

Participant Information Sheet

SOCIAL SUPPORT AND THE EXPERIENCE OF LIVING WITH HIV/AIDS FOR WOMEN IN AUSTRALIA

My name is Jayne Russell and I am a PhD candidate studying at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University under the joint supervision of Professor Anthony Smith and Dr Jeffrey Grierson. Professor Anthony Smith is a Deputy Director of ARCSHS. Dr Jeffrey Grierson is a Senior Research Fellow with the Living with HIV Program at ARCSHS. This research will contribute towards my PhD at La Trobe University.

Description of the project

It is well documented that a lack of social support negatively affects the physical well-being of those living with chronic illnesses. People living with HIV/AIDS (PLWHA) in Australia, face complex physical, psychological and social challenges reducing the opportunities for exchanges of social support. Hence, compromised physical well-being emerges as a real possibility under these extraordinary circumstances. As women living with HIV/AIDS are under-researched, and face unique and distinct challenges, this research focuses on the exchanges of social support occurring within the personal social lives of women living with HIV/AIDS. Circumstances that promote or inhibit these exchanges, including disclosure of HIV positive status will be explored and linked to indicators of self-reported health.

Benefits

Participation in this research will give you the opportunity to reflect on the different types, extent and structures of social support in your everyday life. In addition, a greater understanding of social support from the perspective of a range of women living with HIV/AIDS, will be gained by your contribution and the contribution of all those who participate in this project. The findings of this project will be communicated to HIV health practitioners and organisations, along with research communities and government organisations. As there is little knowledge to draw on for policy or resource development, the findings from this research will provide a relevant knowledge base for use in developing future strategic and support initiatives.

What is required?

As a women living with HIV/AIDS in NSW, who speaks English and is at least 18 yrs of age, you qualify to participate in this research project. Participation involves a brief questionnaire and then a face-to-face interview with me at a time and place that is convenient to you. The interview will take between 60 and 90 minutes. During the interview I will ask for some information about the people you consider important to you. I will not be requiring their name or any details that may identify them, but will be asking you to describe what their relationship is to you, some background information and different types of exchanges you may have with them. Towards the end of the interview I will seek information about your health, and how you see yourself in relation to others. I would like to offer you \$50 before we start the interview, as compensation for your time and any travel expenses you may have incurred. This payment is funded by the Australian Research Centre Sex Health and Society, La Trobe University.

What will happen to this information?

The findings from this project will be published in my PhD thesis and will be submitted to academic publications, conferences and produced in reports to HIV and government organisations. As such this research project has implications for HIV policy and practice in Australia. The Consent Form provides an option for you to request a summary of the findings once the PhD thesis has been successfully completed, and another option to participate in a repeat of this research for comparison with future data.

Confidentiality

Your name will not be written on either the self-administered or structured interview questionnaires, nor recorded in the electronic data files. A number will be assigned to you and this number will be used to differentiate your information from other respondents' information to ensure the confidentiality of your responses. If you consent to participate in this research in the future, a document will be created that links your name and contact details with the assigned number that appears on the self-completed questionnaire and interview data. This linking document and the self-completed questionnaires will be kept in separate folders and draws, in a locked filing cabinet, in my office at ARCSHS (a secured building) while this project is active. And, the data from the self-completed questionnaires and interview questionnaires will be stored electronically in a password secured computer. Once this project is complete, the questionnaires and linking document will be stored in a locked filing cabinet in a secure room at ARCSHS for up to 5 years.

Your rights

You have the right to withdraw from active participation in this project at any time and, further, to demand that data arising from your participation are not used in the research project, provided that this right is exercised within four weeks of the completion of your participation in the project. There are no disadvantages, penalties or adverse consequences for not participating or for withdrawing prematurely from the research. If you would like to withdraw your participation, you are asked to complete the "Withdrawal of Consent Form" or to notify me by email or telephone that you wish to withdraw your consent for your data to be used in this research project.

Interested and/or questions?

If you are interested, and/or have any questions regarding this project please contact me by phone or email (details listed below). If you have any complaints, or queries that I am unable to answer to your satisfaction, you may contact the Secretary, Human Ethics Committee, Research and Graduate Studies Office, La Trobe University, Victoria, 3086, (ph: 03 9479 1443, email: humanethics@latrobe.edu.au).

Thank you for taking the time to read this letter and I look forward to meeting with you,

Ms Jayne Russell



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