

APPENDIX



Research Study: The role of prostate cancer survivors in managing survivorship care: A cross-sectional descriptive study

Prostate Cancer Survivor Survey

Research study title:	The role of prostate cancer survivors in managing survivorship care: A cross-sectional descriptive study
Principal Investigators:	Dr. Janet Papadakos & Dr. Meredith Giuliani Princess Margaret Cancer Centre
Co-Investigators:	Dr. Charles Catton, MD, FRCPC Dr. Ed Kucharski MD, CCFP Dr. Andrew Matthew, Ph.D., C.Psych Naa Kwarley Quartey, MSc

What is this study about?

The aim of this study is to understand the potential role that prostate cancer survivors can play in managing their survivorship care. Survivorship care means the medical, social, emotional and physical needs of prostate cancer survivors.

Who can take part in this study?

You can take part in this study if you are a prostate cancer patient at Princess Margaret Cancer Centre who finished treatment (radiation or surgery) at least 4 years ago and are at least 18 years old.

What can I expect if I take part in the study?

If you decide to take part in this study, you will be asked to fill out a survey. The survey will ask questions about:

- you
- how you understand health information
- your prostate cancer diagnosis
- needs you have as a result of prostate cancer
- your experiences with your follow-up care
- your thoughts on taking a larger role in managing your prostate cancer-related health care

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You may complete the survey on paper or online.

Use the following link if you choose to complete the survey online: <http://bit.ly/2gOwoai>

If you finish the survey on paper, you can:

- Leave the completed survey in a drop box in the Patient & Family Library (main floor of the Princess Margaret).

Or

- Return the survey to the study coordinator in the clinic

Please submit the survey even if you do not finish it.

The survey will take about **20 minutes** to complete.

Important details about the study:

- If you decide to take part in this study, you are only asked to fill out a survey.
- You do not have to take part in this study. You can choose to stop at any time.
- Your care at Princess Margaret will not be affected whether you choose to fill out the survey or not.
- We will hold a focus group with prostate cancer survivors at the end of this study. If you would like to take part in the focus group please contact the study coordinator.
- All the information you share with the study team will be kept confidential (private) and anonymous (unnamed).
- By completing this questionnaire, you consent for your data to be used as part of this research study

Who should I contact if I have any questions?

If you wish to reach the study team, please contact Janet Papadakos, Manager of the Patient and Family Education Program, at 416-581-7679.

If you have any questions or concerns about this study, or your rights as a research participant, please contact the Chair of the University Health Network Research Ethics Board (REB) at 416-581-7849.

The REB is a group of people who watch over the proper (ethical) conduct of this research study. The REB is not part of the study team. Anything you discuss with them will be kept confidential (private).

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Section 1: About You

The study team would like to know a bit about you. Your answers will help describe who took part in the study. The information you share in this survey is anonymous and will not be linked to you. Your answers will help the research team know if those who took part in the study show the diversity of prostate cancer survivors at Princess Margaret.

1. What is your age? _____

2. What is your current work-related activity?

(Please select one)

- ☐ Working (part-time or full-time)
- ☐ Retired
- ☐ Getting disability payment
- ☐ Unemployed (not working)
- ☐ Other (please specify): _____

3. What is the highest level of schooling you have finished?

(Please select one)

- ☐ Grade school to some high school
- ☐ High school to some college/university
- ☐ College/university to graduate school
- ☐ Other (please specify): _____

4. What is your household's annual income for the most recent years?

(Please select one)

- ☐ Less than \$25,000
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ More than \$99,999

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5. What is your race?

(Please select one)

- ☐ Aboriginal (for example, Inuit, Metis, Native Canadian)
- ☐ Arab/West Asian (for example, Armenian, Egyptian, Iranian, Lebanese, Moroccan)
- ☐ Black/African (for example, African-Canadian, Haitian, Jamaican, Somali)
- ☐ East Asian (for example, Chinese, Japanese, Korean)
- ☐ Latin American/Latino
- ☐ South Asian (for example, Indian, Pakistani, Bangladeshi)
- ☐ South East Asian (for example, Filipino, Indonesian, Malaysian)
- ☐ White/Caucasian/European
- ☐ I prefer not to answer
- ☐ Other: _____

6. What is your marital status?

(Please select one)

- ☐ Single, never married
- ☐ Married, Common-law
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ Other: _____

7. What type of treatment did you get to treat your prostate cancer?

(Please select all that apply)

- ☐ Radiation
- ☐ Surgery
- ☐ Hormone therapy
- ☐ Chemotherapy
- ☐ Cryotherapy
- ☐ Other: _____

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Cancer Health Literacy

The research team is interested in knowing how you understand cancer health information. Please select the correct answer to each question below.

1. The normal range for hemoglobin for a male is 13.3-17.2 g/dl. Joe's hemoglobin is 9.7 g/dl. Is Joe within the normal range?

(Please select one)

- ☐ Yes
- ☐ No

2. A biopsy of a tumour is done to:

(Please select one)

- ☐ Remove it
- ☐ Diagnose it
- ☐ Treat it

3. If a patient has stage 1 cancer, it means the cancer is:

(Please select one)

- ☐ Localized
- ☐ In nearby organs
- ☐ In distant sites

4. The role of a physical therapist is to talk to a patient about emotional needs.

(Please select one)

- ☐ True
- ☐ False

5. A tumour is considered "inoperable" when it cannot be treated with:

(Please select one)

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- ☐ Radiation therapy
- ☐ Surgery
- ☐ Chemotherapy

6. Sally will get radiation therapy once a day, Monday through Friday. If Sally has therapy for 4 weeks, how many times will she get radiation therapy?

(Please select one)

- ☐ 5
- ☐ 15
- ☐ 20

Section 2: Self-Efficacy for Managing Chronic Disease

Indicate how confident you are in doing the activities below. For each question below, select the number (1 to 10) that matches your confidence that you can do the tasks at the present time.

1. How confident are you that you can keep the **fatigue** caused by your disease from getting in the way of the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident
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2. How confident are you that you can keep the **physical discomfort or pain** of your disease from getting in the way of the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident
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3. How confident are you that you can keep the **emotional distress** caused by your disease from getting in the way of the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident
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4. How confident are you that you can keep **other symptoms or health problems** you have from getting in the way of the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident
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5. How confident are you that you can do the **different tasks and activities** needed to manage your health condition so as to reduce your need to see a doctor?

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Not at all confident 1 2 3 4 5 6 7 8 9 10 Totally confident

6. How confident are you that you can do the **things other than just taking medication** to reduce how much your illness affects your everyday life?

Not at all confident 1 2 3 4 5 6 7 8 9 10 Totally confident

Section 3: Supportive Care Needs

The questions in this section ask about needs that you have as a result of having prostate cancer. Select only one response for each item.

In the last 6-12 months I have needed...	Not needed or not applicable	Need was fully met	Need was NOT fully met
1. Up –to-date information about my disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Information for my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Information provided in a way that I can understand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The very best medical care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Local health care services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. To feel like I am able to manage my health together with the medical team.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. To know that all my doctors talk to each other to coordinate (manage) my care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. To know that concerns about my care are addressed well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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In the last 6-12 months I have needed...	Not needed or not applicable	Need was fully met	Need was NOT fully met
9. Access to complementary or alternative therapy services (for example, acupuncture, herbal medicine)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Help to reduce stress in my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Help to manage ongoing symptoms and side effects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Help to adjust to changes in my quality of life as a result of the cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Help with having a family due to fertility problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Help to get and/or keep employment (a job).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Help to find out about financial support or government benefits to which I can get.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Help getting life and/or travel insurance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Help accessing legal services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. More accessible hospital parking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Help to manage my concerns about the cancer coming back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Emotional support.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Help to know how to support my partner and/or family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Help to deal with the impact that cancer has had on my relationship with my partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Help developing new relationships after the cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. To talk to others who have had cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Help to handle the topic of cancer in social and/or work situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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In the last 6-12 months I have needed...	Not needed or not applicable	Need was fully met	Need was NOT fully met
26. Help to adjust to changes to the way I feel about my body.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Help to address problems with my/our sex life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. An ongoing case manager to whom I can go to find out about services whenever they are needed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Help to move on with my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Help to cope with changes to my belief that nothing bad will ever happen in my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Help to cope with others who do not understand the impact that cancer has had on my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Help to deal with my own and/or others expectations of me as a "cancer survivor".	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Help to try to make decisions about my life in the context of uncertainty.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. Help to explore my spiritual beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Help to make my life count.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. If applicable, list any other cancer-related needs you have:			
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Section 4: Manage Your Survivorship Care

This section asks questions about your experience with prostate cancer survivorship care. Prostate cancer survivorship care is the care you get from your primary care provider (family doctor) and oncologist (cancer doctor) about your prostate cancer related symptoms and side effects. This includes the medical, social, emotional and physical needs you have as a prostate cancer survivor.

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1. I am pleased with my prostate cancer survivorship care.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

If you strongly disagree (1) or disagree (2), please explain what could make it better.

2. How long ago did your treatment finish (not including hormone therapy)? _____

3. Select the topics below that you wish you had more information about.

(Please select all that apply)

- ☐ Type of cancer treatment received
- ☐ Medications (drugs)
- ☐ Lifestyle changes
- ☐ How to manage symptoms after treatment of prostate cancer
- ☐ Who to contact for further medical care (Primary care provider or other specialist)
- ☐ Surveillance (watching) for reoccurrence of cancer (cancer coming back)
- ☐ How to manage my other health conditions
- ☐ Other: _____

4. How helpful would it be to play a bigger role in your own survivorship care?

(Please select one)

- ☐ Not at all helpful
- ☐ Slightly helpful
- ☐ Neutral
- ☐ Helpful
- ☐ Very helpful

5. What are some of the barriers to getting the survivorship care you need?

(Please select all that apply)

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- ☐ Transportation to appointments
- ☐ Scheduling/changing appointments
- ☐ Financial costs
- ☐ Lack of communication with doctors
- ☐ Language needs (for example, my doctor doesn't speak the same language as me)
- ☐ Other: _____

6. On a scale of 1-5, select your response to the statements below.

Improving my level of engagement in my own prostate cancer survivorship is important.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

When thinking about my prostate health I get stressed out or anxious.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

I would like to become more confident in knowing if I need to go to the primary care provider or if I can take care of a survivorship problem myself.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

With regard to my prostate cancer survivorship, I would like to know more about my symptoms and what I can do about them.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree

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☐ 5 – Strongly Agree

I would like to feel more at ease telling my primary care provider my concerns, even when he or she does not ask.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

I would be willing to attend a workshop to improve my self-management of symptoms related to my prostate cancer.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

I would be willing to use resources to improve my self-management of symptoms related to my prostate cancer.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

I would like to meet other prostate cancer survivors to help me learn more about how to manage my health.

- ☐ 1 - Strongly Disagree
- ☐ 2 - Disagree
- ☐ 3 - Neutral
- ☐ 4 - Agree
- ☐ 5 – Strongly Agree

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Section 5: Manage Your Symptoms

Some prostate cancer survivors have symptoms that are the result of their disease or their treatment. Indicate if you had any of the symptoms listed below in the last **6-12 months**.

Also indicate if you feel you can manage the symptoms on your own if you had the right knowledge and skills.

1. Have you experienced **hot flushes**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the hot flushes?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage hot flushes on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

2. Have you experienced **distress (for example, anxiety, sorrow or upset)** as a result of prostate cancer?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the distress?

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None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage distress on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

3. Have you experienced **fear of cancer recurrence (cancer coming back)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the fear of cancer recurrence (cancer coming back)?

None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage fear of cancer recurrence (cancer coming back) on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

4. Have you experienced **irregular bowels (not going poo regularly)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the irregular bowels?

None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage irregular bowels on your own?

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- ☐ Yes
- ☐ No
- ☐ N/A

5. Have you experienced **cramps**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the cramps?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage cramps on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

6. Have you experienced **diarrhea (loose, watery poo)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the diarrhea (loose, watery poo)?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage diarrhea (loose, watery poo) on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

7. Have you experienced **excessive gas**?

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- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the excessive gas?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage excessive gas on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

8. Have you experienced **rectal/fecal urgency (sudden need to poo)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the rectal/fecal urgency (sudden need to poo)?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage rectal/fecal urgency (sudden need to poo) on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

9. Have you experienced **anal sphincter dysfunction (poo leakage)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago

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- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the anal sphincter dysfunction?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage anal sphincter dysfunction on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

10. Have you experienced **fatigue/decreased activity**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the fatigue/decreased activity?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage fatigue/decreased activity on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

11. Have you experienced **osteoporosis (increased bone loss)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the osteoporosis (accelerated bone loss)?

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None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage osteoporosis (accelerated bone loss) on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

12. Have you experienced **increased risk of bone fracture (for men getting Androgen Deprivation Therapy – ADT)?**

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure
- ☐ N/A

If you answered 'yes' above, how severe was the increased risk of bone fracture?

None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage increased risk of bone fracture on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

13. Have you experienced **decline in lean muscle mass (muscle wasting)?**

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the decline in lean muscle mass?

None 1 2 3 4 5 6 7 8 9 10 Very severe

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Do you think you can learn to manage decline in muscle mass on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

14. Have you experienced **metabolic syndrome (such as, heart disease, high blood pressure, high blood sugar, high cholesterol, weight gain/overweight)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the metabolic syndrome?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage metabolic syndrome on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

15. Have you experienced **decreased/loss of libido (less sexual desire)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If answered 'yes' above, how severe was the decreased/loss of libido (less sexual desire)?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage decreased/loss of libido (less sexual desire) on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

16. Have you experienced **erectile dysfunction**?

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- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the erectile dysfunction?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage erectile dysfunction on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

17. Have you experienced **climacturia (urine leakage at orgasm)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was climacturia?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage climacturia on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

18. Have you experienced a **lack of erection or anejaculation (have an orgasm without ejaculation)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago

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- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the lack of erection or anejaculation?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage lack of erection or anejaculation on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

19. Have you experienced **dribbling or persistent leakage of urine**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the dribbling or persistent leakage?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage dribbling or persistent leakage on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

20. Have you experienced **nocturia (need to pee in the middle of the night)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the nocturia?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage nocturia on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

21. Have you experienced **urgency (sudden need to pee)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the urgency?

None	1	2	3	4	5	6	7	8	9	10	Very severe
------	---	---	---	---	---	---	---	---	---	----	----------------

Do you think you can learn to manage urgency on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

22. Have you experienced **painful urination (hurts to pee)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the painful urination?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage painful urination on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

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23. Have you experienced **urinary retention (trouble going pee)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe was the urinary retention?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage urinary retention on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

24. Have you experienced **challenges with body image (as a result of surgery, hormonal therapy)**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the challenges with body image?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage challenges with body image on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

25. Have you experienced **relationship problems** as a result of your diagnosis?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago

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- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the relationship problems?

None	1	2	3	4	5	6	7	8	9	10	Very severe
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Do you think you can learn to manage relationship problems on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

26. Have you experienced **return to work problems**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the return to work problems?

None	1	2	3	4	5	6	7	8	9	10	Very severe
------	---	---	---	---	---	---	---	---	---	----	----------------

Do you think you can learn to manage return to work problems on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

27. Have you experienced **financial problems**?

- ☐ Yes - Experienced in the last 6-12 months
- ☐ Yes – Experienced it over 1 year ago
- ☐ No - Never experienced
- ☐ Not sure

If you answered 'yes' above, how severe were the financial problems?

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None 1 2 3 4 5 6 7 8 9 10 Very severe

Do you think you can learn to manage financial problems on your own?

- ☐ Yes
- ☐ No
- ☐ N/A

Section 6: Current experiences with your Primary Care Provider

This section asks questions about your experience with your primary care provider (family doctor or nurse practitioner).

1. Do you have a primary care provider (**a family doctor or nurse practitioner**)?

- ☐ Yes – I have a family doctor
- ☐ Yes – I have a nurse practitioner
- ☐ No – I do not have a family doctor or a nurse practitioner

2. How often do you visit your Primary Care provider about prostate cancer survivorship?

- ☐ Once a month
- ☐ Once every 6 months
- ☐ Once a year
- ☐ Once every 2 years
- ☐ Every 3 years or longer
- ☐ I don't visit my primary care provider about my prostate cancer survivorship
- ☐ I don't have a primary care provider

3. Do you feel this is a good number of visits to meet your survivorship needs?

- ☐ Yes
- ☐ No
- ☐ N/A

4. When you think about the survivorship care you get from your primary care provider, what do you think about?

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(Select all that apply.)

- ☐ Care coordination and communication with cancer treatment team and primary care provider
- ☐ Watch for new cancers or return of old cancer
- ☐ Manage physical side effects
- ☐ Manage emotional side effects
- ☐ Manage social side effects
- ☐ Get referral to medical rehabilitation care (physiotherapist or occupational therapist)
- ☐ Get referral for mental health care
- ☐ Get referral for palliative care
- ☐ Information about healthy behaviours (for example diet, exercise)
- ☐ Other: _____

5. What do you do to prepare for your prostate cancer follow-up visits with your primary care provider?

(Select all that apply.)

- ☐ Make a list of the symptoms you experience
- ☐ Make a list of other medical conditions you might have
- ☐ Provide the contact information of your oncologist
- ☐ Make a list of medications that you take
- ☐ Attend the appointment with any/all possible family caregivers
- ☐ Keep an updated list of your eating habits
- ☐ Keep an updated list of your physical activity habits
- ☐ I don't prepare for my appointments
- ☐ Other: _____

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Section 7: Current experiences with your Oncology Specialist

This section asks questions about your experience with your Oncology Specialist (cancer doctor).

1. How often do you visit your oncology specialist (cancer doctor)?

- ☐ Once a month
- ☐ Once every 6 months
- ☐ Once a year
- ☐ Once every 2 years
- ☐ Every 3 years or longer
- ☐ I don't visit my Oncology Specialist

2. Do you feel this is an adequate number of visits to meet your survivorship needs?

- ☐ Yes
- ☐ No

3. When you think about the survivorship care you receive from your oncology specialist, what do you think about?

(Select all that apply.)

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- ☐ Care coordination and communication with cancer treatment team and primary care provider
- ☐ Watch for new cancers or return of old cancer
- ☐ Manage physical effects
- ☐ Manage emotional effects
- ☐ Manage social effects
- ☐ Get referral to medical rehabilitation care (physiotherapist or occupational therapist)
- ☐ Get referral for mental health care
- ☐ Get referral for palliative care
- ☐ Information about healthy behaviours (for example diet, exercise)
- ☐ Other: _____

Section 8: Information Needs and Preferences

This section asks questions about your information needs. The study team would also like to know how you would like to get information.

1. How do you like to get information about your prostate cancer-related drugs and side effects?

- ☐ One-on-one consultation with your doctor or nurse
- ☐ Video
- ☐ Pamphlets
- ☐ Telephone
- ☐ Websites
- ☐ E-learning
- ☐ Podcasts
- ☐ I don't want information on this topic
- ☐ N/A
- ☐ Other: Please specify _____

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2. How do you like to get information about life style changes such as diet and exercise that could improve health?

- ☐ One-on-one consultation with doctor or nurse
- ☐ Video
- ☐ Pamphlets
- ☐ Telephone
- ☐ Websites
- ☐ E-learning
- ☐ Podcast
- ☐ I don't want information on this topic
- ☐ N/A
- ☐ Other: Please specify _____

3. How do you like to get information about how to manage any symptoms you have as a result of your prostate cancer treatment?

- ☐ One-on-one consultation with doctor or nurse
- ☐ Video
- ☐ Pamphlets
- ☐ Telephone
- ☐ Websites
- ☐ E-learning
- ☐ Podcasts
- ☐ I don't want information on this topic
- ☐ N/A
- ☐ Other: Please specify _____

4. How do you like to get information on-going surveillance for reoccurrence of cancer?

- ☐ One-on-one consultation with doctor or nurse
- ☐ Video
- ☐ Pamphlets
- ☐ Telephone
- ☐ Websites
- ☐ E-learning
- ☐ Podcasts
- ☐ I don't want information on this topic
- ☐ N/A

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☐ Other: Please specify _____

5. Do you think prostate cancer survivors can play a bigger role in managing their cancer-related health needs?

☐ Yes

☐ No

If yes, what would that look like? If no, please explain why not.

6. What is the hardest part of your survivorship care?

7. How could you be helped to manage this better?

Are you interested in taking part in a short (1 hour) focus group with other prostate cancer survivors to give feedback on this survey and discuss your survivorship care concerns? The information will help inform the development of resources to help future prostate cancer survivors.

If you would like to take part in this focus group, please contact the research team:

Research Coordinator: Naa Kwarley Quartey

APPENDIX

Phone number: 416-581-7524

Email address: naakwarley.quartey@uhnresearch.ca

That ends the survey. Thank you for taking part in this study.

If you are affected by the content of this questionnaire in such a way that you would like to seek professional help, please contact the Department of Psychosocial Oncology at: 416-946-4525.

If you would like to get a copy of the results of this study once it is finished, please call the study team at: 416-581-7679.