PROSTATE CANCER SUPPORT GROUP - ACT REGION INC.

SUMMARY OF RESULTS FROM ELECTRONIC SURVEY OF MEMBERS' ATTITUDES TOWARDS THE WORK OF THE SUPPORT GROUP, UNDERTAKEN IN SEPTEMBER 2012

(A) BACKGROUND AND INTRODUCTION

Invitations to respond to an electronic survey were sent by email to 105 men and 5 women on 9 September 2012.

The 105 men were those on our membership list who, according to our records, met both these criteria:

1. had attended at least one of our regular monthly meetings, and

2. had been diagnosed with prostate cancer or were concerned that they may have prostate cancer

The 5 women were on our membership list which indicated that they were carers or partners that met all these criteria:

1. had attended at least one of our regular monthly meetings, and

2. were partners or carers of men who had either been diagnosed with prostate cancer or were concerned that they may have prostate cancer, and

3. they were NOT carers or partners of one of the 105 men

On 9 September 2012 the respondents were invited to complete an electronic survey questionnaire. The cut-off date was 22 September 2012. By that date, responses had been received from 46 people - a 42% response rate.

A tabulation of the responses to the closed-response questions are shown in section B that follows. These responses indicate that:

- Taken as a whole, the support group's monthly meetings were seen to be of value to respondents with 80% rating them as being of great value or of moderate value (see Q11 results).
- However, for partners/carers, the monthly meetings appear to be seen as having far less value with only 30% rating them as being of great value or of moderate value (see Q12 results).
- The main activities that occur at meetings were all seen as being useful, with more than two-thirds of respondents rating these aspects as being very useful or moderately useful (see Q9 results):
    - information provided by members (91% rating as very or moderately useful)
    - presentations by guest speakers (86%)
    - support, counsel and advice on problems (72%)
    - housekeeping, organisational matters, what's happening information (72%)
    - socialising and networking with others (72%)
    - getting information and view about nmmedical services and facilities (69%)
- Other meeting activities were not rated quite so highly, although still being rated as being very or moderately useful by a majority of respondents:
    - getting information and views about medical practitioners (64%)
    - accessing llibrary materials (61%)
    - seeing printed materials from other organisations (58%)
    - and talking to medical practitioners and medical workers (45%)

- Other activities of the group (i.e. other than monthly meetings) were also seen to be of value to respondents with 85% rating such activities as a whole as being of great value or moderate value (see Q15 results).
- However, for partners/carers, such extra-meeting activities appear to be perceived to be of far less value with only 38% giving such a rating (see Q16 results).
- These particular extra-meeting activities of the group were rated highly, with more than two-thirds of respondents indicating that they were very useful or moderately useful (see Q13 results):
  - *The Walnut* newsletter (94% rating as very or moderately useful)
  - one-on-one discussions with persons on the executive (79%)
  - our web site (73%)
- While not as strongly rated, these activities were also seen to be of some value to respondents:
  - awareness presentations to groups or clubs (56% as very or moderately useful)
  - our information pamphlets (48%)
  - our library materials (48%)
  - pamphlets and materials of other bodies (39%)
  - the PCFA's "Localised Prostate Cancer Pack" (39%)
- Views were sought on the appropriateness of expending group funds on a number of potential items of expenditure. All but one of the items was rated by more than two-thirds of respondents as being "strongly endorsed" or "would probably endorse" (see Q20 results). The top-rated items were:
  - course fees and materials grants to encourage nurses to undertake courses relevant to prostate cancer (91% would strongly or probably endorse)
  - limited expenses for travel and accommodation costs for executive members to attend critical conferences or to give support to other groups (91%)
  - cost of identifying and contacting ACT groups that would benefit from an awareness presentation (89%)
  - limited financial support for financially disadvantaged prostate cancer patients coming to Canberra from remote regions (88%)
  - urine flow meter for Calvary Public Hospital (85%)

A synthesis of the content that respondents wrote in as open-response answers is provided in Section C, grouped by theme. In total there were a significant number of comments that should be given consideration. However, no particular comment was made by more than one or two respondent. This can be interpreted as indicating that the activities of the group appear to be meeting members needs and expectations. The exception to this generalisation is that the needs of partners and carers should be could be given more attention.

After the Group's executive has had an opportunity to evaluate all the results, a statement of implications will be developed and posted on the web site and published in *The Walnut*. That statement will be the subject of a discussion at a regular monthly meeting in early 2013.

(B) TABULATIONS FOR THE CLOSED-RESPONSE QUESTIONS

Q1 Have you ever had a prostate biopsy?

	Number	% of those answering question
Had a prostate biopsy that detected prostate cancer	**41**	**93%**
Had prostate biopsy or biopsies but none of them detected prostate cancer	**1**	**2%**
Never had a prostate biopsy	**2**	**5%**
answered question	**44**	**100%**
skipped question	**2**	
all respondents	**46**	

Q2 Have you ever had a radiological scan that would have indicated the presence of prostate cancer?

	Number	% of those answering question
Had such a scan that detected prostate cancer	17	40%
Had such a scan or scans, but none of them detected prostate cancer	5	12%
Never had such a scan	21	49%
answered question	43	100%

Q3 Have you undertaken treatment for prostate cancer (including "watchful waiting" as a treatment)?

	Number	% of those answering question
Have not been diagnosed as having prostate cancer, so no treatment undertaken	**4**	**9%**
Diagnosed as having prostate cancer and have decided on only undertaking "watchful waiting"	**4**	**9%**
Diagnosed as having prostate cancer but still evaluating treatment options	**1**	**2%**
Diagnosed as having prostate cancer and am preparing to undertake surgical or radiological or chemical treatment	**3**	**7%**
Diagnosed as having prostate cancer and have had surgical or radiological or chemical treatment	**34**	**74%**
answered question	**46**	**100%**

Q4 Which of these surgical or radiological or chemical treatments for prostate cancer have you had or are undertaking currently? (Click all that apply):

	Number	% of those answering question
Prostatectomy via laparoscopic (keyhole but non-robotic) procedure	**14**	**41%**
Prostatectomy via open surgery	**13**	**38%**
Prostatectomy via "robotic" procedure	**4**	**12%**
Radiotherapy	**4**	**12%**
Hormone therapy / ADT	**6**	**18%**
Other chemical treatment	**0**	**0%**
HDR brachytherapy + EBRT	**1**	**3%**
answered question	**34**	**82%**

Q5 Have you had any of these remedial surgical procedures subsequent to undertaking treatment for prostate cancer? (Click all that apply):

	Number	% of those answering question
Have had no subsequent remedial surgical procedure	23	72%
Pelvic sling	1	3%
Artificial urinary sphincter	3	9%
Penile implant	3	9%
Had other remedial surgical procedure	3	9%
answered question	32	103%

Others:
Supra pelvic catheter
Hernia op. (caused by penile implant)
Widening urethra

Q6 Have you ever attended any of the support group's monthly meetings?

	Number	Percent of those answering question
Yes	**41**	**89%**
No	**5**	**11%**
answered question	**46**	**100%**

Q11/Q12 Taken as a whole, what has been the value of the support group's monthly meetings to you personally (Q11) / to your partner or carer (Q12) ?

									Great value plus Moderate value	
	of great value	of moderate value	of limited value	of a little value	of no value at all	All responses	Excluded from % calcu-lation (see note 2)	Answered question	Number	% of all responses
Q11 - to you personally?	17	11	6	0	1	35	N.A.	35	28	80%
Q12 - to your partner or carer?	see note 1	9	8	9	4	30	5	35	9	30%

Note 1: Q12 was defective - it was missing the "of great value" category

Note 2: 5 without partners or carers were excluded in calculating % for Q12

Q9 How useful to you have these aspects of our group's monthly meetings been?

							Very useful plus Moderately useful	
Answer Options (reordered in terms of strength of endorsement):	**Very useful**	**Moderately useful**	**Of limited use**	**Of a little use**	**Of no use**	**All responses**	**Number**	**% of all responses**
3. Information relating to prostate cancer matters, provided by members	18	14	3	0	0	35	32	91%
1. Presentations by guest speakers	18	13	4	0	0	35	31	86%
4. Support, counsel, advice on my and other members problems	12	14	4	2	1	33	26	72%
2. Housekeeping / organisational / what's happening information from the group's committee	8	18	6	1	1	34	26	72%
5. Socialising & networking with members	10	16	7	1	0	34	26	72%
7. Getting information & views about medical services or facilities	11	14	7	2	0	34	25	69%
6. Getting information & views about medical practitioners	13	10	7	4	0	34	23	64%
9. Materials available from the group's library	15	7	11	1	1	35	22	61%
10. Seeing pamphlets, newsletters & materials from other organisations	9	12	11	0	2	34	21	58%
8. Talking to medical practitioners & medical workers	8	13	11	2	1	35	21	58%
11. Other aspects	2	3	2	2	2	11	5	45%

answered question 36

skipped question 11

Q13 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?

									Great value plus moderate value	
Answer Options (reordered in terms of strength of endorsement):	**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**	**All responses**	**Number**	**% of all responses**
2. The group's newsletter "The Walnut"	17	15	0	2	0	0	0	34	32	94%
7. One-on-one discussion with a person on the group's committee	13	14	1	1	0	2	3	34	27	79%
1. The group's web site	15	9	6	0	0	3	0	33	24	73%
8. Prostate cancer awareness presentation given to a group or club	6	12	0	2	0	1	11	32	18	56%
4. The group's own information pamphlets	9	7	8	3	0	4	2	33	16	48%
6. Materials available from the group's library	10	6	7	1	3	3	3	33	16	48%
5. Pamphlets and materials given to the group by other bodies	4	9	12	3	0	2	3	33	13	39%
3. The PCFA's "Localised Prostate Cancer Pack" (in blue box)	7	6	6	2	0	9	3	33	13	39%
8. Other means	1	2	0	0	0	1	3	7	3	43%

answered question 34
skipped question 12

Q15/Q16 Overall, how much value have been the group's information-providing activities (in Q13) to you personally (Q15) / to your partner or carer (Q16)

	of great value	of moderate value	of limited value	of a little value	of no value at all	All responses	Excluded from % calculation see note)	Answered question	Great value plus Moderate value: Number	Great value plus Moderate value: % of all responses
Q15 - to you personally	14	15	4	0	1	34	N.A.	34	29	85%
Q16 - to your partner or carer (see note)	4	6	8	5	3	26	6	32	10	38%

Note: 6 without partners or carers were excluded in calculating % for Q16

Q 20 Indicate your attitude towards limited expenditure on the following items

						Strongly endorse plus probably endorse	
Answer Options (reordered in terms of strength of endorsement):	I strongly endorse	I would probably endorse	I would probably not endorse	I would definitely not endorse	All responses	Number	% of all responses
1. course fees and materials grants to encourage more nurses to undertake courses relevant to prostate cancer	20	12	2	1	35	32	91%
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	16	16	3	0	35	32	91%
6. costs of identifying and contacting ACT groups that would benefit from an awareness presentation	12	19	4	0	35	31	89%
4. limited financial support for financially disadvantaged prostate cancer patients coming to Canberra from remote regions (e.g. for travel or accommodation)	11	18	2	2	33	29	88%
2. urine flow meter for Calvary Public Hospital	11	18	3	2	34	29	85%
9. supporting grants for ACT post-graduate or advanced certificate students who are researching matters related to prostate cancer	15	11	8	0	34	26	76%
10. printing ICE (In Case of Emergency) cards to keep in wallets	7	18	5	3	33	25	76%
8. microphone and loudspeakers to be used in our meeting room	11	14	8	1	34	25	74%
7. Australian travel or accommodation costs for bringing top level speakers to Canberra	10	13	8	2	33	23	70%
3. art work to enliven the walls in the new cancer center at TCH	1	19	8	6	34	20	59%

answered question *36*
skipped question 10

(C) SYNTHESIS OF OPEN-RESPONSE COMMENTS WRITTEN INTO THE QUESTIONNAIRE BY RESPONDENTS

This is a summation of the comments made by respondents in one or more places of the questionnaire. The comments have been grouped under themes developed during analysis of the comments.

No attempt has been made to tabulate the frequency with which comments were made - this list is simply an aggregation of the content of all comments made.

Many of the comments have been paraphrased to make them succinct and coherent.

FORMAT OF MONTHLY MEETINGS

Meeting time:

- 7:00 pm not a good time

Discussion at meetings:

- promote more discussion between members and seek more information from members about problems and solutions and opportunities
- allocate more time to member discussion and answering all members' questions and revisiting things
- more time for one-on-one discussion with mentor/s who have information about specific matters of concern (e.g. erectile dysfunction, penile implant, vacuum pump, penile injections, post-operative rehabilitation, pads, bed-wetting, catheter, EBRT, brachytherapy, sex resumption, ADT)

Information about what's happening in the prostate cancer world:

- more information from PCFA (e.g. Garvin Institute provides good information)

Getting volunteers to sign up for awareness activities and fund-raising activities:

- "improve planning"; improve communication with members
- seek volunteers through using broadcast emails that provide full details of requirements

Need sound amplification system in the meeting room

PRESENTATIONS AT MONTHLY MEETINGS

Improve some expert speakers' presentions:

- make less technical; pitch at appropriate level; spell out acronyms
- should make tailor-made presentations that suit the audience's needs and knowledge
- provide hard-copy handout of slides and/or commentary

More presentations to be made by:

- urologists
- continence nurses
- nurses working with prostate cancer patients
- members who have information about specific or unusual treatments, rehabilitation, problems/solutions (could be 2 or 3 short presentations at each meeting)

Give more presentations about:

- erectile dysfunction
- radiotherapy, especially EBRT and brachytherapy

- pelvic slings
- artificial urethral sphincters
- early detection and early treatment
- naturopathic approaches
- alternative and complementary approaches
- being positive
- lifestyle: diet, exercise, etc
- health care providers

Give fewer presentations about:

- latest treatment procedures ("because most members have already had treatment")

Occasionally show DVDs instead of having a guest speaker

ADDITIONAL SUPPORT AND ASSISTANCE TO MEMBERS

Facilitate development of mentors and buddies for male and for female members

Identify members who can give one-on-one assistance or advice on specific problems or questions

Have some "men-only and "women only" sessions

Encourage more partners and carers to come to meetings from the outset.

Telephone follow-up with patient after treatment to see if assistance required

Provide lists of specialists, health-care services, treatment facilities (e.g. HDRT, brachytherapy, robotic radical prostatectomy)

Publicise existence of ACT Health's pre-and post-prostatectomy continence clinic sessions

Educate GPs to initiate testing (PSA, DRE, biopsy) earlier

LIBRARY

Make DVDs of expert presentations available for purchase or download

Replace old editions with current editions

Get Wesley hospital publications

Need transcripts of some videos (e.g. Lavis, Enis) because audio is bad

Facilitate on-line access to materials

WEB SITE

Include more personal stories (particularly involving radiotherapy)

Include more information about radiotherapy

Include links to latest research

Include more links to major US and European studies and sites

THE WALNUT NEWSLETTER

Include more personal stories

Include summaries of expert presentations that were made at meetings

Include list of DVDs for sale (note: we do not have any such DVDs - ed.)

PCFA'S LOCALISED PROSTATE CANCER PACK

Improve availability in chemist's shops and publicise outlets

Too bulky and of variable quality; need an "essentials" information kit

Make more visible at meetings

Present formally to new members

AWARENESS ABOUT THE GROUP'S ACTIVITIES AND SERVICES

Run community service ads to publicise the group's existence and activities

Publicise the group's willingness to provide awareness presentations to clubs and interest groups and work groups

Put copies of the group's pamphlets in libraries, clubs, doctors' waiting rooms, specialists' waiting rooms, healthcare providers

Make health care providers more aware of the group and more willing to refer patients to the group, especially before treatment

MEMBER PARTICIPATION IN THE WORK OF THE GROUP

Encourage more members to volunteer for activities of the group so that the work load is shared and so that additional activities can be undertaken and funds raised.

ADDITIONAL ITEMS TO BE CONSIDERED FOR EXPENDITURE OF FUNDS

Educate GPs about the need for PSA and other diagnostic testing and early detection and treatment