

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

APPENDIX

Appendix 1. Part A survey

Case Report Form

1.1 Study ID Number:	
1.2 Date of Assessment:	
1.3 Researcher Name:	

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

Participant Demographic Information: Self-Reported
ID _____

Study

2.1 Demographic Information	
Current age (In years)	
Approximate Height	_____ feet _____ inches OR _____ cm
Approximate Weight	_____ lbs/ _____ kg
Marital Status	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Separated/Divorced <input type="checkbox"/> Widowed
Ethnicity	<input type="checkbox"/> Caucasian <input type="checkbox"/> Asian <input type="checkbox"/> African/Canadian <input type="checkbox"/> Indigenous <input type="checkbox"/> Other
Highest Level of Education	<input type="checkbox"/> Less than grade 12 <input type="checkbox"/> Grade 12 (High school) <input type="checkbox"/> Post-secondary education
Approximate Annual Household Income	<input type="checkbox"/> <25000 <input type="checkbox"/> 25000 – 49999 <input type="checkbox"/> 50000 – 74999 <input type="checkbox"/> 75000 – 99999 <input type="checkbox"/> >100000
Dwelling Location	<input type="checkbox"/> Urban <input type="checkbox"/> Rural
If travelling by car, how many hours would it take you to drive from your home to the Manitoba Prostate Centre?	<input type="checkbox"/> <1 hour <input type="checkbox"/> 1-2 hours <input type="checkbox"/> 2-3 hours <input type="checkbox"/> 3-4 hours <input type="checkbox"/> >4 hours

3.1 REALM-SF (7 words)

Suggested Introduction: “We are studying medical word reading in order to improve communication between healthcare providers and patients. Here is a list of medical words that may be difficult to read.”

Interviewer: Show the participant the Word List.

Then say, “Starting at the top of the list, please read each word aloud to me. If you don’t recognize a word, you can say ‘pass’ and move on to the next word. Your results will be kept strictly confidential and will not be included in your official medical records.”

Interviewer: If the participant takes more than 5 seconds on a word, say “pass” and point to the next word. Hold this scoring sheet so that it is not visible to the participant.

Fat	Not Scored
Flu	Not Scored
1. Behaviour	[] Correct [] Mispronounced [] Not Attempted
2. Exercise	[] Correct [] Mispronounced [] Not Attempted
3. Menopause	[] Correct [] Mispronounced [] Not Attempted
4. Rectal	[] Correct [] Mispronounced [] Not Attempted
5. Antibiotics	[] Correct [] Mispronounced [] Not Attempted
6. Anemia	[] Correct [] Mispronounced [] Not Attempted
7. Jaundice	[] Correct [] Mispronounced [] Not Attempted

Total Correct (0-7)	Grade Level
0	< 3rd grade
1-3	4th - 6th grade

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

4-6	7th - 8th grade	REALM-SF Scoring:
7	> 9th grade	

Participant Comorbidity Information

Study

ID _____

<p>4.1 Heart attack / MI Synonyms: Myocardial Infarction (MI), Ischemic Heart Disease (IHD), Coronary Artery Disease/Occlusion (CAD), STEMI or NSTEMI, Coronary Artery Stenosis</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Date: _____</p>
<p>4.2 Prior angioplasty or stent Synonyms: Percutaneous Coronary Intervention (PCI)</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Date: _____</p>
<p>4.3 Prior cardiac surgery Synonyms: Coronary Artery Bypass Graft (CABG), Valve Replacement (Mitral or Aortic)</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Specify type(s): _____</p>
<p>4.4 Diabetes (type I or II) Synonyms: Diabetes Mellitus (DM)</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Pick one: <input type="checkbox"/> Type I <input type="checkbox"/> Type II</p>
<p>4.5 Hypertension Synonyms: High Blood Pressure</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>4.6 Dyslipidemia Synonyms: Hyperlipidemia, Hypercholesterolemia</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>4.7 Peripheral vascular disease Synonyms: Peripheral Arterial Disease (PAD), Claudication, Stenosis, Atherosclerosis, Thrombosis</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>4.8 Stroke</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

Synonyms: Cerebral Artery Occlusion, Cerebrovascular Accident/ Incident (CVA), Brain Hemorrhage	
4.9 Cerebrovascular disease (other than stroke): Synonyms: Transient Ischemic attack (TIA)	<input type="checkbox"/> Yes <input type="checkbox"/> No Specify type(s): _____
4.10 Other neurologic disease Synonyms: Parkinson's, Alzheimer's, Huntington's, Multiple Sclerosis	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.11 Cirrhosis Synonyms: Liver Disease, Liver failure, Liver fibrosis, Portal Hypertension, End Stage Liver Disease (ESLD)	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.12 Gastro-intestinal disease Synonyms: Gastro-Esophageal Reflux Disorder (GERD), Gastric Ulcer, Hiatal Hernia, upper or lower GI bleed	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.13 Pulmonary hypertension	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.14 COPD (chronic obstructive pulmonary disease) Synonyms: Emphysema, Chronic Bronchitis	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.15 Congestive Heart Failure Synonyms: Pulmonary Edema, CHF, Heart Failure, Left Ventricular Failure	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.16 Previous Malignancy Note: Synonyms include: Tumour, Malignant Growth, sarcoma, adenoma, myeloma, etc	<input type="checkbox"/> Yes <input type="checkbox"/> No
Comments:	

Appendix 2. Part B survey

Case Report Form

1.1 Study ID Number:	
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Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

1.2 Date of Assessment:	
1.3 Researcher Name:	

1.4 Follow up Physician Appointment Completed:	<input type="checkbox"/> Yes
1.5 Prostate Biopsy Results	

2.1 Prostate Cancer Knowledge Assessment		
Based on your last encounter with the doctor, what is your diagnosis?		[] Correct [] Not Sure
What is your Gleason Score? <i>3+3 = 6 (Gleason Grade Group 1)</i> <i>3+4 = 7 (GG 2)</i> <i>4+3 = 7 (GG3)</i> <i>4+4 = 8 (GG4)</i> <i>3+5 = 8 (GG5)</i> <i>4+5 = 9 (GG5)</i> <i>5+4 = 9 (GG5)</i> <i>5+5 = 10 (GG5)</i>		[] Correct [] Not Sure
What is your risk category? <i>Low risk</i> <i>Intermediate risk</i> <i>High risk</i>		[] Correct [] Not Sure
2.2 Prostate Cancer Treatment Options		
	Based on your last doctors' appointment, treatment options were discussed.	
Are you aware of your treatment options?		[] Yes [] Not Sure
2.3 Patient Values		
	When considering <i>prostate cancer</i> treatment, what is important to you? (Please rate whether the following is: very important, a little important, or not important)	
	1. Staying away from regular visits to doctors and hospitals	

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

	<ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>2. Emotional side effects of treatment</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>3. Being able to take care of myself after treatment</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>4. Chance that the prostate cancer returns</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>5. Bladder side effects of treatment (eg. incontinence)</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>6. Sexual side effects of treatment (eg. impotence)</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>7. Bowel side effects of treatment (eg. diarrhea)</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>8. Being a burden to my spouse, family and/or friends</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>9. Being able to remain in my own home</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>10. Additional years of life</p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p>11. <i>Out-of-pocket expenses associated with treatment</i></p>
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Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

	<ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p><i>12. Loss of income due to treatments and/or recovery</i></p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p><i>13. Time away from work</i></p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important <p><i>14. Time required to travel for treatments</i></p> <ul style="list-style-type: none">a. Not importantb. A little importantc. Very important
2.4 Patient engagement	
	<p>1. The role you play in deciding on care for your prostate cancer is important. Please choose one statement that best says how you would like your care decision to be made:</p> <ul style="list-style-type: none">a) I prefer to make the final decision myself after thinking about my doctor's opinionb) I prefer that my doctor and I share the decision about which option is bestc) I prefer that my doctor makes the final decision but thinks about my opinion
2.5 Now we would like to ask you some questions about socioeconomical barriers to care.	
	<p>1. In the past 12 months, how often have you had difficulty paying for health services, equipment, or medications that you needed?</p> <ul style="list-style-type: none">a) Alwaysb) Oftenc) Sometimesd) Rarelye) Never

Rai K, et al. A prospective evaluation of patient perspectives and financial considerations during prostate cancer treatment decision-making

	<p>2. In the past 12 months, how often did you NOT get the services, equipment, or medications you needed due to cost?</p> <ul style="list-style-type: none">a) Alwaysb) Oftenc) Sometimesd) Rarelye) Never <p>3. In the past 12 months, did you work for a job or business (including part-time jobs, seasonal work, contract work, self-employment or any other paid work) regardless of the hours worked?</p> <ul style="list-style-type: none">a) Yesb) Noc) Unable to work <p>4. In the past 12 months, how often did you find it difficult to get healthcare services because of lost income from taking time off work?</p> <ul style="list-style-type: none">a) Alwaysb) Oftenc) Sometimesd) Rarelye) Never <p>5. In the past 12 months, how often did you find it difficult to get healthcare services because it was difficult to get time off work?</p> <ul style="list-style-type: none">a) Alwaysb) Oftenc) Sometimesd) Rarelye) Never
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