

Oral Consent Form – Lifeline Activity and Debrief Session – HIV Positive Participants

Title of the study: The Emotional and Felt Experience of HIV Nondisclosure

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Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Katarina Bogosavljevic under the supervision of Dr. Jennifer M. Kilty. This project is funded by the Social Sciences and Humanities Research Council.

Purpose of the Study: The purpose of the study is to examine how people living with HIV/AIDS feel about experiencing HIV nondisclosure in order to better understand the criminalization of HIV nondisclosure in Canada. Specifically, the researchers are interested in feelings about being diagnosed and living with HIV, feelings related to experiences of a partner not disclosing their HIV status prior to consensual intercourse, and feelings about nondisclosure and disclosure generally. The researchers aim to understand the identities that people may take up in response to these events and the role of emotions and feelings in shaping these identities.

Description of Participation: My participation in this part of the project will include drawing a lifeline either by hand or using computer software I have available to me, in my own time, followed by a debrief session that is scheduled at a time and date most convenient to me. The creative part and debrief session will last approximately one hour and one hour in length respectively.

I am required to draw a lifeline or a visual depiction of my life events as they relate to my HIV diagnosis and the context within which I became HIV positive. Once I have completed my drawing, I will send the researcher my lifeline either by taking a screenshot or picture of my lifeline and emailing it to her or by mailing a physical copy of my lifeline by self-addressed and stamped return envelope that the researcher will mail me. I give permission for the researcher to exhibit and publish my anonymized lifeline in her dissertation, in conference presentations and in publications.

I also consent to participate in a debriefing session. During the session, I will be asked to describe my lifeline and the feelings and emotions I had while drawing my lifeline. I consent to the audio and video recording of the debrief session for transcription purposes.

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Risks: My participation in this study will entail that I volunteer personal information that may bring up memories or moments that feel difficult to recount and may bring about some discomfort or distress. I will never be forced to answer any questions that I do not feel comfortable answering and I may withdraw from the study at any time. I have received assurance from the researcher that every effort will be made to minimize the risks of emotional or psychological discomfort. At the end of the debrief session I will be provided with a list of names and contact phone numbers at local AIDS Service Organizations who I can contact should I continue to feel any distress following the creative activity and debrief session.

Benefits: My participation in this study will contribute to ongoing efforts by HIV/AIDS activists, organizations, people living with HIV/AIDS, and scholars to study the criminalization of HIV nondisclosure in Canada. My participation in this study will also contribute to an area of knowledge in the field of criminology that has not yet been explored. This is the first known study to explore the role of emotions in structuring identity in the context of HIV criminalization. The hope is to make both an academic and policy contribution.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential and that I, as a participant, will be completely anonymous. I understand that the contents of the debriefing session and lifeline will be used only for research and publication purposes and that all identifying names or features (including names of cities, dates, specifics of your HIV story etc) will be removed or modified from the transcripts and publications in order to protect confidentiality. I understand that the anonymized lifeline might be published in another form (e.g. a publication, a report, website, or in print or electronic format). I also understand that the lifeline might be used for educational/teaching purposes, presentations, and secondary analysis after the study is complete. The researchers will protect anonymity by allowing participants to choose a pseudonym. Pseudonyms will be used in any publication and in the writing of the dissertation to protect my identity. I understand that I should avoid putting any identifying information on the lifeline.

Given that debriefing sessions will be held via Zoom, every session will have a different meeting ID/link and password and will use all security measures available on the platform such as using a waiting room where the host (researcher) has to approve entry and the researcher will lock each meeting so no one else can join. In order to minimize the risk of security breaches and to help ensure my confidentiality, the researchers recommend that I use standard safety measures such as using a secure connection and to not share the meeting ID, link and password with anyone else. For privacy and confidentiality purposes, I am encouraged to conduct the online debriefing session in a space that is private to limit the chances of being overheard.

Conservation of data: The lifelines will be kept in a secure manner. Hard copies of the lifelines will be stored in a large art portfolio in the researcher's locked home office and electronic copies of lifelines including screenshots and photos taken by me will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. The lifelines (both electronic and hard copies) will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

The data collected, including the digitally recorded audio and video files and transcripts of the debriefing session will be kept in a secure manner. Hard copies of the transcripts and notes will be stored in a locked box in the researchers home office and audio and video recordings will be stored on a password protected USB key in the researcher's locked box. All other electronic files will be stored in a password protected folder that is in a separate password protected user account on the researcher's personal computer. This user account is disconnected from any cloud services. Audio and video recordings will be deleted as soon as transcription is complete and all other data will be stored for a period of five years following the defence and then will be destroyed using secure deletion protocols.

Compensation: I will be given a \$40 honorarium for generously contributing my time to the creative lifeline activity and \$40 for participating in the debriefing session. I will still be given this \$40 even if I decide to withdraw from the creative activity and/or debrief session at a later time. Compensation will be offered via e-transfer to my personal banking account or through Western Union where I will be able to pick up cash.

Voluntary Participation: I understand that I am under no obligation to participate. If I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions that I do not feel comfortable answering without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be securely deleted from the recording device and destroyed. The destroyed data will not be used in the study. If I choose to withdraw from one or two aspects of the project, the data collected from the task(s) I did not withdraw from can and will still be used in the researcher's dissertation, publications, and conference presentations.

If by participating in this debriefing session, I feel that my memories or emotions are hard to handle, I can contact one of the staff at AIDS Service Organizations that the researcher has provided me with.

REB Contact Information: If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

Consent to participate: I agree that in consenting to participate in this project I do not give up any rights. I have been informed about the different requirements of the research and I agree to take part in the debriefing session. The reason I am not providing my signature and that I am providing oral consent is to protect my anonymity and maintain confidentiality in the research. I agree to participate in the above research study conducted by Katarina Bogosavljevic, a PhD Candidate in the Department of Criminology, University of Ottawa, whose research is under the supervision of Dr. Jennifer Kilty.

Yes No _____ Signature of Researcher _____ Date

With my permission only, photos or screenshots of my lifeline will be taken by me, to be shared for research and teaching purposes including in presentations and publications. I agree to take a photo or screenshot of my lifeline and email it to the researcher or to mail a physical copy of my lifeline to the researcher:

Yes No

With my permission only, the debrief session will be audio and/or video recorded using the recording feature on Zoom or by using a digital recording device if debrief session is held over the phone. Only the researcher will have access to the recordings. If I do not wish to be video recorded, the researcher may audio record the conversation and if I do not wish to be audio or video recorded the researcher will take detailed notes.

I agree to the audio recording of this debrief session:

Yes No

I agree to the video recording of this debrief session:

Yes No

If I have any questions about the study, I may ask them now and/or contact the researcher or her supervisor using the contact information given.

You should save or print a copy of this consent form for your personal records.