



Participant Information Statement

Sexual Wellbeing and Quality of Life after Prostate Cancer: A Comparative Study of Heterosexual and Non-Heterosexual Men

Invitation

We invite you to participate in a study to help us gain new knowledge and understanding of how prostate cancer (PCa) affects sexual wellbeing and quality of life in heterosexual, gay and bisexual men.

This study is being conducted by the Centre for Health Research, University of Western Sydney (UWS). The research project is funded by Prostate Cancer Foundation of Australia (PCFA) and is a collaboration between UWS and Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP). This research has received formal ethics approval from UWS, AIDS Council of Australia (ACON), and Victoria AIDS Council (VAC).

To ensure confidentiality for 45 and Up Study participants invited to take part, the 45 and Up Study coordinating centre at the Sax Institute has sent out invitations to participate on behalf of the research team. The 45 and Up Study has not, and will not, provide any personal details about you to the research team without your consent.

The researchers/investigators on the study are:

- Professor Jane Ussher (University of Western Sydney)
- Associate Professor Janette Perz (University of Western Sydney)
- Professor Suzanne Chambers (Griffith University)
- Associate Professor David Latini (Baylor College of Medicine)
- Professor Ian Davis (Monash University)
- Associate Professor Scott Williams (Peter MacCallum Cancer Centre)
- Mr Alan Brotherton (AIDS Council of NSW)
- Professor Gary Dowsett (La Trobe University)

To help you decide if you want to take part, it is important for you to understand why the research is being conducted and what is involved.

What is the study about?

The purpose of this study is to examine the implications of changes to sexual wellbeing, sexual identity and intimate relationships in heterosexual and non-heterosexual men with prostate cancer. We want to gain information that will help inform health care providers to deliver interventions and facilitate ongoing support and thus prevent difficulties and distress with sexual wellbeing to those who have been affected by prostate cancer.

Who are we looking for?

- Heterosexual identified men who currently have, or have had, prostate cancer
- Gay and/or bisexual identified men who have, or have had, prostate cancer

Do you have a choice?

Participation is voluntary. If you decide to be involved, it will not affect you in any way and it will not affect the relationships you have with any of the organisations involved. You can withdraw at any time without giving any reason.

Your role?

If you are willing to take part in this study, we ask that you complete a survey, which may take about 30 minutes to complete. The survey has questions about the impact of prostate cancer, and your thoughts about sexual practices, sexual identity, intimate relationships and quality of life.

What are the benefits / positives

This study will provide the research team with a comparative understanding of the specific experiences and needs of heterosexual, gay and bisexual men with prostate cancer. This information and knowledge will be used to inform health care providers to deliver tailored interventions and facilitate ongoing support to heterosexual, gay and bisexual men with prostate cancer and prevent difficulties and distress with sexual wellbeing post-cancer.

If you are interested in participating in Stage 2 of this study, which is an interview, please advise us of your contact details in the space provided at the end of the survey.

Are there any risks?

We know answering questions or talking about cancer and how it has affected you can be difficult, so if you decide to take part in the study, we will do what we can to make sure you feel safe and comfortable.

If you feel some discomfort during or after completing the survey, and feel as though you would like to talk to someone, please contact the services below for help.

- The Cancer Council Helpline 13 11 20
- ACON Counselling Service (02) 9206 2000 or Free Call 1800 063 060

Confidentiality / Privacy

Everything you say to us will be confidential. No one will know you have taken part in this study except those you tell or the researchers involved in the study. The 45 and Up Study is bound by Commonwealth and State privacy legislation.

All information collected will be treated with absolute confidentiality and used for health research only.

No information will be released in a way that would enable an individual or household to be identified, except as is required by law. Information gathered will be stored, analysed and reported on with all individual identifying details removed to ensure total security, confidentiality and anonymity.

In addition to meeting Commonwealth and State legal requirements, the 45 and Up Study is overseen by the University of NSW Human Research Ethics Committee to guarantee complete security, confidentiality and anonymity of participants. If you choose to participate in this University of Western Sydney study, all your information will be stored safely and securely, and all data will be de-identified.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. If you were to take part in an interview with us, you will be reimbursed for your time and reasonable travel expenses to the amount of \$25.

What will happen with the results?

We plan to talk about the results with other organisations (e.g., Prostate Cancer Foundation of Australia, ACON, ANZUP) so other people can learn about the sexual wellbeing and quality of life after prostate cancer for heterosexual, gay and bisexual men. We will do this by presenting and discussing the results with people who look after men with prostate cancer. Whenever we present or discuss the results, your name will not be mentioned and no one will know you participated in the study. If you want to know the findings of the study, please contact us via email for any updates.

Complaints

This study has been approved by the University of Western Sydney Human Research Ethics Committee (ID: H10013). If you have any concerns about the conduct of the study, or your rights as a study participant, you may

contact the Ethics Committee through the Research Ethics Officer on 02 4736 0229 or humanethics@uws.edu.au.

If you have a concern or complaint about the conduct of the 45 and Up Study, you can contact the Ethics Secretariat at the University of New South Wales, on 02 9385 4234 or email ethics.sec@unsw.edu.au

Contact details

If you would like to know more about this project or the 45 and Up Study, please contact the 45 and Up Study Infoline on 1300 45 11 45 or email 45andUp@saxinstitute.org.au. You can also write to Professor Emily Banks, Scientific Director, The 45 and Up Study, PO Box K617, Haymarket NSW 1240.

You can also contact a member of the research team on 1800 19 20 02 or email cancerandsexuality@uws.edu.au

If you wish to take part, please complete the Sexual Wellbeing and Quality of Life after Prostate Cancer Survey. You can return it to us in the reply paid envelope provided.