



Prostate Cancer
Foundation of Australia

PROSTATE CANCER: THE NEXT GENERATION

2013

COMMUNITY
ATTITUDES
SURVEY

Our Vision, Mission and Values

Prostate Cancer Foundation of Australia (PCFA) is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

We do this by:

- Promoting and funding world leading, innovative research into prostate cancer
- Implementing awareness campaigns and education programs for the Australian community, health professionals and Government
- Supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses

PCFA receives Government funding for specific projects and relies on the generosity of individuals, the community and partnerships, such as those with the Movember Foundation and Commonwealth Bank, to carry out our essential work.

Acknowledgements

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Bayer is once again proud to partner with Prostate Cancer Foundation of Australia for this important initiative.

The survey plays a significant role in identifying and understanding the myriad health issues and situations faced by men confronted with tackling and treating prostate cancer. We are committed to supporting this project so Bayer can provide a positive contribution to men and their families in the hope of improving health outcomes.

Rene Klemm
Country Representative, Bayer HealthCare

FOREWORD



Traditionally, many men have not been proactive about their prostate health. They have seen prostate cancer as a disease that old men die with, not of. Unfortunately, the statistics tell a very different story.

Prostate cancer is the most common cancer diagnosed in Australia, with almost 20,000 men diagnosed each year. Australia and New Zealand have the highest incidence in the world, with one in seven men diagnosed by age 75 and one in five diagnosed by age 85¹.

In Australia about 3,300 men die of the disease each year. It is second only to lung cancer as the most common cause of cancer deaths in men. More men die from prostate cancer than women do from breast cancer².

There are many reasons men give for not talking to their doctor about their prostate health. Some see it as unmanly. Others worry about the digital rectal examination, or that a diagnosis will ruin their sex lives. Controversy in the media about the blood, or PSA, test has not helped.

Previously, our annual Community Attitudes Survey has focused on men aged 40 to 74, largely because less than 3% of prostate cancer diagnoses occur in men younger than 50¹. But what about the next generation, what is their perspective? Do they see prostate cancer as an important health issue and what are their attitudes towards testing, and sources of information and support? This year, our survey provides insight into the attitudes and experiences of men aged 18 to 50.

This survey also marks the first time we have asked participants about their sexual orientation. We were surprised that more than 13% of respondents identified as being gay or bisexual, or did not identify as being heterosexual. The experience of gay and bisexual men with prostate cancer is under researched, so we have reported these findings separately in Section 5.

I trust you will read the report with interest, and join with PCFA on our mission to reduce the impact of prostate cancer on Australian men, their partners and families, and the wider community, through research, awareness and support.

A handwritten signature in black ink that reads "Anthony Lowe". The signature is written in a cursive, slightly slanted style.

Associate Professor Anthony Lowe
Chief Executive Officer



I. METHODS

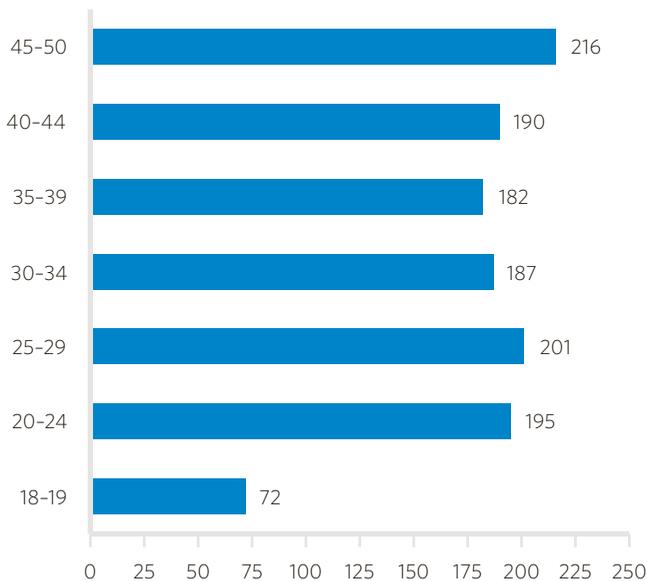
The 2013 survey was conducted on behalf of PCFA by QAI Consulting. The research was hosted by pureprofile and used an online data collection methodology with a sample sourced from a commercial panel of 320,000 Australians.

A total of 1,243 men aged between 18 and 50 participated in the survey. The sample size gives a 95% confidence level with a confidence interval of $\pm 3\%$ in our results.

The data was collected in the period 26 March to 30 March 2013. The collection period was chosen to avoid times, such as September and November*, when significant prostate cancer awareness and fundraising campaigns take place.

Participants in the survey did not have prior knowledge of the research topic. In order to mitigate against possible bias from knowledge about prostate cancer the survey was framed in terms of community health issues, moving to male health issues and then to prostate cancer. Response rates were closely monitored to ensure that response rates and completion times were comparable across the survey. Monitoring of the response rates of each section showed no bias towards men with a high level of awareness of prostate cancer.

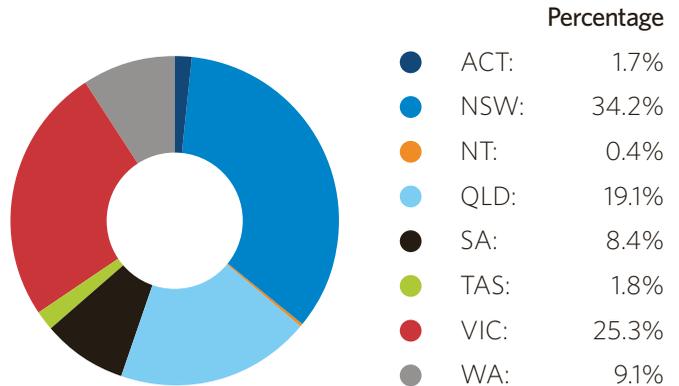
Fig. 1.1: Distribution of participants by age



*September is International Prostate Cancer Awareness Month and November is when the Movember campaign takes place.

The data was weighted to 2012 Australian population data as published by the Australian Bureau of Statistics. The results are nationally representative with the distribution between States and Territories as shown in Fig. 1.2.

Fig. 1.2: Distribution of participants by State and Territory



Almost two-thirds of participants self-identify as being in a relationship. The percentage is highest amongst men over age 30, with the highest percentage of 82% in the 35 to 39 age group.

Twenty (20) men (1.6%) who participated in the survey reported that they have been diagnosed with prostate cancer, which is broadly in line with what we would expect from Australian Institute of Health and Welfare statistics¹.

2. AWARENESS OF PROSTATE CANCER AS AN IMPORTANT HEALTH ISSUE

Less than 3% of prostate cancer diagnoses occur in men under 50¹, so we were interested to know whether men aged 18 to 50 consider it an important health issue and how much they know about it.

Results

We asked participants to name, unprompted, the single most important health issue facing men. Prostate cancer ranked first, followed by obesity, heart disease, mental health and cancer generally.

Somewhat surprisingly, the highest level of concern was amongst 18 and 19 year olds with 38% of men in this age group naming prostate cancer as the single most important disease facing men.

Table 2.1: Thinking just about men, what do you consider the single most important disease facing men?

Health Issue	Percentage
Prostate Cancer	25%
Obesity	15%
Heart Disease	13%
Mental Health	12%
Cancer	4%

To validate the unprompted responses, we subsequently asked participants to pick the single most important health issue facing men from a list of 12 health issues. The results are shown in Table 2.2.

Table 2.2: From the following list of health issues which do you consider is the single most important health issue facing men?

Health Issue	Percentage
Prostate Cancer	32%
Obesity	18%
Heart Disease	15%
Depression	14%
Drug and Alcohol Related Issues	10%
Diabetes	2%
Lung Cancer	2%
Skin Cancer	2%
Bowel Cancer	2%
Stroke	1%
HIV/AIDS	1%
Alzheimer's	1%

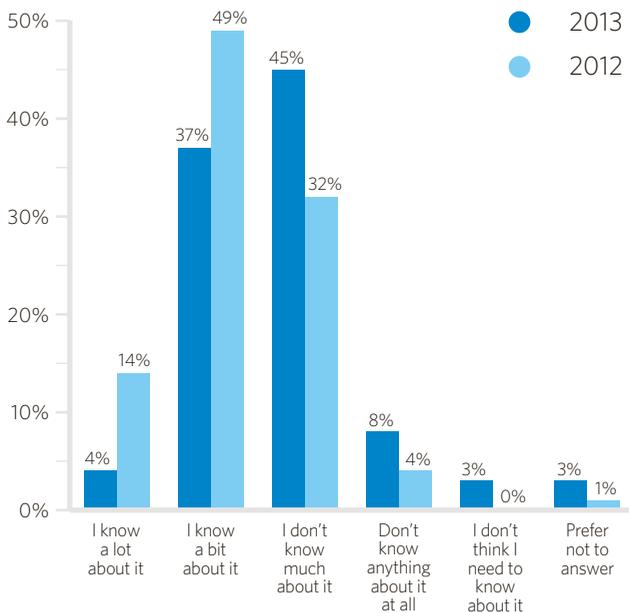
The results from unprompted and prompted mentions are very similar and confirm that participants see prostate cancer as the single most important health issue facing men, followed by obesity, heart disease and depression. Drug and alcohol related issues are also of concern to men aged 18 to 50.

Expanding the focus on men's health issues to the top three health issues faced by men, the importance of prostate cancer was confirmed. Fifty-eight per cent (58%) of participants consider prostate cancer to be one of the top three health issues that confront men. This is followed by obesity (51%), heart disease (48%), depression (34%) and drug and alcohol related issues (29%).

We asked participants how much they believe they know about prostate cancer. Forty-one per cent (41%) said "I know a lot about it" or "I know a bit about it" and 53% said "I don't know much about it" or "I don't know anything at all about it". Gratifyingly, only 3% said "I don't think I need to know about it".

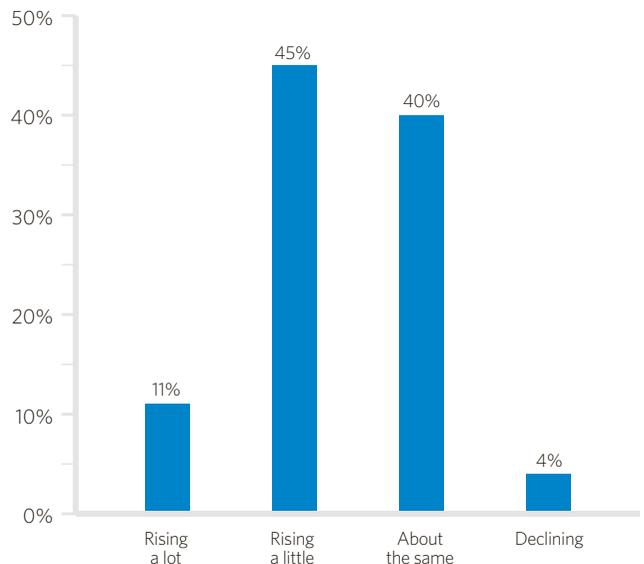
It is interesting to compare these results to those from the 2012 survey³, remembering that 2013 participants are aged 18 to 50, and the 2012 participants were aged 40 to 74. As shown in Fig. 2.1, the younger participants in this year's survey felt significantly less well informed than the older men from 2012.

Fig. 2.1: How much do you believe you know about prostate cancer?



We were interested to understand whether the younger cohort in this year's survey felt that community awareness of prostate cancer was changing and, if so, what they believe contributed to the change. As shown in Fig. 2.2, the majority (56%) felt awareness was 'rising a lot' or 'rising a little', while 40% said it was 'about the same'. Only 4% said it was 'declining'.

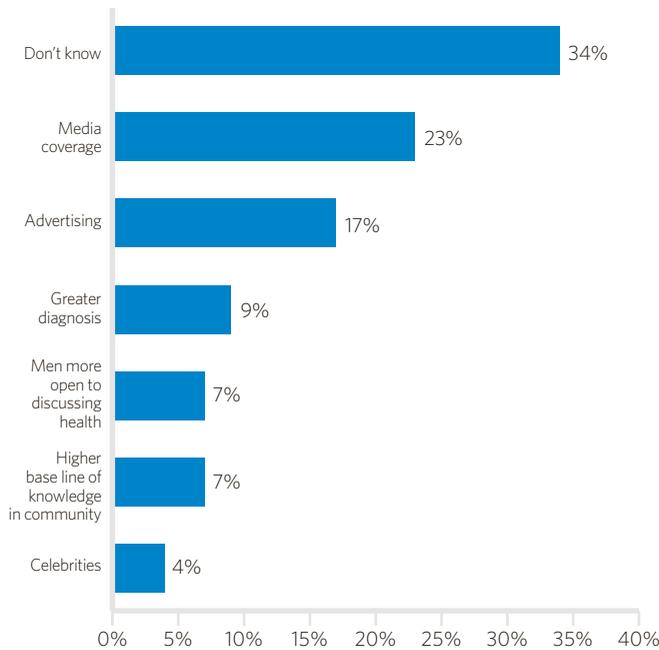
Fig. 2.2: Do you think that awareness of prostate cancer in the community is rising, staying about the same or even declining?



2. AWARENESS OF PROSTATE CANCER AS AN IMPORTANT HEALTH ISSUE

Of the 136 participants who indicated community awareness has risen in the past year, 34% could give no concrete reason for their view. Aside from this group, the key factor nominated was media coverage (23%), followed by advertising (17%).

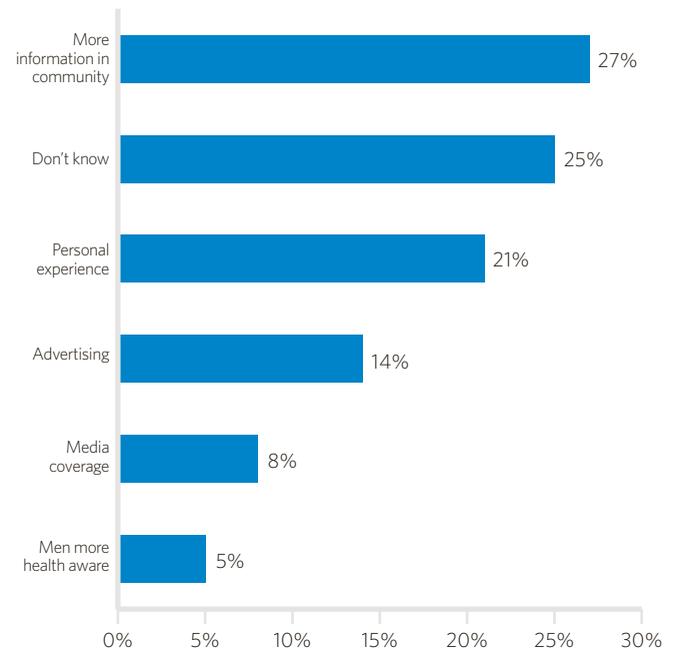
Fig. 2.3: What do you think is causing the change in awareness?



We wanted to understand if increased community awareness translated to increased personal awareness. Most participants (67%) said their awareness was about the same and 10% felt less informed.

Of the 12% of participants who said they felt more informed about prostate cancer over the past 12 months, 27% said it was due to more information being available in the community, 25% did not know why and 21% attributed it to personal experience.

Fig. 2.4: What has made you feel more informed about this health issue?



Discussion

Notwithstanding that prostate cancer is primarily a disease of older men with more than 97% of diagnoses occurring in men over age 50, younger men aged 18 to 50 clearly see prostate cancer as an important male health issue alongside obesity and heart disease. Perhaps not surprisingly, younger men also see mental health/depression and drug and alcohol related issues as top five male health issues.

Younger men also clearly believe that community awareness of prostate cancer is increasing with 56% of participants saying it is “rising a lot” or “rising a little”, although many are unable to identify the factors which have led to this view. The increase in community awareness has not led to a corresponding increase in personal awareness with only 12% of participants saying they feel more informed about prostate cancer over the last 12 months.

These findings are corroborated by the lower self-reported level of knowledge of prostate cancer than in the group of men aged 40 to 74 who participated in PCFA's 2012 Community Attitudes Survey. Forty-one per cent (41%) of participants said they know “a lot” or “a bit” about prostate cancer compared to 63% of men aged 40 to 74 in the 2012 survey. Clearly there is still much work to be done to educate men under age 50 about prostate cancer.

3. KNOWLEDGE OF SYMPTOMS AND ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

Testing for prostate cancer remains controversial and contentious. Medical colleges, Cancer Councils and other parties give conflicting advice to Australian men about whether they should be tested, at what ages and how frequently. Some bodies, including PCFA, advocate for testing with informed consent whilst others recommend against testing of asymptomatic men in all circumstances⁴.

We were interested to understand what men aged 18 to 50 understand about symptoms, their self-identifying patterns and attitudes towards testing, the age they believe testing should start and what influences them to be tested.

Results

Participants were asked, unprompted, about prostate cancer symptoms. The results are shown in Table 3.1.

Table 3.1: What are the symptoms of prostate cancer?

Symptom	Percentage
Don't know	58%
Difficulty urinating	15%
Sudden need to urinate	6%
Anal bleeding	4%
Discomfort when urinating	3%
Blood in urine/semen	3%
Pain in abdomen	3%
No symptoms	2%
Lumps in groin	2%
Waking to urinate	1%
Pain in testicles	1%
Reduced ability to get an erection	1%

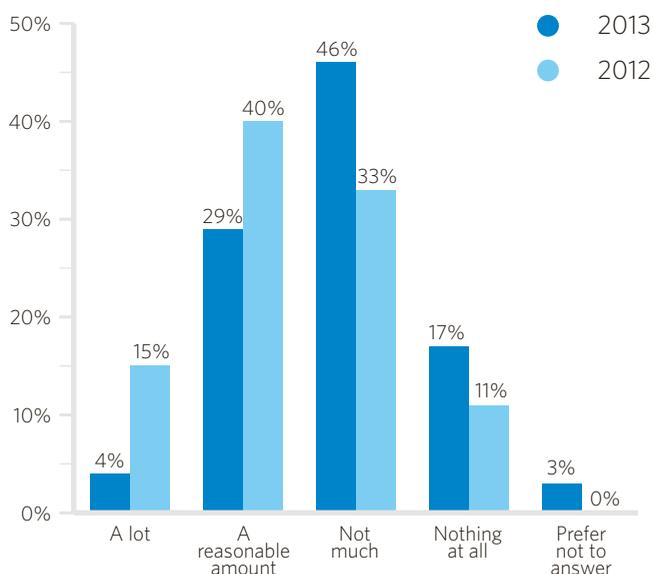
The majority (58%) of participants reported that they do not know what the symptoms of prostate cancer are. Perhaps not unexpectedly the level of knowledge increases with age. Sixty-five per cent (65%) of participants aged between 25 and 29, but only 52% of participants aged between 45 and 50, reported that they do not know what the symptoms of prostate cancer are.

A significant number of participants (28%) correctly identified issues with urination (difficulty or discomfort urinating, sudden need to urinate, waking to urinate, or blood in the urine/semen) as symptoms of prostate cancer. Understanding of these symptoms also increased with age, with 31% of participants in the 40 to 45 age group, and 41% of participants in the 45 to 50 age group identifying these as symptoms of prostate cancer.

Only a very small percentage (2%) of participants correctly identified that, in the early stages, prostate cancer may not be accompanied by any symptoms.

Participants were asked about their knowledge of prostate cancer testing and what age testing should start. The results are shown in Fig. 3.1 and Table 3.2.

Fig. 3.1: How much do you feel you know about the procedure involved in getting tested for prostate cancer?



Only one third of participants (33%) said they knew ‘a lot’ or a ‘reasonable amount’ about the procedure involved in getting tested for prostate cancer, compared to 55% of last year’s older cohort of men aged 40 to 74.

Similarly, 63% of this year’s younger cohort said they knew ‘not much’ or ‘nothing at all’, compared with 44% of last year’s older participants. Significantly, 73% of this year’s younger cohort does not think the information available to them clearly sets out what tests they should have or what they entail.

Table 3.2: At what age do you think a man should start to be examined for prostate cancer?

Age of survey participants	Average age a man should start being examined
18 to 19	34.4
20 to 24	37.3
25 to 29	35.6
30 to 34	38.0
35 to 39	41.0
40 to 44	42.8
45 to 50	43.7
Total	39.5

Men aged 18 to 50 are of the view that men should begin having prostate cancer tests at age 40. Men in their twenties consider the appropriate age is in their mid-thirties, whilst older men tend to push back the starting age a little.

3. KNOWLEDGE OF SYMPTOMS AND ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

We were also interested to understand if participants had ever had a test for prostate cancer and, if so, whether they were tested because they were experiencing symptoms or because they were concerned about the possibility of having prostate cancer. The results are shown in Fig. 3.2 and Fig. 3.3.

Eight per cent (8%) of men aged between 18 and 39 report that they have been tested for prostate cancer and this rises rapidly from age 40 onwards with 25% of men aged 40 to 44 and 37% of men aged 45 to 50 reporting that they have been tested. Overall 16% of men aged between 18 and 50 reported that they had been tested for prostate cancer.

Fig. 3.2: Have you ever had a test for prostate cancer?

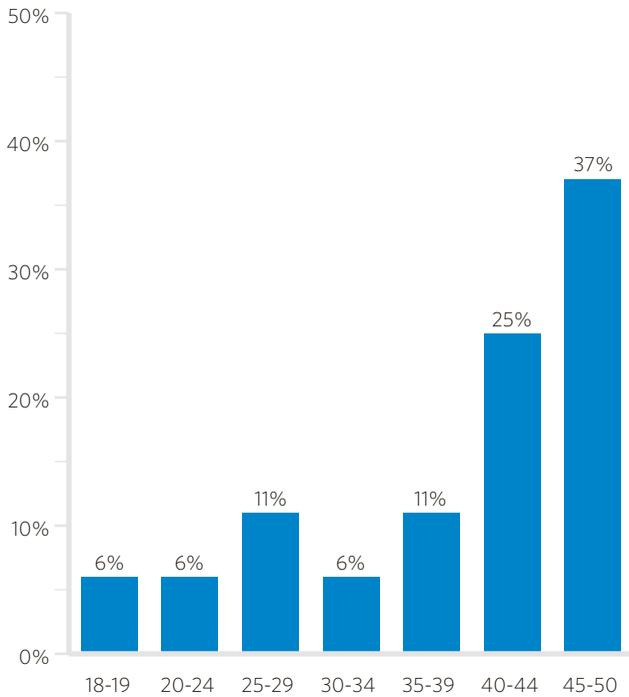
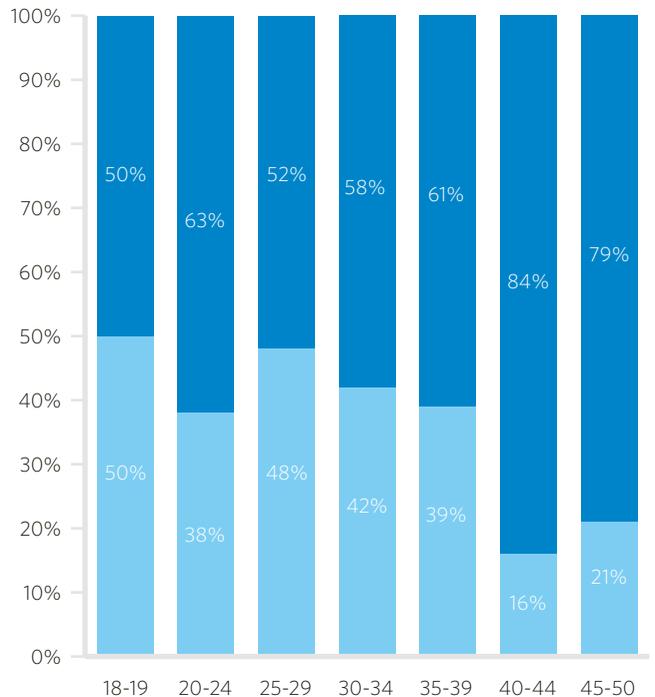


Fig. 3.3: Did you have the test because you were experiencing symptoms?



- Not experiencing symptoms but were concerned about the possibility of having prostate cancer
- Experiencing symptoms

The majority of participants (73%) reported that their motivation for having the test was not because they were experiencing symptoms, but because they were concerned about the possibility of having prostate cancer.

Almost half (49%) of participants indicated that they would “definitely”, “probably” or “maybe” have an examination for prostate cancer in the next 12 months. As shown in Table 3.3 these percentages rise as men enter their forties.

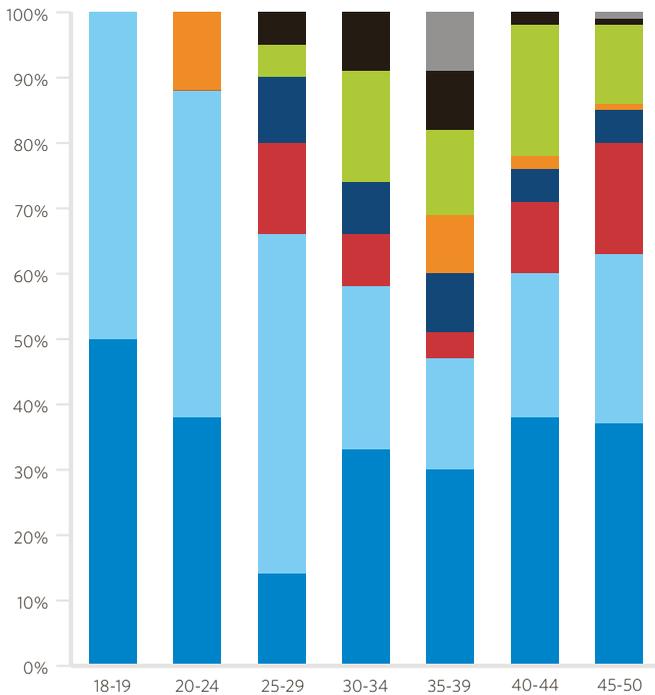
Table 3.3: How likely are you to have an examination for prostate cancer in the next 12 months?

	18 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 50	Total
Definitely will have an examination	6%	4%	4%	5%	8%	11%	15%	8%
Probably will have an examination	3%	13%	17%	10%	13%	17%	19%	14%
Maybe will have an examination	21%	13%	25%	30%	29%	33%	37%	27%
Probably won't have an examination	38%	39%	39%	40%	37%	32%	24%	35%
Definitely won't have an examination	32%	32%	15%	16%	12%	6%	4%	15%

3. KNOWLEDGE OF SYMPTOMS AND ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

The survey asked participants who have been tested how or why they came to be tested. The results are shown in Fig. 3.4.

Fig. 3.4: How did you come to have the test?



- I asked about it
- My GP suggested
- My GP just conducted the blood test
- My wife/partner suggested it
- A friend or relative suggested it
- Part of a routine check up
- Experiencing urinary problems
- Family history of prostate disease

Overall, 34% of participants said they asked for the test, with the highest percentage (50%) aged 18 to 19.

GPs were the main influencers for testing. About one-third of participants (29%) said their GP suggested the test, 12% said it was part of a routine check-up and 12% said their GP just conducted the test.

Few participants (3%) had a test because they had experienced urinary problems. Similarly, only 1% asked for the test because of a family history of prostate disease.

Discussion

We were surprised to find that whilst two-thirds of participants in the survey (63%) say they know “not much” or “nothing at all” about the procedure involved in being tested for prostate cancer, men reported being tested from a very early age. Six per cent (6%) of participants aged 18 to 24 reported that they had been tested, rising to 25% and 37% in the 40 to 44 and 45 to 50 age groups respectively. Participants were of the view that men should begin being tested from age 40 onwards and almost half (49%) of participants indicate that they will or may have an examination in the next 12 months.

Three-quarters of participants who report that they have been tested for prostate cancer say the reason for being tested was a concern about the possibility of having prostate cancer, with 27% reporting they were tested because they were experiencing symptoms. The main influencers for testing are GPs with 53% of participants who report they have been tested saying their GP suggested or just conducted a blood test, or that it was part of a routine check-up.

Taken together the results further demonstrate that, despite public health and primary care advice to the contrary, Australia has an unorganised de-facto screening program for prostate cancer being delivered in General Practice, with men starting to be tested from their twenties onwards. By the time they reach their early forties one quarter of men report that they have been tested. Problematically, 73% of participants do not think the information available to them clearly sets out what tests they should have and what they entail. It therefore seems highly likely that some men in the 18 to 50 age group are being tested inappropriately. These findings add weight to the argument that evidence-based national guidelines for prostate cancer testing are needed.



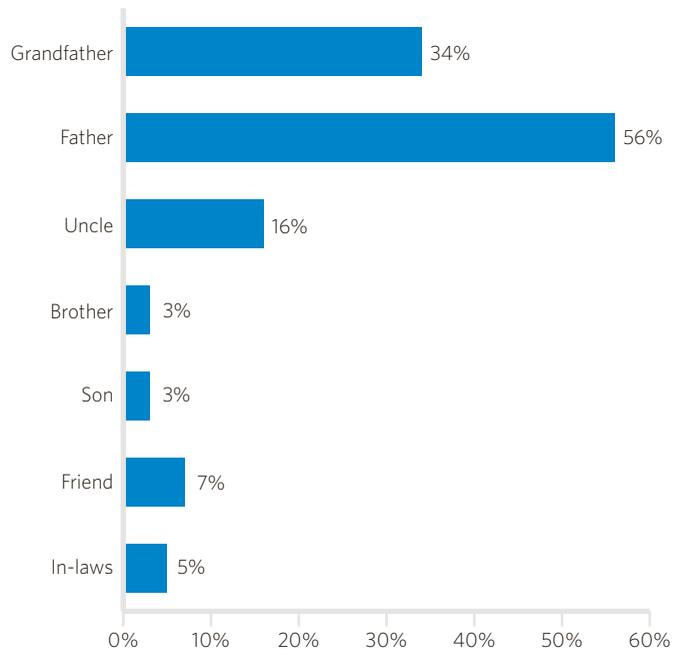
4. YOUNGER MEN'S CONVERSATIONS ABOUT PROSTATE CANCER AND HEALTH

We were interested to understand whether younger men feel comfortable talking to family and friends about prostate cancer and their health generally. We also wanted to understand their sources of emotional support. We were particularly interested to see whether fathers and grandfathers, who had been diagnosed, were willing to speak to their sons and grandsons about their diagnosis and treatment.

Results

Six per cent (6%) of participants have at least one family member or close friend who has been diagnosed with prostate cancer. As shown in Fig. 4.1, in more than half the cases the family member was the participant's father, followed by their grandfather (34%) and uncle (16%).

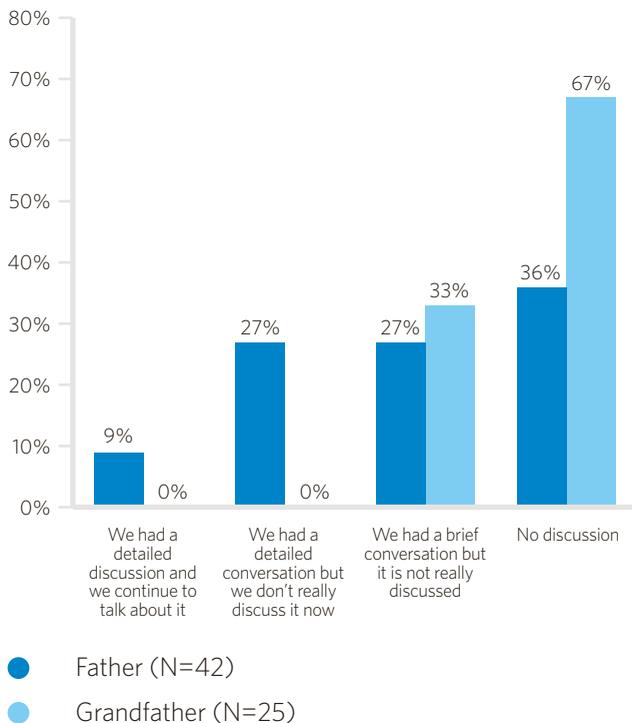
Fig. 4.1: Has anyone in your immediate family been diagnosed with prostate cancer?



4. YOUNGER MEN'S CONVERSATIONS ABOUT PROSTATE CANCER AND HEALTH

Men with fathers and grandfathers diagnosed with prostate cancer were asked about the conversations they had had about diagnosis and treatment. We found, not surprisingly, that older men did not feel comfortable or willing to talk about these issues.

Fig. 4.2: Which of the following best describes any conversations you have had with your father or grandfathers about diagnosis and treatment?



However, men's attitudes are changing with each generation, as fathers were more open to discussions than grandfathers. One in ten participants said they had ongoing discussions about the disease and its treatment with their fathers and 27% said they had one detailed discussion. While this is positive, it is concerning that most men have not had a detailed discussion with their father about his diagnosis and treatment. One quarter of respondents had only a brief discussion and 36% have not had any meaningful discussion at all.

Discussions about diagnosis and treatment appear to be occurring with others though, as a quarter of men said they discussed their father's or grandfather's diagnosis with their GP and 29% were more likely to discuss their father's condition than their grandfather's condition. Men were also more likely to speak to their partners (38%) and almost half (46%) of men whose fathers were diagnosed with prostate cancer spoke to their partners about it.

We found that men are comfortable talking to a family member or male friend about prostate cancer generally. Almost two thirds (63%) are comfortable talking about the issue with a male family member, 58% with a female family member and 61% with a male friend. Unfortunately, more than one third of men are not comfortable talking with friends or family. This was most likely in men aged 20 to 30. Men older than 40 were most comfortable talking about the issue, and interestingly, men in regional centres were more open to discussion than men from metropolitan or rural locations.

Turning to men’s health generally, we found that family members were a strong source of encouragement to visit a GP for a health check, with 44% of men reporting that family members encouraged them.

Table 4.1: Have you ever been encouraged by a family member to visit a GP?

Age Group	Yes	No	Can't Recall
18 - 19	44%	44%	12%
20 - 24	35%	53%	13%
25 - 29	44%	46%	10%
30 - 34	42%	49%	9%
35 - 39	46%	48%	6%
40 - 44	49%	43%	8%
45 - 50	48%	44%	8%
Total	44%	47%	9%

As shown in Table 4.2, partners played a very active role in encouraging men to attend a GP to get a health check, as some 70% of men older than 35 mentioned their partner as a prime encourager. Mothers were particularly influential over the younger generation, as 80% of men younger than 25 were influenced by their mother and 40% by their father. As men get older, their parents’ influence reduced significantly. Brothers, sisters, aunts and uncles played a secondary role to parents, particularly among younger men.

Table 4.2: Have you ever been encouraged by a family member to visit a GP? If so, who?

Age Group	Mother	Father	Brother	Sister	Cousin	Aunt	Uncle	Partner
18 - 19	80%	40%	13%	7%	13%	7%	7%	0%
20 - 24	80%	41%	4%	6%	2%	6%	4%	12%
25 - 29	53%	27%	7%	9%	2%	7%	2%	34%
30 - 34	39%	17%	6%	4%	0%	0%	0%	55%
35 - 39	37%	17%	1%	8%	0%	0%	0%	71%
40 - 44	38%	15%	2%	7%	1%	1%	0%	63%
45 - 50	28%	9%	4%	5%	0%	0%	2%	70%
Total	46%	21%	4%	7%	2%	2%	2%	50%

4. YOUNGER MEN'S CONVERSATIONS ABOUT PROSTATE CANCER AND HEALTH

Older men were more health-aware than younger men, as about 45% of men over 40 said they had been for a health check in the past two years without being ill, compared to only 29% of men younger than 30. Men with higher education were more likely to have a health check-up than others.

Of men encouraged to visit a GP, 72% went for a check-up. The lowest level of action was among men aged 20 to 24. In this age group only 53% who had been encouraged actually attended a GP for a check-up. Men who didn't visit a GP, despite being encouraged to, most commonly said it was because they were not sick enough (26%) or not sick at all (4%). Others mentioned not having the time (22%), personal choice (18%), poor view of GPs (9%) and cost (5%).

Fortunately, 72% of men felt they had someone in their life that could provide emotional support. Older men typically had their life partner and the fall-back of parents, while younger men tended to rely on parents. Interestingly, men in rural locations perceived a lower level of emotional support than was perceived by men in metropolitan locations and regional centres.

Table 4.3: Do you have someone in your life who you feel can support you emotionally?

Age Group	Yes	No	Prefer not to answer
18 - 19	74%	24%	3%
20 - 24	64%	27%	9%
25 - 29	68%	25%	8%
30 - 34	76%	18%	6%
35 - 39	80%	16%	4%
40 - 44	75%	21%	4%
45 - 50	72%	22%	6%
Total	72%	22%	6%

Although support from parents was considered important across all ages, this was particularly true for younger men. Both parents decrease in importance as men age, but fathers more than mothers.

For men with a partner, it was the partner who provided the majority of emotional support. Younger men, who do not necessarily have a long-term partner to support them, were more likely to rely on friends. Interestingly, female friends appear to play an important role for men aged 18 to 19, second only to their mothers.

Table 4.4: Do you have someone in your life who you feel can support you emotionally? If so, who?

	18 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 50	Total
Grandfather	4%	7%	3%	3%	1%	0%	1%	3%
Grandmother	8%	9%	5%	3%	1%	0%	1%	3%
Mother	48%	54%	46%	27%	28%	25%	17%	33%
Father	36%	37%	27%	15%	19%	15%	8%	21%
Brother	12%	18%	13%	9%	6%	15%	10%	12%
Sister	16%	19%	11%	11%	14%	17%	8%	13%
Cousin	4%	5%	2%	1%	2%	1%	2%	2%
Aunt	0%	10%	5%	2%	3%	2%	2%	3%
Uncle	0%	2%	3%	3%	3%	1%	1%	2%
Female friend	40%	24%	16%	14%	13%	13%	17%	17%
Male friend	24%	22%	14%	11%	17%	15%	12%	16%
Partner	12%	38%	60%	69%	75%	70%	75%	62%

4. YOUNGER MEN'S CONVERSATIONS ABOUT PROSTATE CANCER AND HEALTH

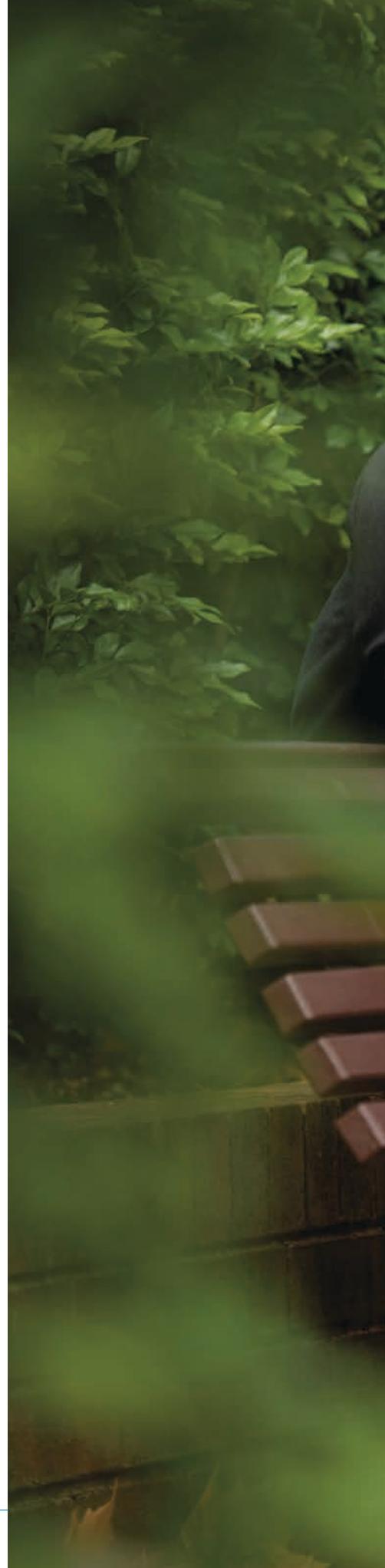
Discussion

Perhaps not surprisingly, men who have been diagnosed with prostate cancer do not generally feel comfortable talking about their diagnosis and treatment with their sons and grandsons. However, the good news is that attitudes are changing, with a greater willingness among fathers to discuss their diagnosis and treatment, suggesting progress with each generation. Discussions about diagnosis and treatment appear to be occurring with others though, as a quarter of men said they discussed their father's or grandfather's diagnosis with their GP and almost half of men whose fathers were diagnosed with prostate cancer spoke to their partners about it.

Men are comfortable talking to a family member or male friend about prostate cancer generally. Almost two thirds are comfortable talking about the issue with a family member, or male friend. Men older than 40 were most comfortable talking about the issue, and interestingly, men in regional centres were more open to discussion than men from metropolitan or rural locations.

Partners had a strong influence over men visiting their GP for a health check-up, as more than 70% of men over 35 said they were encouraged by their partner. Younger men, who might not yet have long-term relationships, appear more influenced by family members, especially their parents. Younger men were less health-aware than their older counterparts. Only 29% of men under 30 had had a health check in the previous two years, compared to 45% of men over 40.

Clearly, work needs to be done to help men feel comfortable discussing prostate cancer and looking after their prostate health. We need to ensure that there is greater awareness and accessible information for younger men and their families, in formats they are comfortable accessing.





5. GAY AND BISEXUAL MEN

We wanted to elicit the views and experiences of gay, bisexual and other non-heterosexually identified men[#] because sexual orientation is overlooked in most research which examines the impact prostate cancer has on men. The absence of information about sexual orientation means that the views and experiences of gay and bisexual men with cancer are poorly understood^{5,6}.

Results

Of the survey's 1,243 participants, 83 men identified as gay, 48 identified as bisexual, and 33 did not identify as heterosexual, gay or bisexual. The 164 men who did not identify as heterosexual represent 13% of respondents. This sample size is significant, as we can present information on gay and bisexual men's attitudes, knowledge and understanding of prostate cancer and a meaningful insight into their needs.

Seventy per cent (70%) of gay and bisexual men who responded were aged 30 to 50. Men from all States and Territories, except Tasmania, were represented and 81% lived in a metropolitan area. Forty-nine per cent (49%) reported that they were in a relationship, 32% that they were not in a relationship and 11% that they had never been. Nine per cent (9%) preferred not to say.

Twenty-nine per cent (29%) of the gay and bisexual participants reported experiencing other significant health issues compared with 17% of the heterosexual participants. Men in both groups reported similar significant health issues, being diabetes, heart disease and obesity. Ten (10) gay and bisexual participants, and no heterosexual participants, reported being HIV seropositive.

It is important to note that 13% of gay and bisexual participants reported experiencing mental health issues, compared with 4% of heterosexual participants. More gay and bisexual participants reported experiencing depression (6%), or anxiety (4%), compared with 3% and 1% of heterosexual participants respectively.

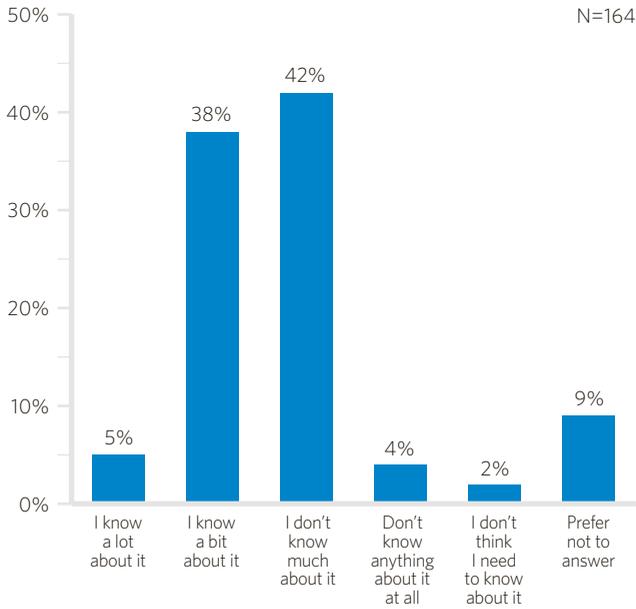
When asked about their health-seeking behaviour, 45% of gay and bisexual men reported having visited a doctor in the past two years when they were not ill, compared with 37% of heterosexual men.

When asked, unprompted, about the single most important health issue facing men, 28% of gay and bisexual men nominated different forms of cancer and 22% nominated prostate cancer. When subsequently asked to pick the single most important health issue from the list of health issues, 28% nominated prostate cancer as the single most important health issue facing men.

[#]For the purpose of this report, 'gay and bisexual men' will be used to refer to men who did not identify as heterosexual.

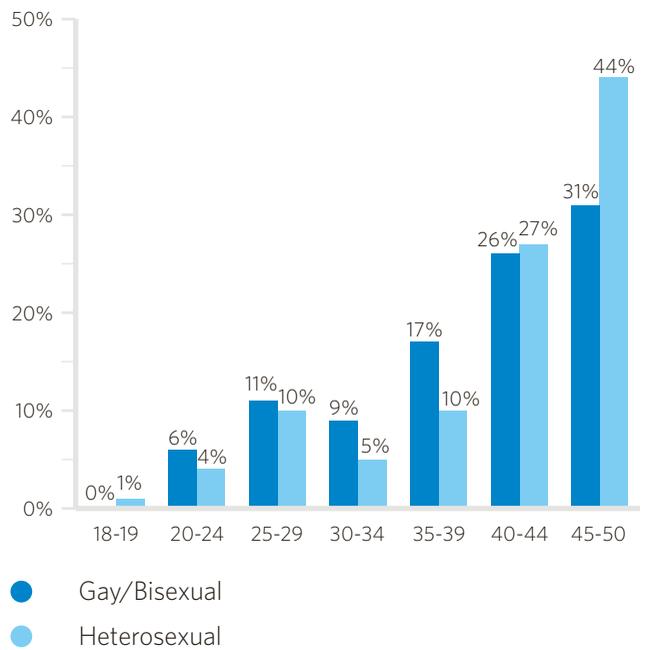
We asked gay and bisexual participants how much they believe they know about prostate cancer. The responses are shown in Fig. 5.1.

Fig. 5.1: How much do you believe you know about prostate cancer?



Interestingly, gay and bisexual men under age 40 appear to experience higher levels of testing than heterosexual men. In this age group, 43% of gay and bisexual men had been tested compared to 30% of heterosexual men. As shown in Fig. 5.2, this trend appears to reverse over age 45, with 31% of gay and bisexual men having been tested compared to 44% of heterosexual men.

Fig. 5.2: Have you ever had a test for prostate cancer?

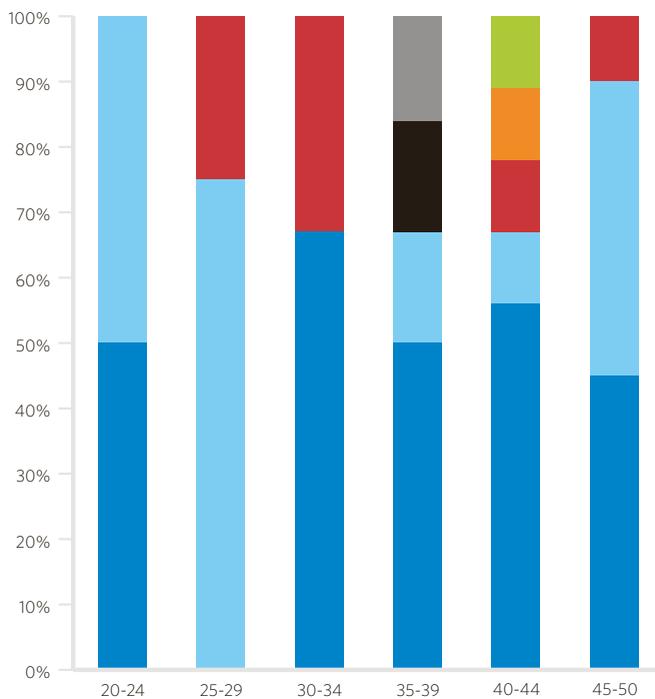


5. GAY AND BISEXUAL MEN

When asked why they had the test for prostate cancer, the majority (60%) of gay and bisexual participants said they were concerned about the possibility of having prostate cancer, despite not experiencing symptoms.

The survey asked the 35 gay and bisexual participants who have been tested how they came to be tested. The results are shown in Fig. 5.3.

Fig. 5.3: How did you come to have the test?



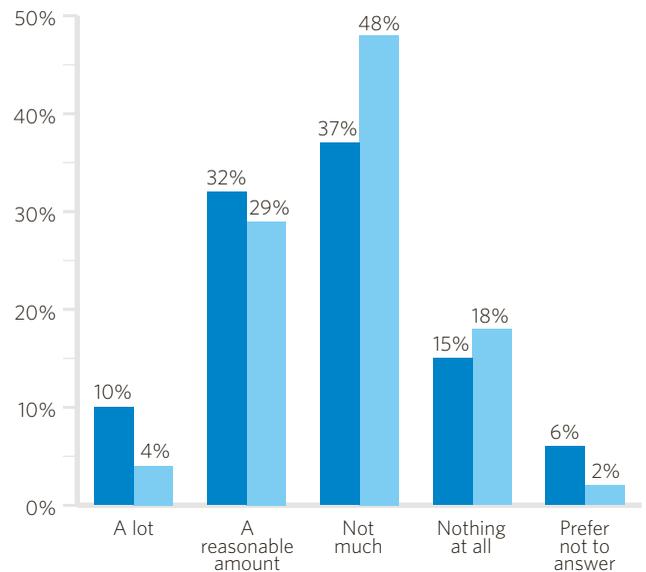
- I asked about it
- My GP suggested
- My GP just conducted the blood test
- My wife/partner suggested it
- A friend or relative suggested it
- Part of a routine check up
- Experiencing urinary problems
- Family history of prostate disease

The top two responses to how they had come to have the test were 'I asked about it' (46%), and 'My GP suggested' (31%).

Those who did not undertake a prostate examination were asked why. Thirty per cent (30%) of gay and bisexual participants said there was no need, 18% suggested their age did not warrant a prostate examination and 6% cited a lack of symptoms.

About half of gay and bisexual men felt they lacked knowledge about the testing procedure for prostate cancer. Their responses are detailed in Fig. 5.4.

Fig. 5.4: How much do you know about the procedure involved in getting tested for prostate cancer?

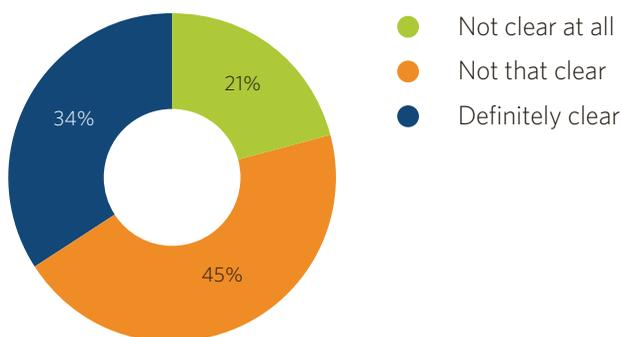


- Gay/Bisexual
- Heterosexual

When asked whether they had concerns about prostate cancer examination, 65% of gay and bisexual participants reported they had 'none', 30% had 'a few', and 5% had 'a lot'. Four per cent (4%) reported the examination process was a source of 'embarrassment', which might be a barrier to seeking medical advice, even when it is necessary.

When asked whether they were clear about what examinations they should undertake, based on what they have heard or read about prostate cancer, about two-thirds of the men were unclear. Their responses are detailed in Fig. 5.5.

Fig. 5.5: From the information available is it clear what examinations you should take?



Fewer gay and bisexual men (64%) reported having someone they could obtain emotional support from compared to heterosexual men (74%). A comparison of sources of support is provided in Table 5.1.

Table 5.1: Do you have someone in your life who you feel can support you emotionally? If so, who?

Source of support	Gay/Bisexual (N=164)	Heterosexual (N=1079)
Partner	32%	50%
Male friend	22%	9%
Female friend	20%	11%
Extended and immediate family (grandparents, parents, uncles/aunts, siblings, cousins)	59%	64%
Immediate family (parents, siblings)	46%	56%
Parents	29%	38%
Siblings	17%	18%

Gay and bisexual respondents felt they are supported by extended and immediate family members (59%), followed by immediate family members (46%) and friends (42%). Heterosexual participants also nominated extended and immediate family members as the main source of support (64%), followed by immediate family members (56%), and partners (50%).

5. GAY AND BISEXUAL MEN

Discussion

Engaging with gay and bisexual men aged 18 to 50 provided insight into their views and experiences, and how they differ to those of heterosexual men. While care needs to be taken when interpreting self-reported information, these findings will enable PCFA to make sense of younger gay and bisexual men's experiences, in order to facilitate more appropriate service delivery and information.

Gay and bisexual men were more likely to have significant health issues than heterosexual men. Importantly, 12% of gay and bisexual participants reported experiencing mental health issues, compared with only 4% of heterosexual participants. More gay and bisexual participants experienced depression (6%) and anxiety (4%) than heterosexual men (3% and 1% respectively).

This is consistent with previous research findings that gay and bisexual men are more likely to experience depression and anxiety than the general population⁷. There is clear evidence that men with prostate cancer commonly experience anxiety and depression⁸. Our survey suggests that gay and bisexual men with prostate cancer are also likely to face other significant health issues; something that needs to be considered when supporting them.

A notable finding was the extent of prostate cancer testing. Gay and bisexual participants under age 40 were more likely to have been tested than their heterosexual counterparts. The pattern of prostate cancer testing for gay and bisexual men could be explained by these men being more likely than heterosexual men to consult with a doctor when they are not ill (45% compared to 37%). They are also more likely to ask about testing than heterosexual men (46% compared to 32%). It could be argued that health promotional material targeting gay and bisexual men in the area of sexual health and HIV⁹ has produced an acceptance of the importance of regular health checks. Notwithstanding the challenges and difficulties experienced by gay and bisexual men when engaging with the healthcare system, for example, discrimination¹⁰, they are aware of the importance of health checks and monitoring.

The availability of emotional support for gay and bisexual men diagnosed with prostate cancer is important. While about two-thirds (64%) of respondents reported having someone they can obtain emotional support from, this was fewer than heterosexual men (74%).

Like heterosexual men, gay and bisexual men identified family members and partners as people who could support them emotionally, but gay and bisexual men were more likely to nominate friends (42%) than heterosexual men (20%). This highlights the importance of people aside from family members within gay and bisexual men's support networks and challenges the notion that a family member or partner will provide their main support.

While gay and bisexual men understand that prostate cancer is an important health issue, they appear to lack knowledge and information about symptoms, testing and treatment options. While it is positive that they have healthcare checks, they are also susceptible to over testing. This highlights the need for prostate health and cancer information to be developed specifically for this population group and distributed to them.



6. WHERE TO NEXT?

Over the past ten years that PCFA has been conducting our annual Community Attitudes Survey we have focused on men aged 40 to 74. This year we set out to understand the perspective of the next generation – men aged 18 to 50. The results demonstrate that much work remains to be done to educate younger men about prostate cancer and to encourage them to have conversations with older men in their lives that have been diagnosed.

There are four very clear pointers to action from the survey responses:

1. ACTION TO EDUCATE MEN UNDER AGE 50 ABOUT PROSTATE CANCER

Men aged 18 to 50 clearly see prostate cancer as an important male health issue alongside obesity and heart disease. They also clearly believe that community awareness of prostate cancer is increasing with 56% of participants saying it is “rising a lot” or “rising a little”, although many are unable to identify the factors which have led to this view.

However, the increase in community awareness has not led to a corresponding increase in personal awareness. The level of self-reported knowledge of prostate cancer is significantly lower than in the group of men aged 40 to 74 who participated in PCFA’s 2012 Community Attitudes Survey. Forty-one per cent (41%) of participants said they know “a lot” or “a little” about prostate cancer compared to 63% of men aged 40 to 74 in the 2012 survey. Furthermore, only 12% of participants saying they feel more informed about prostate cancer over the last 12 months.

Clearly, more work must be done to educate men under age 50 about prostate cancer. They may not yet be at serious risk of developing the disease, but it is important that men develop a level of awareness and understanding before they reach their mid-forties.

PCFA has established two support groups specifically to meet the needs of younger men with prostate cancer. The Australian Government, through Cancer Australia, is funding PCFA to develop evidence-based consumer information and resources on prostate cancer for men under age 50. These will be launched to the community in September 2013.

2. DEVELOP NATIONAL CLINICAL GUIDELINES FOR PSA TESTING

Testing of asymptomatic men for prostate cancer remains controversial and contentious. Conflicting advice is given to Australian men about whether they should be tested, at what ages, and how frequently by the various medical colleges and other interested parties. Problematically, 73% of men in the survey do not think that the information available to them clearly sets out what tests they should have or what they entail.

The reality, though, is that significant numbers of Australian men under age 50 either have been or intend to be tested for prostate cancer in the next 12 months. Sixteen per cent (16%) of men in the survey reported that they have been tested for prostate cancer. In effect, therefore, Australia has an unorganised de-facto screening program with testing starting when men are in their early twenties.

The opportunity exists to end the confusion and to bring order to the situation by developing national evidence-based clinical guidelines for PSA testing. At PCFA we believe that such guidelines, supported by every medical college and all other interested parties, would in the best interests of the Australian community.

We are pleased to report that PCFA is working in collaboration with Cancer Council Australia to develop national clinical guidelines for PSA testing and early management of test-detected prostate cancer. The guidelines are being developed on Cancer Council Australia's wiki platform using the NHMRC externally developed guidelines standards and procedures.

3. ENCOURAGE INTERGENERATIONAL CONVERSATIONS ABOUT PROSTATE CANCER

Men who have a father or brother who has been diagnosed with prostate cancer are at twice the risk of developing the disease as men with no relatives affected¹¹. Additionally, there is a trend of increasing risk with increasing number of affected family members such that men with two or three first degree relatives affected have a five and eleven fold increased risk of developing the disease. It is therefore vitally important for men to be aware of their family history.

We found that men who have been diagnosed with prostate cancer do not generally feel comfortable talking about their diagnosis and treatment with their sons and grandsons. The good news, however, is that attitudes appear to be changing, with a greater willingness among fathers suggesting progress with each generation.

Clearly, more work needs to be done to encourage intergenerational discussions about prostate cancer. This is a focus area for PCFA's awareness campaigns.

4. ENHANCE RESOURCES AND SUPPORT FOR GAY AND BISEXUAL MEN AFFECTED BY PROSTATE CANCER

The absence of information about sexual orientation in much of prostate cancer research means that the experiences of gay and bisexual men with prostate cancer are poorly understood. It is therefore important, and exciting, that we are able to provide a meaningful insight into the experiences of this group of men for whom prostate cancer is a significant health issue.

Gay and bisexual men who participated in the survey reported that they experience more significant health issues than the heterosexually identified participants. Consistent with existing research findings, the gay and bisexual participants also reported a higher incidence of depression and anxiety. This is of concern given these mental health issues are likely to be experienced by men with prostate cancer in general.

In terms of support, the support network utilised by gay and bisexual participants is different to that of heterosexual men, for they are more likely to draw support from their friends. This highlights the importance of non-family members as significant members of gay and bisexual men's support network, and challenges the notion that a family member or partner is the person's main support.

Gay and bisexual men with prostate cancer need resources and support that appropriately reflect their unique needs. In meeting this need, PCFA, through its Gay and Bisexual Men's Prostate Cancer Initiative, has established three support groups specifically for gay and bisexual men in Sydney, Melbourne and Brisbane. The aim is to establish more gay and bisexual men support groups in other capital cities. Moreover, the Australian Government, through Cancer Australia, is funding PCFA to develop evidence based consumer information and resources on prostate cancer for this group of men. These will be launched to the community in October 2013.

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RESEARCH AWARENESS SUPPORT

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