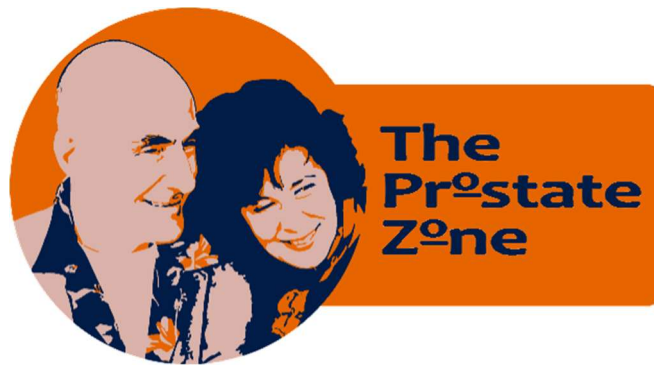




Survey Results

Pathways to Prostate Cancer Diagnosis

May 2025

Our thanks to all those men who participated by completing this survey. 264 responses were received – we really appreciate each and every one of them.

Brief survey of prostate cancer patients' diagnostic pathways

A brief online survey was conducted via [The Prostate Zone](#) website.

Designed to capture a “snapshot” of men’s individual pathways to their diagnosis with prostate cancer.

The survey ran from 24th April 2025 to 16th May 2025. 264 responses were received.

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THEMES THAT EMERGED FROM RESPONDENTS' COMMENTS

Low PSA scores did not always correlate with Gleason scores

"Did Active Surveillance for 10 years. At 59, annual DRE with the Urologist showed the gland was firm, biopsy found cancer close to the edge. Without the DRE, the cancer is likely to have spread. PSA was only 1.9, but free-to-total PSA was 12%."

(49 years' old at first diagnosis, 59 years' old at second diagnosis, metro area, no family history, PSA of 1.9, Gleason 4+3)

"Never more than 3!! And yet histology showed it had nearly escaped the capsule"

(58 years' old, metro area, family history, Gleason 7)

"DRE during a Colonoscopy/Gastroscopy as a follow-up for severe stomach reflux cramps"

(57 years' old at diagnosis, regional area, family history, PSA of 1.6, Gleason 9)

Concerns regarding GP knowledge / oversight

"It was misdiagnosed, but when a doctor says it's nothing to worry about. You only have blood in your urine because you're getting old, you're happy it's not cancer and don't worry about it. But after four years I followed it up with another doctor and he said there was sign from the previous tests. So disappointing."

(52 years' old, metro area, family history, PSA of 12)

"I asked to be tested. My GP had missed an elevated PSA 3 years earlier"

(60 years' old, metro area, no family, PSA of 19.4, Gleason 9)

"DRE was performed by Urologist after PSA result known. He saved my life. In my case I was NOT told by my GP that my annual medical checkup blood test would include a PSA test. I only found this out when hearing the results of blood test for annual medical. Is this professional medical conduct, is this in accordance with RACGP prostate testing guidelines?"

(73 years' old, regional area, no family history, PSA of 22, can't remember Gleason)

Diagnosis by accident / good fortune

"PSA test added to other blood test requested for knee surgery – I was lucky!"

(50 years' old at diagnosis, metro area, no family history, PSA of 5.4, Gleason 3+4)

"I was in hospital with GBS and they found it"

(66 years' old at diagnosis, regional area, family history)

Diagnosis following TURP

"Tailings tested after a TURP showed prostate cancer, after which PET scan showed PC had travelled to my pelvic glands"

(75 years' old, regional area, no family history, PSA of 33)

"Sent to urologist to deal with low flow and nighttime frequency a possible TURP intervention"

(70 years' old, regional area, no family history, PSA of 1.8, Gleason 9)

Men needing more education about prostate cancer testing

"I was given a pamphlet when I attended a community event in my home town"

(62 years' old, regional area, did not know family history, PSA of 7.8, Gleason 8)

"Information night where urologist did not like my doubling PSA"

(70 years' old, metro area, no family history, PSA of 8.5, Gleason 3+4)

"At 70 I had no knowledge of a PSA test !!!"

(70 years' old, regional area, no family history, PSA of 27, Gleason 8)

Men having to advocate for their own health

"I had to convince doctor I wanted a test he said I had no symptoms but I had a premonition"

(63 years' old, rural/remote area, no family history, PSA of 9, Gleason 8)

"I demanded a PSA test"

(72 years' old, regional area, no family history, PSA of 12, Gleason 9)

"Stand alone PSA and free test at my request"

(72 years' old, metro area, no family history, PSA of 6.8, Gleason 7)

Delays leading to worse diagnostic outcomes

"Very poor GP follow through and first referral to urologist who indicated no need to pursue follow up. A delay in two years resulted in a Gleason score of 9 and hence urgent prostatectomy. Now six years later small lymph radiation outside prostate"

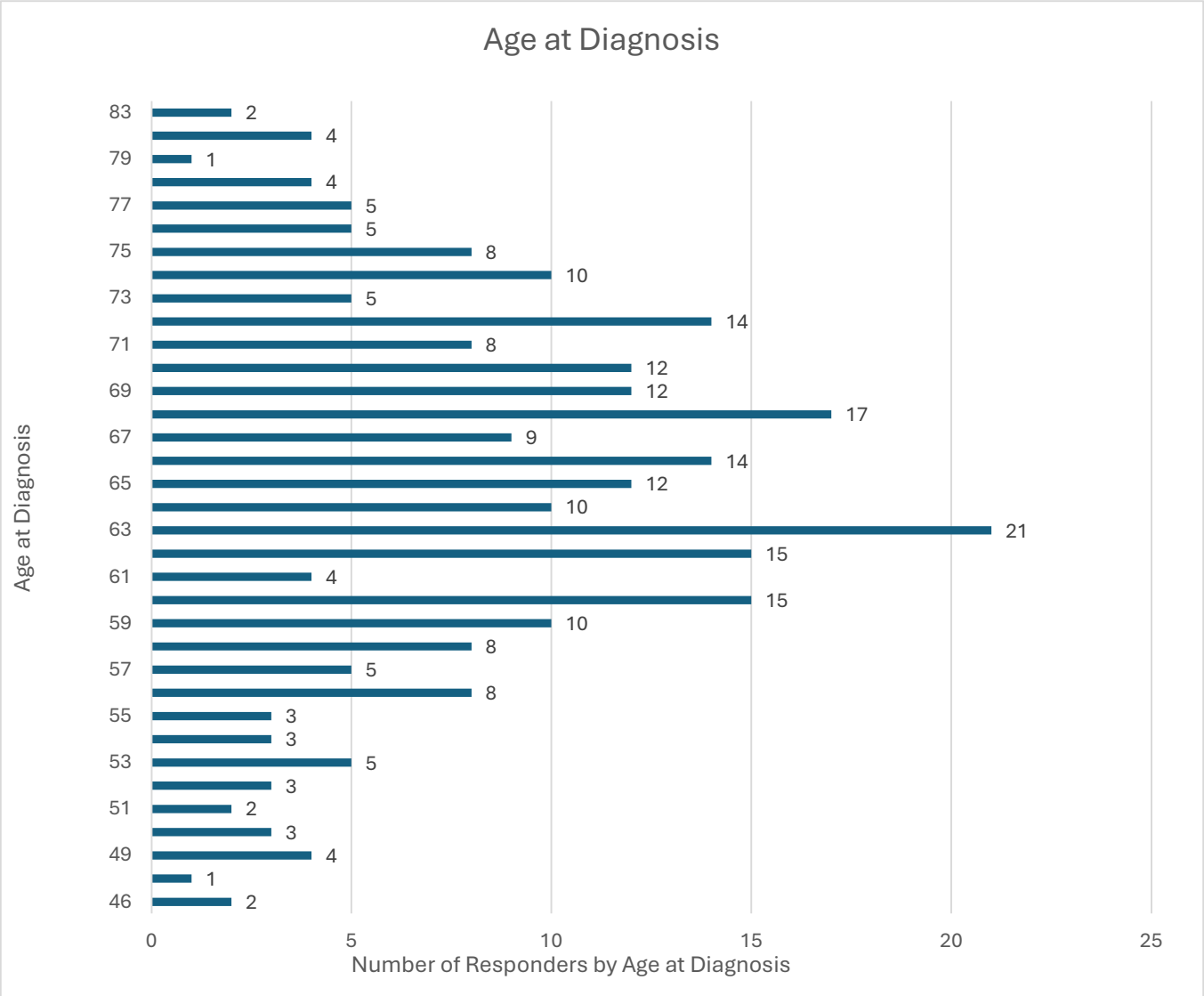
(71 years' old, regional area, family history unknown, PSA forgotten, Gleason 9)

"Initially had UTI with septicemia, and PSA 36. Follow up blind biopsy 12 months later at PSA 10. Missed the spot, follow up irregular testing showed a fall to 5.2 and 3.9 followed by marked rise to 8.2 over 2 years. Missed the diagnosis at 54"

(60 years' old, metro area, family history unknown, PSA of 8.4, Gleason 3+4)

ANALYSIS OF RESPONSES

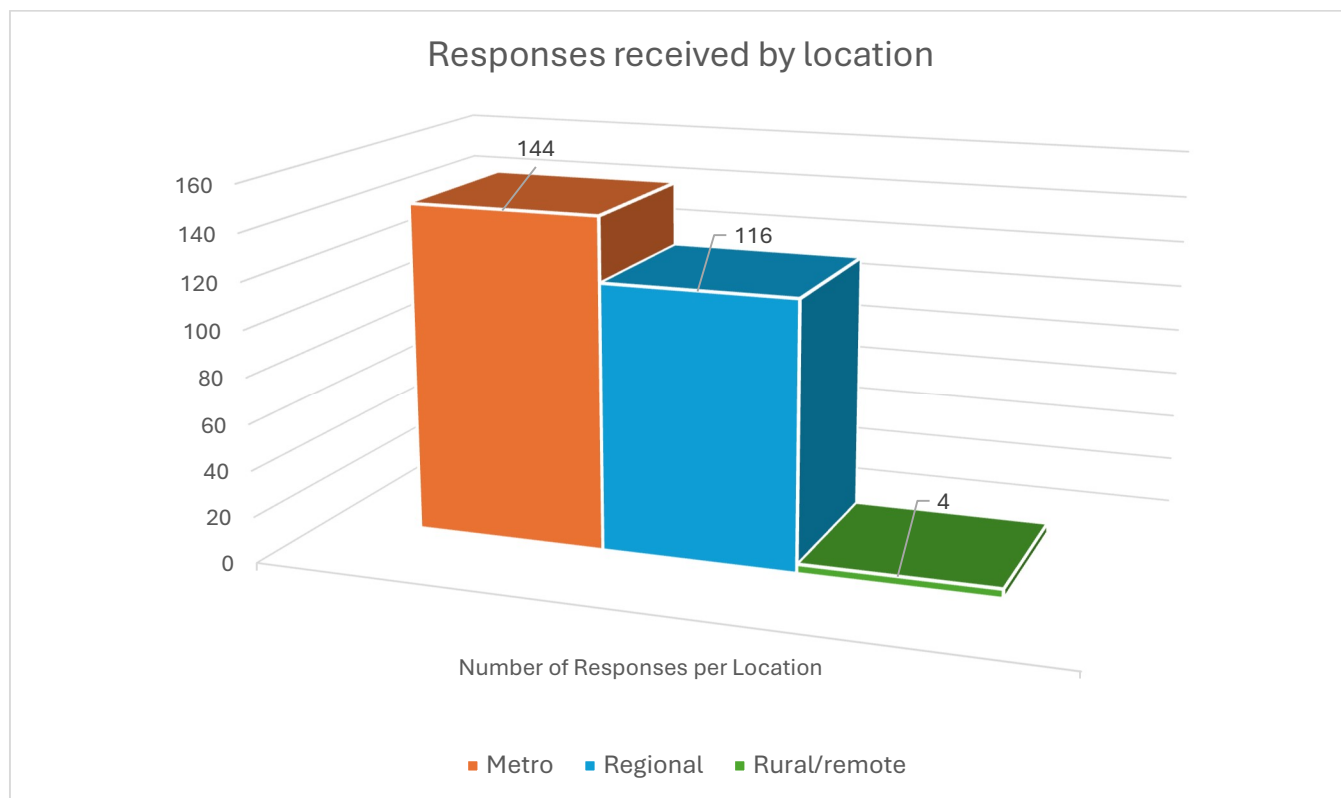
Question 1: How old were you when you were first diagnosed with prostate cancer?



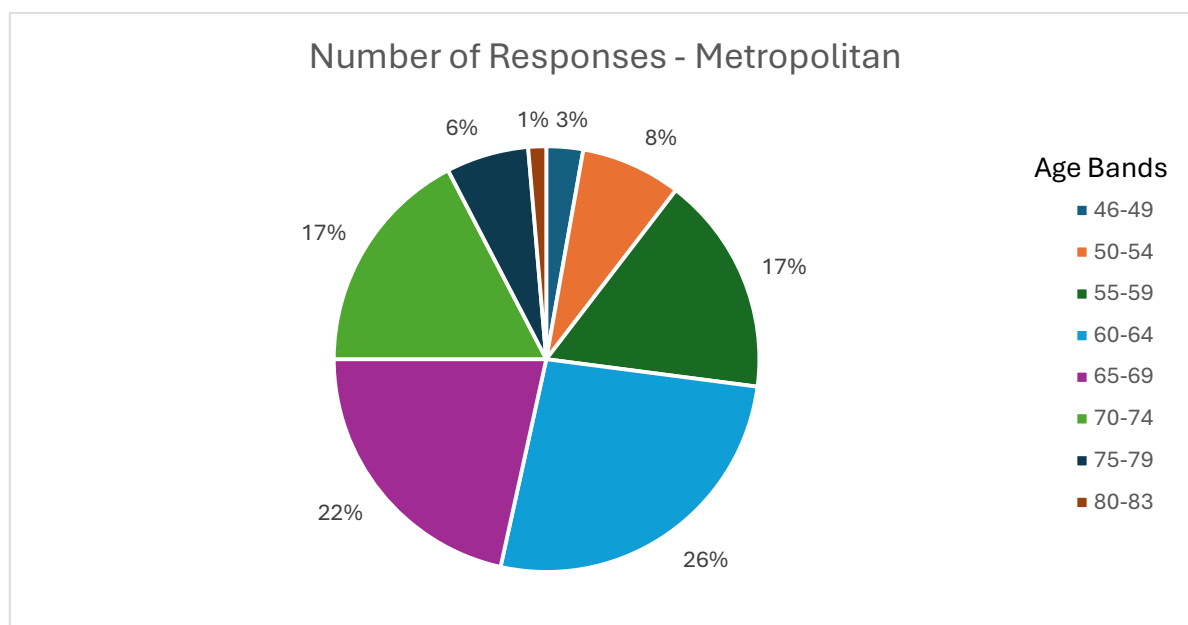
As the large spread of ages (from 46 to 83) proved unwieldy to work with, a set of age bands was created.

Age Bands	Number of Responses
46-49	7
50-54	16
55-59	34
60-64	65
65-69	64
70-74	49
75-79	23
80-83	6
	264

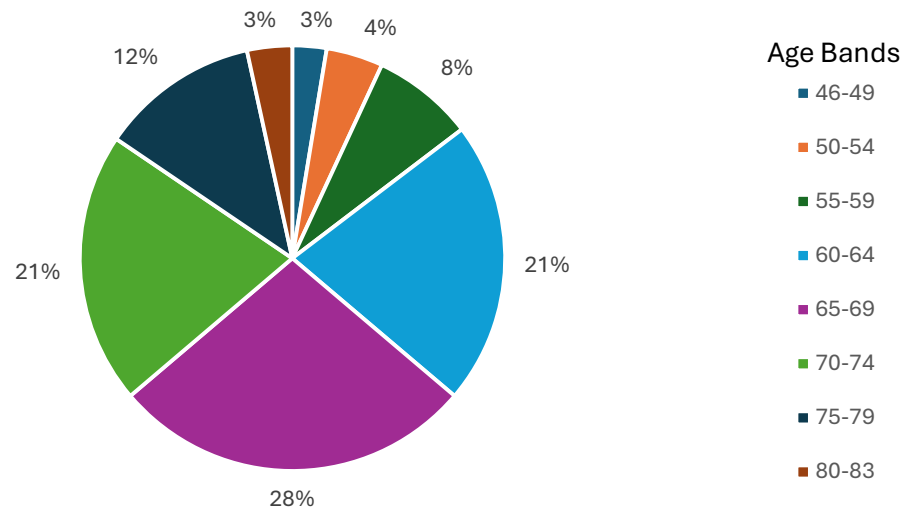
Question 2: Where were you living when you received your prostate cancer diagnosis?



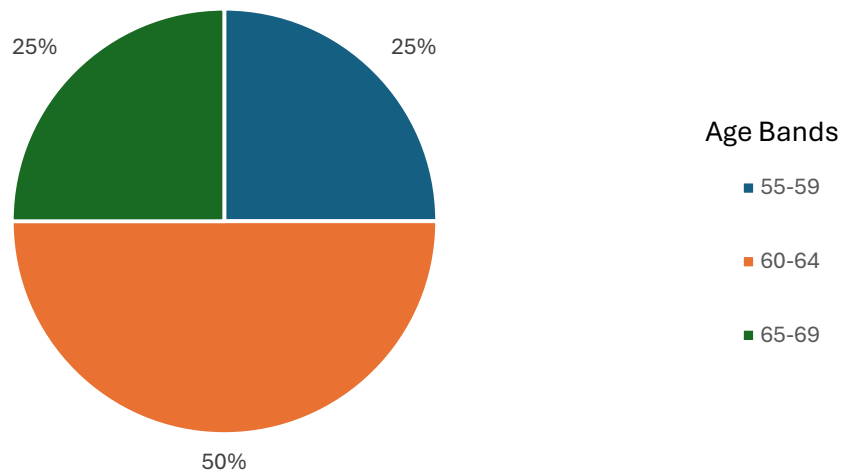
NB: Two responders listed their location at diagnosis as "Canberra" and one listed theirs as Tasmania. I chose to assign those three responses to the "Regional" category.



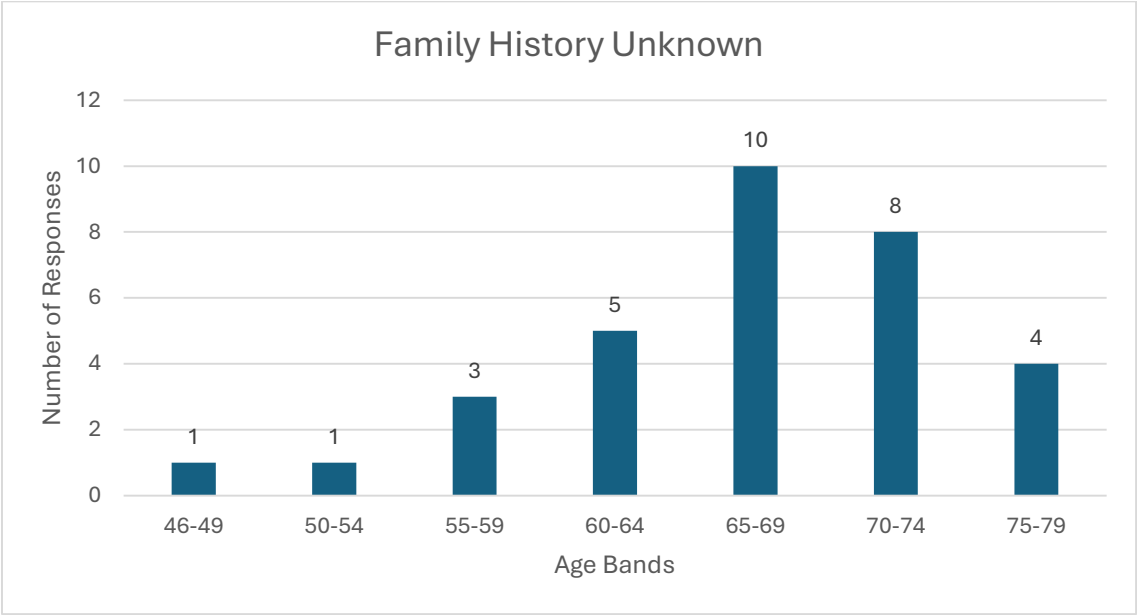
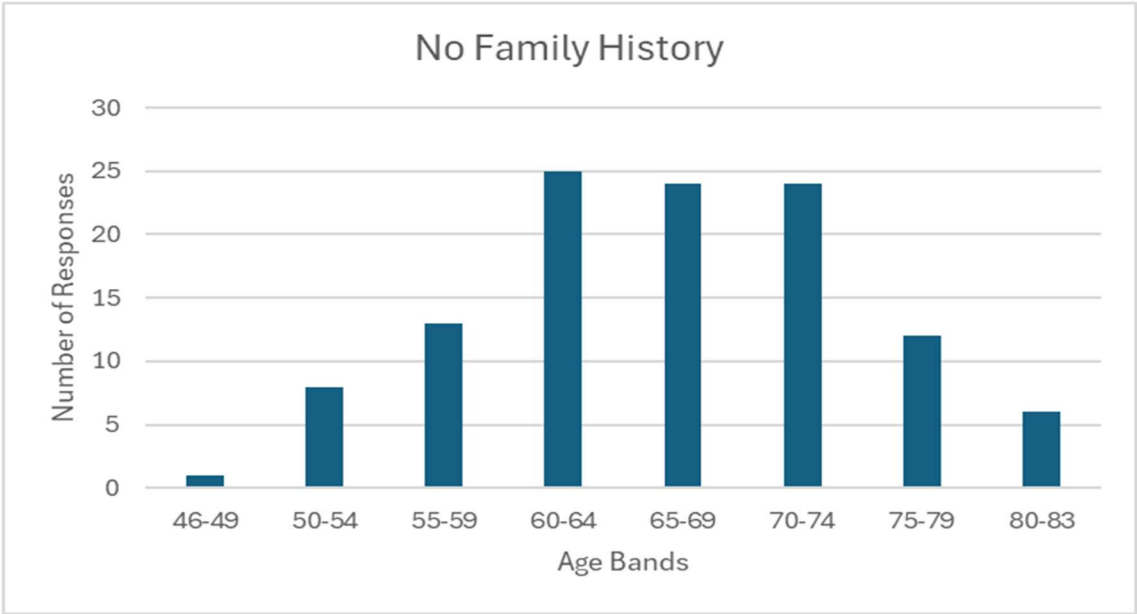
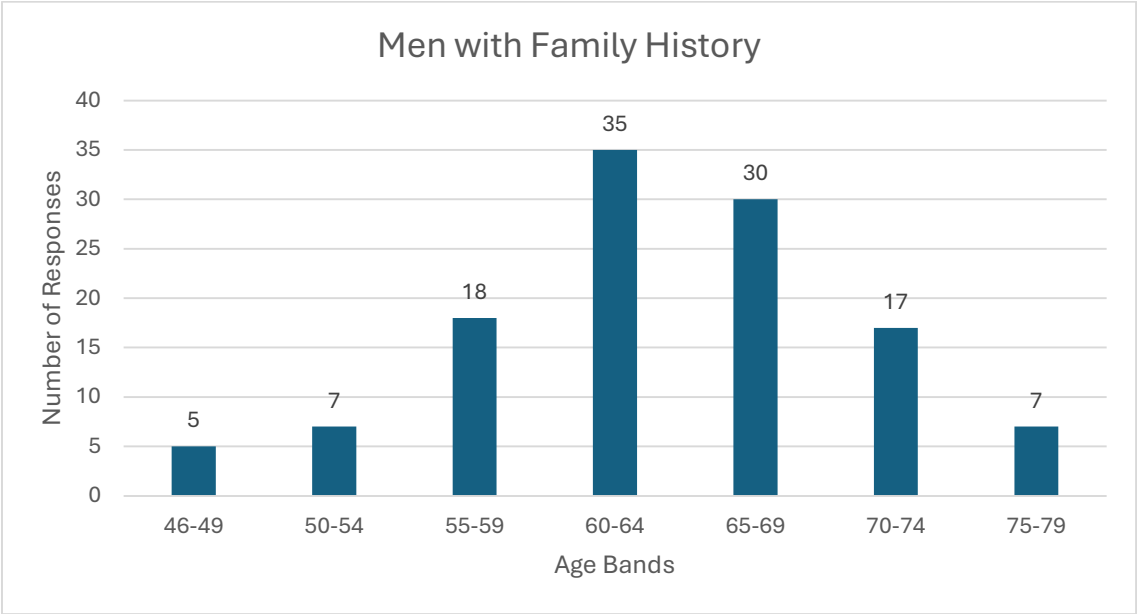
Number of Responses - Regional

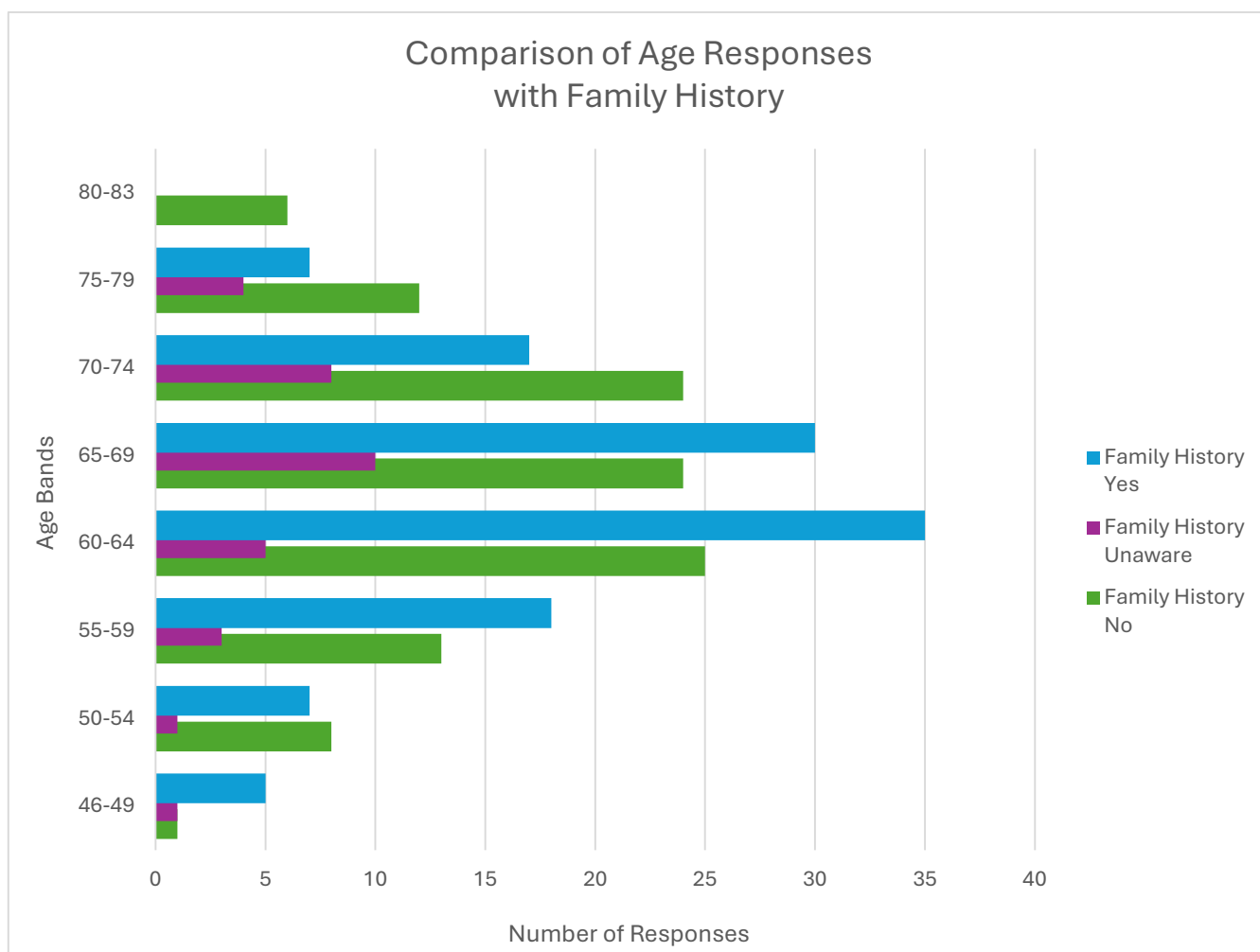


Number of Responses - Rural or Remote



Question 3: Do you know if anyone else in your family (parent, grandparent, sibling) had prostate cancer, breast cancer or ovarian cancer?





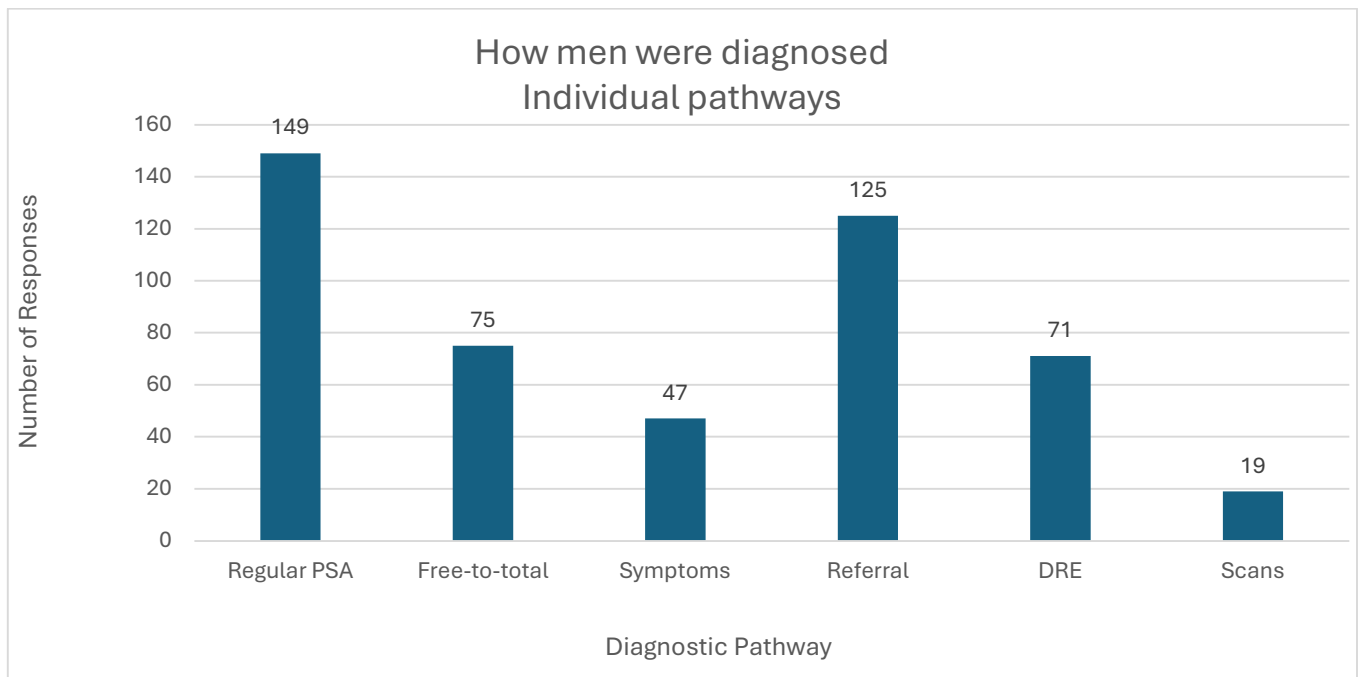
Question 4: How did you come to be diagnosed with prostate cancer?

- Regular testing routine (standard PSA)
- Follow-up testing by GP (Free-to-Total PSA)
- Symptomatic visit to GP
- Referral by GP to specialist due to test results
- DRE (digital rectal examination)
- X-ray or scan showed cancer spread
- Other

With the benefit of hindsight, this question could have been approached differently. Many men selected multiple steps (or pathways) which led to their diagnosis with prostate cancer.

In light of the move to end GPs conducting digital rectal examinations, it was interesting to see the large number of responses where DRE was part of the process (in some instances, men highlighted the DRE as being critical to their diagnosis).

One benefit of including the “other” category in this question was the large number of responses that included detailed descriptions of diagnosis and issues that arose for many men.



The final two questions proved extremely difficult to analyse in a meaningful way. Many respondents were unable to remember these figures.

Question 5: What was your PSA level?

Of those respondents who did list their PSA levels, it would appear that the lowest PSA level was 0.07 ng/ml and the highest listed was 583 ng/ml.

Question 6: What was your Gleason score or cancer grading?

Again, many respondents could not remember their scores. The highest score listed was 9.

REMARKS ABOUT THIS SURVEY

This survey was created to get a snapshot of men's journeys through their prostate cancer diagnoses. It was put together very quickly so that the responses could be used to inform our submission to the Draft 2025 Guidelines for the Early Detection of Prostate Cancer in Australia.

If I had taken longer to consider the structure of the survey, I would have liked to incorporate a couple of additional questions.

It would have been interesting to ask the following questions –

- What kind of treatment did you choose?
 - Active surveillance
 - Surgery
 - Radiation (brachytherapy, etc.)
- Were you treated in the public or the private health system?
- Were you diagnosed with advanced (metastatic) prostate cancer?
- What year were you diagnosed with prostate cancer?
- Since your diagnosis, have you spoken with other men about the need for prostate cancer testing?

It is also worth noting that I would have loved to have help from someone with better mathematical and/or analytical and/or graph-making skills. Any offers for future surveys will be gratefully considered.