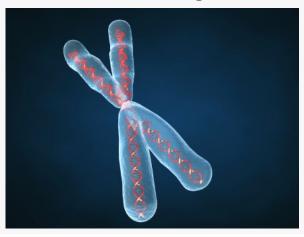






Start

Study of Preferences for Delivery of A Genetic Test for Treatment of a Fast-acting Curable Cancer



Next







11

Introduction

Thank you for participating in this survey that we are conducting at the \underline{BC} Cancer Research Center to measure people's preferences regarding the use of genetic tests in cancer treatment. This study is being sponsored by \underline{Genome} \underline{BC} .

12

About the survey

This survey will take approximately 20 minutes to complete. Your participation is optional, and you may choose to not answer any survey questions and/or withdraw your participation at any time. Your rights to privacy are protected by both federal and provincial laws which ensure that any responses you provide will be kept confidential.

The survey will describe a hypothetical disease scenario. Then you will be asked a series of questions regarding your preferences for a genetic test. This genetic test can help you to decide among your treatment options. Please read the following introduction about the survey questions. You can go back to review or change your answers by clicking back button of your internet browser at any point in the survey.







13

Curable cancer

Imagine that you have recently been diagnosed with a fast-acting but curable form of cancer. Currently, approximately 50 out of 100 (50%) of patients are cured after the first round of chemotherapy. If you are cured by this initial treatment, you will have a normal life expectancy, otherwise your life expectancy is approximately 1 year. In this case you will be given the secound round of chemotherapy but your chance of being cured is about 10 out of 100 (10%).

14

The new medication for curable cancer

By adding a new medication to the first round of chemotherapy the cure rate increases from 50 out of 100 (50%) to 75 out of 100 (75%). However, only some of individuals can benefit from the new medication (responders) and other individuals receive absolutely no benefit from adding the new medication to the standard chemotherapy (non-responders).

The downside of adding the new medication to the standard chemotherapy is that it increases the likelihood and severity of treatment side-effects.







15

The genetic test associated with the new medication

A new genetic test has just been developed for predicting whether you are a responder or a non-responder to the new medication. If you choose to not take the genetic test, you will receive the new medication in addition to standard chemotherapy without knowing if you are a responder or a non-responder.

16

The benefits of the genetic test

The advantage of taking the genetic test is that if you learn that you are a non-responder you would recieve the standard chemotherapy without adding the new medication and therefore you could avoid the associated side effects of the new medication.

17

The downsides of the genetic test

The problem of the genetic test is that sometimes it gives incorrect results:

Some responders will be diagnosed as non-responders. These patients who could be cured by taking the new medication, will not receive it based on the wrong genetic test results.

Also some non-responders will be diagnosed as responders and the new medication will be added to their regular chemotherapy. They will receive absolutely no additional benefit from the new medication. However, they may experience side-effects of the new medication.







A 1

Before you start the survey:

There are several characteristics ("Attributes") of the genetic test and the new medication that may influence your decision for choosing among your treatment options. Below, you can find descriptions of these attributes.

Α2

1. Untreated Responders

Proportion of patients who could be cured by the new medication (responders) but will not receive it as a result of wrong genetic test result. This proportion shows how much error is involved in the genetic test results and it is better to be as low as possible.

A 4

2. Unnecessary Treatment of Non-responders

Proportion of patients who would not benefit from the new medication (non-responders) but will receive it as a result of wrong genetic test result. These patients will experience the additional side effects of the new medication without getting any benefit from that. This proportion shows how much error is involved in genetic test results and it is better to be as low as possible

А3

3. Severity of Side Effects

The new medication may be associated with side effects such as nausea, hair loss, skin rash and fatigue. In the questionnaire below, the potential levels of Side Effect Severity are:

- Severe: Presence of one or more of the examples listed above. Assume that the treatment and/or test side effects would significantly impact your quality of life and that this impact would be comparable to or worse than living with the disease.
- Moderate: Some side effects associated with both the genetic test and the treatment. If there are any side effects, they are less severe than living with the disease.
- *Minimal*: No side effects or minimal side effects associated with both the genetic test and the treatment. If there are any side effects, they are much less severe than living with the disease.

Α6

4. Likelihood of Side Effects

The side effects described in Attribute 3 will not necessarily occur for all individuals. Instead, they will occur with a particular percentage chance. For example, if the likelihood of experiencing side effects is 25%, then 25 out of 100 people would be expected to experience side effects, while the remaining 75 people would experience no side effects

Α5

5. Genetic Test Cost

Under the British Columbia Medical Services Plan, you would not be expected to pay for the genetic test and treatment medications. However, we are interested in knowing how highly you value these genetic test results. For the purposes of this exercise, please assume that you would be paying only for the genetic test out-of-pocket.

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A7
6. Genetic Test Turnaround Time The time required to obtain the genetic test results, after the test has been performed.
A8
7. Genetic Test Procedure Type of the procedure that is needed for doing the genetic test. The genetic test can be a simple procedure such as mouth swab or blood sample or it can involve an invasive procedure such as collecting a liver or bone marrow sample using a needle following a local anesthesia.
Next 100%







Q2 Please answer the following questions about yourself: 1. What is your age? Q3 2. What is your sex? Q3_1 © Female Q3_2 © Male Q4 Q4_4 Bachelor Q4_6 Doctorate Q4_5 Master e degree € degree Q6 4. How many dependent children do you have? Q6_1 € O 5. How do you describe your current health?

OB_1
Excellent

OB_2
Very
Good
Good Q8_4 With some Q8_5 Having serious € good health problems health problems Q 9 6. Do you know any one among your family or friends who has been diagnosed with cancer? Q13 Q13_4 Between 75000 Q13_6 125000 or Q13_5 Between 100000 € to 100000 € to e to 125000 € 25000 € more 50000 a 75000 a а vear vear year a year Next 0% 100%







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Questionnaire

I magine that you have been diagnosed with a fast-acting but curable cancer and you should decide whether to receive the new treatment in addition to regular chemotherapy. The genetic test can potentially predict whether you are a responder or a non-responder to the new medication.

Please answer the following questions about your preferences for the new medication and its associated genetic test. In each question you can choose between option A or option B based on their attributes. Also you may prefer not to be tested by choosing the neither option. If you don't take a genetic test, you will be given the new medication in addition to standard chemoterapy without knowing if you are a responder or a non-responder.







If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

ove the mouse over each attribute for its definition.					
Attributes	Option A	Option B	Neither		
Untreated Responders	50 out of 100	5 out of 100	0 out of 100		
<u>Unnecessary Treatment</u> of Non-responders	50 out of 100	5 out of 100	100 out of 100		
Severity of Side Effects	Moderate	Mild	Severe		
<u>Likelihood of Side</u> <u>Effects</u>	50 out of 100	5 out of 100	95 out of 100		
Cost	\$1000	\$500	\$0		
Test Turnaround Time	7 days	2 days	0 days		
Genetic Test Procedure	Bone Marrow Biopsy	Blood Sample	None		
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

ove the mouse over each attribute for its definition.					
Attributes	Option A	Option B	Neither		
<u>Untreated Responders</u>	35 out of 100	20 out of 100	0 out of 100		
<u>Unnecessary Treatment</u> of Non-responders	20 out of 100	35 out of 100	100 out of 100		
Severity of Side Effects	Severe	Mild	Severe		
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100	50 out of 100	95 out of 100		
Cost	\$50	\$1500	\$O		
<u>Test Turnaround Time</u>	12 days	2 days	0 days		
Genetic Test Procedure	Tumor Biopsy	Mouth Swab	None		
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.						
Attributes	Attributes Option A Option B					
<u>Untreated Responders</u>	5 out of 100		20 out of 100		0 out of 100	
<u>Unnecessary Treatment</u> of Non-responders	35 out of 100		5 out of 100		100 out of 100	
Severity of Side Effects	Moderate		Severe		Severe	
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100		5 out of 100		95 out of 100	
Cost	\$500		\$1000		\$O	
Test Turnaround Time	7 days		12 days		0 days	
Genetic Test Procedure	Tumor Biopsy		Liver Biopsy		None	
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

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Attributes	Option A	Option B	Neither
Untreated Responders	35 out of 100	50 out of 100	0 out of 100
<u>Unnecessary Treatment</u> <u>of Non-responders</u>	50 out of 100	20 out of 100	100 out of 100
Severity of Side Effects	Mild	Moderate	Severe
<u>Likelihood of Side</u> <u>Effects</u>	5 out of 100	95 out of 100	95 out of 100
Cost	\$50	\$1500	\$0
<u>Test Turnaround Time</u>	7 days	2 days	0 days
Genetic Test Procedure	Mouth Swab	Liver Biopsy	None
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If these were your only options, which would you choose?

Move the mouse over each attribute for its definition.

love the mouse over each attribute for its definition.					
Attributes	Option A	Option B	Neither		
<u>Untreated Responders</u>	5 out of 100	20 out of 100	0 out of 100		
<u>Unnecessary Treatment</u> of Non-responders	5 out of 100	35 out of 100	100 out of 100		
Severity of Side Effects	Mild	Moderate	Severe		
<u>Likelihood of Side</u> <u>Effects</u>	5 out of 100	50 out of 100	95 out of 100		
Cost	\$50	\$500	\$0		
Test Turnaround Time	2 days	7 days	0 days		
Genetic Test Procedure	Mouth Swab	Bone Marrow Biopsy	None		
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

Attributes	Option A	Option B	Neither
<u>Untreated Responders</u>	5 out of 100	20 out of	100 0 out of 100
<u>Unnecessary Treatment</u> of Non-responders	50 out of 100	5 out of 1	100 out of 100
Severity of Side Effects	Severe	Mild	Severe
<u>Likelihood of Side</u> <u>Effects</u>	50 out of 100	95 out of	95 out of 100
Cost	\$1500	\$50	\$O
Test Turnaround Time	12 days	7 days	0 days
Genetic Test Procedure	Blood Sample	Bone Marı Biopsy	
	J	Ja	J

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Attributes	Option A	Option B	Neither
<u>Untreated Responders</u>	50 out of 100	35 out of 100	0 out of 100
<u>Unnecessary Treatment</u> <u>of Non-responders</u>	35 out of 100	20 out of 100	100 out of 100
Severity of Side Effects	Moderate	Severe	Severe
<u>Likelihood of Side</u> <u>Effects</u>	5 out of 100	50 out of 100	95 out of 100
Cost	\$1000	\$500	\$O
<u>Test Turnaround Time</u>	12 days	2 days	0 days
Genetic Test Procedure	Mouth Swab	Bone Marrow Biopsy	None
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

The mouse over each e			
Attributes	Option A	Option B	Neither
<u>Untreated Responders</u>	20 out of 100	50 out of 100	0 out of 100
<u>Unnecessary Treatment</u> <u>of Non-responders</u>	20 out of 100	5 out of 100	100 out of 100
Severity of Side Effects	Moderate	Mild	Severe
<u>Likelihood of Side</u> <u>Effects</u>	5 out of 100	50 out of 100	95 out of 100
Cost	\$1500	\$500	\$0
<u>Test Turnaround Time</u>	7 days	12 days	0 days
Genetic Test Procedure	Blood Sample	Tumor Biopsy	None
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these were your only options, which would you choose? ove the mouse over each attribute for its definition.					
Attributes	Option A	Option B	Neither		
<u>Untreated Responders</u>	5 out of 100	35 out of 100	0 out of 100		
<u>Unnecessary Treatment</u> of Non-responders	50 out of 100	35 out of 100	100 out of 100		
Severity of Side Effects	Severe	Moderate	Severe		
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100	50 out of 100	95 out of 100		
Cost	\$1000	\$50	\$O		
Test Turnaround Time	2 days	12 days	0 days		
Genetic Test Procedure	Liver Biopsy	Blood Sample	None		
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CBCFIX2

If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

Attributes	Option A	Option B	Neither
<u>Untreated Responders</u>	20 out of 100	5 out of 100	0 out of 100
<u>Unnecessary Treatment</u> of Non-responders	35 out of 100	5 out of 100	100 out of 100
Severity of Side Effects	Moderate	Mild	Severe
<u>Likelihood of Side</u> <u>Effects</u>	50 out of 100	5 out of 100	95 out of 100
Cost	\$500	\$50	\$0
Test Turnaround Time	7 days	2 days	0 days
Genetic Test Procedure	Bone Marrow Biopsy	Mouth Swab	None
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.							
Attributes	Attributes Option A Option B						
<u>Untreated Responders</u>	5 out of 100	50 out of 100	0 out of 100				
<u>Unnecessary Treatment</u> of Non-responders	20 out of 100	35 out of 100	100 out of 100				
Severity of Side Effects	Mild	Severe	Severe				
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100	5 out of 100	95 out of 100				
Cost	\$1000	\$50	\$O				
Test Turnaround Time	7 days	2 days	0 days				
Genetic Test Procedure	Mouth Swab	Tumor Biopsy	None				
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

Attributes	Option A	Option B	Neither
<u>Untreated Responders</u>	20 out of 100	35 out of 100	0 out of 100
<u>Unnecessary Treatment</u> of Non-responders	50 out of 100	5 out of 100	100 out of 100
Severity of Side Effects	Moderate	Severe	Severe
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100	50 out of 100	95 out of 100
Cost	\$500	\$1500	\$0
Test Turnaround Time	12 days	7 days	0 days
Genetic Test Procedure	Bone Marrow Biopsy	Liver Biopsy	/ None
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these were your only options, which would you choose? ove the mouse over each attribute for its definition.							
Attributes	Option A		Option B		Neither		
<u>Untreated Responders</u>	50 out of 100		35 out of 100		0 out of 100		
<u>Unnecessary Treatment</u> <u>of Non-responders</u>	35 out of 100		50 out of 100		100 out of 100		
Severity of Side Effects	Severe		Mild		Severe		
<u>Likelihood of Side</u> <u>Effects</u>	95 out of 100		5 out of 100		95 out of 100		
Cost	\$500		\$1000		\$ 0		
Test Turnaround Time	7 days		2 days		0 days		
Genetic Test Procedure	Blood Sample		Tumor Biopsy		None		
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If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

Attributes	Option A	Option A Option B		Neither		
<u>Untreated Responders</u>	5 out of 100		20 out of 100		0 out of 100	
<u>Unnecessary Treatment</u> of Non-responders	5 out of 100		20 out of 100		100 out of 100	
Severity of Side Effects	Moderate		Mild		Severe	
<u>Likelihood of Side</u> <u>Effects</u>	50 out of 100		5 out of 100		95 out of 100	
Cost	\$50		\$1500		\$O	
Test Turnaround Time	2 days		12 days		0 days	
Genetic Test Procedure	Mouth Swab		Bone Marrow Biopsy		None	
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these were your only options, which would you choose? love the mouse over each attribute for its definition.						
Attributes	Option A	Option B	Neither			
<u>Untreated Responders</u>	35 out of 100	50 out of 100	0 out of 100			
<u>Unnecessary Treatment</u> of Non-responders	5 out of 100	20 out of 100	100 out of 100			
Severity of Side Effects	Moderate	Mild	Severe			
Likelihood of Side Effects	95 out of 100	50 out of 100	95 out of 100			
Cost	\$1000	\$50	\$0			
Test Turnaround Time	2 days	7 days	0 days			
Genetic Test Procedure	Blood Sample	Liver Biopsy	None			
	ja	J	Ja			

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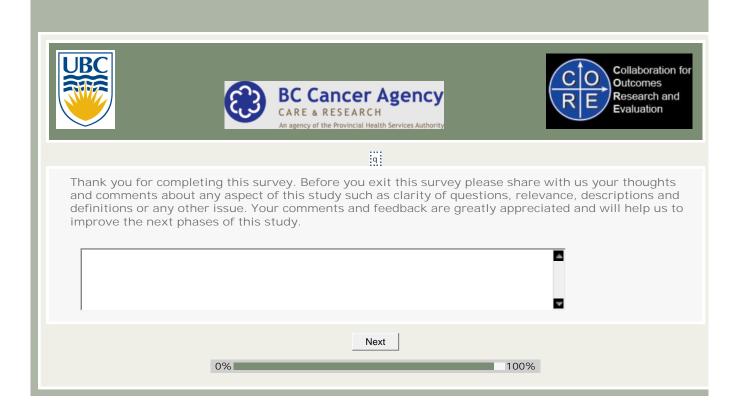




If these were your only options, which would you choose? Move the mouse over each attribute for its definition.

Attributes	Option A	Option B		Neither
Untreated Responders	20 out of 100	5	out of 100	0 out of 100
<u>Unnecessary Treatment</u> of Non-responders	50 out of 100	3	5 out of 100	100 out of 100
Severity of Side Effects	Moderate		Severe	Severe
<u>Likelihood of Side</u> <u>Effects</u>	50 out of 100	5	out of 100	95 out of 100
Cost	\$500		\$1500	\$0
Test Turnaround Time	7 days		12 days	0 days
Genetic Test Procedure	Tumor Biopsy	В	one Marrow Biopsy	None
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