

AUSTRALIAN JEWISH BREAST CANCER STUDY - FOLLOW-UP QUESTIONNAIRE 2002**SECTION A.**

1. How did you hear about the Australian Jewish Breast Cancer Study? (please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Australian Jewish News | <input type="checkbox"/> GP |
| <input type="checkbox"/> Information Evening | <input type="checkbox"/> Friend or relative |
| <input type="checkbox"/> Breast Specialist or Gynaecologist | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> Genetic Clinic | <input type="checkbox"/> Other, please specify _____ |

SECTION B *This section asks about your knowledge of breast cancer and the BRCA1 and BRCA2 genes. For each question, please tick one answer only.*

- | | |
|---|--|
| <p>1. Breast cancer is always inherited</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>2. Men can have a mutation (fault) in the BRCA1 or BRCA2 genes</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>3. There is more than one gene which can cause breast or ovarian cancer if faulty</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>4. All women who have a mutation (fault) in the BRCA1 or BRCA2 gene will get breast or ovarian cancer</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>5. A woman who does not have a mutation (fault) in BRCA1 or BRCA2 can still get breast or ovarian cancer</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>6. Mutations (faults) in the BRCA1 or BRCA2 gene may also increase the risk for cancers other than those of the breast and ovary</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> | <p>7. Mammography will always detect breast cancer</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>8. A genetic test for breast and ovarian cancer will also detect other abnormalities</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>9. If a woman looks like a relative with breast or ovarian cancer, she is likely to have inherited a fault in the breast cancer gene</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>10. Some mutations (faults) in BRCA1 or BRCA2 are more common in people of Jewish descent</p> <p><input type="checkbox"/> True</p> <p><input type="checkbox"/> False</p> <p><input type="checkbox"/> Don't know</p> <p>11. What is the chance that a woman who has a mutation (fault) in BRCA1 or BRCA2 will develop breast cancer in her life?</p> <p><input type="checkbox"/> About the same as a woman who does not have a mutation</p> <p><input type="checkbox"/> Higher than a woman who does not have a mutation</p> <p><input type="checkbox"/> Lower than a woman who does not have a mutation</p> <p><input type="checkbox"/> Don't know</p> |
|---|--|

	Not at all	A little	Moderately so	Very much so	Don't know	Not applicable
H. Helped me get ready for good or bad news	<input type="checkbox"/>					
I. Helped me decide whether to have a gene test	<input type="checkbox"/>					
J. Helped me to cope with the test result	<input type="checkbox"/>					
K. Informed me of options for breast and ovarian cancer prevention and surveillance	<input type="checkbox"/>					
L. Helped me decide what surveillance for breast and ovarian cancer I should have	<input type="checkbox"/>					
M. Provided advice on what to say to my family about gene testing	<input type="checkbox"/>					
N. Provided emotional support for me	<input type="checkbox"/>					
O. Provided emotional support for my family	<input type="checkbox"/>					
P. Helped me decide what to do after learning the test result	<input type="checkbox"/>					

SECTION G *These questions ask about concerns with genetic testing*

1. *On a personal level for you and your family*
2. *Due to views of individuals or groups within the Jewish Community*
2. *Due to views of individuals or groups outside the Jewish Community*

That is, TO WHAT EXTENT WERE/ARE YOU CONCERNED about issues that may arise

In YOUR FAMILY?	Not at all	A little	Moderately	Very much	Not applicable
A. That if you have a faulty gene, it will put pressure on your relationship with your husband or partner	<input type="checkbox"/>				
B. That you will want to protect family from possible bad news	<input type="checkbox"/>				
C. That you will feel guilty if you have passed a faulty gene to your children	<input type="checkbox"/>				
D. That you will bear the burden of telling your family any 'bad' news	<input type="checkbox"/>				
E. That your family may be upset with you because they don't want to know if there is a faulty gene in the family	<input type="checkbox"/>				
F. That your family will put pressure on you to learn your test result when you are not sure if you really want to know	<input type="checkbox"/>				

From WITHIN the Jewish community?	Not at all	A little	Moderately	Very much	Not applicable
G. That it may alter your marriage prospects	<input type="checkbox"/>				
H. That it may alter marriage prospects for other family members	<input type="checkbox"/>				
I. That if you have a faulty gene, others in the Jewish community may talk about, or view, you and your family differently	<input type="checkbox"/>				
J. That if you have a faulty gene, you have 'let down' Jewish people	<input type="checkbox"/>				
K. That genetic clinic or research staff who work within the Jewish community may not be discrete with your genetic test results	<input type="checkbox"/>				

From OUTSIDE the Jewish community?	Not at all	A little	Moderately	Very much	Not applicable
L. That gene tests are too focussed on Jewish people	<input type="checkbox"/>				
M. That gene tests may be used for racial discrimination	<input type="checkbox"/>				
N. That gene tests may be used for discrimination with regard to health, life or disability insurance	<input type="checkbox"/>				
O. That your clinical record is not secure	<input type="checkbox"/>				
P. That details provided to researchers may be passed onto others	<input type="checkbox"/>				

Your personal experience as a participant in this study is valuable feedback. Please feel free to write about any positive or negative experiences, worries or difficulties that occurred through your involvement in this research study:

SECTION H *This section asks what you PREFER from genetic clinics. Your answers may help to improve the genetic counselling and testing appointments, to provide a better service. To answer these questions, we ask you first to consider some potential topics for discussion at a genetic clinic (below), which you will be asked about in following questions.*

Potential topics for discussion at the genetic counselling appointment include:

1. Genetic and cancer risk information (information)
 Counsellors and doctors provide information about breast and ovarian cancer and associated genes; they provide an estimate of your risk of developing breast or ovarian cancer given your personal and family cancer history.

2. Preparation for testing (preparation)
 Counsellors and doctors discuss the possible benefits and limitations of having a genetic test, to help you to get ready for possible good or bad news, how you might feel after learning your test result, and any other personal issues relating to the test which may be of concern to you.

3. Surveillance advice (surveillance)
 Counsellors and doctors talk to you about options for early detection of breast and ovarian cancer and provide recommendations for the frequency of mammography, ultrasound and other means of early detection appropriate for you.

4. Deciding whether or not to have a genetic test (direction)
 Counsellors and doctors discuss the decision whether or not to have a genetic test. In particular, they would give their opinion as to whether you should go through genetic testing, to help give you direction in deciding what to do.

1. Please **rank these four topics** in order of importance to you using a scale of 1 - 4, where 1 is the most important issue for discussion and 4 the least important. Please place a number in **EVERY** box.

1. Information	<div style="background-color: #FFD700; padding: 2px; font-weight: bold;">Rank</div> <div style="border: 1px solid black; height: 30px; width: 100%;"></div> <div style="border: 1px solid black; height: 30px; width: 100%;"></div> <div style="border: 1px solid black; height: 30px; width: 100%;"></div> <div style="border: 1px solid black; height: 30px; width: 100%;"></div>
2. Preparation	
3. Surveillance	
4. Direction	

2. Please **rank how much** discussion you would **prefer** for each of the topics by using the numbers 1 - 3, where 1 = highest preference and 3 = lowest preference.

Example: The ranking below indicates that this person would most prefer some discussion of the information; followed by no discussion of the information and; would least prefer a lot of discussion of the information.

	None	Some	A lot
1. Information	<input style="border: 1px solid black; width: 20px; height: 20px;" type="text" value="2"/>	<input style="border: 1px solid black; width: 20px; height: 20px;" type="text" value="1"/>	<input style="border: 1px solid black; width: 20px; height: 20px;" type="text" value="3"/>

For each topic please rank how much discussion you would prefer using the numbers 1 - 3, where 1 = highest preference and 3 = lowest preference:

	None	Some	A lot
1. Information	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>
2. Preparation	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>
3. Surveillance	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>
4. Direction	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>

Please answer the questions below by placing a tick (✓) in the box to indicate **whether you would prefer Appointment A or Appointment B**. THESE QUESTIONS ARE DESIGNED TO LOOK SIMILAR, but each is different and provides us with different information, so please think about each question individually, and ignore your responses to the previous questions.

3. Which appointment would you prefer?

1. Information
2. Preparation
3. Surveillance
4. Direction

Which would you prefer? (tick one only)

4. Which appointment would you prefer?

1. Information
2. Preparation
3. Surveillance
4. Direction

Which would you prefer? (tick one only)

5. Which appointment would you prefer?

1. Information
2. Preparation
3. Surveillance
4. Direction

Which would you prefer? (tick one only)

6. Which appointment would you prefer?

1. Information
2. Preparation
3. Surveillance
4. Direction

Which would you prefer? (tick one only)

7. Which appointment would you prefer?

1. Information
2. Preparation
3. Surveillance
4. Direction

Which would you prefer? (tick one only)

Appointment A	Appointment B
Amount of discussion	Amount of discussion
Some	A lot
A lot	None
A lot	
None	A lot

Prefer A

Prefer B

Appointment A	Appointment B
Amount of discussion	Amount of discussion
Some	
None	Some
Some	A lot
Some	None

Prefer A

Prefer B

Appointment A	Appointment B
Amount of discussion	Amount of discussion
Some	None
Some	None
Some	
A lot	None

Prefer A

Prefer B

Appointment A	Appointment B
Amount of discussion	Amount of discussion
None	
Some	A lot
A lot	None
Some	A lot

Prefer A

Prefer B

Appointment A	Appointment B
Amount of discussion	Amount of discussion
Some	None
None	A lot
None	A lot
Some	

Prefer A

Prefer B

8. Are there any other issues that you would like discussed at a genetic clinic appointment? _____

SECTION I

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate value to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

ALMOST NEVER
SOMETIMES
OFTEN
ALMOST ALWAYS

- | | | | | |
|---|---|---|---|---|
| 1. I feel pleasant | 1 | 2 | 3 | 4 |
| 2. I feel nervous and restless | 1 | 2 | 3 | 4 |
| 3. I feel satisfied with myself | 1 | 2 | 3 | 4 |
| 4. I wish I could be as happy as others seem to be | 1 | 2 | 3 | 4 |
| 5. I feel like a failure | 1 | 2 | 3 | 4 |
| 6. I feel rested | 1 | 2 | 3 | 4 |
| 7. I am "calm, cool, and collected" | 1 | 2 | 3 | 4 |
| 8. I feel that difficulties are piling up so that I cannot overcome them..... | 1 | 2 | 3 | 4 |
| 9. I worry too much over something that really doesn't matter | 1 | 2 | 3 | 4 |
| 10. I am happy | 1 | 2 | 3 | 4 |
| 11. I have disturbing thoughts | 1 | 2 | 3 | 4 |
| 12. I lack self-confidence | 1 | 2 | 3 | 4 |
| 13. I feel secure | 1 | 2 | 3 | 4 |
| 14. I make decisions easily | 1 | 2 | 3 | 4 |
| 15. I feel inadequate | 1 | 2 | 3 | 4 |
| 16. I am content | 1 | 2 | 3 | 4 |
| 17. Some unimportant thought runs through my mind and bothers me | 1 | 2 | 3 | 4 |
| 18. I take disappointments so keenly that I can't put them out of my mind | 1 | 2 | 3 | 4 |
| 19. I am a steady person | 1 | 2 | 3 | 4 |
| 20. I get in a state of tension or turmoil as I think over my recent concerns and interests | 1 | 2 | 3 | 4 |