The SHARE Study
A qualitative study of patient and provider perspectives on overcoming barriers to HIV care and retention

PARTICIPANT INFORMATION AND CONSENT FORM

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INTRODUCTION

You are being invited to take part in this research study because you are a person living with human immunodeficiency virus (PLWH) who has:

- stopped and restarted taking your HIV antiretroviral therapy (ART); or
- starting ART was delayed after you were diagnosed with HIV

If you are a participant in the SHAPE Study you are being contacted because you gave prior consent to being contacted by the SHAPE Study research team for purposes of participating in future sub-studies related to that project.

We want to learn more about the barriers to patients receiving ART and suggest ways for improving patients' access to HIV-related healthcare and treatment.

STUDY PROCEDURES

This study involves '*Qualitative research'*. Qualitative research involves collecting information about personal experiences, life story, observations and interactions which are significant moments and meaningful in peoples' lives via interviews (or questionnaires) to answer research questions. Qualitative Research uses words, rather than numbers, to study people's experiences.

If you are eligible and agree to participate in this study, you will be invited to attend an interview with the study coordinator. This interview can be done either by phone or in person at one of our offices at 1026 Nelson St, Vancouver, or at 625 Powell St, Vancouver. Due to the COVID pandemic all interviews will be done over the phone.

A Peer Research Associate (PRA) trained in qualitative research and the study coordinator will conduct the qualitative interview. Collaboratively. A Peer Research Associate (PRA) is a person living with HIV (PLWH) who is trained to support research tasks and who has experiences and identities in common with study participants. The interview will take approximately one hour and will be audio recorded.

During the interview, you will be asked questions about your experience with HIV-related healthcare services and ART medication, the things that have made it easier or harder to access HIV care, as well as general questions about your life, like your relationships and living situation. We want to ask you these general questions because we want to better understand how other things that are happening in your life might affect how you access HIV-related healthcare services. Examples of questions you may be asked in the interview are: "What makes it difficult for you to access healthcare services?" and "What helps you to keep taking your medication?".

The collected information will later be transcribed and analyzed using a computer program.

If you agree, by checking the box on the signature page of this consent form, to be re-contacted regarding the study, you will be kept updated regarding the progress of the study and study findings.

POTENTIAL RISKS OF THIS STUDY

Some of the questions in the interview deal with sensitive and personal issues, such as experiences with discrimination, housing and food insecurity, and substance use, which may cause you to feel uncomfortable, emotional or upset. You are not required to answer any questions that make you feel uncomfortable and you are welcome to stop, or end, the interview at any time. The interviewer will provide you with a list of places or people you can contact and/or help to arrange for an appointment if you would like to speak with someone about how you are feeling. If the interview triggers feelings of distress or recalls past traumas, and you require immediate attention, staff will help you arrange a counselling appointment at the Immunodeficiency Clinic at St. Paul's Hospital; however, any costs associated with such

counselling will not be covered by the study. For those outside of the Vancouver are a list of counselling services you can access by phone, along with the phone number of the Crisis Line, will be provided.

There is a minimal risk of loss of confidentiality. [Refer to CONFIDENTIALITY below] There is a risk of loss of confidentiality when conducting interviews via the phone. When the study coordinator is speaking with you via the phone, the conversation will occur in a private space where they cannot be overheard by others.

POTENTIAL BENEFITS OF THE STUDY

We do not think taking part in this study will help you. However, in the future, others may benefit from what we learn in this study.

CONFIDENTIALITY

Your confidentiality will be respected. Information that discloses your identity will not be released without your consent, unless required by law. You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during the course of this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator or designate. Direct quotes that do not use any identifiers of the participant quoting, will be used in this study.

Electronic data will be stored on a secure server at the BC Centre for Excellence in HIV/AIDS and all study documentation will be kept in a secure area in locked cabinets.

Audio Recordings: Your name and anyone else's name that you mention will not be transcribed or shared with anyone outside the researchers listed on this consent. The audio recordings will be kept in separate locked cabinets which only the researchers working on this study will have access to. No information that identifies you, your staff, or your patients will be kept in the file containing the audio recordings from this interview. After audio recordings have been transcribed and reviewed the recordings will immediately be destroyed.

COMPENSATION

There is no cost for participating in this study. You will receive a $40 honorarium at the completion of the interview to compensate you for your time. If you decide for any reason to withdraw your participation in this study, you will still receive the honorarium. You do not have to complete the interview in order to receive the honorarium

WITHDRAWAL

You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the

extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let the study coordinator know.

WHO DO I CONTACT IF I HAVE QUESTIONS OR CONCERNS?

If you have any questions or desire further information about this study before or during participation you can contact Dr. David Moore at 604-806-8478 or the study coordinator at 604-682-2344 ext. 63945.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line appropriate to the Health Authority you are located in:

UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598. Please reference the study number H19-00957 when calling so the Complaint Line staff can better assist you.

STUDY RESULTS

The main study findings will be published in academic journal articles. Study findings and publications will be available on the BC Centre for Excellence website. If you consent to be contacted about our findings, we will keep you updated on our research by your preferred contact method.

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PARTICIPANT CONSENT AND SIGNATURE PAGE

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand the interview will be audio recorded.

Signature of Participant	Name (Print)	Date

FOLLOW UP:

□ I consent to being contacted by the research team for purposes of learning about study results.

□ I consent to being contacted by the research team for purposes of participating in future sub-studies related to this project.