

# Survey by the Prostate Cancer Support Group - ACT Region

## 1. INTRODUCTION

This survey is being undertaken by the Prostate Cancer Support Group - ACT Region. The information collected will be used to identify ways in which the Group's activities might be enhanced to meet the needs of people that we regard as being our primary target audience. That is:

- \* men diagnosed with prostate cancer and who are considering treatment options
- \* men diagnosed with prostate cancer and who are undertaking "watchful waiting"
- \* men who have undertaken treatment for prostate cancer
- \* men not yet diagnosed but have reasons to believe that they may have prostate cancer and/or who have a higher than normal risk of prostate cancer
- \* the partners or carers of such men

The invitation to respond has been sent to you because you are on the mailing list for our Group's newsletter and our records indicate that you have sought advice from a member of our committee and/or have attended one of our monthly meetings.

If you are not in our primary target audience, please do not complete this survey.

The information you provide is totally anonymous and we do not collect any information such as names, email addresses or IP addresses that could be used to identify you.

If any question does not make sense or you need clarification on any matter, send an email to: [mboesen2@gmail.com](mailto:mboesen2@gmail.com)

Responses are required not later than 22 September 2012 please.

HOW TO SEND THE SURVEY TO US: simply click the "SURVEY COMPLETED - SEND IT" button at the bottom of the last page of the survey when you have completed your answers.

## 2. HAS PROSTATE CANCER BEEN DIAGNOSED?

### 1. Have you ever had a prostate biopsy?

- Had a prostate biopsy that detected prostate cancer
- Had prostate biopsy or biopsies but none of them detected prostate cancer
- Never had a prostate biopsy

### 2. Have you ever had a radiological scan that would have indicated the presence of prostate cancer?

- Had such a scan that detected prostate cancer
- Had such a scan or scans, but none of them detected prostate cancer
- Never had such a scan

If you had a scan, what type of scan was it?

## 3. TREATMENTS UNDERTAKEN?

### 3. Have you undertaken treatment for prostate cancer (including "watchful waiting" as a treatment)?

- Have not been diagnosed as having prostate cancer, so no treatment undertaken
- Diagnosed as having prostate cancer and have decided on only undertaking "watchful waiting"
- Diagnosed as having prostate cancer but still evaluating treatment options
- Diagnosed as having prostate cancer and am preparing to undertake surgical or radiological or chemical treatment
- Diagnosed as having prostate cancer and have had surgical or radiological or chemical treatment

## 4. SURGICAL OR RADIOLOGICAL OR CHEMICAL TREATMENTS UNDERTAKEN?

**4. Which of these surgical or radiological or chemical treatments for prostate cancer have you had or are undertaking currently? (Click all that apply):**

- Prostatectomy via open surgery
- Prostatectomy via "robotic" procedure
- Prostatectomy via laparoscopic (keyhole but non-robotic) procedure
- Radiotherapy
- Hormone therapy / ADT
- Other chemical treatment

If "other" please specify:

## 5. REMEDIAL SURGICAL PROCEDURES

**5. Have you had any of these remedial surgical procedures subsequent to undertaking treatment for prostate cancer? (Click all that apply):**

- Have had no subsequent remedial surgical procedure
- Pelvic sling
- Artificial urinary sphincter
- Penile implant
- Had other remedial surgical procedure

If "other remedial surgical procedure" please specify:

**6. ATTENDED ANY OF OUR SUPPORT GROUP'S MONTHLY MEETINGS?**

**6. Have you ever attended any of the support group's monthly meetings?**

- Yes
- No

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## 7. NUMBER OF MEETINGS ATTENDED; VIEWS ABOUT MEETINGS

**7. Approximately how many of our monthly meetings have you ever attended?**

**8. In the last 2 years, how many of our group's monthly meetings have you attended?**

**Type in a number between 0 and 22:**

**9. How useful to you have these aspects of our group's monthly meetings been?**

	Very useful	Moderately useful	Of limited use	Of a little use	Of no use
1. Presentations by guest speakers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Housekeeping / organisational / what's happening information from the group's committee	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Information relating to prostate cancer matters, provided by members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Support, counsel, advice on my and other members problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Socialising & networking with members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Getting information & views about medical practitioners	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Getting information & views about medical services or facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Talking to medical practitioners & medical workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Materials available from the group's library	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Seeing pamphlets, newsletters & materials from other organisations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Other aspects (specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The other aspects:

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## 10. What suggestions can you make about improving these activities at our group's monthly meetings?

**Note: you can type as many words as you like into the boxes - the input words will scroll across to meet your needs.**

1. Presentations from guest speakers
2. Housekeeping / organisational / what's happening information from the group's committee
3. Information relating to prostate cancer, provided by all members
4. Support, counsel, advice on my and others members problems
5. Socialising & networking with members
6. Getting information & views about medical practitioners
7. Getting information & views about medical services or facilities
8. Talking to medical practitioners and medical workers
9. Materials available through the group's library
10. Seeing pamphlets and newsletters and materials from other organisations
11. Other aspects

## 11. Taken as a whole, what has been the value of the support group's monthly meetings to you personally?

- of great value to me
- of moderate value to me
- of limited value to me
- of a little value to me
- of no value at all to me

## 12. Taken as a whole, what has been the value of the support group's monthly meetings to your partner or carer?

- no partner/carer
- of moderate value to partner/carer
- of limited value to partner/carer
- of a little value to partner/carer
- of no value at all to partner/carer



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## 8. VIEWS ON GROUP'S ACTIVITIES AND PRODUCTS

**13. Apart from the monthly meetings, the group provides information about prostate cancer and its treatment through other means.**

**What has been the value to you (and partner/carer) of the following means of providing information?**

	of great value	of moderate value	of limited value	of a little value	of no value at all	not aware of that	aware of but never used yet
1. The group's web site	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The group's newsletter "The Walnut"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The PCFA's "Localised Prostate Cancer Pack" (in blue box)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The group's own information pamphlets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Pamphlets and materials given to the group by other bodies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Materials available from the group's library	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. One-on-one discussion with a person on the group's committee	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Prostate cancer awareness presentation given to a group or club	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Other means (specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The other activities or products:

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## 14. What suggestions can you make about improving the value to you (and partner/carer) of each of the following means of providing information:

**Note: you can type as many words as you like into the boxes - the input words will scroll across to meet your needs.**

1. The group's web site
2. Monthly newsletter "The Walnut"
3. The PCFA's "Localised Prostate Cancer Pack" (in blue box)
4. The group's own information pamphlets
5. Pamphlets and materials we get from other bodies
6. Library loan materials
7. One-on-one discussion
8. Awareness presentations

## 15. Overall, of how much value to you personally have been the group's information-providing activities that are listed above on this page?

- of great value to me
- of moderate value
- of limited value
- of a little value
- of no value at all

## 16. Overall, of how much value to your partner or carer have been the group's information-providing activities that are listed above on this page?

- no partner or carer
- of great value to partner/carer
- of moderate value
- of limited value
- of a little value
- of no value at all

## 17. Can you suggest any other means of providing information that should be used by the support group?

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**18. What more could the support group have done to help you personally?**

**19. What more could the support group have done to help your partner or carer?**

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## 9. VIEWS ABOUT THINGS ON WHICH WE MIGHT EXPEND OUR SCARCE FINANCIAL RESOURCES

**20. In addition to the activities mentioned above, the support group provides a community service through work by our members and in some cases through financial support for these activities:**

- \* awareness presentations to groups, associations, clubs and work groups
- \* awareness marquees at community and club events (e.g. multicultural festival)
- \* course fees and materials grants to nurses undertaking specialised courses relating to prostate cancer
- \* advisory support to the Cooma prostate cancer support group
- \* urine flow meter for The Canberra Hospital

**While we have very limited funds, the executive is giving consideration to a number of other things on which we might possibly expend group funds. Please indicate your attitude towards limited expenditure on the following items, and add other items if you have suggestions:**

	I strongly endorse	I would probably endorse	I would probably not endorse	I would definitely not endorse
1. course fees and materials grants to encourage more nurses to undertake courses relevant to prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. urine flow meter for Calvary Public Hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. art work to enliven the walls in the new cancer center at TCH	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. limited financial support for financially disadvantaged prostate cancer patients coming to Canberra from remote regions (e.g. for travel or accommodation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. limited support for travel and accommodation for members of our executive that have to travel outside Canberra to attend critical conferences or to provide support to other groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. costs of identifying and contacting ACT groups that would benefit from an awareness presentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Australian travel or accommodation costs for bringing top level speakers to Canberra	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. microphone and loudspeakers to be used in our meeting room	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. supporting grants for ACT post-graduate or advanced certificate students who are researching matters related to prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. printing ICE (In Case of Emergency) cards to keep in wallets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please specify your "others"

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## 10. THANK YOU

Thank you for participating in this survey. The results of the survey will be of value to the group's executive. In a future meeting, the support group will be informed about the findings from the survey and their implications discussed.

If you have any comments to make about the content or nature of this survey or to provide views on any matters that are not canvassed in the survey, please provide them here.

Please then submit the survey by clicking on the button below that is labelled "SURVEY COMPLETED - SEND IT"

## 21. Comments: