

Summary of Consumer Consultation Findings

Review of the 2016 Clinical Practice Guidelines for PSA Testing

Call for consultation

Consultation period: April 18 – June 3, 2024.

Respondents (N=70)

Refer Appendix 1 for demographics table.

Key Findings

Seven questions were asked in the consultation call (refer next page), with the following six overarching themes identified.

1. Simpler consumer-friendly guidelines

- Dedicated version of guidelines for consumers
- Simple messaging, easy to read and understand
- Advocate for benefits of testing (versus harms of testing)
- Support decision making
- Regularly updated to align with evolving diagnostic technology and treatment options
- Incorporate quality of life considerations and connection to survivorship supports
- Include partners in the messaging

2. PSA testing parameters

Irrespective of risk factors or presence of symptoms:

- Commence testing from age 40
- No age limit for ceasing testing
- Annual testing
- Lower PSA threshold for investigation to 2.0 ng/mL
- Look to fluctuations in PSA as a trigger for further investigation even if PSA under threshold
- Raise awareness of family history and need for earlier testing
- Support/encourage GPs to proactively offer PSA testing

3. National screening and awareness program

- Establish a national screening and awareness program for prostate cancer with annual testing reminders

4. Health professional education and support

- Targeted health professional awareness and education program to raise awareness of PSA testing guidelines, prostate cancer generally and dispel misinformation
- Focus on benefits versus harms of testing
- Sentiment that some GPs actively discourage PSA testing or are reluctant to test

5. One national guideline

- Ensure one uniform national guideline
- Ensure alignment of Royal Australian College of General Practitioners (RACGP) guidelines with updated NHMRC guidelines

6. Marginalised communities and socioeconomic considerations

- Consider marginalised and at-risk communities as risk-factor in itself and escalate testing accordingly
- Dedicated awareness raising for rural/remote communities, appropriate resources/awareness initiatives for CALD groups
- Consider changes to PBS and Medicare to support free PSA testing and reduced costs of diagnostics
- Streamline testing and results processes (referrals, minimise GP appointments)

Consultation Questions

A summary of responses by questions are given below.

1. Have the 2016 Guidelines been effective? Please explain your view (n=57)

- No: 68% (n=39)
 - Somewhat: 14% (n=8)
 - Unsure: 9% (n=5)
 - Yes at the time, but need updating: 5% (n=3)
 - Yes: 4% (n=2)
- Guidelines discourage early detection and monitoring with focus on harms of testing
 - Ambiguous, too wordy/lengthy to clearly understand
 - Lack adequate consideration of family history
 - Conflict with RACGP guidelines – need single national guideline
 - Not consumer friendly
 - Do not consider quality of life/survivorship needs
 - GP refusal/reluctance to test despite guidelines – do not encourage proactive screening/testing

2. How can the Guidelines be strengthened to improve outcomes for people impacted by prostate cancer?

- Start screening at 40, no age limit
- Consider earlier screening if family history of prostate cancer
- Mandate annual testing
- Focus on changes in trajectory of repeated PSA tests
- Guidelines should encourage proactive testing and information provision – change the focus from harms of testing
- Dedicated consumer version:
 - simpler messaging
 - easier to read and understand
 - supports decision making
- Integrate survivorship care, e.g., quality of life considerations, links to prostate cancer specialist nurses, support group awareness
- Make testing more accessible and affordable
- More timely and frequent reviews reflecting advances in diagnostics and treatment

3. In your experience, have the Guidelines aided decision-making at the General Practice level in Australia? Please explain your view.

- Written to discourage over testing – focus is on harms of testing
- Too wordy and ambiguous
- Do not encourage proactive testing
- GPs lack awareness of guidelines and knowledge of how to apply, need dedicated education to support use and uptake



- Outdated attitudes still prevalent (old man's disease, die with not of prostate cancer, PSA over testing, etc.) which impacts willingness to test
- Not enough focus on family history

4. Do you consider the 2016 Guidelines easy to understand? Please explain your view.

- Lack of clarity promotes inconsistency
- Poor guidance overall – too subjective
- Lacking in readily accessible quality information
- Too long and wordy, too technical
- Ideally a short (less than 4-page) summary for consumers which is visually easy to read
- Plain English summary to explain guidelines and what men can expect from their GPs

5. How can we improve the effectiveness of the Guidelines for the Australian community broadly, and for marginalised communities and at-risk groups?

Broadly:

- Simplify the guidelines
- Raise awareness of guidelines and testing
- Focus on early detection
- Clearer messaging on risks and benefits, clear communication strategy for the general public
- Educate GPs in guideline use and more broadly about prostate cancer
- Develop a consumer friendly summary

Marginalised communities and at-risk groups:

- Dedicated awareness raising for rural/remote communities
- Ensure appropriate resources/awareness initiatives for CALD groups
- Ensure marginalised communities and at-risk groups are included in lobbying efforts
- Involve community leaders
- Consider as risk-factor and escalate testing accordingly
- Make PSA testing free

6. Are there any other comments you would like the Guideline Steering Committee to consider?

- Ensure guidelines are regularly reviewed and updated
- There is an urgent need for a consumer-friendly version of the guidelines
- Establish a national screening and awareness program with regular reminders, as currently exists for bowel and breast cancer
- Improve access to testing – costs and processes
- Focus on quality of life versus mortality:
 - early engagement of prostate cancer specialist nurses and support groups
 - psychological support for men and partners/families
 - integrated survivorship care

7. Please tell us more about your experience of prostate cancer, in relationship to the Guidelines

Proactive GPs identify prostate cancer early and often outside current guideline parameters

I was fortunate to have a practitioner who noted a rise in my PSA from 3.2 to 4.2 at age 62 and advised I see a urologist even though I had no other signs of a problem. The urologist decided to do a biopsy even though he was unable to determine any other signs of prostate disease and the biopsy showed I had a highly malignant tumour. After other tests I underwent a radical prostatectomy and now 17 years later I have not had any reoccurrence of the cancer. This experience is so unlike many of my friends who did not have PSA tests and have since died of the disease. I'm sure deaths which could have been prevented with regular routine testing of their PSA.

ID_43

What happens to the men we miss?

I asked my GP to test me at 50 but he talked me out of it due to the 'risk' of unnecessary invasive procedures and lack of family history. He was guided by the guidelines. At 54 I had a radical prostatectomy but invasion outside the capsule. Had I been diagnosed 4 years earlier my risk of recurrence might be much lower or even zero. ID_61

Appendix 1

Table 1: Respondent Demographics

		N=70	(%)
Gender	Male	63	(90)
	Female	6	(8.6)
	Did not answer	1	(1.4)
Regionality	MM1- Metropolitan	39	(55.7)
	MM5 - Small rural towns	13	(18.6)
	MM2 - Regional centres	8	(11.4)
	MM3 - Large rural towns	4	(5.7)
	MM6 - Remote communities	1	(1.4)
	MM7 – Very remote communities	1	(1.4)
	Did not answer	4	(5.7)
State or Territory	Victoria	24	(34.3)
	New South Wales	12	(17.1)
	Queensland	11	(15.7)
	Western Australia	6	(8.6)
	South Australia	5	(7.1)
	Tasmania	3	(4.3)
	Australian Capital Territory	3	(4.3)
	Northern Territory	2	(2.9)
	Did not answer	4	(5.7)
Response type	Individual	67	(95.7)
	Support or consumer group	3	(4.3)
Identifies as	Living in rural or remote area	10	(14.3)
	Aboriginal and Torres Strait Islander	1	(1.4)
	Nil	59	(84.3)
Individual background	Consumer, diagnosed with prostate cancer	52	(74.3)
	Prostate cancer support group leader or member	7	(10)
	Partner of man diagnosed with prostate cancer	4	(5.7)
	Friend of man diagnosed with prostate cancer	1	(1.4)
	Member of the general public	1	(1.4)
	Allied Health	1	(1.4)
	N/A - Organisation/Group Response	3	(4.3)
	Did not answer	1	(1.4)