

Prostate Cancer and Health...

You are being approached because you have been diagnosed with prostate cancer. Even though it is called “cancer”, prostate cancer aggressiveness can differ from one person to another – it doesn’t always kill people; sometimes people live with it for decades without being affected.

As you may have heard, PSA (the blood test for ‘prostate specific antigen’) is not always accurate about the presence of cancer. But more importantly, it is not always accurate about how badly the cancer might affect long term health.

Biomarkers other than PSA

Besides PSA, there may be other tests (other biomarkers) that could reveal the true nature of prostate cancer. The focus of the APCaRI teams is to find them in blood, urine, semen, or biopsy (or surgery) samples, and see if they will identify aggressive cancers.

These biomarkers can be genes, proteins, even fragments of cancer cells that could be detected using modern laboratory technologies. We believe that the range of prostate cancers and their aggressiveness can be studied in far greater detail with these technologies and for that we need samples from patients like you.

What is the Alberta Prostate Cancer Registry and Biorepository?

In order to learn about how prostate cancers can be characterized by new biomarkers, many “biospecimens” – samples of blood, fluids, tissue materials – will have to be collected from different groups before and after prostate cancer is diagnosed.

The Alberta Prostate Cancer Registry and Biorepository is a research program designed to collect and store biospecimens (in a “biobank” or “biorepository”) along with individual health information over many years. Participation is voluntary. Consenting patients will follow standard medical advice and care through their doctors.

Because people continue their usual care without interference from the researchers, cohort studies like this are known as “natural experiments”. The researchers have no influence on how and what kind of cancer treatment should be given. They make their observations by collecting information from you directly, in the form of biospecimens and health surveys, and from health service providers and managers such as Alberta Health Services.

As the Registry builds over thousands of patient visits and observations over ten or more years, information can be turned into knowledge that will inform future generations of doctors and patients.

Visit our web portal at
www.APCaRI.ca

What we hope to achieve

Biologists tend to think about what happens inside the cell. Doctors tend to think whether surgery is necessary, how much radiation or drug therapies to use. Within our teams, biologists and doctors, as well as epidemiologists, biostatisticians, and other researchers, are working together to better understand prostate cancer through markers of biological change and their implications on future cancer and health problems.

Rather than being frightened by the word ‘cancer’, we want to learn how to identify aggressive prostate cancer well before complications happen. That way, we can weigh carefully the pros and cons of available treatments. It is true that we cannot predict the future with precision, but that shouldn’t stop us from learning how to make educated guesses. In the process, we expect new and important discoveries for better therapies to be developed. The word “cancer” may be scary, but what is truly scary is ignorance.

How you can help

If this is sounding interesting to you, please take a moment to chat with our friendly research coordinator or nurse

If you are uninterested or you think it is too much of a hassle, we want to hear about it too. This is how we learn. After visiting our website or reading more in the research study consent form, you can decide whether you want to participate in this study.

What it means to be in a study

Being in this research study means that you (your health as it relates to prostate problems, prostate cancer or other chronic conditions) will be observed by researchers. There are two components to observation: active and passive.

Active observations require your attention, which include collecting samples from you (blood, urine, etc.) and asking you questions directly through surveys once a year for five to ten years.

Passive observations do not require your attention, which include researchers requesting on your behalf relevant clinical and related information from your health care providers, such as your urologist and Alberta Health Services which administrate all hospital-based services, for at least 10 years.

Participation in a research study is voluntary, which means even after you signed consent, you can also quit being in this study if you choose to.

Thank you for giving thought to this important initiative!

If you have more concerns or unanswered questions please contact:

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Making an Impact on Prostate Cancer Outcomes and Quality of Life



“What can we do to make a difference tomorrow?”

Frank Sojonyk 1928-2012

