

Methods and Processes

Two members of the PCRC team undertook interviews with patients both over the phone and in person in March and April 2019. We spoke to 14 people affected by prostate cancer, both patients and family members. We asked specific questions to each but also allowed the conversation to move naturally where interviewees felt comfortable.

Call Guide

- What's your experience of prostate cancer?
- How did you tell your family? OR How did you find talking about it?
- Where did you find support?
- Is there anything else you didn't have which would have helped you?
- What treatments do you wish were available?
- What do you think research charities like us should prioritise?

Diagnosis

Just over half of the participants reported prostate related issues, such as frequent urination in the night, as the prompt for a visit to the doctors for testing. The other half reported no symptoms, and their prostate cancer was caught in routine tests.

After diagnosis, only a few participants felt that good quality useful information was given to them by doctors, with many spending a lot of time researching and selecting their treatment options based on internet searches. Two participants also had private health insurance which were able to offer treatment guidance and oncologist recommendations.

Two described dedicated cancer nurses as providing the most useful information regarding therapies. Consequently, the majority wanted more clinician guidance, clearer literature and suggested a detailed information leaflet with their treatment options. A few also felt that there should be more information surrounding PSA testing awareness for men who are concerned with visiting their GP.

Treatment

Roughly half of the participants opted for a prostatectomy in the first instance. Of those who had the prostatectomy, nearly all reported the side effects of erectile dysfunction and incontinence as very inconvenient. A few commented that the incontinence side effect was not very well explained, and has improved somewhat since the operation. Three callers had to undergo further radiotherapy and hormone therapy after their operation due to raised PSA levels.

Of the callers who didn't opt for surgery, the majority went for the alternatives of radiotherapy and hormone therapy because of worries of operation side effects. Others were recommended it at early stage or because of tumour placement. The biggest complaint of side effects from hormone therapy and radiotherapy was extreme

fatigue, with many requesting to stop Hormone Therapy because of this. Only one caller was placed on chemotherapy, as part of STAMPEDE.

Two callers reported very few side effects or no side effects at all during their prostate cancer treatments.

Support

Nearly all described a high standard of care during treatments with many callers being very appreciative of the support given by cancer nurses. A majority spoke of the invaluable support provided by family and friends, and one caller mentioned that more support should be given to family members going through the process.

Many found speaking with others diagnosed with prostate cancer very helpful, one of which was connected through Prostate Cancer UK, who was grateful for their additional support. A few talk about the mental side of the illness and feelings of loneliness and depression, with some wanting better support groups or a person of contact. One caller highlighted the need for support groups for those who aren't seriously ill.

A number of the men spoke of the mental health issues they have faced since their diagnosis and treatment. One commented that it is particularly difficult given that you cannot see or feel anything, as you may be able to with different cancer. One other commented that the time between PSA tests could be difficult, as six months can feel like a long time.

Others spoke of the of side effects that have an adverse effects on their mental health: incontinence and erectile dysfunction.

Research Focuses

The main research focus areas outlined by the callers were early detection, cancer spreading to advanced stage and improving side effects. Two callers felt that they did not know enough about research or have the expertise to comment on treatment options. Other areas outlined were: immunotherapy, treatment accuracy, improving surgery outcomes and using existing treatments more effectively, for example, like STAMPEDE.