

LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Project:

Women and HIV/AIDS Initiative Situational Analysis (Participants)

Principal Investigator:

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Student Researcher:

Katie Standish, *BSW Placement Student* AIDS Committee of Windsor 511 Pelissier Street Windsor, Ontario N9A 4L2 Tel: 519-973-0222 Ext. 103 Fax: 519-973-7389 Email: standis@uwindsor.ca

Funders:

AIDS Bureau through the Ministry of Health & Long-term Care

INTRODUCTION

You are asked to participate in this study because you: (1) identify as a woman, (2) are HIV positive, (3) are 18 years of age or older, and (4) live in Windsor-Essex County. Before agreeing to take part in this study, it is important that you read and understand this informed consent form. This research has been reviewed and granted clearance through the University of Windsor Office Of Research Ethics Board.

Voluntary Participation and/or Withdrawal

It is completely your choice if you decide to take part in this study; participation is 100% voluntary. At any time up to June 1, 2016 you can choose to remove yourself from the study without it affecting to your medical care, social support, or participation in other studies. This means that before June 1, 2016 you can chose to no longer have the information you shared be part of this study. However, after June 1, 2016 this option is no longer offered to you. You also do not have to answer questions that make you feel uncomfortable or may make you feel anxious. Please ask the researcher to explain anything you do not understand. Before clicking "Yes, I am comfortable consenting to this process" on the online application, Fluidsurvey, please make sure all of your questions have been answered.



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Background

The number of women who make up the population of people living with HIV has been increasing because of many things including that women are more likely to acquire the HIV infection because of how their body is made up and other social aspects like income, gender, and ethnic background. For services providers to be able to support women living with HIV, the experiences and needs of those women need to be included when programs and services are being made.

Purpose

The purpose of this study is to find out about the needs are priorities of women living with HIV told by women living with HIV who live in Windsor-Essex County and how they experience service providers in Windsor-Essex County. The experiences of stakeholders who support women living with HIV will be looked at to gain an understanding of how service providers see issues that may face women living with HIV and see the connections between the two groups.

Procedure

If you choose to take part in this study you will be asked to take part in an online survey, through the online application, Fluidsurvey, taking about an hour to an hour and a half of your time. The survey will take place in a quiet, private space at either AIDS Committee of Windsor (ACW, an interview room at the University of Windsor, Windsor Women Working with Immigrant Women (W5), or Women's Enterprise Skills Training of Windsor (WEST of Windsor) or a place of your choosing. The information you share will be saved on a secure online website. This survey will include topics such as demographic information, medical/ HIV information, health care and support service utilization, reproductive health, stigma and discrimination, substance use, violence and abuse, sexual health, emotional well-being, resiliency, and health related quality of life, community agencies and needs/priorities. Once the survey is finished you will be \$40 in cash as a way of saying "thank you" for your time and that the information you shared is important to this process. You will also be given two cards that you may give to two other women you think may be interested in taking part in this survey as well. If a woman takes your card and comes into participate with that card, you will be contacted at your preferred contact and a time will be set up where you can get an additional \$15 in cash. This can be done with two women, making the maximum total you can get, in addition to the \$40, is \$30.

Confidentiality

All information that you share during this process will be treated confidentially and will be analyzed so that you remain anonymous throughout. This means that what you share will not be attached to any identifying information (i.e your name) and it will remain between you and the researcher. When the survey appointment is scheduled, you will be asked for one piece of contact information so that if the interview needs to be rescheduled the researcher has a preferred method to contact you. This information will be stored on a password-protected computer at ACW and will be erased from the system once all information is gathered in May 2016. No other identifying information will be asked of you to provide.

To protect your identity, the online survey will begin with this informed consent document and ask you to click "Yes, I am comfortable consenting to this process" if you consent to participate in the survey. This means that you do not have to sign a document that would identify you. You will be provided a paper copy of this informed consent to take with you if you want to and the form will also be available on the ACW website (www.aidswindsor.org).

All the information collected from the surveys will be kept on an ACW secure password-protected computer. If



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the survey is finished at a place other than ACW then the information will be collected on a password-protected laptop, moved to an ACW secure, password-protected computer upon completion of the survey, and deleted from the laptop.

The final information will be in a report, in which your identity will not be given. The only way that confidentiality does not apply is if you share to the researcher that there is significant self-harm, harm to others, or child abuse that put yourself or others at risk. If you choose to withdraw from this study at any time there will be no penalty to you and the information you have provided will be deleted.

Reimbursement

There will be no cost to you for taking part in the survey. You will receive \$40 cash when you have **finished** the survey to cover any travel, childcare, time, or other costs that you have used to attend this survey process. Receipts are not required. If you recruit participants, you will receive \$15 cash for each recruit up to \$30 meaning that you can recruit a **maximum of two participants**. You will be given two cards with a corresponding number on it to be given to the participants that you recruit. Your recruited participant(s) will need to provide the researcher the card with your corresponding number on it **before** you receive the \$15 compensation. Once the researcher has your card(s) from the woman/women you recruit you will be contacted to arrange a pick up date to receive the \$15. Receiving the \$15 is **NOT** conditional on your recruited participant(s) finishing the survey; meaning that if your recruited participant withdraws from the survey after agreeing to participate you will still receive compensation. However, once the number of participants in this survey reaches 20, the researcher(s) will no longer be able to honor the referral system, meaning that recruited women will not be accepted.

Potential Risks

Some of the survey questions are very personal and may bring up feelings of discomfort, sadness, grief, stress, or anger. During the survey you can skip sections or questions you do not want to answer by selecting "Prefer not to answer". If you feel like you no longer want to participate for any reason and wish to withdraw from the study you are able to do so at any time. At the end of the survey you will be provided a list of resources and counseling services should you want to access them.

Potential Benefits

You should not anticipate any direct benefits from taking part in this research; however, WHAI and ACW will have a better understanding of your needs and priorities and will be better able to better support you.

Signature of Principal Investigator and Student Researcher

These are the terms at which I will conduct the situational analysis.

Signature of Principal Investigator

Date

Signature of Student Researcher

Date



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PARTICIPANT CONSENT

I have read this consent form or it has been read to me and I agree to participate in the WHAI Situational Analysis for Windsor Essex County conducted by the regional WHAI Coordinator, Kimberly Levergood, and BSW student, Katie Standish. I have been given the opportunity to receive any additional details I wanted about the study. I have been given enough time to consider the above information and to seek advice if I choose to do so. I will be given a paper copy of this consent form and can access it online at www.aidswindsor.org. I understand that I may withdraw this consent at any time by telling the principal investigator or the student researcher before June 1, 2016. In addition, I also understand that this study has been reviewed and clearance granted by the Office of Research Ethics Board at the University of Windsor, and that I can contact this office if any concerns or comments arise about this study. By clicking "Yes, I am comfortable consenting to this process" you are consenting to participate in this study.

Rights of Research Participants

If you have questions regarding your rights as a research participant, contact the University of Windsor's Research Ethics coordinator at (519) 253 3000 ext. 3948 or email Ethics@uwindsor.ca

OR

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OR

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