Has this research been approved?

PCOR-QLD has been reviewed and approved by the Human Research Ethics Committees at Health Institutions across Queensland . The research will conform to the principles set out by the National Statement on Ethical Conduct in Human Research and Good Clinical Practice guidelines.

For more information

If you have any questions, you can speak to your doctor or you can call the PCOR-QLD Clinical Registry Manager, Dr Mary-Anne Kedda on (07) 3176 7432.

If you have any concerns about the ethics of the research, please contact the Metro South Hospital and Health Service Human Research Ethics Committee on (07) 3443 8049. In case of a medical emergency, you should contact the usual services, for example, your GP, ambulance etc.

MONASH University





PROSTATE Cancer Outcomes REGISTRY AUSTRALIA & NEW ZEALAND

PROSTATE CANCER OUTCOMES REGISTRY QUEENSLAND







PCOR-QLD Brochure v1.2 11 December 2015

The Prostate Cancer Registry

The Prostate Cancer Outcomes Registry — Australia and New Zealand (PCOR-ANZ) is a prostate cancer registry that is funded by the Movember Foundation and managed by Monash University.

The Registry is designed to monitor patterns and quality of care for men who have prostate cancer. It will provide valuable information for patients, doctors and hospitals, and a world-class research tool to better understand and manage prostate cancer.

PCOR-QLD

The Queensland Registry (PCOR-QLD) is managed through the Queensland University of Technology (QUT) Australian Prostate Cancer Research Centre -Queensland, which is based at the Princess Alexandra Hospital in Brisbane. PCOR-QLD will collect health information for all men diagnosed with prostate cancer in Queensland. This information will be included in the binational registry.

Your involvement in the Registry

The Registry will collect health information for all men diagnosed with prostate cancer in Australia and New Zealand. Your doctor has given you this brochure to tell you about the Registry. Your decision to participate in PCOR-QLD is **voluntary**. If you decide to participate, you do not need to do anything. If you prefer not to participate, you will need to let us know that you wish to "opt-out" of the Registry. You can opt out of the Registry by calling the free call number 1 800 771 410.

You may not receive any direct benefit from being in PCOR-QLD, however men with prostate cancer in the future may benefit from healthcare improvements produced by the research that is done using information from the Registry.

Are there any costs?

There are no costs associated with participating in PCOR-QLD. You will not receive any payment for participating in the Registry.

What information will be in the binational PCOR-ANZ Registry?

Data within the PCOR-ANZ Registry will be identifiable. The Registry will include your name and address, clinical information related to your treatment, and some information about your general health. Most of this information will be obtained from your medical records. We may also send you some quality of life questionnaires to complete, to assess how you are feeling. All the data will be protected through State and Commonwealth privacy laws. The information will be stored securely and will be accessed only by Registry officers. The Registry is ongoing and your information will remain in the Registry indefinitely. No reports will contain identifying information about you.

Who is funding the Registry?

The Registry is funded by the Movember Foundation, with the support of all clinical specialties managing prostate cancer and local state organisations.