Participant Information Form

Project Title
What are the barriers and facilitators to multidisciplinary models of person-centred supportive care in the context of penile cancer? A mixed methods study

Researcher
Professor Catherine Paterson
Faculty of Health
Phone: 0416860535
Email: Catherine.paterson@canberra.edu.au

Project Aim
The aim of this study is to find out people's experiences of penile cancer and follow-up care to help identify if care delivery can be improved.

General Outline of the Project

The project will help to understand the care needs of men affected by penile and their loved ones to help informed clinical services design and person-centred models of rehabilitation.

The information gained from the research will be used to inform new models of care and help to develop future research.

This project is funded through the Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) Below the Belt Priority Funding.

Participant Involvement

Participants who agree to participate in the research will be asked to:

1. Complete an anonymous online survey which will take approximately 45 minutes. The survey will ask you about demographic and clinical information, questions about your quality of life, experiences of care, depression, anxiety, and distress.

2. It is optional to take part in a semi-structured interview to explore your experiences of care. The interview will ask a series of open questions which will take approximately 45 minutes via Microsoft Teams/Telephone.

Participation in the research is completely voluntary and participants may, without any penalty, decline to take part or withdraw at any time without providing an explanation or refuse to answer a question. To do this please

tell the study team that you wish to withdraw from the study. Information that has been collected about you, prior to your withdrawal, will be anonymous and will continue to be used in the data analysis. No new information will be collected or used after you have let the team know and withdrawn from the study.

Benefits of Participation

You may benefit by participating in this research through sharing your experiences of different models of supportive care which sometimes patients find it helpful to express their experiences. The results are likely to benefit other patients in the future because we will gather information about the best models of care, however the results may not benefit you directly.

Risks of Participation

There should be no harmful effect on you if you choose to participate in the study. The information we gather may not benefit you directly, but we hope that it will be of help in the future to people with the same condition.

As this study does not affect the treatment that you are receiving, there are no real side effects of taking part. Although some people may find it upsetting to focus on their symptoms by completing questionnaires, others find this helpful or don't notice any difference. If you do feel that taking part in the study is making you think too much about your symptoms and causing upset, then you can withdraw at any time without having any effect on your future treatment and care. You should discuss these feelings or concerns with your doctor or nurse. The questionnaires and taking part in the interviews are time consuming and will take approximately 45 minutes each which may cause inconvenience in your schedule.

You should discuss these feelings or concerns with your doctor or nurse. It is important that if you feel that you require access to psychological support, please contact:

- Beyond Blue: 1300 22 4636 | www.beyondblue.org.au
- Lifeline 24-hour counselling service: 13 11 14
- Your General Practitioner.

Confidentiality

Only the researcher/s will have access to the individual information provided by participants. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences and written up for publication. However, in all these publications, the privacy and confidentiality of individuals will be protected.

The online survey is completely anonymous, meaning we will not be able to identify you from your responses. Information shared during the qualitative interviews will be de-identified and remain strictly confidential. This information will only be disclosed with your permission, or as required by law. Only the researchers involved in the study will have access to your details and results that will be held securely at the University of Canberra.

Anonymity

All reports and publications of the research will contain no information that can identify any individual and all information will be kept in the strictest confidence.

Data Storage

The information collected will be stored securely on a password protected computer throughout the project and then stored at the University of Canberra for the required five-year period after which it will be destroyed according to university protocols.

Ethics Committee Clearance

The project has been approved by the Human Research Ethics Committee of the University of Canberra (HREC – 10382).

Queries and Concerns

Queries or concerns regarding the research can be directed to the researcher.
Contact details are at the top of this form.
If you have any complaints or reservations about the ethical conduct of this research, you may contact the University of Canberra's Research Ethics & Integrity Unit team via telephone 02 6206 3916 or email humanethicscommittee@canberra.edu.au or researchethicsandintegrity@canberra.edu.au

If you would like some guidance on the questions you could ask about your participation please refer to the Participants' Guide located at http://www.canberra.edu.au/ucresearch/attachments/pdf/a-m/Agreeing-to-participate-in-research.pdf