



Report of the Results of Online Surveys of Researchers and Non-Scientists

March 2012

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1. Executive Summary

Prostate Cancer Canada (PCC) is embarking on a process to develop a research strategy. This report describes the results of two online surveys that will provide direction for the development of the strategy. The surveys were intended to gather the thoughts and perspectives of key stakeholders in prostate cancer research, namely researchers, patients and survivors, their family members and concerned members of the public.

The surveys identified broad agreement as to the gaps in funding and research priorities, as well as some areas with a divergence of opinion.

For the public survey, of the 1,203 who started the survey, 611 were completed for a completion rate of 51%. A further 76 incomplete responses contained data and are also included in this report. The results of the survey were:

- 54% of respondents were either survivors or currently being treated for prostate cancer
- 46% of respondents were from Ontario and 85% were male
- Concerned members of the public were most interested in finding the cause and prevention of prostate cancer
- Improving treatment while reducing side effects was the most pressing issue for men undergoing prostate cancer treatment
- Most survivors and family members indicated they wanted to know more about the cause of prostate cancer
- 60% of respondents were satisfied with research progress. Most satisfied were survivors; least satisfied were men currently undergoing treatment
- Almost 50% of the public suggested that non-researchers should be involved in setting research priorities

Of the 171 researchers who started the survey, 129 were completed. The completion rate was 75% and the response rate 40%. The survey indicated that:

- Development of effective biomarkers, particularly focused on differentiating indolent from aggressive disease, was the greatest priority
- Canada's greatest strength was thought to be the high level of collaboration between researchers across the country
- The major resource gap identified was the lack of project funding
- More smaller grants were thought by 57% of researchers to offer the best 'bang for the buck'
- Greater than 57% indicated a stronger preference for open competitions than strategic programs
- Differentiating between indolent and aggressive disease and improving treatment while reducing side effects were the areas where research was thought likely to have the greatest impact

These results will be used to inform the identification of priority areas for research in Prostate Cancer Canada's research strategy.

2. Rationale

This report describes the results of two online surveys that are intended to provide direction for the development of a research strategy for Prostate Cancer Canada. These surveys follow a similar approach to that employed in developing the CCRA Pan-Canadian Cancer Research Strategy.

The CCRA researcher survey showed that researchers thought that they were best placed to provide advice about research priorities. The researcher community is most aware of the state of science and with the resources necessary to accelerate its progress. Also, it is critical to seek the thoughts of the ultimate beneficiaries of the results of the research conducted and who provide the funds for Prostate Cancer Canada's research through donations. Therefore a second survey of prostate cancer survivors, their family members and concerned members of the public was conducted.

3. Methods

Online survey methodology was employed for both surveys as it allowed an efficient and economical means to collect data and it eliminated data entry and processing steps. FluidSurveys was used to create, publish and host the surveys.

3.1 Survey Design and Administration

3.1.1 Public Survey

The survey of patients, survivors, their family members and concerned members of the public is referred to as the **public survey** for the remainder of the report.

The Public Survey consisted of closed- and open-ended questions on prostate cancer research. Specifically, respondents were asked about:

- Allocation of research investments in areas of prostate cancer research (six research areas; continuous variables)
- Role non-scientists play in setting research priorities (three choices)
- Satisfaction with progress made in prostate cancer research (five point rating scale)
- Most pressing priority for research (open- ended)

The survey also contained a series of closed-ended questions relating to the respondent, such as perspective, province/territory of residence, community size and gender. The survey was only made available in English. A copy of the full survey is provided in Appendix A.

The survey was launched on March 7th by email to 142 chairs or co-chairs of support groups of the Prostate Cancer Canada Network (PCCN). Recipients were encouraged to promote the survey as broadly as possible. A link to the survey was also posted on the virtual support group site. In addition, on March 8th an email message was sent to 16,954 legitimate addresses on the general PCC mailing list. The survey closed on March 17th 2012.

Of the 1,203 who started the survey, only 611 were completed for a completion rate of 51%. A further 76 incomplete responses contained data and are also included in this report.

3.1.2 Researcher Survey

The Researcher Survey consisted of eleven multi-pronged questions on prostate cancer research and PCC's existing research programs. Specifically, questions focused on:

- Gaps in knowledge in prostate cancer (open-ended)
- Canada's strengths in prostate cancer (open-ended)
- Greatest challenges to conducting prostate cancer research (five choices)
- Need for increased investment (ten choices)
- Most pressing priority for research (open- ended)
- Grant size/quantity (two choices)
- Optimal balance between open investigator-initiated competitions and strategic considerations (two choices)
- Evaluation of PCC's Pilot Grant Program (five point rating scale)

- Evaluation of PCC's Clinician Scientist Award Program (five point rating scale)

Additional closed-ended questions were asked relating to respondent characteristics including research area and province of residence. Survey questions were prefaced with a brief introduction. A copy of the survey is provided in Appendix B.

The survey was sent to individuals identified as prostate cancer researchers in the CCRA Canadian Cancer Research Survey database. This contains information on cancer research projects and their affiliated personnel funded by 37 organizations/initiatives for four calendar years, 2005 to 2008 together with publicly available email addresses. Researchers who had applied for funding to PCC in any year were also sent the survey. The survey population was 321. The survey was launched with personalized email messages sent on February 17, 2012. A follow-up personalized message was sent by email on February 28 with a final reminder to respond sent on March 5, the day the survey closed. Of the 171 who started the survey, 129 were completed. The completion rate was 75% and the response rate 40%. Only the results from completed surveys are presented in this report.

3.2 Data Analysis

A number of conventions were used to analyse the data.

1. Respondents were asked to indicate their research area from a list of nine choices and were permitted to select as many areas as were applicable. In analyses, this variable was treated as an interval scale such that each area selected was equally weighted and, when summed together, would equal 1 (e.g., if the respondent selected "Biology", "Etiology", "Treatment" and "Survivorship", each area was weighted at 0.25).
2. The responses to open-ended questions were grouped according to the use of similar phrases or terminology. For some questions, more than one variable was captured in a response. In such cases, each variable was considered and is presented as a unique response.

4. Findings

4.1 Respondents

4.1.1 Public Survey

There were 687 responses to the survey. Most respondents were male (Table 4.1.1). A greater representation of responses occurred from smaller communities. While responses were received from all provinces and one of the three territories, just over 50% of respondents resided in Ontario. A poorer response from Quebec likely reflects the fact that the survey was made available in English only.

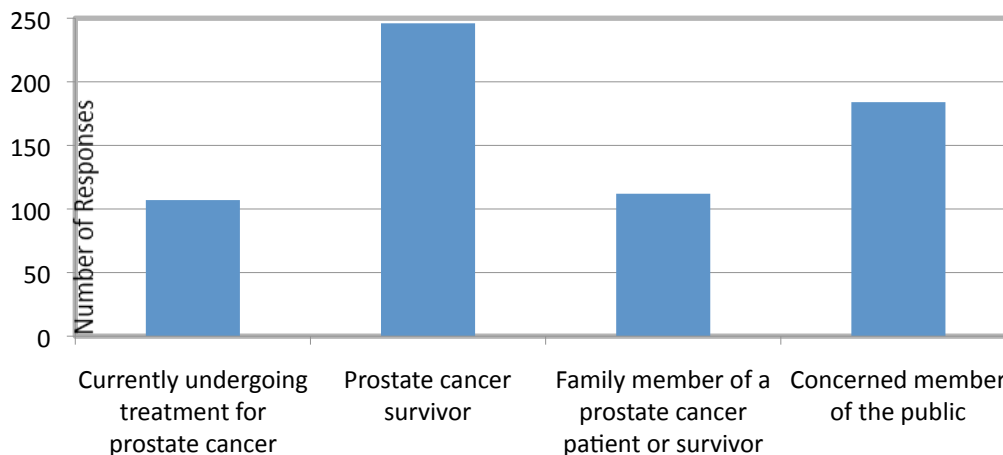
TABLE 4.1.1 RESPONDENTS OF THE PUBLIC SURVEY BY PROVINCE, COMMUNITY SIZE AND SEX

	Response	Total (N=687)	
		N	%
Province/Territory	Alberta	85	12.4%
	British Columbia	97	14.1%
	Manitoba	14	2.0%
	New Brunswick	6	0.9%
	Newfoundland & Labrador	7	1.0%
	Northwest Territories	1	0.1%
	Nova Scotia	41	6.0%
	Nunavut	0	0.0%
	Ontario	317	46.1%
	Prince Edward Island	2	0.3%
	Quebec	40	5.8%
	Saskatchewan	26	3.8%
	Yukon	2	0.3%
No response	39	5.7%	
Community Size	Rural area/low population density	44	6.4%
	Population under 10,000	40	5.8%
	10,001 - 99,000	136	19.8%
	100,000 - 499,999	156	22.7%
	500,000 - 1,499,999	142	20.6%
	1,500,000 and over	124	18.0%
	No response	45	6.6%
Sex	Male	583	84.9%
	Female	67	9.8%
	No response	37	5.3%

Over half of the respondents had been directly affected by prostate cancer, with 38% of respondents being prostate cancer survivors and 16% currently undergoing treatment (Figure 4.1.1). This survey elicited a response from a larger percentage of concerned members of the public than the previous similar survey conducted by the CCRA¹. Around 17% of respondents were family members of a prostate cancer patient or survivor.

¹ http://www.ccra-acrc.ca/PDF%20Files/Survey_Report_Sept_2010.pdf

FIGURE 4.1.1 THE CONNECTION OF RESPONDENTS OF THE PUBLIC SURVEY TO PROSTATE CANCER



4.1.2 Researcher Survey

A total of 129 researchers completed the survey, which represents 40% of those approached. Figure 4.1.2 shows the distribution of respondents to the survey compared to those invited to respond. With respect to province, respondents are broadly representative of the prostate cancer research community. Over 25% of the researchers indicated that they worked in translational research (Figure 4.1.3). This was the most frequently selected area of research – over two-thirds of respondents stated that at least one of their areas of research was translational. No individual selected only etiology, prevention or palliative/end-of-life care as their area of research – these were only indicated with other research areas.

4.2 Gaps in Knowledge, Canadian Strengths and Challenges

The 274 responses regarding gaps in knowledge were grouped into five categories as shown in Figure 4.2.1. Most indicated biomarkers as a gap with 43% of the responses. One-third of those responses specifically noted the gap in distinguishing aggressive from indolent disease. This represented the largest single gap (14% of the total). Other specific gaps identified include the identification of better biomarkers (8.8% of total responses), the development of novel therapeutics (6.9%), understanding disease pathogenesis (6.2%), diagnostic biomarkers (6.2%), understanding the mechanism of metastasis (5.8%), general survivorship issues (5.2%) and predictive biomarkers (5.1%).

Canada’s strengths in prostate cancer research were highlighted (Figure 4.2.2). Of the 169 responses to this question, the most common comment related to the level of collaboration. One in every six respondents noted the collaboration between the basic and clinical research communities. Others identified the strong clinical trial infrastructure that exists in Canada (13.6% of all responses).

With respect to specific challenges, 38% of the total responses related to the lack of project funding (Figure 4.2.3). The lack of project funding was identified by 90% of respondents. Lack of funding for

infrastructure and the availability of funds for trainees were the next most common responses identified by 47% and 42% respectively. Of those who indicated “Other”, the majority suggested that the lack of funding to support multidisciplinary teams was a challenge (3.7%). The lack of project funding and the availability of funds for trainees were particularly concerning to those working in the areas of biology and translational research. Lack of funding for infrastructure was a greater relative concern to researchers in Ontario than in other provinces.

4.3 Satisfaction with Research Progress

Respondents to the public survey were asked to rate their satisfaction with the progress being made in prostate cancer research. Three out of five respondents indicated that they were satisfied (very or somewhat) with the progress being made (Figure 4.3.1). Survivors represented the most satisfied group. Respondents who are currently undergoing treatment for prostate cancer were found to be least satisfied with progress.

4.4 Role of Non-Scientists in Research Priority Setting

Of the respondents to the public survey, 47% indicated that there should be a formal involvement of non-scientists in setting research priorities (Figure 4.4.1). This finding was independent of the respondent’s connection to prostate cancer or their province of residence.

FIGURE 4.1.2 DISTRIBUTION OF INVITED RESEARCHERS AND RESPONDENTS OF THE RESEARCHER SURVEY BY PROVINCE

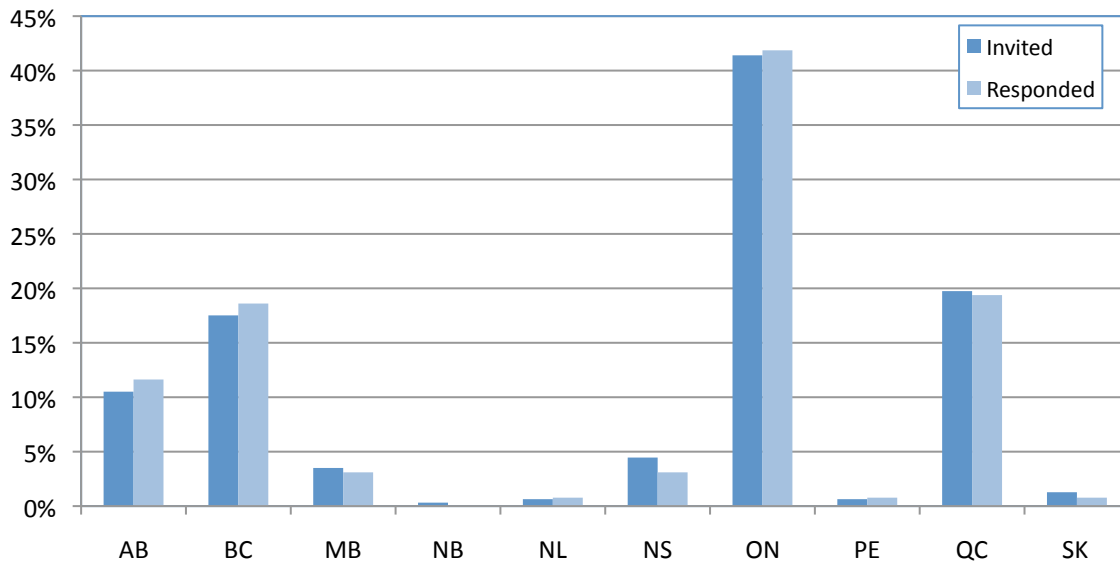


FIGURE 4.1.3 DISTRIBUTION OF AREAS OF RESEARCH (WEIGHTED) - RESEARCHER SURVEY

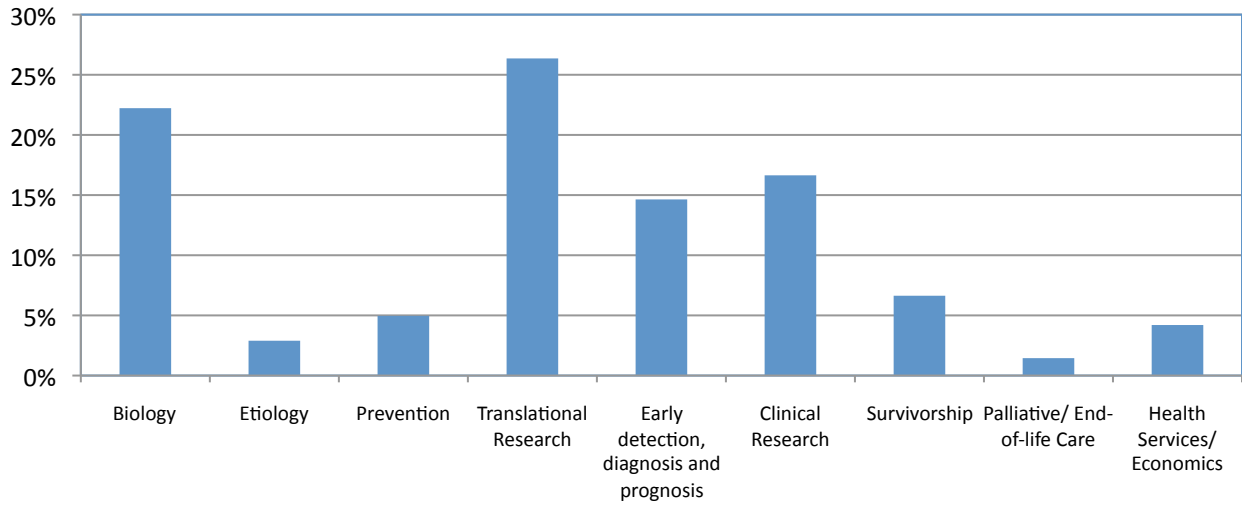


FIGURE 4.2.1 IDENTIFIED KEY GAPS IN KNOWLEDGE IN PROSTATE CANCER - RESEARCHER SURVEY

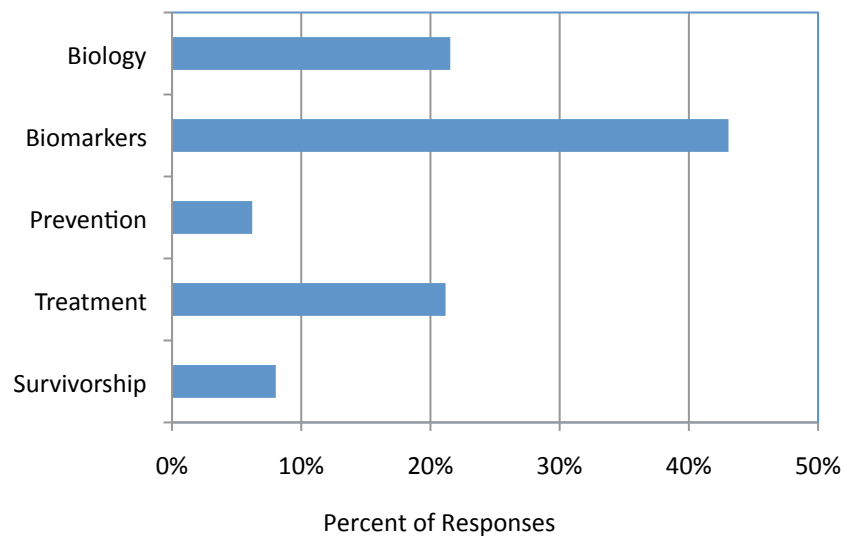


FIGURE 4.2.2 CANADA’S STRENGTHS IN PROSTATE CANCER RESEARCH – RESEARCHER SURVEY

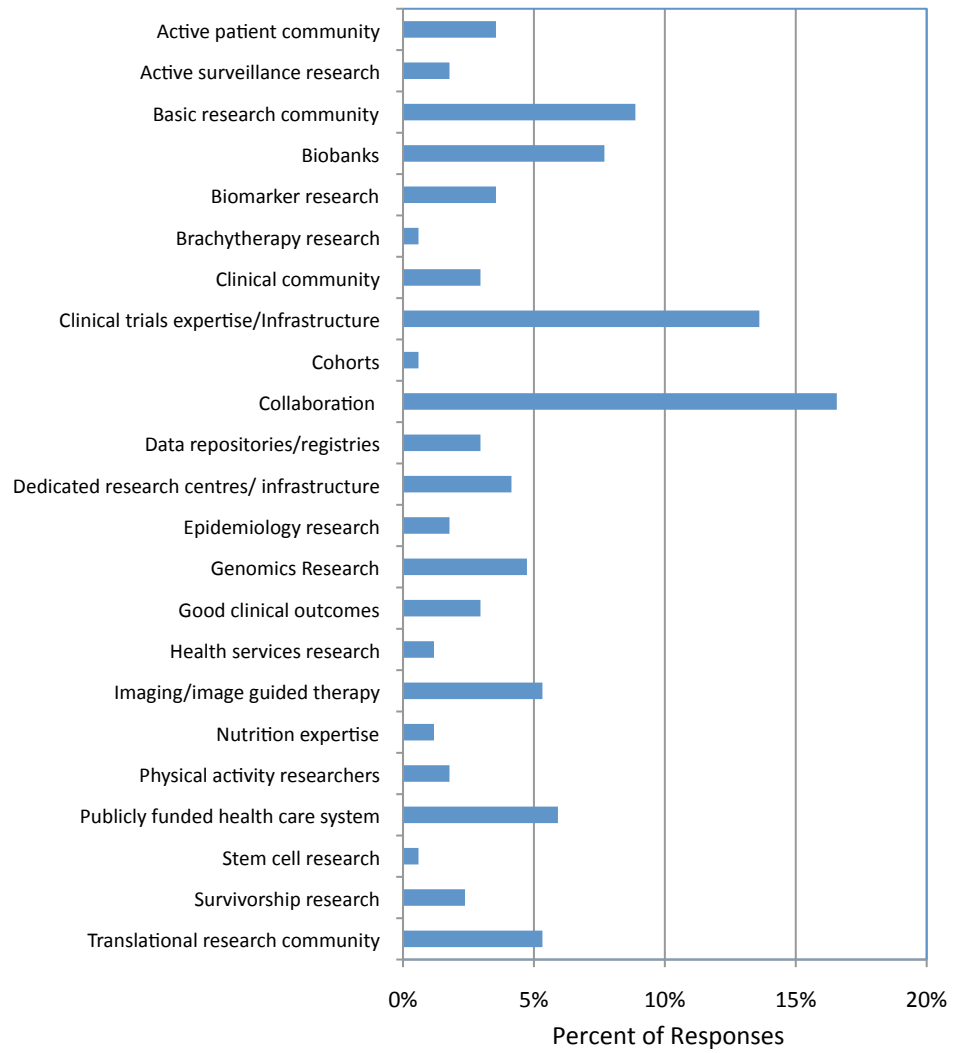


FIGURE 4.2.3 GREATEST CHALLENGES IN CONDUCTING PROSTATE CANCER RESEARCH IN CANADA – RESEARCHER SURVEY

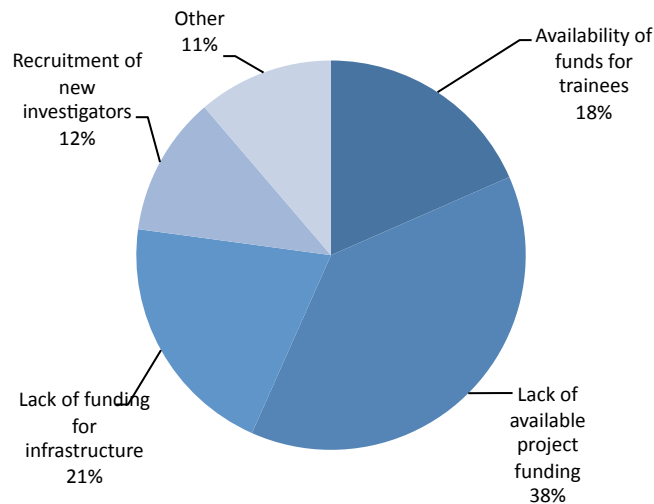


FIGURE 4.3.1 DISTRIBUTION OF RATINGS OF SATISFACTION WITH RESEARCH PROGRESS BY CONNECTION WITH PROSTATE CANCER – PUBLIC SURVEY

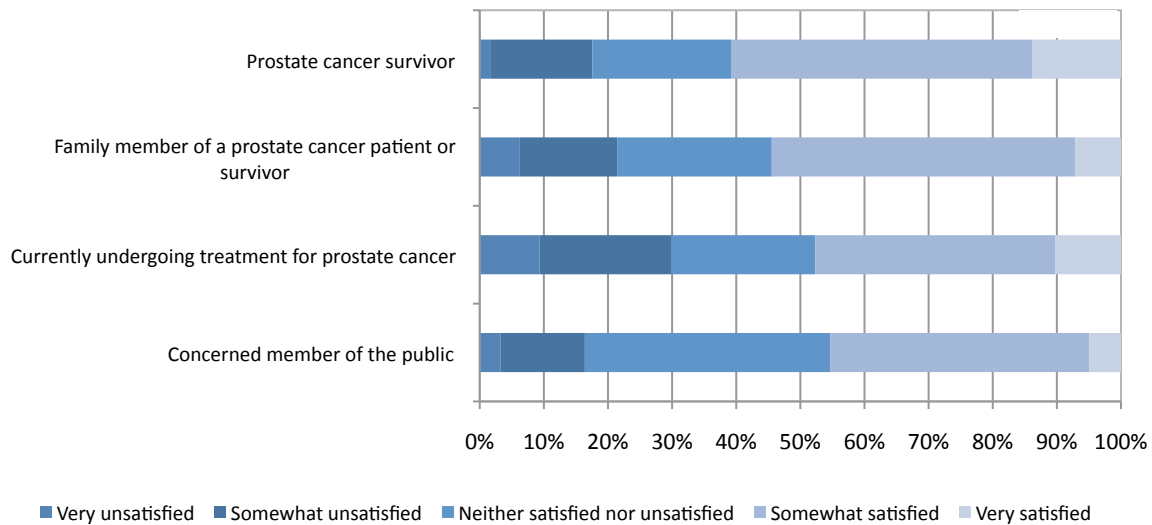
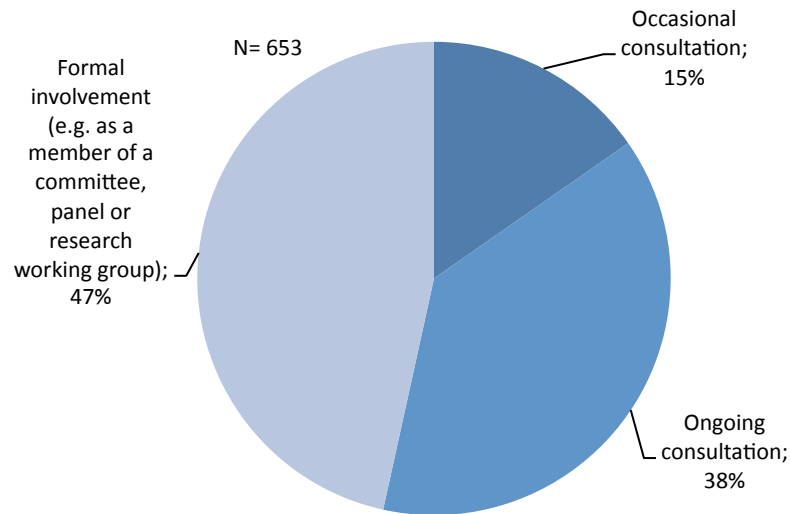


FIGURE 4.4.1 DISTRIBUTION OF OPINIONS ON THE INVOLVEMENT OF NON-SCIENTISTS – PUBLIC SURVEY



4.5 Where Investments Could Be Made

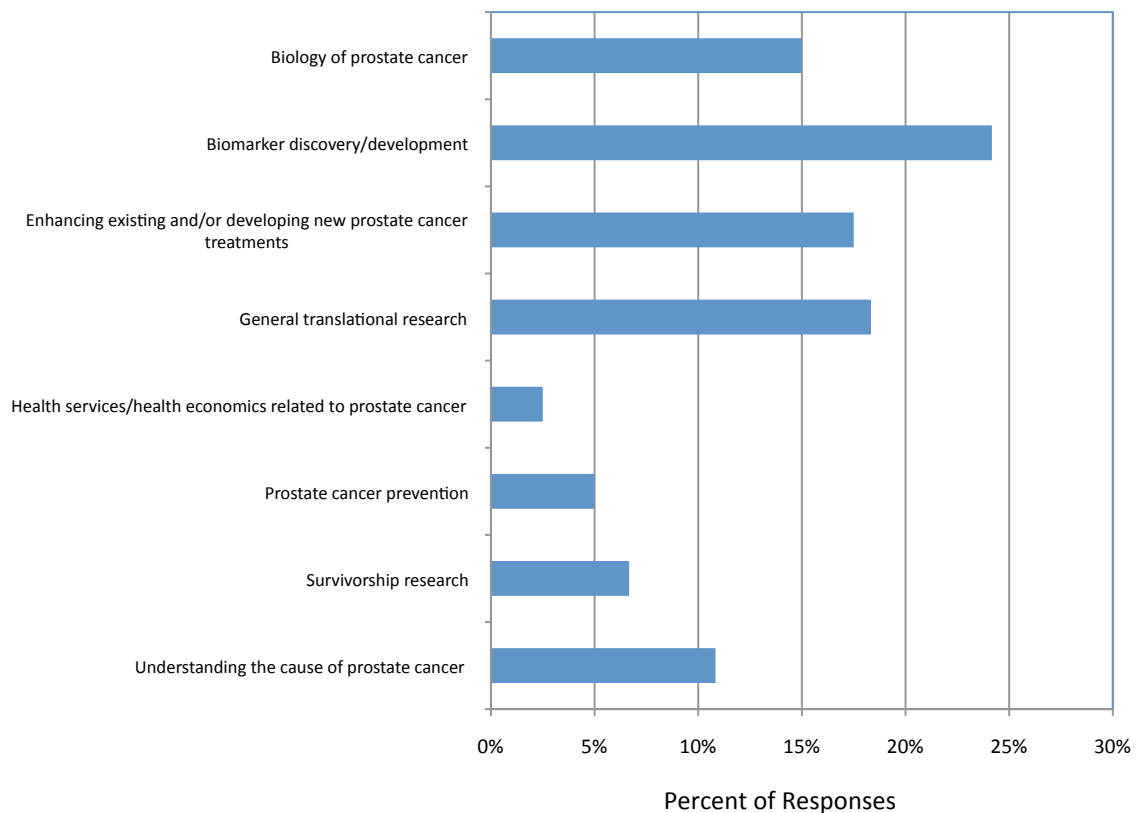
One in four researchers indicated that additional investment in biomarker discovery/development in Canada would have the greatest impact (Figure 4.5.1). A disproportionate number of researchers in Quebec highlighted the potential of investment in the biology of prostate cancer. Survivorship research was strongly supported by researchers in British Columbia, Alberta and Nova Scotia.

When respondents to the public survey were asked how they would invest \$100 across 6 different areas of prostate cancer research there were no significant differences noted in total allocation of respondents (Figure 4.5.2). This corroborates the findings presented in the CCRA Public Survey².

With respect to the size of investment, 57% agreed that more grants of smaller sizes were more important (Figure 4.5.3). This trend was reinforced in every province with the exception of British Columbia; 60% of researchers from British Columbia expressed a preference for fewer, larger grants. Many researchers suggested that a mix was necessary depending on the nature of the research. While some respondents suggested that many smaller grants may provide the opportunity to explore different areas simultaneously and may result in a better ratio of results to dollars invested, others highlighted that economies of scale may make funding larger projects more cost-effective.

Researchers were also asked what they considered to be the optimal balance between open investigator-initiated competitions and more strategic investments. More than half of the researcher respondents indicated that greater than 50 % of research investments should be made through open investigator-initiated competitions (Figure 4.5.4). Approximately one in four respondents thought the split should be equal.

FIGURE 4.5.1 AREAS OF PROSTATE CANCER RESEARCH WHERE INCREASED INVESTMENT COULD ACHIEVE THE GREATEST IMPACT – RESEARCHER SURVEY



^{2 2} http://www.ccra-acrc.ca/PDF%20Files/Survey_Report_Sept_2010.pdf

FIGURE 4.5.2 DISTRIBUTION OF INVESTMENT ACROSS RESEARCH AREAS – PUBLIC SURVEY

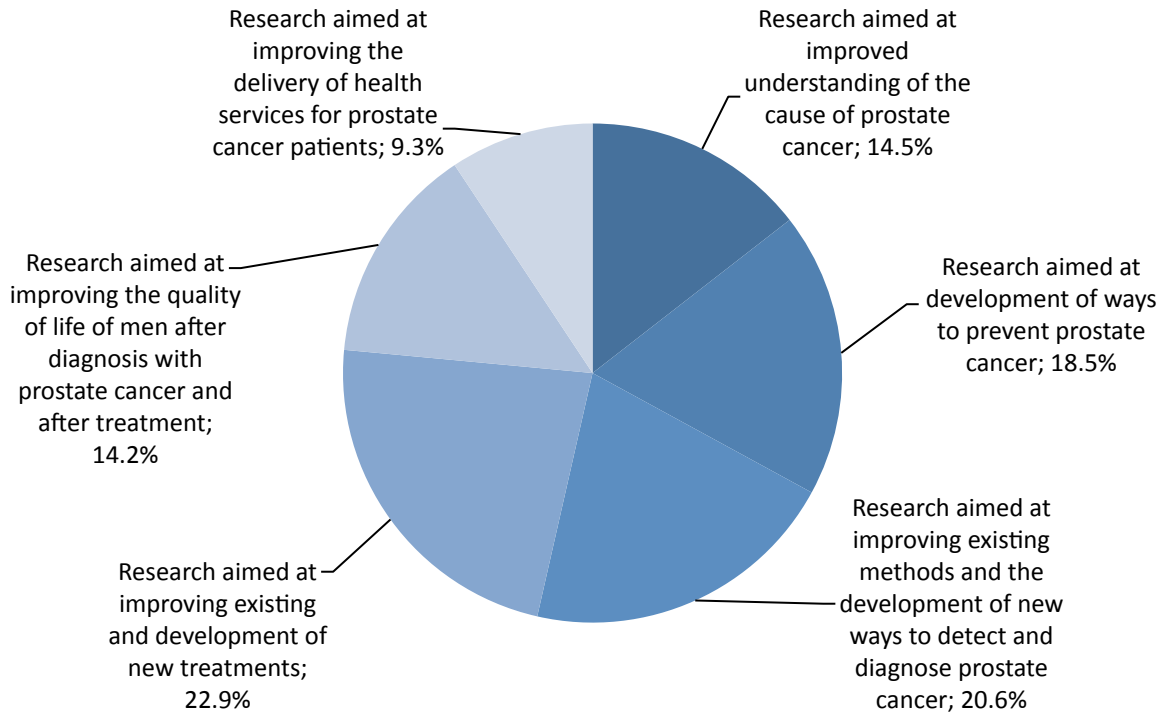


FIGURE 4.5.3 DISTRIBUTION OF OPINIONS ON THE QUANTITY AND SIZE OF GRANTS – RESEARCHER SURVEY

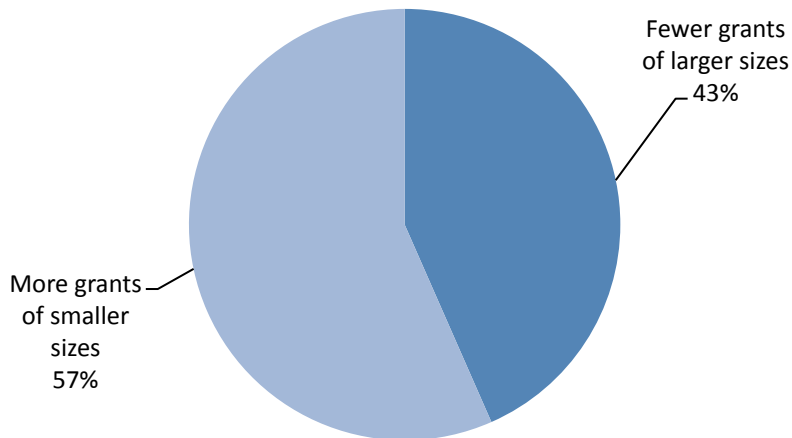
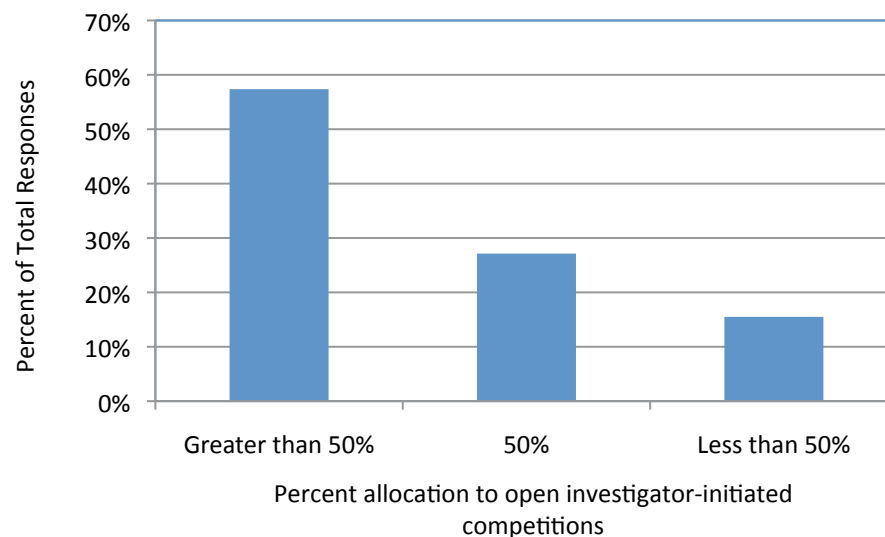


FIGURE 4.5.4 PERCENTAGE OF RESPONDENTS ALLOCATING TO OPEN COMPETITIONS – RESEARCHER SURVEY



4.6 The Most Pressing Question

Both surveys asked what respondents believed would be the most pressing question related to prostate cancer that could be addressed through research. Multiple answers to this question were treated as individual comments in the analysis. Figure 4.6.1 shows the responses to this question in the two surveys. Considerably more respondents in the public survey stressed the importance of prevention, early detection and understanding the cause of prostate cancer than was seen in responses from researchers. The most common question for researchers, with 415 of responses, related to distinguishing between those who need to be treated and those who could be on surveillance. Optimizing treatment and reducing side effects was seen to be equally important by both groups surveyed. Researchers were also more interested in understanding biological mechanisms of the disease compared to those responding to the public survey. This response was particularly strong from researchers based in British Columbia. Responses correlated well with researchers' indicated area of research.

Concerned members of the public placed a higher priority on understanding the cause of prostate cancer and its prevention (Figure 4.6.2). Improving treatment and reducing side effects was the area that men currently undergoing treatment and family members of survivors and patients placed the greatest emphasis on. While prostate cancer survivors also prioritized this area, the most popular question this group would like answered relates to the cause of prostate cancer. Interestingly, survivors tended to place less of an emphasis on prevention.

FIGURE 4.6.1 COMPARISON OF RESPONSES TO THE MOST PRESSING QUESTION IN PROSTATE CANCER - BOTH SURVEYS

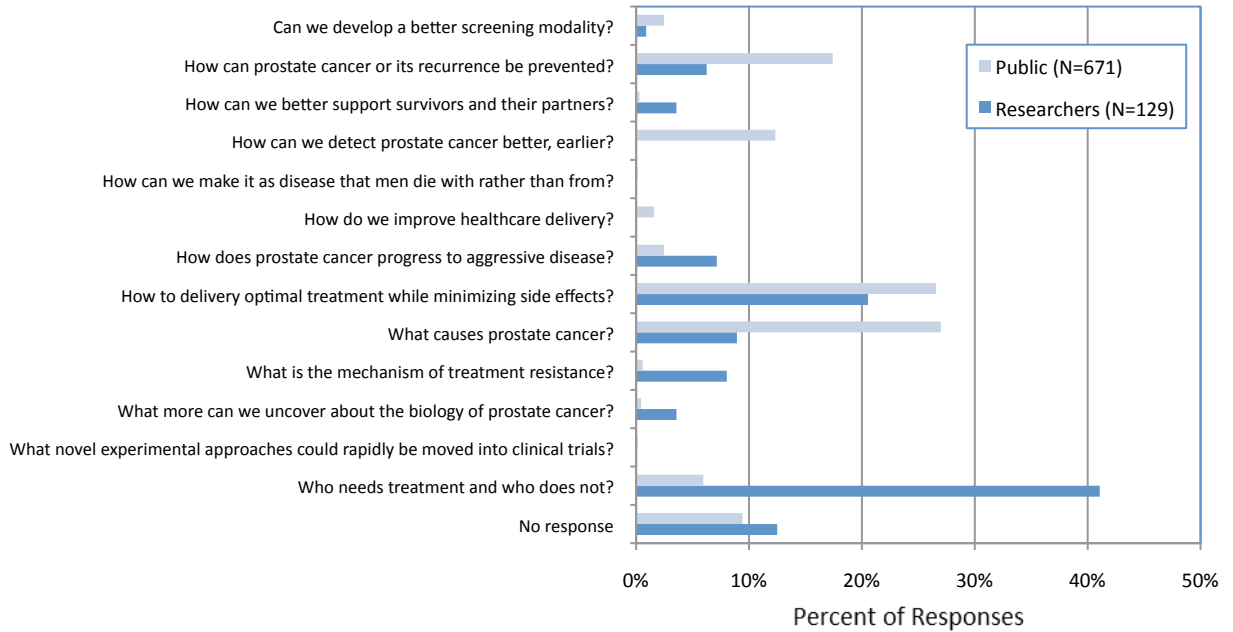
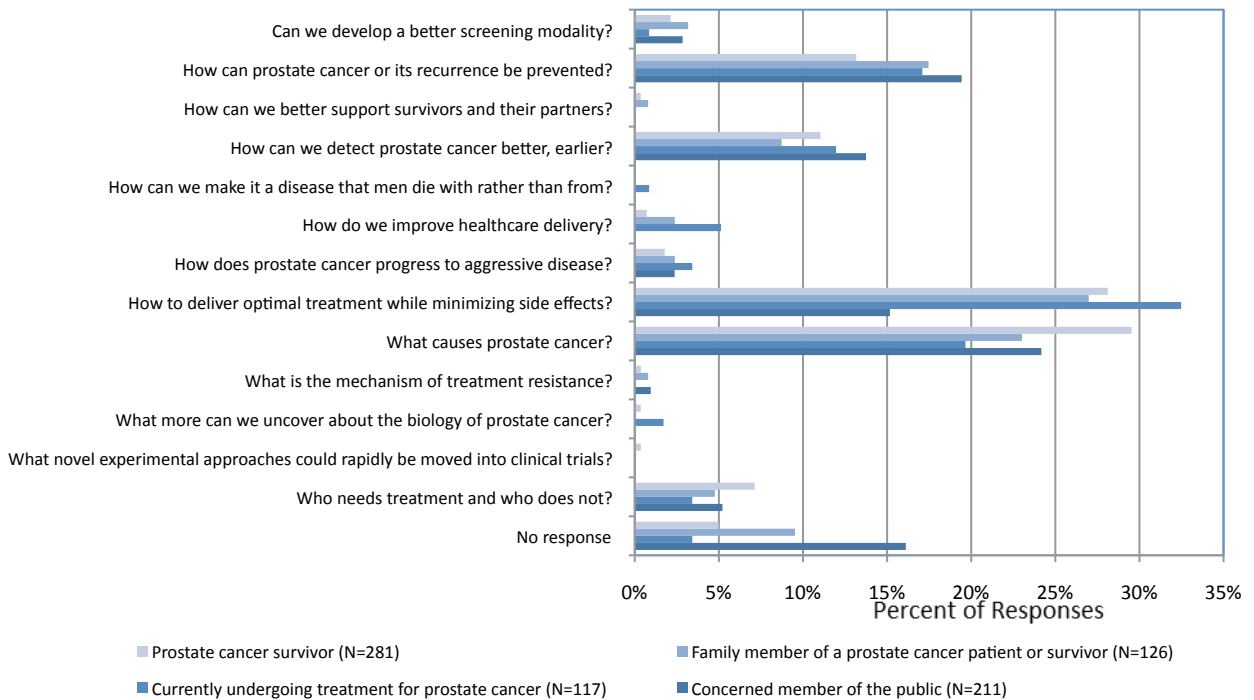


FIGURE 4.6.2 RESPONSE TO MOST PRESSING QUESTION BY CONNECTION TO PROSTATE CANCER – PUBLIC SURVEY



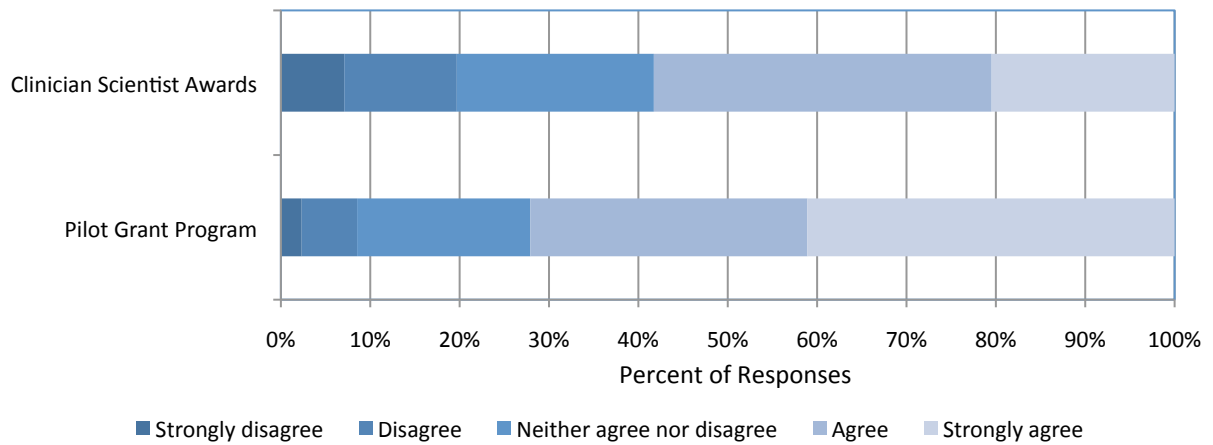
4.7 Programs of Prostate Cancer Canada

Researchers were asked to provide their thoughts on PCC’s existing Pilot Grant Program and Clinician Scientist Awards. The responses were positive for the Pilot Grant Program, with 72% of respondents agreeing that this program represents a good investment in research (Figure 4.7.1). Most agreed that

pilot grants provide a good mechanism for seed funding to explore innovative ideas in prostate cancer. Some expressed a concern that grants funded in the past through this program tended to be safe projects rather than higher risk projects that could reap greater rewards.

For the Clinician Scientist Awards, 58% thought that this was a good investment. Many commented on the need to support and build a strong clinician scientist community. However, others were sceptical about whether the program is successful in protecting time for funded clinicians and suggested that the scope was too narrow. Some identified the need for non-clinical scientists and research trainees (students and postdoctoral fellows) to be supported.

FIGURE 4.7.1 DISTRIBUTION OF RATINGS OF SUPPORT FOR PCC'S EXISTING RESEARCH COMPETITIONS



Acknowledgements

Prostate Cancer Canada would like to thank Kim Badovinac from the Canadian Cancer Research Alliance for providing data from the CCRA survey. Susan Graham Walker prepared the surveys in FluidSurveys and we are grateful to Susan, Maureen Rowlands and Katherine Patterson for review of the public survey prior to launch. In addition, Ada Chidichimo Keon and Matthew Tavares were instrumental in promoting the public survey to relevant stakeholders. Finally we would like to thank Susan Graham Walker and Dr. Josée Guimond for review of the final report.

This report was prepared by Dr. Stuart Edmonds with advice and guidance from Dr. Laurence Klotz. Both surveys were conducted on behalf of the PCC Research Advisory Panel.

Appendix A

General Survey - Prostate Cancer Research in Canada

1. Introduction

Prostate Cancer Canada (PCC) is redesigning its research program. This has been made possible largely due to the considerable success of Movember in Canada which, will allow PCC to fund new prostate cancer research in Canada. To determine which areas of prostate cancer research PCC should focus on in the future, we feel it is important to seek the views of those who have been affected by prostate cancer in Canada and who would benefit from new prostate cancer research discoveries. This survey asks questions to gather your opinions about what you think are priorities in prostate cancer research. This is your opportunity to have input into the development of PCC's research plan. Please be assured that your answers are private. You will not be asked to provide your name or any other information that could be used to identify you individually. Thank you for taking the time to complete the survey.

Stuart Edmonds PhD Senior Vice-President, Research Prostate Cancer Canada
Laurence Klotz MD Chair, Research Advisory Panel Prostate Cancer Canada

2. Consider the choices faced in allocating funds for research. Rate the importance of each area of prostate cancer research by imagining you have \$100 to distribute across the categories.

- a) Research aimed at improved understanding of the cause of prostate cancer None
- b) Research aimed at development of ways to prevent prostate cancer None
- c) Research aimed at improving existing methods and the development of new ways to detect and diagnose prostate cancer None
- d) Research aimed at improving existing and development of new treatments None
- e) Research aimed at improving the quality of life of men after diagnosis with prostate cancer and after treatment None
- f) Research aimed at improving the delivery of health services for prostate cancer patients None

3. Why did you allocate the funds the way you did?

None

4. What role should non-scientists play in setting research priorities?

- Occasional consultation
- Ongoing consultation
- Formal involvement (e.g. as a member of a committee, panel or research working group)

5. Please explain your choice.

None

6. From your perspective how satisfied are you with the progress being made in prostate cancer research?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor unsatisfied
- Somewhat unsatisfied
- Very unsatisfied

7. Please explain your choice:

None

8. What do you believe is the most pressing question regarding prostate cancer that could be investigated through research?

None

9. The following questions deal with demographics.

This information will be used to determine how well the survey reflects opinions from across the country.

I am a:

- Currently undergoing treatment for prostate cancer
- Prostate cancer survivor

- Family member of a prostate cancer patient or survivor
- Concerned member of the public

I live in:

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland & Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

The population of the community I live in:

- Rural area / low population density
- Population under 10,000
- 10,001 - 99,000
- 100,000 - 499,999
- 500,000 - 1,499,999
- 1,500,000 and over

Your gender

- Male
- Female

10. Thank you

Appendix B

Provide input into Prostate Cancer Canada's research strategy

1. Introduction

Prostate Cancer Canada is in the process of developing a new research strategy with the first step being a broad consultation with the research community. As you have either applied for funding to PCC or been funded for a prostate cancer research project by PCC and other agencies in Canada in the last 5 years, your knowledge of the research area and the prostate cancer research landscape in your region and nationally is critical to us. This is your opportunity to have input into this important process. The results of this survey will determine how these funds are finally allocated. We need your help! This survey will take approximately 15 minutes to complete. The deadline for completion is Monday March 5th, 2012. Your answers to the survey questions are private. You will not be asked to provide your name, or any other information that could be used to identify you individually. Thank you for your contribution to this process. Your views are important to us.

Laurence Klotz MD Chair of the PCC Research Advisory Panel
Stuart Edmonds PhD Senior Vice-President, Research Prostate Cancer Canada

2. Area(s) of research

Please indicate your area(s) of research (check all that apply):

- Biology
- Etiology
- Prevention
- Translational research
- Early detection, diagnosis and prognosis
- Clinical research
- Survivorship
- Palliative / end of life care
- Health services / economics
- Other _____

3. Province

In which province do you reside?

- British Columbia
- Alberta
- Saskatchewan
- Manitoba
- Ontario
- Quebec
- New Brunswick
- Prince Edward Island
- Nova Scotia
- Newfoundland and Labrador

4. Gaps in knowledge

What are the key gaps in knowledge in prostate cancer?

None

5. Canada's strengths

What are Canada's strengths in prostate cancer research? Where can Canada make a unique contribution to global prostate cancer research efforts?

None

6. Greatest challenges

What are the greatest challenges to conducting prostate cancer research in Canada? Select all that apply.

- Lack of available project funding
- Recruitment of new investigators
- Availability of funds for trainees
- Lack of funding for research infrastructure
- Other, please specify: _____

7. Please explain your response.

None

8. Need for increased investment

In what area of prostate cancer research do you feel an increased investment in Canada will achieve the greatest impact on the disease?

- Biology of prostate cancer
- Prostate cancer prevention
- Understanding the cause of prostate cancer
- General translational research
- Biomarker discovery/development
- Enhancing existing and/or developing new prostate cancer treatments
- Survivorship research
- Palliative/end-of-life care research
- Health services/health economics related to prostate cancer
- Other, please specify: _____

9. Please explain your response.

None

10. One question ...

What do you believe is the most pressing question regarding prostate cancer that could be answered through research?

None

11. What is better for prostate cancer research funding ...

In an era of scarce funding for cancer research, do you believe it is better for the cancer research funding organizations to fund:

- Fewer grants of larger sizes
- More grants of smaller sizes

17. PCC offers a limited number of awards to provide salary and research support for outstanding Clinician Scientists initiating a career as independent investigators/junior faculty in prostate cancer research. These awards provide new faculty with an MD degree or equivalent, who are licensed to practice in Canada and with three or fewer years of service as independent investigators with the opportunity to develop and demonstrate independence in initiating and conducting prostate cancer research.

The current PCC Clinician Scientist Award program represents a good investment in prostate cancer research in Canada, achieving significant impact.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

18. Please explain your response.

None

19. Thank you.

Thank you for completing the survey. Your input is extremely important to this process. A report of the survey will be made available in due course.