



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

## Centre for Community-Driven Research

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### CHIEF INVESTIGATOR

**Dr Catherine Holliday**

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## PARTICIPANT INFORMATION

### *Personal Experience, Expectations and Knowledge (PEEK) study: Prostate cancer*

#### **(1) What is this study about?**

You are invited to take part in a research study to help us understand the experience of people diagnosed with prostate cancer and their expectations of the health system, including opinions on access to affordable treatments and holistic care.

You have been invited to participate in this study because you are currently or have previously been treated for prostate cancer. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

#### **(2) Who is running the study?**

The study is being carried out by the Centre for Community-Driven Research (CCDR). CCDR are a charity that conducts research to help patients have their voice heard.

This study is being sponsored by AstraZeneca. The sponsor had no input into the methodology, data collection, data analysis or reporting.

#### **What will the study involve for me and how much of my time will the study take?**

The study will include an online questionnaire that will take approximately 45 – 60 minutes to complete, as well as a structured interview by telephone that will take approximately 45 – 60 minutes. The structured interview is conducted with one of our lovely researchers and is a great opportunity for patients to talk about and document their experience to benefit others in the future. This interview will be recorded and transcribed, however we remove any identifiable information such as names, locations or anything that could identify who you are (such as your occupation or where you work). Once we complete data collection, we will develop a report that we will share with government, charities, clinicians and decision-makers so that they can ensure their decisions address the needs of people with prostate cancer.

### **Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the Centre for Community-Driven Research (CCDR) or your treatment team.

If you decide to take part in the study and then change your mind later, you are free to withdraw at any time. You can do this by emailing [research@cc-dr.org](mailto:research@cc-dr.org)

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also pass on any questions that you do not wish to answer during the interview. If you would like a transcript of your interview, please ask your interviewer for this and we can send that through to you.

### **Are there any risks associated with being in the study?**

Aside from giving up your time, we do not expect that there will be any risks associated with taking part in this study.

### **Are there any benefits associated with being in the study?**

We cannot guarantee that you will receive any direct benefits from being in the study, however in our past studies, participants have found that participating in the study made them feel good because they had the chance to reflect on their experience and talk about it, and also help others in the future.

### **What will happen to information about me that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. This information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications. We will also keep all the data, de-identified, in a repository so that in the future, other researchers can also use all the information collected in this study, for other studies.

### **Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

### **What if I would like further information about the study?**

When you have read this information, Catherine Holliday will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Catherine at [cmholliday@cc-dr.org](mailto:cmholliday@cc-dr.org).

### **Will I be told the results of the study?**

Yes! We will provide all participants with a copy of the study results.

### **What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called an Ethics Committee (EC). The ethical aspects of this study have been approved by the University of Wollongong (UOW) Human Research Ethics Committee (Reference). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies. If you are concerned about the way this study is being conducted you can contact the chief investigator (Catherine Holliday [cmholliday@cc-dr.org](mailto:cmholliday@cc-dr.org)) at any time. If you wish to make a complaint to someone independent from the study, please contact the UOW Ethics Officer email [rso-ethics@uow.edu.au](mailto:rso-ethics@uow.edu.au).