tapes of the workshop and discussions will be kept in secure locked storage for seven years, after which they will be destroyed or erased. The findings of the study may be printed in a newspaper or journal, or used in presentations for research or teaching purposes, but your name will not be used. If we want to use the findings of this study for other research at a later date, we will ask for another ethics approval.

As well, we will avoid suggesting that you have HIV/AIDS to those who might see information we give to you about the study. We will refer to the study's title in only general terms. For example, when we send you the summary of the research findings, we will call the study "Promising Practices of Involving the Public in Health Organizations" and we will not refer to HIV/AIDS.

**Contacts:** If you would like any additional information about this study or about your rights as a study subject, you may contact the principal investigator of this study, Dr. Barbara Paterson, at the toll free number for the study (XXX-XXX-XXXX) or by e-mail at [bapaterson@tru.ca](mailto:bapaterson@tru.ca). If you should wish to discuss this research with someone who is not involved with the project, you may contact Dr. Ulrich Scheck, Vice-President Academic and Provost at Thompson Rivers University (Telephone: 1-250-377-6126; E-mail: [uscheck@tru.ca](mailto:uscheck@tru.ca)) or the Chair of Thompson Rivers University Ethical Review Board, Dr. Michael Woloszyn (Telephone: 1-250-377-6148; E-mail: [mwoloszyn@tru.ca](mailto:mwoloszyn@tru.ca)).

**Consent Form (TRU REB #     )**

**Project Title:** PROMISING PRACTICES IN THE ENGAGEMENT OF PEOPLE LIVING WITH OR AT-RISK FOR HIV/AIDS IN RURAL CANADA

**Investigators:** Dr. Barbara Paterson and colleagues (see list above)

Do you know that you are invited to be part of a research study?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you know the purpose of the study and your part in it?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you understand the benefits and risks involved?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Were you able to ask questions and discuss this research?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you know that you are free to choose what parts you take part in or to stop at any time without a reason?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Has confidentiality been explained to you?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you know who will have access to the study material?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Do you feel comfortable with the information provided?	Yes <input type="checkbox"/> No <input type="checkbox"/>

This study was explained to me by \_\_\_\_\_

- I understand the reasons and my role in this study. I agree to take part.
- I agree that any information and photos I provide can to be used in presentations, journal articles, books, and/or teaching materials.
- I agree that transcripts and photos, with my name and personal information removed, can be used for other studies.
- My name will not be made public unless I pre-approve it.
- Signing this also shows that I have read and received a copy of the description of the study and the consent form

Signature of the Participant	Date	Witness
Printed name	Printed Name	

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of the Recruiter	Date

