



Dr. Liviana Calzavara, Principal Investigator

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Positive Plus One:

A research study of relationships where one partner is HIV positive and the other is HIV negative

Survey Consent Form

Research Study Description:

Thank you for your interest in helping us in this research study. As HIV rates have stabilized, HIV-positive individuals are living longer lives. More and more people today are in relationships where only one of the two people has HIV – this is known as an HIV-serodiscordant relationship. While there has been research on living with HIV, far less is known about the unique issues faced by HIV-serodiscordant couples. Many diseases can bring stress to a relationship, but the impact of HIV is potentially unique, because people in serodiscordant relationships may face the ongoing potential for HIV transmission between partners. They may also encounter social stigma that impacts disclosure of the relationship to their family and friends. There have also been rapid changes in HIV technology that people in serodiscordant relationships must take into consideration. This study will provide critical new evidence about these issues, by talking to both the HIV-positive and the HIV-negative person in the relationship. Your experiences may help other couples, and may lead to better health and support programs for all.

This study is unique, because we want to hear from both partners in a primary relationship. By primary relationship, we mean where you consider yourselves to be “a couple,” “together,” or “dating.” If you currently have a partner with a different HIV status from you, we will ask you to invite them to complete a survey when you have finished yours. Each of you will complete the survey on your own, and not in the presence of your partner. We recommend that you complete the survey in a private place, in order to be able to answer freely. If your partner is not interested, you can still participate in the study.

If you agree to participate, you will be asked to complete an anonymous survey. The survey should take about 30 minutes to finish. You will be asked questions about:

- a) **Yourself**, for example: your age, sex, gender, sexual history, HIV history (if HIV-positive) etc.
- b) **Your relationship**, for example: relationship length, how you manage HIV risk, relationship satisfaction, how you communicate with each other, etc.
- c) **Your social world**, for example: access to HIV testing and treatment, health care, social support, stigma, etc.

Eligibility Criteria:

In order to participate, you must meet the following five criteria:

- 1) You are currently in a relationship where one partner is HIV-positive and the other is HIV-negative and the relationship has lasted 3 months or longer, OR you were in one in the past 2 years,
- 2) You live in Canada, and lived in Canada during the relationship,
- 3) You are at least 18 years old,
- 4) You speak either English or French,
- 5) If you are HIV-positive, you have disclosed your status to your HIV-negative partner.

Anonymity and Confidentiality:

Participation in this research study is voluntary and all your answers are anonymous. We will not share your responses with your partner, or anyone else. It is up to you to decide whether you want to tell your partner how you answered these questions. You can skip answering any question, and you can withdraw from the study at any time; however, since the survey is anonymous, once you click on 'submit answers' at the end of the survey, your answers will remain in the study records. At the end of the survey, if you currently have a partner with a different HIV status from you, we will ask you to invite them to complete a survey when you have finished yours. You will be asked to create a unique code to give to your partner, which they will use to begin their survey. At that time, your partner can choose whether they would like to take part in the survey or not. Your partner will not be able to see your answers, and you will not be able to see their answers.

If you agree to provide your name and address in order to receive a token of appreciation from us, this information will be collected and stored in a secure (password-protected, encrypted) database, separate from your survey and interview responses. Your mailing address will be deleted once we mail you the gift card. If you volunteer for the in-depth interview, we will delete your telephone number/email address once you participate. Only 120 volunteers will be interviewed, so if we do not contact you, we will delete this information once all interviews have been completed. Before its deletion, only the Project Manager will have access to your contact information.

Security of Information Collected:

The University of Toronto is the sole owner of all survey responses. Online survey data will be encrypted and stored on password-protected servers. Contact information will only be accessible by the Project Manager. Approved study staff and investigators will be allowed access to the anonymous survey data for analysis and to prepare study reports, presentations, and publications. No one will be able to identify you, your partner, or any participants in any of the publications and presentations that come out of this survey. Your consent form and survey answers will be stored on a password-protected computer until publications have been completed. Research staff will sign an oath of confidentiality, to protect your privacy.

If you learned about this study from a clinic or service organization, they will not be told about your participation in this project unless you choose to tell them. Your access to services will not be affected in any way by your participation.

Benefits and Risks of Participation:

We believe it is crucial to understand the experiences of individuals in serodiscordant relationships, in order to provide timely information, services, and support. First, we want to identify who is in most need of services, and what services they need. Second, we want to understand how everyday relationship satisfaction and stress varies across Canada. Learning about these things may help us to improve quality of life, relationship quality, and service availability for you and other people living in serodiscordant relationships.

The risks of participation in this study are minimal. It is possible that you may experience minor embarrassment or discomfort, since some of the questions will be personal. You could also experience discomfort or stress if you or your partner tell each other something that you previously kept secret. In rare cases this could lead to anger, distrust, or violence. Therefore, you may want to carefully consider what new information you tell your partner or other confidants. To reduce the impact of any of these potential risks, a list of resources will be provided to you—with contact information for local health professionals, counsellors, and HIV/AIDS education and support providers.

A Token of our Appreciation:

We appreciate the time and effort required to answer our questions completely and accurately. If you complete the survey you will be mailed a \$20 gift card as a token of our appreciation. At the end of the survey, you will be

directed to a separate form to complete with your name and address for the purpose of mailing your gift card. This information will be stored completely separate from your survey answers, to maintain the anonymity of your responses. Nobody but the Project Manager will be able to link your name or address with your answers. Gift cards can only be mailed to locations within Canada. If you prefer to not provide us with your name and mailing address, you can also opt to not receive the gift card.

Study Results:

Study results will be available on the study website: www.positiveplusone.ca upon completion of the project (estimated to be July, 2016). You may also contact Drs. Bullock or Calzavara (see below) directly to have a copy of the study results sent to you. Published reports will contain only grouped data (e.g., 55% of survey participants had been in a previous serodiscordant relationship), and no one will be able to identify you, your partner, or any other participants.

If you have any questions about the study, please contact:

Dr. Sandra Bullock, Project Manager
The Dalla Lana School of Public Health
155 College Street, Room 500
Phone: 1-888-740-1166 / 416-978-1224
Email: s.bullock@utoronto.ca
info@PositivePlusOne.ca

Dr. Liviana Calzavara, Principal Investigator
The Dalla Lana School of Public Health
155 College Street, Room 518
Phone: 416-978-4643
Email: liviana.calzavara@utoronto.ca

If you have any questions to ask or concerns to address before you consent to participate, please contact the Project Manager now. If you have any questions while you are taking the survey, go to the bottom of the page and click on the words: "SAVE YOUR ANSWERS AND RESUME LATER." You will be provided a security code and asked to create a password. When you are ready to continue with the survey later, enter the survey as you did the first time. Then click on the words: "RESUME WITH PREVIOUSLY SAVED ANSWERS" enter your security code and password and you will be placed back into the survey where you left off.

This research project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Toronto. You may contact this office directly at ethics.review@utoronto.ca or 416- 946-3273 if you have any questions about your rights as a participant of this project.

The research study you are participating in may be reviewed for quality assurance to make sure that the required laws and guidelines are followed. If chosen, (a) representative(s) of the Human Research Ethics Program (HREP) may access study-related data and/or consent materials as part of the review. All information accessed by the HREP will be upheld to the same level of confidentiality that has been stated by the research team.

Statement of Consent:

By clicking on "I agree" below, I am indicating that I give my consent to begin the on-line survey.

I agree to participate I don't wish to participate

Click 'next' to continue.