

## ***Participant Information Sheet (GU Ref No. 2016/156)***

### **Men and Sexual Health-Prostate Cancer Study**

Many men report that prostate cancer has an effect on their sexual lives. This questionnaire asks you about your sexual experience following your diagnosis of prostate cancer and how this has impacted your life. This study is intended to provide valuable information to improve available services and support. We do acknowledge that some parts of this questionnaire may not be relevant to all men however your participation is encouraged to help move knowledge forward in this area.

You are invited to participate in a research project exploring the views of men about their cancer-related concerns and priorities and any help you may have sought to manage treatment side-effects. This is a collaborative project between Griffith University, Cancer Council Queensland, the Prostate Cancer Foundation of Australia, the Australian & New Zealand Urogenital and Prostate Cancer Trials Group and the Prostate Cancer Foundation of New Zealand.

**Participation in this project is completely voluntary and if you agree to take part you will be asked to:**

1. Read this information sheet.
2. Tick the yes option to consent to the study.
3. Complete and submit the online survey. We will contact you again 6 and 12 months after this survey. Each survey will take approximately 30-40 minutes to complete.

In each survey we will ask you some questions about your background characteristics, treatment, experience with prostate cancer, views on seeking support, support you may have accessed and physical and emotional cancer-related concerns and priorities.

#### **How will your information remain confidential?**

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will only be used for research purposes and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. Your survey responses will be stored separately to your confidential details. Your confidential details will be stored in a password protected database. To link your responses for each survey we will use a computer generated study identification number so we know that the responses are from the same participant, but your identity remains unknown. Further, a de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded.

Your responses will be stored in a password protected electronic file on a secure Griffith University network drive. Your responses will be accessible only to the research investigators on this project. The electronic data file containing your anonymous responses will be kept for the required 5 years in the secure location described above after which time it will be destroyed via university approved methods.

For more information about confidentiality and privacy, please refer to the Griffith University website at [www.griffith.edu.au/privacy-plan](http://www.griffith.edu.au/privacy-plan) or telephone (07) 3735 4375. Alternatively you may wish to access Cancer Council Queensland's Privacy Policy at [http://www.cancerqld.org.au/page/about\\_us/policies/privacy\\_policy/](http://www.cancerqld.org.au/page/about_us/policies/privacy_policy/)

When the project has been completed, generalised non-identifiable results will be delivered in the form of journal articles, reports and research presentations and will be used to further our

understanding of the experience and needs of men with prostate cancer and the best possible ways in which we can support men who have been diagnosed with prostate cancer. A summary of the project results will be available to participants at the conclusion of the project and can be accessed by emailing the Project Manager (details below).

### **Are there any risks and benefits to taking part in the study?**

Besides your time, we see no foreseeable risk or drawbacks from participating in this study. If you feel you need to talk to someone about your cancer experience, please contact the Cancer Council Australia Helpline on 13 11 20, Prostate Cancer Foundation of Australia on 1800 22 00 99, Prostate Cancer Foundation of New Zealand on 0800 477 678 or Prostate Cancer Canada on 1 855 722 4636. By taking part in this study you will provide us with important information about the cancer-related concerns and priorities of men with prostate cancer.

Your participation in this project is entirely voluntary and has no bearing on your relationship with Griffith University, Cancer Council Queensland, the Prostate Cancer Foundation of Australia, the Australian & New Zealand Urogenital and Prostate Cancer Trials Group, or Prostate Cancer Foundation of New Zealand. You may stop taking part at any time, should you so wish, without giving reasons. In the event that you withdraw your consent, information collected about you prior to the date of your withdrawal will continue to be used and form part of this project, unless you inform the research team otherwise.

### **Who can I contact if I have questions or need more information?**

If you have any questions with regard to this project please contact Kirstyn Laurie by phone: (07) 3634 5115 or email: [k.laurie@griffith.edu.au](mailto:k.laurie@griffith.edu.au) or [KirstynLaurie@cancerqld.org.au](mailto:KirstynLaurie@cancerqld.org.au).

### **The ethical conduct of this research**

This study has been reviewed and approved by the Griffith University Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Human Research (2007). Should you wish to discuss the study with someone not directly involved in the project, about the ethical conduct of the study, or your rights as a participant, or should you wish to make an independent complaint, you can contact the Manager, Research Ethics on 07 3735 4375 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au)

On behalf of the team, we sincerely thank you in advance for your support.

### **Professor Suzanne Chambers**

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