



Prostate Cancer  
Foundation  
of Australia

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# RESEARCH, AWARENESS, SUPPORT: TEN YEARS OF PROGRESS IN PROSTATE CANCER

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2012 COMMUNITY ATTITUDES SURVEY

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## Our Vision, Mission and Values

Prostate Cancer Foundation of Australia (PCFA) is 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 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.

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Bayer is delighted to have the opportunity to partner with Prostate Cancer Foundation of Australia for this very important initiative.

We have known for some time of the difficulties faced by men navigating complex and often emotional treatment pathways, and are committed to playing our part in supporting patients. We believe supporting this project can contribute to providing men and their families with the necessary tools to make their journey more manageable and in turn improve health outcomes.

**Rene Klemm**  
Country Representative, Bayer HealthCare



## Prostate cancer is an important public health issue. It is the most commonly diagnosed non-cutaneous cancer in Australian men.

The latest available figures from the Australian Institute of Health and Welfare show

that prostate cancer diagnoses doubled from 10,113 in 1998 to 20,750 in 2008.<sup>1</sup> In 2008, men were estimated to have a 1 in 7 chance of being diagnosed with prostate cancer by age 75 and a 1 in 4 chance of being diagnosed by age 85. With the rising Australian population, increasing life expectancy, and the expectation of continuing increases in prostate cancer incidence, the Australian Institute of Health and Welfare has estimated that by 2020 the number of prostate cancers diagnosed in Australia will be somewhere between 25,000 and 31,000.<sup>2</sup>

The latest available figures also show that 2,938 Australian men died from prostate cancer in 2007.<sup>3</sup> That represents 4.2% of all deaths in men and 13.0% of all cancer deaths in men, making prostate cancer second only to lung cancer as the most common cause of cancer death in men. It has been estimated that 42,500 disability adjusted life years (DALYs) were lost to prostate cancer in 2010. Again making prostate cancer second to lung cancer, which had 56,800 DALYs lost to it.<sup>4</sup>

In order to better understand community attitudes towards prostate cancer, and to gauge how they are changing over time, Prostate Cancer Foundation of Australia conducts an annual Community Attitudes Survey. This year, 2012, represents the 10th anniversary of the survey.

In this report we focus on three key issues and take the opportunity to look back over the past decade to see how things have changed. These issues are:

- Australian men's perceptions of prostate cancer as a top health issue
- Attitudes towards testing for prostate cancer
- Attitudes towards available support services, including additional services which would benefit men, their partners and families.

Importantly, we found that Australian men see prostate cancer as the single most important health issue they face and one of the top five health issues for the community at large. It is clear that awareness and knowledge of prostate cancer is steadily, but modestly, increasing with a 12% increase in the percentage of men who feel informed about the disease over the past decade. There is a clear need for improved awareness and knowledge about prostate cancer in our community. The key role that PCFA plays in raising awareness could not be more crucial.

Consistent with this, whilst awareness and knowledge of the PSA test has also increased, and large numbers of men are being tested every year, almost 40% of men believe the advice they receive about testing is confusing. The need for clear and consistent advice about testing, supported by every medical college and all other interested parties, is evident.

What is also very clear is that GPs are the main influencers for men to be tested with 61% of men who have been tested reporting they had a test either because their GP recommended, or just conducted, it. The role of the GP in men's prostate health is central.

Contrary to common perceptions amongst health professionals, we found that almost one quarter of men who have been diagnosed with or are undergoing further investigation for prostate cancer contacted a support organisation and found it to be a very valuable source of information and support. However, we also found that men lack knowledge of support services and need health professionals to be more active in guiding them to appropriate information and support.

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

A handwritten signature in black ink that reads "Anthony Lowe".

Dr Anthony Lowe  
Chief Executive Officer

# INTRODUCTION

## **2012 marks the 10th anniversary of Prostate Cancer Foundation of Australia's Community Attitudes Survey.**

In this report we highlight the key results of the 2012 survey, especially in the areas of community awareness of prostate cancer as a top health issue; attitudes and behaviour towards testing; and attitudes towards available support services.

We also take the opportunity to look back over the past decade to see how community attitudes towards prostate cancer have changed.

# I. METHODS

The 2012 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 1,431 men aged between 40 and 74 participated in the survey. The sample size gives a 95% confidence level with a confidence interval of  $\pm 3\%$  in our results.

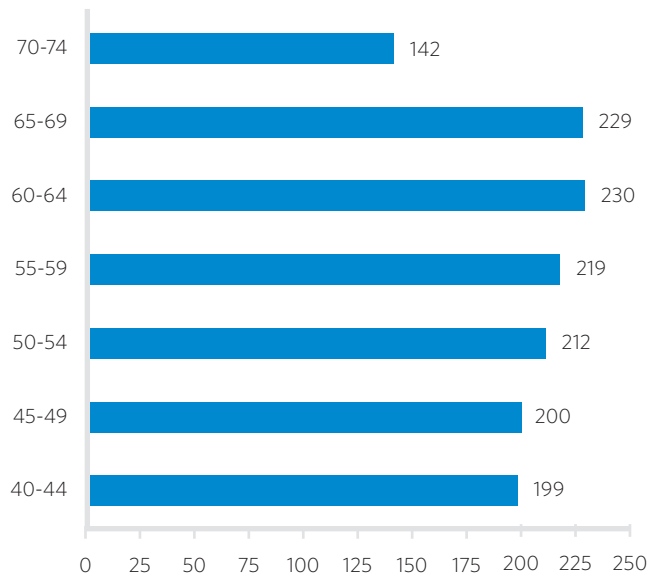
The data was collected in the period 20 March to 2 April 2012. The collection period was chosen to avoid times, such as September and November\*, when significant prostate cancer awareness and fundraising campaigns take place.

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.

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

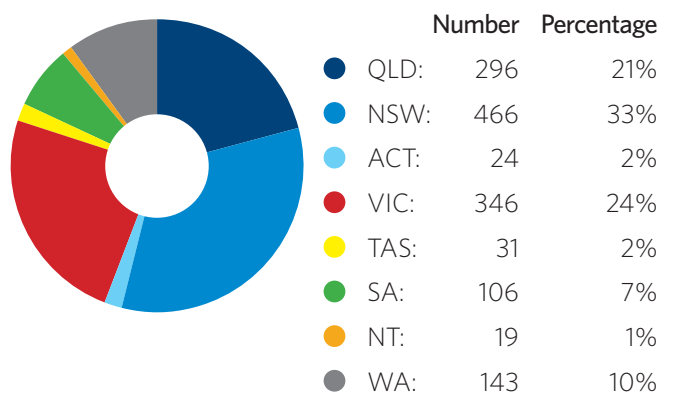
Fig. 1.1 shows the distribution of participants by age.

**Fig. 1.1: Distribution of participants by age**



The distribution between States and Territories was broadly representative of the Australian population as shown in Fig 1.2.

**Fig. 1.2: Distribution of participants by State and Territory**



Participants were asked if they live in a metropolitan or rural/ regional location. Sixty-five per cent (65%/ N=933) said they live in a metropolitan and 35% (N=498) in a rural/ regional location.

## 2. AWARENESS OF PROSTATE CANCER AS AN IMPORTANT HEALTH ISSUE

We were interested to understand whether men see prostate cancer as an important health issue and also their level of understanding of the disease. We asked participants to name, unprompted, the single most important disease facing men. Survey participants considered prostate cancer to be the most important disease, with 49% naming it as the single most important disease facing men, followed by heart disease (18%), depression (7%), obesity (7%) and cancer generally (6%).

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

| Health Issue    | Percentage |
|-----------------|------------|
| Prostate Cancer | 49%        |
| Heart Disease   | 18%        |
| Depression      | 7%         |
| Obesity         | 7%         |
| Cancer          | 6%         |

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

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

| Health Issue    | Percentage |
|-----------------|------------|
| Prostate Cancer | 51%        |
| Heart Disease   | 19%        |
| Obesity         | 9%         |
| Depression      | 9%         |
| Bowel Cancer    | 4%         |
| Diabetes        | 4%         |
| Alzheimer's     | 1%         |
| Stroke          | 1%         |
| Lung Cancer     | 1%         |
| Skin Cancer     | 1%         |
| HIV/ AIDS       | 0%         |
| Breast Cancer   | 0%         |

The results from unprompted and prompted mentions are very similar and confirm that participants see prostate cancer as the single most important disease facing men, followed by heart disease, obesity and depression.

Expanding the focus on men's health issues to the top three health issues faced by men, the importance of prostate cancer was confirmed. Three-quarters (76%) of participants consider prostate cancer to be one of the top three health issues that confront men. This is followed by heart disease (59%), obesity (39%), depression (27%) and diabetes (25%).

We were also interested to understand whether men see prostate cancer as an important health issue for the community generally. We asked participants to pick the top three health issues facing the community from the same list of 12 named diseases shown in Table 2.2. The top 10 ranked health issues facing the community as reported by survey participants are shown in Table 2.3.

**Table 2.3: From the list of diseases below, which do you consider the most important health issues facing the community? Please select three.**

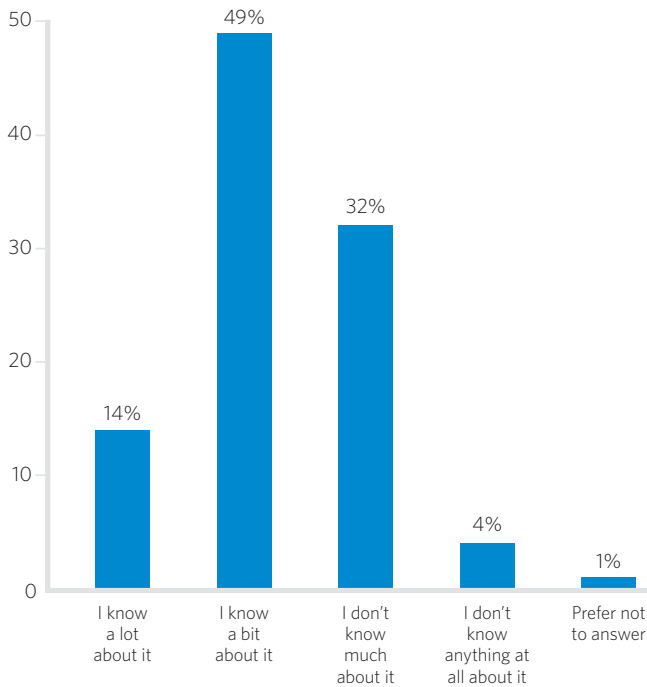
| Health Issue    | Percentage |
|-----------------|------------|
| Heart Disease   | 59%        |
| Obesity         | 56%        |
| Diabetes        | 36%        |
| Depression      | 31%        |
| Prostate Cancer | 26%        |
| Alzheimer's     | 19%        |
| Breast Cancer   | 17%        |
| Bowel Cancer    | 15%        |
| Skin Cancer     | 14%        |
| Stroke          | 13%        |

Prostate cancer ranked number five and was named as amongst the top three health issues by one quarter of participants, rising to one third for participants over age 60.

## 2. AWARENESS OF PROSTATE CANCER AS AN IMPORTANT HEALTH ISSUE

We asked participants how much they believe they know about prostate cancer. Overall participants felt informed, with two-thirds (63%) of participants saying “I know a lot about it” or “I know a bit about it” and one-third (36%) saying “I don’t know much about it” or “I don’t know anything at all about it”.

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



We have seen a steady, but measurable, increase in community knowledge of prostate cancer over the past decade. The comparable figures from the 2002 survey were that 51% of participants felt “very” or “quite” informed and 48% felt “not very” or “not at all” informed about prostate cancer. This trend is corroborated by the percentage of 2012 survey participants who say that community awareness of prostate cancer is “rising a lot” (15%), or “rising a little” (53%). Twenty-nine per cent (29%) said community awareness of prostate cancer is “about the same” and only 3% said that awareness is “declining”.

### Discussion

It is clear from the survey results that men aged 40 to 74 see prostate cancer as amongst the top five health issues facing the community generally and the single most important health issue facing men.

It is also clear that awareness and knowledge of prostate cancer is steadily, but measurably, increasing with a 12% increase in the percentage of men who feel informed about the disease over the past decade.

There have been significant changes in perceptions of the top three health issues facing the community over the past decade. In 2002 heart disease ranked first, as it does in 2012, with 63% of participants naming it amongst the top three health issues. In 2002 breast cancer ranked second with 52% followed by prostate cancer (32%), skin cancer (33%), and lung cancer (29%).

Perhaps unsurprisingly obesity, diabetes and depression, which did not feature in the top five in 2002, have emerged as top three health issues over the past decade.



Roger Climpson, OAM, one of the founders of PCFA.



# 3. ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

Testing 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, Cancer Councils and other interested parties. Some bodies, including PCFA, advocate for testing with informed consent whilst others recommend against testing of asymptomatic men in all circumstances.

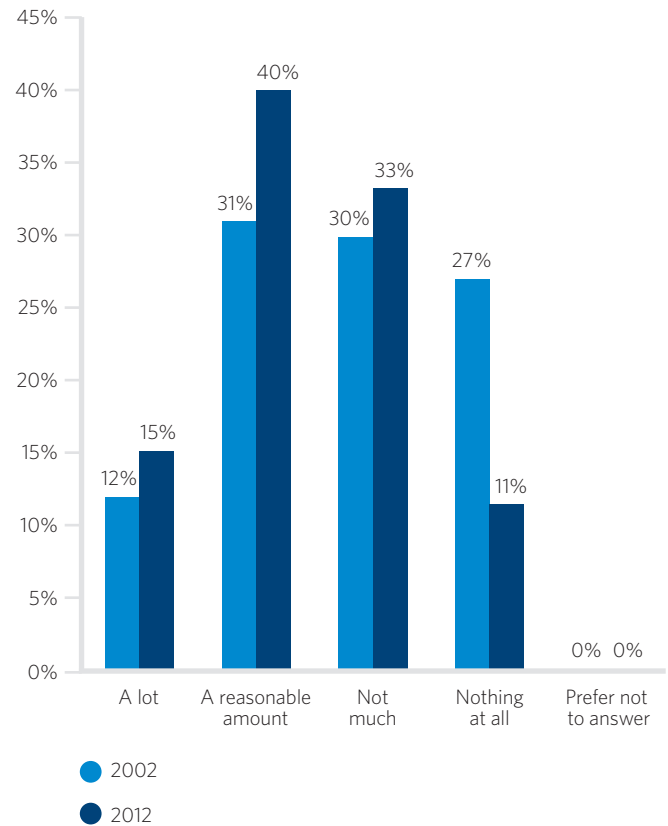
The Royal Australian College of General Practitioners (RACGP) recommends against routine testing for prostate cancer with digital rectal examination (DRE), prostate specific antigen (PSA) or transabdominal ultrasound.<sup>5</sup> Despite this, analysis of Medical Benefits Schedule records indicates that testing occurs at very high rates in Australia with at least 20% of men aged between 45 and 74 having a PSA test with screening intent each year.<sup>6,7,8</sup>

We were interested to understand the reasons why men undergo testing despite advice against it; the self-identifying patterns and attitudes of men about the PSA test; and what the influencers are for men to be tested.

## Results

Participants were asked about their knowledge of the initial screening test for prostate cancer and how frequently men over age 50 should be tested. The results are shown in Figs. 3.1 and 3.2.

**Fig. 3.1: How much do you feel you know about the procedure involved in the initial screening test for prostate cancer?**



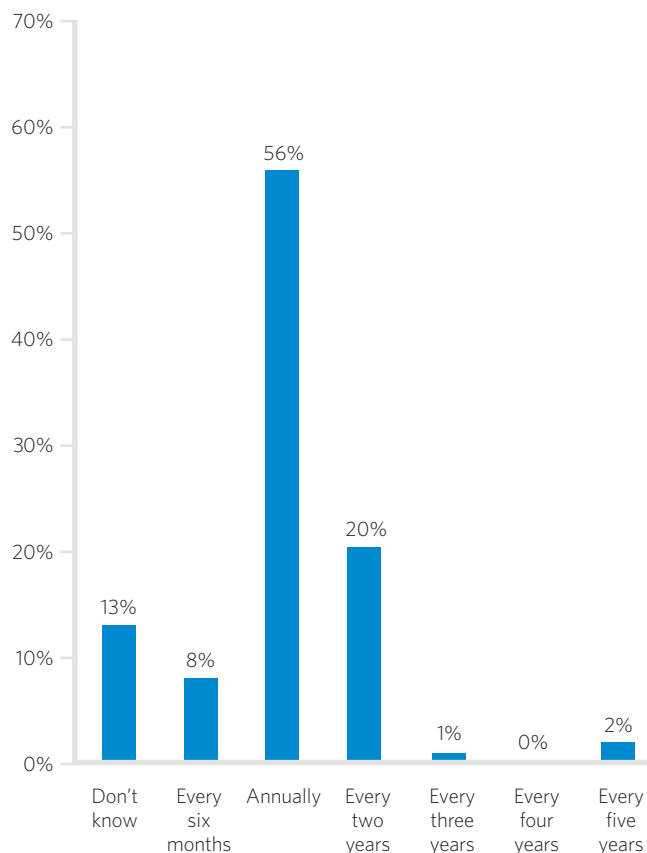
There has been a significant increase in perceived knowledge about testing over the past 10 years. The percentage of participants who say they know “nothing at all” has more than halved from 27% in 2002 to 11% in 2012. There are corresponding increases in the percentage of participants who say they know “a lot” or a “reasonable amount” about the procedure involved in the initial screening test for prostate cancer.

The 2012 results are fairly evenly divided between those who feel informed and those who do not, with 55% of participants saying they know “a lot” or a “reasonable amount” about the procedure involved in the initial screening test for prostate cancer and 45% saying they know “not much” or “nothing at all”.

A significant percentage of 2012 survey participants believe that advice about testing is confusing with 8% of participants saying they “strongly agree” and 30% that they “agree” with the statement that “the advice about the usefulness of the test is confusing”. Three per cent (3%) “strongly disagree” and (17%) “disagree” with this statement, whilst 42% “neither agree nor disagree”.

Direct comparison between the 2002 and 2012 results on frequency of testing is not possible. Fifty-six per cent (56%) of participants in the 2012 survey said that men over age 50 should be tested annually and 20% of participants said every two years. There is very little variation in responses between States and Territories or between participants who live in metropolitan and rural / regional locations, although we note that 16% of Tasmanian participants (N=31) said that men over age 50 should be tested every six months.

**Fig 3.2: How frequently should men over 50 years be tested?**

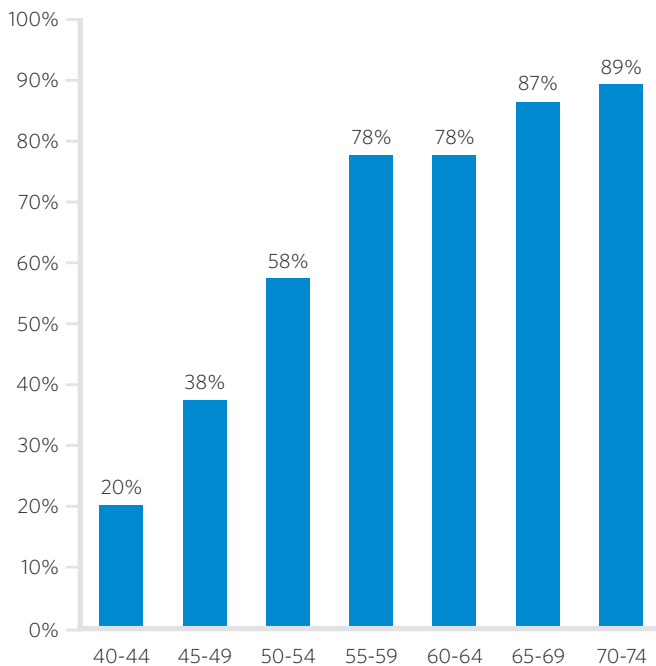


### 3. ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

There is also very little variation in responses between men who report that they have been tested at least once for prostate cancer and those who report that they have never been tested. Of participants who have been tested at least once (N=912), 63% said that men over age 50 should be tested annually and 20% said every two years.

The 2012 survey asked participants if they had ever had a test for prostate cancer and if they had been tested in the last 12 months. The results are shown in Figs. 3.4 and 3.5.

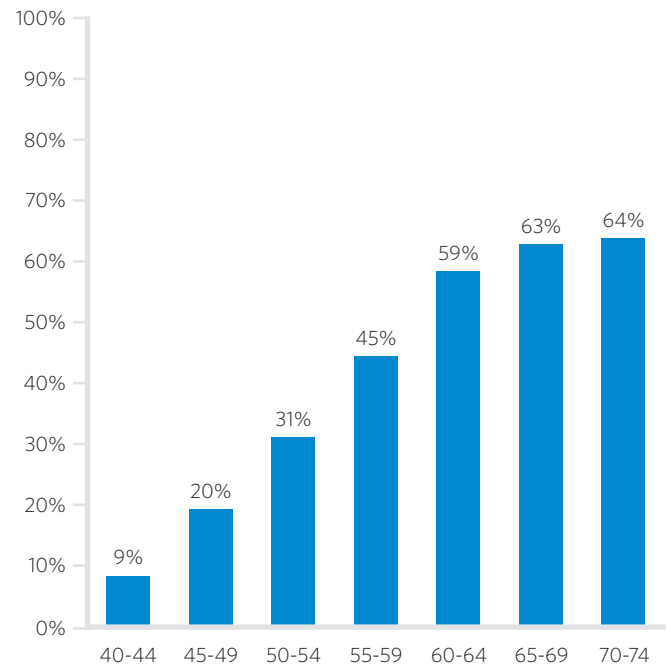
**Fig. 3.4: Have you ever had a test for prostate cancer?**



Reported rates of testing are very high with 20% of participants aged between 40 and 44 reporting that they have been tested for prostate cancer at least once rising to 89% for participants aged between 70 and 74. The reported rates of testing rise rapidly between ages 40 and 59 with 78% of participants aged between 55 and 59 reporting that they have been tested at least once.

Overall 64% of participants aged between 40 and 74 reported that they have been tested for prostate cancer at least once. Reported rates of testing were marginally higher for participants who live in rural/ regional than those who live in metropolitan locations. Overall rates for rural/ regional and metropolitan participants were 71% and 60% respectively.

**Fig. 3.5: Have you had a prostate cancer test in the last 12 months?**

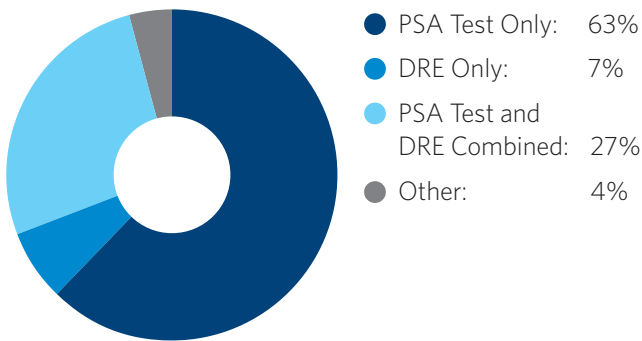


Reported rates of testing in the last 12 months are also very high with 31% of participants aged between 50 and 54 reporting that they have been tested in the last 12 months rising to 64% for participants aged between 70 and 74.

Overall, 41% of men aged 40 to 74 reported that they have been tested for prostate cancer in the last 12 months. This is consistent with results from analysis of MBS records.<sup>4</sup>

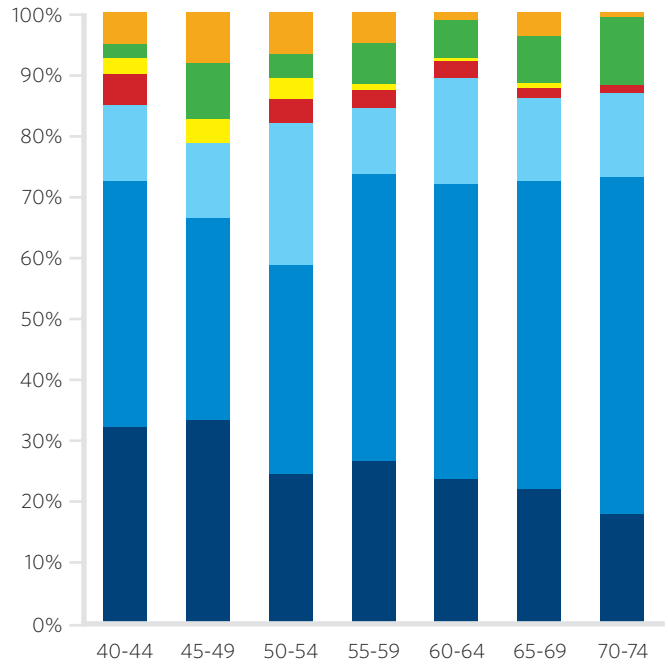
As shown in Fig 3.6, amongst participants who report that they have been tested in the last 12 months, 63% said that they had a PSA test, 7% that they had a DRE and 27% that they had a PSA test and a DRE combined.

**Fig. 3.6: Which of the following procedures did the last test for prostate cancer involve?**



The survey asked participants who have been tested at least once how or why they came to be tested. The results are shown in Fig. 3.7.

**Fig. 3.7: How did you come to have the test?**



- I asked
- GP suggested as part of routine check-up
- GP just conducted blood test
- Wife / Partner suggested
- Friend / Relative suggested
- Experiencing urinary problems
- Family history of prostate disease

Overall, 24% of participants reported that they asked for the test with the percentage declining steadily from 33% for participants aged between 40 and 45 to 18% for participants aged between 70 and 74.

GPs were the main influencers for testing with 46% of participants reporting that their GP suggested the test as part of a routine check-up and 15% reporting that their GP just conducted the test.

The percentage of participants who had a test because they were symptomatic was small with 7% reporting they had the test because they were experiencing urinary problems. The percentage of men who asked for the test because of a family history of prostate disease peaks at 8% in the 45 to 49 age group.

### 3. ATTITUDES TOWARDS TESTING FOR PROSTATE CANCER

Participants who report that they have never been tested were asked about their attitude to being tested in future. The results are shown in Table 3.1.

**Table 3.1: Do you anticipate having a test for prostate cancer sometime in the future?**

| Age Group | Definitely | Yes, probably | Unlikely | No  | Don't know |
|-----------|------------|---------------|----------|-----|------------|
| 40-44     | 23%        | 60%           | 3%       | 3%  | 11%        |
| 45-49     | 24%        | 50%           | 10%      | 8%  | 7%         |
| 50-54     | 14%        | 52%           | 11%      | 11% | 11%        |
| 55-59     | 10%        | 59%           | 6%       | 14% | 10%        |
| 60-64     | 8%         | 53%           | 14%      | 12% | 14%        |
| 65-69     | 20%        | 27%           | 20%      | 3%  | 30%        |
| 70-74     | 0%         | 53%           | 13%      | 7%  | 27%        |
| Overall   | 18%        | 54%           | 9%       | 8%  | 12%        |

Over the past 10 years there has been a marked increase in participants who have never been tested who said they would “definitely” or “yes, probably” be tested for prostate cancer sometime in the future from 42% in 2002 to 72% in 2012.

A high percentage of younger participants in the 2012 survey expect to be tested sometime in the future. In the 40 to 44 and 45 to 49 age groups the percentage of participants who have never been tested said they would “definitely” or “yes, probably” be tested for prostate cancer sometime in the future were 83% and 74% respectively.

Amongst participants who had never been tested for prostate cancer, 19% indicated that their GP had previously suggested that they should be tested.

#### Discussion

Care must be taken when interpreting self-identifying data. Nevertheless, it would appear that testing for prostate cancer is more prevalent than previously understood, especially between ages 50 and 74. In this age group, 77% of men in the sample said that they had been tested for prostate cancer at least once and 52% said they had been tested in the last 12 months. Note, that amongst men who have been tested at least once, a significant percentage (20%), believe that men over age 50 should be tested every two years rather than annually. A significant number (29%) of men between 40 and 49 have been tested at least once, indicating that men are being tested from an early age.

The survey indicates that GPs are the key influencer for men to be tested for prostate cancer either by suggesting a test as part of a routine check-up or by conducting a PSA test without prior consultation. Amongst participants who had never been tested for prostate cancer, 19% indicated that their GP had previously suggested that they should be tested.

The percentage of men who have never been tested who indicated that they anticipate having a test in the future is also high, with 72% of the sample indicating they would “definitely” or “yes, probably” have a test for prostate cancer sometime in the future.

We did not see significant variation in responses between participants who live in metropolitan and rural/ regional locations. This is in contrast to previous studies which have shown a gap between urban and rural prostate cancer screening rates in Australia.<sup>8,9</sup>

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 very high percentages of men in the relevant age group indicating that they either have been or intend to be tested at some point in the future. Problematically almost 40% of participants either “strongly agree” or “agree” that advice about the usefulness of the test is confusing; and it also seems likely that some men are being tested at an inappropriately high frequency. These findings add weight to the argument that evidence-based national guidelines for prostate cancer testing are needed.

Dennis Lamshed, prostate cancer survivor,  
and his wife Meredith Lamshed



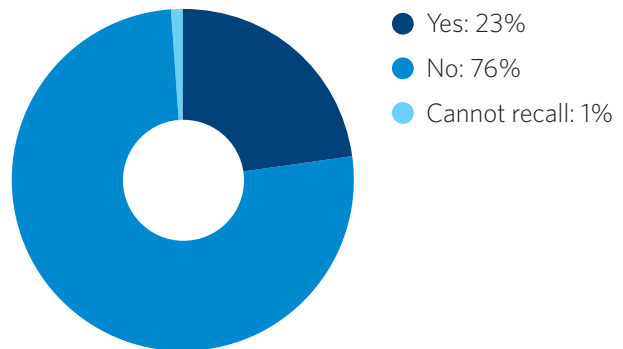
# 4. ATTITUDES TOWARDS AVAILABLE SUPPORT SERVICES

There is a perception amongst health service professionals that only a very small percentage of men access support services and that typically they do not make use of the full range of options available to them. There are counter views that health services are child and female friendly and less “friendly” to men.<sup>10</sup> Our study shows a much more positive picture than this.

In the 2012 survey almost one quarter of men diagnosed with or undergoing further investigation for prostate cancer (N=231) claim to have contacted a cancer support organisation.

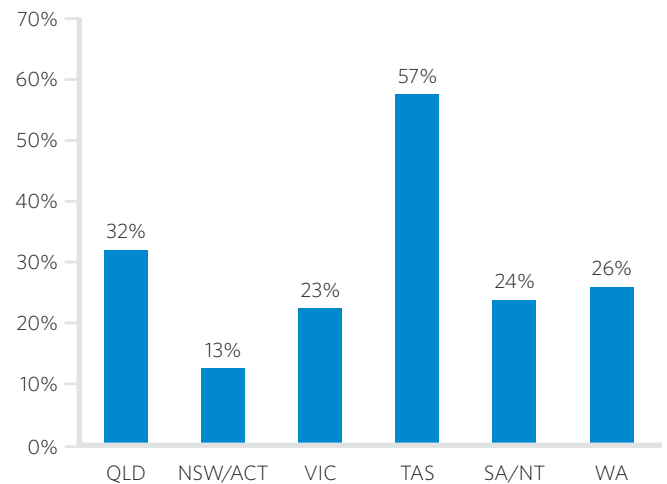
Participants in our sample had poor recall of the name of the support organisation they contacted. However, it was clear from their responses that they contacted either a PCFA affiliated prostate cancer support group or a Cancer Council recognised support group.

**Fig. 4.1: On learning about your condition did you contact any support organisations?**



Participation in support groups was higher in rural/ regional locations (32%) compared to metropolitan areas (17%) and was highest in Tasmania (57%) and lowest in NSW/ ACT (13%) as shown in Fig 4.2.

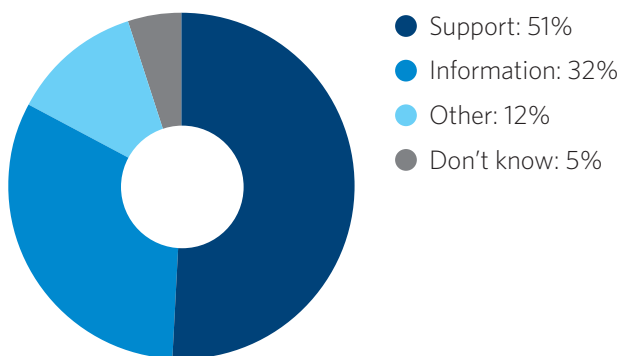
**Fig. 4.2: On learning about your condition did you contact any support organisations?**



Men who joined support groups tended to do so after diagnosis and indicated that the main services offered were support and information as shown in Fig 4.3.



**Fig. 4.3: What did the support organisation offer you?**



*“My experience was more after my operation and settling into my new situation. It was good to talk to other men who had been diagnosed.”*

*“Supportive in providing information on disease and options. Encouraging to find the survival periods encountered.”*

We asked men who attended a PCFA affiliated prostate cancer support group about their satisfaction with the experience. They were asked to rate their satisfaction using a scale from 1 to 10, where 10 represents very satisfied, and 1 not at all satisfied. The resulting mean score was 8.0 reflecting a strong level of satisfaction. Almost 40% of those who participated in a group awarded a score of 10 and two-thirds gave a score of 8 or higher, clearly indicating high levels of satisfaction with the experience. In contrast only 13% awarded a score less than 6.

*“We have a close group who meet in a very caring and supportive atmosphere. There seems to be no limit to subjects and personal experiences we share together which I believe helps to the overall success of our group.”*

*“Very informative and it was good to hear other men talk about the disease and how they were treated.”*

*“Information and talks given by visiting medical people are very helpful. The range of literature is excellent and is most informative. I have been made to feel very welcome at all the meetings I have attended. It can be a bit confronting to talk about these very personal areas.”*

Using a scale from 1 to 10, where 10 represents extremely useful, and 1 not at all useful, participants were asked to rate how useful possible support services would be to men who have been diagnosed with prostate cancer. The results are shown in Table 4.1.

**Table 4.1: Usefulness of possible support services**

| Support Service                         | Average Rating |
|---|----------------|
| Face to Face Support                    | 7.9            |
| Written Material                        | 7.5            |
| Prostate Cancer Specific Support Groups | 7.4            |
| Telephone Support                       | 6.7            |
| Online Forums                           | 6.5            |
| Email Support                           | 6.4            |
| Community Forums                        | 6.2            |
| Social Interest Groups                  | 6.1            |

Face to face support emerged as the most useful support service. However men also indicated that written material, prostate cancer specific support groups, telephone support, online forums, and email support would be useful to them.

Significantly 20% of participants indicated that more needed to be done to build awareness and make it easier for men to access support once diagnosed. Health professionals and partner/carers were cited as significant for support provision and guiding men to appropriate services and information.

*“I wish I had found them earlier and certainly prior to making a decision post diagnosis on which path to take. Only challenge is to get information out to men to inform them of support groups and their advantages.”*

Some men emphasised the importance of having variety in support group structures and the challenges for some in discussing personal issues when women were also present in the group.

*“Many people at a meeting want different things so programs must be varied.”*

*“I find it a little embarrassing particularly with females at the meeting talking or asking questions about erectile dysfunction, incontinence and depression.”*

The reasons participants cited for not joining a support group ranged from a preference to wait until a clear diagnosis had been made, to having limited information about support groups, a lack of availability of a support group in their region, and unwillingness to speak about a personal health matter with others.

**Table 4.2: Reasons for not joining a support group**

| Reason                          | Percentage |
|---------------------------------|------------|
| Not Fully Diagnosed             | 22%        |
| Unaware                         | 15%        |
| Health Care Professional Enough | 13%        |
| Don't Wish to Discuss           | 12%        |
| Did Not Need                    | 8%         |
| No Group Available Locally      | 7%         |
| Other                           | 16%        |
| Don't Know                      | 7%         |

### Discussion

It is clear from our research that men are willing to access support services, including attendance at support groups, where available. However, we also found that men lack knowledge about the availability of support services and need health professionals to be more active in guiding them to appropriate information and support.

Whilst face to face support was cited as the most useful support service, a wide range of other information, resources and services, including written material, telephone support, online forums and email support, were all seen as very useful.

Consistent with previous research<sup>11</sup>, satisfaction levels amongst men who have attended a PCFA affiliated prostate cancer support group were high and it is clear that men value the opportunity to talk to others who have experienced a prostate cancer journey.

*"I found listening to other bloke's stories and journey was most informative."*



Tony Maxwell, PCFA NSW/ACT Chapter Councillor



# SUPPLEMENT: PARTNERS AND CARERS

Evidence indicates that prostate cancer has a significant impact on the partners and carers of men diagnosed with the disease.<sup>12</sup>

As one person commented: "Prostate cancer is not only a man's disease; it's a couple's disease."

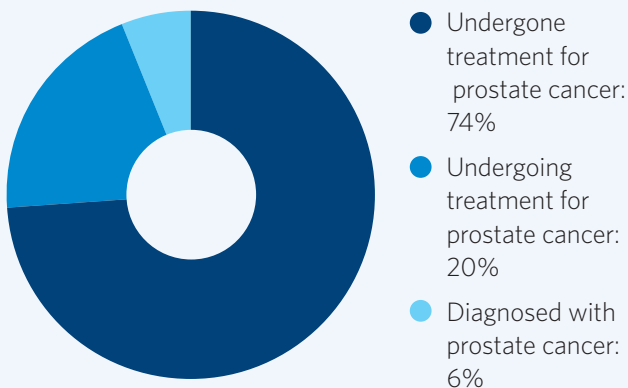
In previous Community Attitudes Surveys partners have been asked about testing for prostate cancer. In 2012 a separate adjunct survey for partners and carers was developed and distributed through PCFA support groups, carer organisations and cancer specific carer groups. The survey aimed to better understand attitudes towards prostate cancer held by partners and carers, and the types of support services they would value.

A total of 61 people responded, of whom 90% were women. Independently of the survey two people provided written stories about their experiences and a further eight people met with PCFA staff to discuss the impact of prostate cancer on them.

## DIAGNOSIS AND TREATMENT STATUS

The majority of men (74%) linked to survey respondents had already undergone treatment for prostate cancer, with 20% currently undergoing treatment and 6% recently diagnosed.

**Fig S.1: Do you care for a man who has been diagnosed with prostate cancer, or is having or had treatment for prostate cancer?**



## IMPACT OF DIAGNOSIS

Participants reported a deep sense of shock at a diagnosis of prostate cancer in their partner.

**Table S.1: How did his diagnosis with prostate cancer affect you?**

| Reason                      | Percentage |
|-----------------------------|------------|
| Was shattered/ shocked      | 66%        |
| Had a positive attitude     | 10%        |
| Was concerned               | 10%        |
| Worried about the long term | 70%        |
| Changed lifestyle           | 70%        |
| Provided support            | 5%         |
| Became depressed            | 3%         |
| Found it hard to bear       | 3%         |
| Got on with it              | 2%         |
| Took a caring role          | 2%         |
| Other                       | 5%         |

For some participants prostate cancer was an additional illness they had to face.

*“I was really shocked. My husband had a pre-existing chronic medical condition and this was ‘the icing on the cake’. We both felt overwhelmed.”*

*“It was devastating as he had bowel cancer twice before at ages of 26 and 35.”*

These partners were supporting men through a wide range of treatments as well as the aftermaths of treatment.

**Table S.2: What treatments has he had since he was diagnosed?**

| Treatment experienced | Percentage |
|-----------------------|------------|
| Surgery               | 57%        |
| Radiotherapy          | 38%        |
| Hormone therapy       | 28%        |
| Brachytherapy         | 16%        |
| Chemotherapy          | 3%         |
| Other                 | 10%        |

*“It was a worrying time, and now we have to cope with the added side effects of the operation”*

*“Getting him to the treatments 6 days a week for 6 weeks then again for 5 weeks.”*

An immediate reaction on diagnosis was to seek more information. Doctors were seen by participants as primary information source, along with online information, discussions with family members and linking to cancer organisations.

**Table S.3: On discovering he had prostate cancer what did you do?**

| Action on Diagnosis                              | Percentage |
|--|------------|
| Sought information from doctors                  | 69%        |
| Went online and searched for information         | 64%        |
| Talked to family and friends                     | 54%        |
| Contacted specific prostate cancer organisations | 25%        |
| Contacted the Cancer Council                     | 23%        |
| Contacted other medical organisations            | 10%        |
| Other  | 15%        |

Communication about the diagnosis of prostate cancer between partners and carers and others highlights the importance of communication with children, other family members and GPs. The survey also revealed that partners and carers are frequently the ones who communicate the diagnosis to other people.

**Table S.4 : Who did you first speak to about his condition?**

| Who Spoken to First  | Percentage |
|----------------------|------------|
| Child/ children      | 36%        |
| Other family members | 25%        |
| GP                   | 18%        |
| Other                | 16%        |
| Friends              | 5%         |

# SUPPLEMENT: PARTNERS AND CARERS

## IMPACT OF SIDE EFFECTS AND RELATIONSHIP CHANGES

Participants had a good understanding of the side effects of treatment and, significantly, identified depression as one of the top three side effects.

**Table S.5: What are the possible side effects, if any, of any of the treatments for prostate cancer?**

| Treatment Side Effects | Percentage |
|------------------------|------------|
| Incontinence           | 57%        |
| Erectile dysfunction   | 56%        |
| Depression             | 31%        |
| Loss of libido         | 10%        |
| Infertility            | 3%         |
| Other                  | 36%        |
| Don't Know             | 18%        |

Participants also reported impacts on their own health and coping abilities, as well as worry about the potential loss of their partner.

*"It was scary as it (referring to prostate cancer) was described as quite aggressive and you are suddenly faced with the possibility of losing the person you love, not to mention dealing with the aftermath of treatment."*

*"I now suffer from anxiety and get depressed about any medical issues. I cannot cope like I used to be prior. I was a stronger person before all of this."*

There is some evidence in the survey results and from discussions with partners and carers that they are often unable to discuss the impacts of diagnosis and treatment with other people due to their partner's embarrassment about having prostate cancer and its side effects. These people frequently suffer in a silence.

Some women had an inter-generational experience with prostate cancer reporting a grandfather, father, and husband affected by prostate cancer.

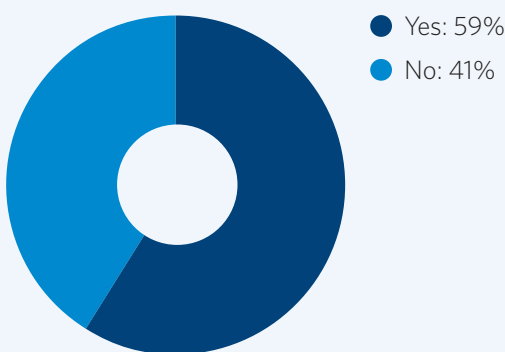
*"I have lost all the special men in my life: my grandfather, my father and my husband to prostate cancer. My youngest brother has had a biopsy for prostate cancer recently along with other tests and is currently awaiting results. I pray he is not next!"*

Women consistently spoke about diagnosis and treatment impacts which affect their relationships such as personality changes and mood swings in their partners, erectile dysfunction, and withdrawal of intimacy.

## PARTICIPATION IN SUPPORT GROUPS

Seventy per cent (70%) of men linked to survey respondents have attended a PCFA affiliated prostate cancer support group and 59% of participants in the survey attended a support group themselves. Participants placed high value on the emotional support they received.

**Fig S.2: Have you attended a PCFA prostate cancer support group?**



It is not known how many were attending to support their partner and assist their engagement with the group and how many were there for their own support needs. However, significant numbers of participants receive little support and those who do mainly receive this through a specific support group or friends and family members.

**Table S.6: What support did you receive or are continuing to receive as a carer and from whom?**

| Source of Support     | Percentage |
|-----------------------|------------|
| None                  | 41%        |
| Support group         | 25%        |
| Family and friends    | 20%        |
| Medical professionals | 13%        |
| Counselling           | 8%         |
| In home carers        | 2%         |
| Cancer counselling    | 2%         |
| Other                 | 2%         |
| Don't know            | 5%         |

## SUPPORT SERVICES NEEDED

Participants were able to articulate the additional support services needed by men and identified availability of information, support groups and opportunities for men to meet other men as key areas for development.

**Table S.7: What else do you think could be a good idea to support men diagnosed with prostate cancer?**

| Source of Support           | Percentage |
|-----------------------------|------------|
| More information            | 30%        |
| Support group               | 30%        |
| Meet other men              | 21%        |
| Psychological support       | 13%        |
| Family                      | 8%         |
| GP                          | 8%         |
| Post treatment support      | 7%         |
| Male prostate cancer nurses | 3%         |
| Specialised clinics         | 3%         |
| Talking in the community    | 3%         |
| Other                       | 2%         |
| Don't know                  | 8%         |

Participants indicated that men need more encouragement to talk about their disease and its impacts and that partners, carers and family members need avenues for support and that this is particularly so at diagnosis and post treatment.

## Discussion

Whilst based on a small sample size of 61 participants, our research provides a valuable window on the enormous psychosocial impact of a diagnosis of prostate cancer on partners and carers. Sixty-six per cent (66%) of participants reported that their initial reaction at the diagnosis was one of being shattered/ in shock.

Significant numbers of participants receive little support and those who do mainly receive this through a specific support group or friends and family members. Participants also indicated that they need additional strategies to assist them in managing personality changes, mood swings and withdrawal of intimacy from their partners at various stages on the prostate cancer journey.

Participants indicated that men need additional information, support services and social interaction opportunities with other men as part of their supportive care.

# WHERE TO NEXT?

PCFA's 2012 Community Attitudes Survey demonstrates that, over the past 10 years, significant progress has been made in community awareness and knowledge of prostate cancer. Despite this, much work still remains to be done.

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

## 1. 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. Almost 40% of the men in the survey believe that the advice they receive about testing is confusing.

The reality, though, is that large numbers of Australian men either have been or intend to be tested for prostate cancer at some point in the future. Sixty-four per cent (64%) of men in the survey reported that they have been tested for prostate cancer at least once and 41% that they have been tested in the last 12 months. In effect, therefore, Australia has an unorganised de-facto screening program.

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 be in the best interests of the Australian community.

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



## 2. EXPAND PCFA AFFILIATED PROSTATE CANCER SUPPORT GROUP NETWORK

Almost one quarter of men in the survey who have been diagnosed with or are undergoing further investigation for prostate cancer contacted a support organisation. They found the organisation to be a very valuable source of information and support. It is clear that men value the opportunity to talk to others who have experienced a prostate cancer journey.

Satisfaction levels with PCFA affiliated prostate cancer support groups were high with a mean satisfaction score of 8.0 on a scale of 1 to 10, where 10 represents very satisfied, and 1 not at all satisfied.

The Australian Government, through Cancer Australia, is funding PCFA to grow our network of affiliated prostate cancer support groups from 110 at 1 July 2011 to 200 by 30 June 2014. We are pleased to report good progress towards this goal with 127 affiliated support groups at 30 June 2012, including two support groups, in Melbourne and Sydney, specifically for gay and bisexual men and more to follow in other cities.

## 3. INCREASE AWARENESS OF SUPPORT GROUPS AMONGST HEALTH PROFESSIONALS

Twenty per cent (20%) of men in the survey indicated that more needed to be done to build awareness and make it easier for men to access support once diagnosed. Health professionals were cited as significant for guiding men to appropriate services and information.

Education on prostate cancer and awareness of the benefits of support groups for medical specialists, GPs and allied health professionals are current focus areas for PCFA.

## 4. DIVERSIFY SOURCES OF INFORMATION AND SUPPORT

Whilst face to face support was cited as the most useful support service, a wide range of other information, resources and services, including written material, telephone support, online forums and email support, were all seen as very useful.

The Australian Government, through Cancer Australia, is funding PCFA to devise and implement web based resources and support for men and their families affected by prostate cancer. By 30 June 2014, PCFA will develop a 'social' website linked to peak consumer organisations; create an internet-based communications hub for prostate cancer support groups using social networking tools; and develop and make available online versions of evidence-based fact sheets and educational resources.

This initiative will significantly improve access to information and resources, especially for men and their families in regional and rural Australia.

## 5. UNDERTAKE FURTHER RESEARCH INTO SUPPORT NEEDS OF PARTNERS AND CARERS

Whilst based on a small sample size of 61 participants, our research provides a valuable window on the enormous psychosocial impact of a diagnosis of prostate cancer on partners and carers. Importantly, significant numbers of partners and carers in the survey indicate that they receive little or no support.

Partners and carers also indicated that they need additional strategies to assist them in managing personality changes, mood swings and withdrawal of intimacy from their partners at various stages on the prostate cancer journey.

The support needs of partners and carers are an area of heightened focus at PCFA with further research already underway.

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# RESEARCH AWARENESS SUPPORT

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