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Lessons from the implementation of the Australian 2016 prostate specific antigen testing clinical practice guidelines: a descriptive study

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Abstract

Introduction: In 2025, prostate cancer is the most common cancer in Australia, regardless of gender, and is the second most common cause of cancer death despite the opportunities for cure. In 2016, Australian Clinical Practice Guidelines for Prostate Specific Antigen (PSA) testing were published to improve early detection and management of prostate cancer. This study reports on a public consultation into the implementation and impact of these guidelines on prostate cancer diagnosis and outcomes.
Methods: Thematic analysis of responses from a public consultation conducted in accordance with best-practice guideline development processes. A national Call for Submissions, using a coordinated public notification strategy, was made, inviting consumers with an interest in PSA testing for prostate cancer to share their experiences via an online platform. Seven questions were posed to all respondents.
Results: Consumers described the 2016 Guidelines as ineffective based on negative message framing, lack of uptake of the guidelines by key primary care groups, and low community awareness. Although a small number of men reported that they were able to access early detection and subsequent curative treatment, the majority of men reported missed opportunities for testing, resulting in diagnoses with late-stage disease. Suggestions for future successful implementation included a consumer companion to the guidelines, regular guideline review, a national education and awareness program, and targeted education for health professionals.
Conclusions: Australia's future response to the growing burden of prostate cancer rests on key stakeholders across the health system to ensure alignment and compliance with updated Guidelines. Effective implementation of such guidelines in the future requires a well-resourced education and awareness program for both the lay and clinician communities, and consistency in adoption and practice across key medical groups.

Introduction

Evidence-based clinical practice guidelines ('guidelines') are intended to optimize patient care by providing best practice recommendations for health professionals informed by a systematic review of evidence and assessment of the harms and benefits of alternative care options.[1] For health professionals, guidelines provide a concise summary of large amounts of evidence on a specific topic to facilitate optimal evidence-based decisions for patients in a time-efficient manner.[2] A primary benefit of guidelines is to improve quality of care for patients by promoting interventions with positive clinical outcomes and discouraging the use of

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potentially harmful or ineffective interventions.[2] Guidelines can also support patients to make informed decisions about their healthcare, reduce unwanted variation in clinical practice, and influence public policy.[3]

However, guideline development is labour-intensive and costly, and development alone does not guarantee uptake by health professionals or improved patient care,[4] evidenced by a worldwide lack of adherence to guidelines across conditions, disciplines, and levels of care.[5–7] Rather, targeted and effective dissemination and implementation strategies are required to support guideline adoption, use and sustainability following development and release.[8–10] Increasingly, the development of guidelines in clinical practice standard mandates dissemination and/or implementation strategy planning as part of guideline development.[11,12] This includes, where possible, evaluating the implementation of current/previous guidelines when guidelines are updated.[11] In addition, a limitation of many clinical guidelines is the failure to include a genuine consumer perspective.[13] It is argued that consumer involvement in health policy and care is a moral right that brings value to the process by incorporating real-world experience that supports patient-centred care.[14]

PSA testing guidelines for prostate cancer

Prostate cancer is the second most commonly diagnosed cancer globally, with almost 1.5 million new cases diagnosed in 2022.[15] Excluding skin cancer, prostate cancer is the most frequently diagnosed cancer in men and second only to lung cancer in terms of mortality.[15,16] Globally, almost 400 000 men will die of prostate cancer annually, a number that is expected to increase as prostate cancer incidence is projected to more than double to 2.9 million annually by 2040.[17] In Australia, prostate cancer is the most commonly diagnosed cancer, irrespective of gender, with ~26 000 men diagnosed annually, and almost 4000 men dying from prostate cancer each year.[18]

Since the early 1990s, in countries other than Australia, guidelines for testing programs using PSA testing have been promoted to facilitate early detection and management of prostate cancer and reduce prostate cancer-specific mortality.[19–21] Prior to the advent of PSA testing, one in every two to three men diagnosed with prostate cancer died from their disease, with most men diagnosed with late stage incurable disease.[22]

PSA is a sensitive but relatively non-specific marker for prostate cancer. Elevated serum PSA has long been associated with prostatic malignancy,[23] however, it is not specific to prostate cancer and can be the result of both malignant and benign processes. Consequently, while early PSA testing programs were effective in reducing prostate cancer–specific mortality rates,[24] there was insufficient knowledge to distinguish between significant and insignificant cancer. This resulted in overtesting, overdiagnosis, and overtreatment of asymptomatic men with indolent prostate cancer that would not have presented symptomatically in their lifetime.[25] Actual harms of testing in this period included unnecessary biopsies and associated risks (e.g., sepsis), psychological distress related to diagnosis, and resultant treatment morbidities such as erectile dysfunction and urinary incontinence, which can have severe and persistent effects on quality of life.[26] To date, PSA testing has been a contentious issue, particularly in primary health care, with wide variations in clinical practice guidelines,[27–29] despite advances in diagnostic processes, for example, multiparametric magnetic resonance imaging, ultrasound-guided transperineal biopsy and use of active surveillance, which substantially mitigate potential harms of testing.[17]

In Australia, PSA testing first became widely used in the 1990s as a *de facto* screening measure for prostate cancer.[30] In 1995, the Australian Cancer Society advised against PSA screening in a policy statement for health professionals.[31] This position was supported in 1996 by the Royal Australian College of General Practitioners (RACGP), and the Australian Health Technology Advisory Committee, who reported that the evidence for screening using PSA testing did not meet accepted criteria for benefits, risks and costs,[32] however, acknowledged that the evidence for *de facto* screening must be monitored and reviewed as developments occurred. Despite these recommendations, the rates of *de facto* screening in Australian men aged over 50 was high, with a five-fold increase in men being tested between 1989 and 1996 (1.1 million men tested), and a doubling of PSA tests per year between 1994 and 2006.[30]

In 2007 the Urological Society of Australia and New Zealand (USANZ) recommended that healthy men aged 50–70 years be screened after giving appropriately informed consent.[33,34] Subsequently, the Prostate Cancer Foundation of Australia (PCFA) and Cancer Council Australia released national evidence-based clinical practice guidelines in 2016 for PSA testing and early management of test-detected prostate cancer (‘2016 Guidelines’).[35] These guidelines were developed to support the appropriate use of PSA testing, and facilitate men and their doctors to be able to discuss testing openly and enable men to make informed decisions about testing based on the latest available evidence and their own personal values and health priorities.[35] The 2016 Guidelines recommend that men at average risk of prostate cancer who have been informed of the benefits and harms, and who decide to undergo regular testing, should be offered testing every 2 years from 50 to 69 years.[35]

With the expiration of the 2016 Guidelines in 2021, the Australian Federal Government announced funding in 2022 to update these Guidelines. In 2023, the PCFA, under an Agreement with the Commonwealth Department of Health, commenced a review and update of the 2016 Guidelines following National Health and Medical Research Council (NHMRC) procedures and requirements for Guideline development.[36] A core requirement of guideline review per the NHMRC is the consideration of factors related to guideline implementability to ensure effective dissemination and uptake of updated guidelines.[11] Hence, as part of this guideline review, PCFA undertook a public consultation to explore consumer experiences of the 2016 Guidelines to inform the implementation of the updated Guidelines.

The aim of this study is to report consumer perspectives of the 2016 Guidelines and the identification of factors affecting guideline implementation.

Methods

Ethics statement

This project was reviewed by the University of Southern Queensland Human Research Ethics Committee and deemed exempt from ethical review (Exemption ID: ETH2024-0299).

Public consultation

The PCFA released a Call for Submissions (‘the Call’) inviting Australians interested in PSA testing for prostate cancer to share their views on the 2016 Guidelines. The Call was open for 6 weeks from April to June 2024 and conducted in accordance with the five steps for Public Consultation in the NHMRC Guidelines for Guidelines Handbook.[36] Seven questions were agreed upon by the Project Steering Committee and posed to all respondents (Table S1). A coordinated public notification strategy was implemented comprising national newspaper advertisements, social media posts, press releases, blog posts, and PCFA network and website distribution. Combined reach was an audience of ~3.1 million people.

Data extraction and analysis

Upon closing the Call, submissions were extracted into a de-identified excel spreadsheet by PCFA and provided to the University of Southern Queensland, Centre for Health Research, Cancer Survivorship Research Group for independent analysis. Thematic analysis[37] of responses was undertaken. Initial data coding was guided by the submission questions, with codes and collated data examined for potential themes. Overarching themes between questions were identified and further synthesized. To ensure rigor, the preliminary themes were identified independently (NH and JD) and refined through collaborative analysis until the final themes and subthemes were confirmed.

Findings

Respondent demographics

Seventy respondents submitted to the Call, of which 94% ($n = 66$) were male. All Australian States and Territories were represented, with 56% of respondents residing in metropolitan regions. The majority of respondents (87%, $n = 61$) replied as individuals with a current or previous diagnosis of prostate cancer, with four respondents (6%) replying on behalf of a prostate cancer organization/group. Five (7%) respondents identified as partners ($n = 4$) or friends ($n = 1$) of men with prostate cancer (refer Table 1).

Table 1 Respondent demographics

		$N = 70$	(%)
Gender	Male	66	(94.3)
	Female	4	(5.7)
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	12	(17.1)
	Western Australia	5	(7.1)
	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	66	(94.3)
	Support or consumer group	4	(5.7)
Identifies as	Living in rural or remote area	10	(14.3)
	Aboriginal and Torres Strait Islander	1	(1.4)
	Nil	59	(84.3)
Respondent background	Man diagnosed with prostate cancer	61	(87.1)
	Partner of man diagnosed with prostate cancer	4	(5.7)
	Prostate cancer Organization/ Group response	4	(5.7)
	Friend of man diagnosed with prostate cancer	1	(1.4)

Themes

Five primary themes and six subthemes were identified in the qualitative analysis (Textbox 1). Two contrasting experiences were apparent across the submissions. The first was reports from men for whom discussions about PSA testing were not raised and/or were denied or advised against initial/further testing by their General Practitioner (GP) on the basis that they were asymptomatic or did not meet age or PSA thresholds set out by the guidelines. Second, men whose prostate cancer was diagnosed early as a result of proactive testing and monitoring by their GP and often outside the 2016 Guideline recommendations. Respondents identified four key areas for consideration for implementing the updated guideline: a simple consumer companion to the Guidelines; timely and regular Guideline review; raising Guideline awareness and accessibility; and targeted education for health professionals. The corresponding tables below include examples of quotes for each theme and subtheme.

Textbox 1 Themes and subthemes.

Theme 1: These guidelines are not effective – a focus on ‘harms of testing’ denied me early detection
  Subtheme 1: What happens to the men we miss?
  Subtheme 2: Conflicting guidelines are dangerous
Theme 2: Proactive testing, outside the Guideline recommendations, saved my life
Theme 3: PSA testing parameters that support proactive testing
Theme 4: Where is the survivorship care?
Theme 5: Implementation considerations for updated Guidelines
  Subtheme 3: Simple consumer companion to the Guidelines
  Subtheme 4: Timely and regular Guideline review
  Subtheme 5: Awareness and accessibility
  Subtheme 6: Targeted education for health professionals

Theme 1: These guidelines are not effective – a focus on ‘harms of testing’ denied me early detection

The majority of respondents felt the 2016 Guidelines were ineffective in facilitating early detection and management of prostate cancer. This was largely due to the guideline’s perceived focus on the harms of testing and downstream management, which discouraged proactive testing and subsequent early detection and monitoring. Numerous respondents reported GP reluctance or refusal to test PSA despite men meeting guideline criteria for testing (Table 2).

Subtheme 1: What happens to the men we miss?. For many respondents, PSA testing was not raised at all by their GPs, their requests for testing were dismissed or denied, or they were not referred for further investigation, resulting in late diagnoses with non-localized or advanced disease and resultant poor quality of life outcomes. Respondents stressed the need for less ambiguity for GPs in the updated Guidelines and a focus on supporting proactive PSA testing and information provision by GPs.

Subtheme 2: Differing guidelines are dangerous. Respondents called specifically for active uptake of the 2025 Guidelines into current editions of the RACGP Guidelines for Preventive Activities in General Practice (Red Book), which were perceived to offer differing testing guidelines regarding how to initiate PSA testing in asymptomatic men. Numerous respondents highlighted the need for a single uniform guideline as the perception that differing guidelines issued by peak bodies were contributing to GPs reluctance to proactively offer PSA testing.

Theme 2: Proactive testing, outside the Guideline recommendations, saved my life

A minority of men reported that GPs initiated and/or supported PSA testing and further investigations, regardless of men's ages, and that initial PSA results sometimes fell outside the 2016 Guideline testing parameters. Men credited these proactive GPs with diagnosing asymptomatic prostate cancer before it became advanced disease (Table 3).

Table 2 Theme 1 respondent quotes

Theme 1: These guidelines are not effective – a focus on 'harms of testing' denied me early detection
There is far too much focus on advising men of the potential harms of testing. Offer any man an excuse not to have a medical test and they will take it. The number of men that I know that have requested a PSA test and the doctors have basically refused or said things like 'I don't want you to get a false positive'. They have created a situation where Doctors focus on the risk of testing instead of the risk of not testing. (ID03)
I had to basically force my doctor to have a PSA test, he said I had no symptoms even though I was 62. And the reading turned out to be very close to the problem limit, but he did nothing except say let's check it again next year. Well, when next year came around my reading was very high so then off to specialists for a prostatectomy, radiation, hormone therapy and a lot of anxious medical time. (ID42)
Subtheme 1: What happens to the men we miss?
I am now 69 years old and was diagnosed with de-novo metastatic prostate cancer after my very first PSA test (at age 66). Previously, I had queried my GPs on whether I should be doing a test for prostate cancer – initially soon after I turned 50, and again (with a different GP) soon after turning 60. On both occasions I was informed that testing was not recommended unless there was a family history or symptoms. There was no further discussion entered into or pamphlet or websites given. After my brother was diagnosed with prostate cancer, my GP did refer me for a PSA test. It came back over 70 μg/L, so I was referred for further testing and to a Urologist. Distant metastases were identified and systemic treatments are ongoing to slow the incurable cancer. I sought and followed my health professional's specific advice (a reasonable action for a non-medical person) and did not get screened for PC. I now have incurable stage 4 cancer, a poor prognosis and ongoing treatment side effects. (ID56)
I had a PSA above 3 and was not advised to re-test. Two years later I had a PSA above 8 and a Gleason score of 9. I am now stage IV and considered terminal. (ID03)
Too often new members come to our support group with advanced or metastatic prostate cancer because there was no PSA test until they asked their GP about their urinary symptoms. Others were actively discouraged or refused a PSA referral until they complained about the effects of prostate enlargement. (ID07)
I left it four and a half years between test, I was told by a urologist after examination that I was an unlikely candidate for prostate cancer 13 years ago only to be diagnosed with severe prostate cancer that has metastasised. GPs were having my blood tested for all sorts but not a PSA until I insisted and not for the first time GPs generally seem reluctant to have a PSA done. (ID21)
The GP didn't do anything when my husband had many symptoms…just because his PSA was 'low of, 5.3'. If the GP was equipped with the right knowledge, he would have sent my husband to a scan and specialist. He didn't till 3 years later with stage 4 cancer. Who can I blame? Nobody as according to him, he followed the 'guideline'. He was afraid of over-diagnosing as men tend to get depression. (ID26)
The implementation of the guidelines has certainly not been effective in minimizing harm in my own case. I was twice cautioned away from starting PSA testing by GPs stating that the risks outweighed the benefits, only to eventually be diagnosed with incurable metastatic prostate cancer after finally being given a test. (ID56)
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. (ID61)
I recall one man who had waited the two years for testing and had gone from no need for further follow-up to having advanced prostate cancer with not much time left to live. A one-year break between PSA testing probably would have detected the cancer earlier and at a treatable stage. I have experienced discussion with many men over the years where a two-year gap has led to a much more aggressive and life-threatening prostate cancer. (ID69)
While the 2016 guidelines may have reduced 'overdiagnosis' and 'overtreatment' this has been achieved this at the expense of a cohort of patients who have not been diagnosed until after their cancer has unnecessarily progressed, including some whose cancer has progressed to incurable Stage 4 on initial diagnosis. (ID70)
Subtheme 2: Conflicting guidelines are dangerous
The NHMRC, RACGP, pathologists and urologist colleges all have subtly different guidelines. The most dangerous is that of the RACGP where their interpretation and communication to members is that they are not obliged to offer this test to asymptomatic men. Worse still, they imply that their guideline is in line with the NHMRC 2016 guidelines. (ID41)
As the 2016 guidelines have not been incorporated into the RACGP's guidelines, considerable ambiguity has been created for GP's who seem to be discouraged from suggesting or advocating that patients get screened for prostate cancer. The RACGP needs to be fully on board with the new revised guidelines and need to fully incorporate them into the RACGP's own guidelines. My GPs interpreted…the RACGP guidelines as recommending that PSA testing was not to be undertaken for males at normal risk of [prostate cancer]. This has had significant consequences for me. (ID70).

Table 3 Theme 2 respondent quotes

Theme 2: Proactive testing, outside the Guideline recommendations, saved my life
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. (ID43)
Fortunately, I had a GP who noticed that despite my PSA never being above 3, it had risen slightly, so I was referred to a urologist who found the cancer after a series of tests. The tumour had nearly escaped the prostate. No symptoms. PSA below 3. (ID45)

Theme 3: PSA testing parameters that support proactive testing

Irrespective of their experiences with PSA testing, respondents repeatedly called for changes to the current PSA testing recommendations to support proactive testing. Earlier routine testing was suggested by the large majority of respondents, with many reporting personal experience with a prostate cancer diagnosis under 50 years or having friends who had been diagnosed well under 50 years of age with advanced disease. The upper age recommendation of ceasing testing at 70 years was also questioned, with respondents noting that many men experience long, healthy, and active lives past the age of 70. In addition to extended testing ages, respondents suggested lowering the PSA threshold for investigation to 2.0 ng/mL and monitoring fluctuations in PSA as a trigger for further investigation even if PSA is under the threshold. Many respondents reported that it was this approach that detected their prostate cancer early. Several respondents also suggested increased frequency of routine PSA testing to (at least) annually, versus biennially, which would facilitate earlier detection of PSA fluctuations and could be easily incorporated into annual health checks (Table 4).

Table 4 Theme 3 respondent quotes

Theme 3: PSA testing parameters that support proactive testing
I had a prostatectomy at 47, so I am in the 1% club. Whilst I had clear margins at surgery, some microscopic cells have got away and I will be needing radiation in the next 2–3 years, as my PSA is rising again. It was only picked up as a result of my GP doing a PSA test when I was 46 years of age. Current guidelines for it being for men over 50 don't cover men like me under 50 and are therefore ineffective for all. (ID17)
I think the attitude to stop regular PSA tests at age 69 is ageist and disrespectful. Many men will live active lives into their late 80s and 90s and would not like to die of prostate cancer at age 76 because testing stopped when they turned 69. (ID53)
I think that the 2016 guidelines would not have found my Prostate Cancer. Fortunately, I had a GP who noticed that despite my PSA never being above 3, it had risen slightly, so I was referred to a urologist who found the cancer after a series of tests. The tumour had nearly escaped the prostate. No symptoms. PSA below 3. (ID45)
I believe PSA tests should be part of a man's annual health check-up – along with blood pressure, cholesterol levels, blood sugar, etc. (ID48)

Theme 4: Where is the survivorship care?

Respondents noted an absence of quality of life and survivorship support considerations in the 2016, particularly for men who had been diagnosed with advanced disease. Guidelines and urged inclusion of both in the updated guidelines. For multiple respondents, early referral to a prostate cancer specialist nurse had been instrumental in supporting their survivorship care needs. For others, specialist prostate cancer nursing services and provided '*…care, support, advice, education' (ID27)* that was lacking from other health professionals in their care team (Table 5).

Theme 5: Implementation considerations for updated Guidelines

Based on their own experiences with the 2016 Guidelines, respondents identified four key areas to support the effective implementation of the updated Guidelines: (i) a simple consumer companion to the Guidelines; (ii) timely and regular Guideline review; (iii) raising Guideline awareness and accessibility; and (iv) targeted education for health professionals (Table 6).

Subtheme 3: A simple consumer companion to the Guidelines. Overwhelmingly respondents called for a consumer-friendly companion to the guidelines: '*make a simplified summary, if men are expected to decide then they need to understand*' (ID05). A consumer companion should have clear and simple messaging that advocates for the benefits of testing (versus harms) to support decision-making.

Subtheme 4: Timely and regular Guideline review. Timely and regular guideline review was considered essential going forward as they were seen as '*outdated and no longer reflective of current circumstances*' (ID12). Ongoing, regular reviews were seen as essential to reflect and align with rapidly evolving, less invasive, diagnostic technologies.

Subtheme 5: Raising Guideline awareness and accessibility. There was strong support for both a national guideline awareness program, with '*…guidelines published and advertised in a manner that people can become aware of them*' (ID52), to facilitate uptake of the updated Guidelines, and a national reminder program to

Table 5 Theme 4 respondent quotes

Theme 4: Where is the survivorship care?
I attend a prostate cancer support group and have met quite a few men whose cancers were detected too late for a cure and now have a vastly reduced quality of life due to ongoing treatment and/or mental health issues. There should be more emphasis placed on maintaining quality of life rather than concentrating on mortality. Although the current survival rate is very good, many men are suffering through their later years because their cancer was not detected while it was curable. (ID06)
Include in the guidelines a recommendation that all newly diagnosed patients be referred to a support group and a PCFA specialist nurse or the PCFA telenursing service. (ID47)
The urologist that did my robotic did not deal with the management of sexual rehabilitation at all, and there is a need for staff experienced in discussing this with patients…. (ID39)

Table 6 Theme 5 respondent quotes

Theme 5: Implementation considerations for updated Guidelines
Subtheme 3: Simple consumer companion to the Guidelines
The guidelines are written for GP's and health professionals rather than the general public. They are not easy to interpret. While the shorter Overview of the Recommendations provides a useful (though limited) summary for both health professionals and the general public, an education source in plain English is sorely needed to explain the new guidelines and what blokes can expect their GP s to provide. (ID70)
Subtheme 4: Timely and regular Guideline review
Is it possible for a national advertising/education campaign to be considered so that the message about Prostate Cancer reaches the general population more? There seems to be national adverts about breast cancer, bowel cancer, skin cancer etc. but NOTHING about Prostate Cancer (I sometimes feel that Prostate Cancer is the 'forgotten' cancer because it is only males that experience it). (ID04)
Subtheme 5: Awareness and accessibility
A National Prostate cancer scheme like Breast Cancer, Colon cancer, and Cervical cancer screening schemes would be a very beneficial way to detect prostate cancer early giving better outcomes for the patient. (ID30)
Bowel cancer and breast cancer mail out to all individuals either the information or test kit once in the respective age group. Funding needs to sought from the government to do a similar mail out once a male attains the correct age – which I suggest would be 40. This being more important that we now know that prostate cancer is the highest diagnosed cancer in Australia and the second higher cancer killer of men. (ID69)
Many people are reluctant to visit GPs due to the cost of appointments. People on lower incomes are more vulnerable to missing cancer diagnoses as a result of visiting GPs less often. (ID44)
PSA screening should be free as it is for breast cancer screening mammograms and bowel cancer screening occult blood stool testing. (ID65)
My only comment as a man over 75 years of age is a purely practical one. At my age a regular (say annual) PSA test would seem to be a 'no brainer'. But to get a PSA test I must visit a GP to get a referral, then go to a pathologist to get the PSA test done and then have another GP consultation to get the result. That's two GP visits which add no value at all but impose an extra burden on an already stretched medical system not to mention my time and Medicare. (ID11)
Subtheme 6: Targeted education for health professionals
There needs to be more education geared towards GPs about PSA testing…to think about the risks for the man if the cancer is missed. It seems many GP's are not up to speed unless they have a real interest in the area. (ID27)
…many GP's actively discourage PSA testing…because of what was seen as over treatment where men were pushed into invasive treatments where it may not have been necessary or desirable. Advances in the 8 years since the guidelines were written mean there are now many non-invasive tests that are used before invasive procedures are undertaken." (ID47)
Correcting the perception that men can live with prostate cancer, believing they will die with it but not from it. This is still very much a perception in the community. (ID37)
Also, there are still too many GP's who believe that PSA testing is too common, there is 'over testing' done & that Prostate Cancer is still regarded as an 'Old Man's Disease'. (ID04)

encourage earlier detection of prostate cancer. Many respondents felt '*…the general public doesn't know the guidelines exist until they are told by their GP*' (ID13). Respondents noted that awareness campaigns should extend to prostate cancer more broadly, in addition to dedicated campaigns to promote the updated guidelines. The desire for a national reminder/screening program, akin to existing programs for breast, bowel and cervical cancers, was also suggested as a strategy to improve early detection of prostate cancer. Affordability of PSA testing was noted as a priority alongside the release of the revised guidelines and any subsequent changes to testing recommendations. Respondents also highlighted process issues within the heath system itself that would benefit from streamlining to reduce consumer and health system burden.

Subtheme 6: Targeted education for health professionals. Targeted education and awareness raising for health professionals was seen as essential for future guideline implementation, particularly for GPs. In addition, encouraging proactive testing and dispelling perceived commonly held attitudes and entrenched beliefs around prostate cancer and PSA testing among health professionals was seen as a priority.

Discussion

From a consumer perspective, implementation of the 2016 Guidelines was not effective due to the Guidelines' perceived focus on the harms of testing and treatment, which discouraged proactive testing and subsequent early detection and monitoring of prostate cancer, and poor alignment of the Guidelines across the health sector. Of note, this is a qualitative analysis of public consultation feedback on guideline implementation, and does not examine the effectiveness of the 2016 Guidelines on prostate cancer outcomes.

For many respondents, attitudes from general practitioners around PSA testing were perceived as outdated and negative (e.g., a consistent theme that GPs consider the harms of testing outweigh the benefits, or that PSA is an overused test). These attitudes were seen as driving the varied testing practices respondents experienced primarily in General Practice, in conflict with a guideline's primary purpose of reducing unwanted variations in clinical practice.[38–40] For men seeking PSA testing, their care experience appeared contingent on the reasoning, practice preferences, and responsiveness to patient preferences of the general practitioner, and the practitioner's views and approach to over/underdiagnosis of prostate cancer.[40]

Another key implementation failure lay in the perception of differing recommendations in a second national guideline. Although the 2016 Guidelines were endorsed by the RACGP,[35] the RACGP Guidelines for Preventive Activities in General Practice (Red Book), were, until 2023, subtly different in approach to the 2016 Guidelines.[41–43] The RACGP guidelines suggested that PSA testing only be performed at the patient's request, who should then be informed of the benefits and risks associated with the test. In contrast, the 2016 Guidelines suggested offering PSA testing to men who were informed of testing benefits and harms. Respondents perceived these differing recommendations contributed to variations in PSA testing at the primary care level in Australia, with the opportunity to discuss PSA testing and the decision to screen appearing more influenced by primary health care providers' personal views, rather than consumer preferences.[44,45]

Most respondents reported that the 2016 Guidelines were not easy to understand and called for a consumer-friendly companion to the guidelines, with clear and simple messaging that advocates for the benefits of testing to support decision making. Consumer companions to guidelines, and/or supporting resources aimed at consumers, have long been shown to empower patients to make more informed healthcare choices based on their personal preferences and needs,[3,46] which, in turn, underpins effective guideline implementation.[47]

Respondents also strongly recommended a national guideline awareness program to facilitate the uptake of the updated guidelines at the primary care level and raise public awareness of the updated guidelines. Research conducted by the PCFA in 2021 found that ~75% of Australians were unaware of the 2016 Guidelines, even 5 years after their release[48] which supports these findings.

Given the implementation shortcomings identified by consumers, priorities for the updated Guidelines must include federally funded strategies for a population-wide national guideline awareness and education campaign encompassing: an evidence-based communication and education strategy; targeted approaches for general practitioners and consumers; development of a consumer companion to the updated guidelines that communicates the risks and benefits of testing to support informed choice and shared decision making; and ensuring there is a single national guideline and alignment of the RACGP Red Book with the updated guideline recommendations.

Study limitations

Although a broad public notification strategy was employed to seek participants in feedback, respondents were entirely consumers or consumer representatives who were already actively engaged with prostate cancer management and/or testing. Additionally, despite a national effort for submissions, respondent numbers were small. The cohort of respondents, while broad in representation geographically, were notably homogenous in their experience of prostate cancer. It is possible that those who responded were more likely to have had a negative experience with PSA testing and resultant negative outcomes, and those who had a positive testing experience/outcome may not have been represented. Of note, no respondents reported negative outcomes from testing and/or subsequent treatment. These factors represent a potential bias and limitation of the findings.

Conclusions

There are strong and clear messages from consumers on the implementation limitations of the 2016 Guidelines. Notwithstanding the 2016 Guideline recommendations and state of evidence at the time of development, respondents perceived attitudes to PSA testing in General Practice to be outdated, with a focus on the harms of testing rather than the benefits of early detection and patient-centred management. Non-alignment of the 2016 Guidelines across the health system, coupled with a negative framing of PSA testing, has likely led to wide variations in testing and management of prostate cancer to the detriment of Australian men.

Further, the absence of public awareness and education activities around the 2016 Guidelines and the failure to produce a plain English consumer companion served to amplify confusion and misinformation, leading to frustration and dissatisfaction in the community. In addition, priority populations and those at a higher risk did not benefit from targeted or culturally tailored strategies to address their specific circumstances.

Australia's future response to the growing burden of prostate cancer now rests on key stakeholders across the health system to ensure alignment and compliance with updated Guidelines. A critical priority in the implementation of future Guidelines is the alignment of all providers and sectors in the health system to deliver consistent messaging on PSA testing and facilitate a risk-adapted response to the early detection and management of prostate cancer. Only then, with the support of appropriate and well-resourced education and consumer engagement campaigns, will the Australian community gain maximum benefit from advances in the early detection of prostate cancer.

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