

ID: _____



CANCER & FERTILITY STUDY

As part of the Cancer & Fertility Study being conducted at the University of Western Sydney, we are interested in your experiences of fertility in the context of cancer and your overall health and wellbeing.

Taking part in this study is voluntary. You don't have to complete this survey if you don't want to.

If you are in a relationship, we are also interested in the experiences of your partner. Your partner can complete a separate survey.

Instructions

- The survey will take about 30-45 minutes to complete.
- Please answer all questions.
- Please read the instructions for each set of questions before answering.
- There are no right or wrong answers, just choose the answer that is right for you.
- The information you provide is confidential so no one will know you have taken part in the study.
- Space is provided at the end of the survey for any other comments you may want to add.

Your participation in this study is greatly appreciated.

Section 1: General questions about you

1. What is today's date? (dd/mm/yyyy)

___ / ___ / 20 ___

2. What is your age? _____ yrs

3. Where did you find out about this study?

(please tick as many as appropriate)

- Cancer Council NSW
- National Breast Cancer Foundation/Register4
- CanTeen
- Family Planning NSW
- Westmead Hospital
- Nepean Hospital
- University of Western Sydney
- BCNA
- Newsletter
- Cancer Support Groups
- Other (please specify) _____

4. Are you

- A **PERSON** who has/had cancer
- A **PARTNER** of a person who has/had cancer
- Both my partner **AND** I have/had cancer

5. What is your gender?

- Male Female
- I identify as _____

6. With which ethnic or cultural group do you identify?

7. With which religious group do you identify?

8. What is your Australian postcode? _____

If you live overseas, please specify country:

9. How would you describe where you live?

- Metropolitan (e.g., major city)
- Rural
- Regional
- Remote

10. What is the highest level of education you have achieved?

- Still in school
- Left school with no school certificate
- School Certificate / HSC
- Trade / apprenticeship qualification / certificate / diploma
- University degree or higher
- Other (Please specify)

—

11. What is your employment status?

- Student
- Working Full-time
- Casual Work
- On leave from work
- Not working / Retired
- Other (please specify)
- Home duties
- Working Part-time
- Volunteer
- Unemployed (looking for work)

If working,

a) On average, how many hours of paid work do you do per week? _____ hrs

b) On average, how many hours of unpaid/volunteer work outside the home do you do per week? _____ hrs

12. Do you identify as:

- Heterosexual (i.e., straight)
- Non-Heterosexual (e.g., gay, lesbian)

I identify as _____

- 13. What is your current relationship status?**
- Have **never** been in a relationship
 - Not in a relationship – The relationship ended **before** the cancer diagnosis
 - Not in a relationship – The relationship ended **after** the cancer diagnosis
 - Not in a relationship – Partner has passed away
 - In a relationship - The relationship started **before** the cancer diagnosis
 - In a relationship - The relationship started **after** the cancer diagnosis
 - Other (please specify)

- Biological children
- Other (please specify):

- b)** If they are your biological children, were any conceived after the cancer diagnosis?
- Yes No N/A

c) How many children do you have? _____

d) What are their gender and ages?

Gender (M/F)						
Age (yrs)						

a) How long have you been in this relationship OR how long ago was your last relationship? _____ (yrs/mths)

- 15. Prior to the cancer diagnosis, were you planning to have children or more children?**
- Yes No

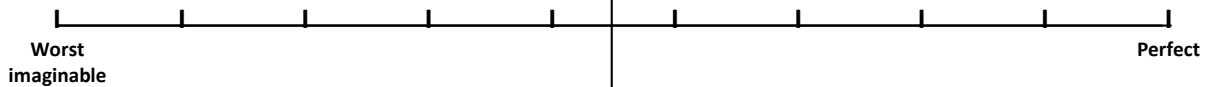
- 14. Do you have children?**
- Yes No

If NO, please go to Q.15.

a) If YES, are they (please tick both if appropriate)

Section 2: Questions about your general wellbeing

16. How would you rate your quality of life? (please put a 'X' on the line below)



The following questions (Q.17-Q.26) concern how you have been feeling recently, please tick the box that best represents how you have been.

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
17. How often do you feel tired for no good reason?					
18. How often do you feel nervous?					
19. How often do you feel so nervous that nothing could calm you down?					
20. How often do you feel hopeless?					
21. How often do you feel restless or fidgety?					
22. How often do you feel so restless you could not sit still?					

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
23. How often do you feel depressed?					
24. How often do you feel that everything is an effort?					
25. How often do you feel so sad that nothing can cheer you up?					
26. How often do you feel worthless?					

Section 3: Questions about your cancer experience

Note: If both you and your partner have/had cancer, please complete the following questions from your perspective.

27. In which year were you or your partner diagnosed with cancer?

28. What type of cancer were you or your partner diagnosed with?

29. At what stage was the cancer when it was first diagnosed?

- Early Advanced
 Unsure Other

If Other, please specify

30. Have you or your partner been diagnosed with another PRIMARY cancer (not your cancer coming back) since the first diagnosis?

- Yes No

If YES,

a) What was the cancer?

b) _____
In which year was it diagnosed?

31. What has happened to the cancer(s) since it was diagnosed?

1 st Cancer	2 nd Cancer	
<input type="checkbox"/>	<input type="checkbox"/>	Currently being treated
<input type="checkbox"/>	<input type="checkbox"/>	The cancer was cured (no evidence of cancer at the moment)
<input type="checkbox"/>	<input type="checkbox"/>	The cancer came back and was cured again
<input type="checkbox"/>	<input type="checkbox"/>	The cancer came back and is being treated again
<input type="checkbox"/>	<input type="checkbox"/>	The cancer came back and is being monitored at the moment
<input type="checkbox"/>	<input type="checkbox"/>	No further treatment possible / palliative care
<input type="checkbox"/>	<input type="checkbox"/>	Other (please specify)

32. What treatments have you or your partner received for the cancer(s) in the past and now? (please tick as many as appropriate)

Past	Now	
<input type="checkbox"/>	<input type="checkbox"/>	No Treatments
<input type="checkbox"/>	<input type="checkbox"/>	Surgery (e.g., mastectomy, prostatectomy, hysterectomy)
<input type="checkbox"/>	<input type="checkbox"/>	Radiotherapy (e.g., external beam, brachytherapy)
<input type="checkbox"/>	<input type="checkbox"/>	Chemotherapy
<input type="checkbox"/>	<input type="checkbox"/>	Hormonal treatment (e.g., Tamoxifen or similar tablets, Zoladex implants, Lucrein injections)
<input type="checkbox"/>	<input type="checkbox"/>	Complementary Medicine (e.g., naturopathy, acupuncture, herbal remedies, yoga)
<input type="checkbox"/>	<input type="checkbox"/>	I am not sure
<input type="checkbox"/>	<input type="checkbox"/>	Other (please specify) _____ _____

33. Have you, or your woman partner, experienced menopause as a result of cancer or cancer treatment?

Yes No N/A

If YES, please clarify

34. Some cancer diagnoses might be associated with a genetic mutation, have you or your partner been offered genetic testing?

Yes No

a) If YES, did you or your partner have the test?

Yes No

b) If YES, have you or your partner been found to have a genetic mutation?

Yes No result yet
 Inconclusive / negative

The following statements (Q.35-Q.42) are about how your or your partner's cancer has affected you. Please circle the best response for you. There are no right answers to any of the questions.

	Strongly Agree				Strongly Disagree	N/A
35. I have a hard time adjusting to the limitations of cancer.	1	2	3	4	5	X
36. Because of cancer, I miss the things I like to do most.	1	2	3	4	5	X
37. Cancer makes me feel useless at times.	1	2	3	4	5	X
38. Cancer makes me more dependent on others than I want to be.	1	2	3	4	5	X
39. Cancer makes me a burden on my family and friends.	1	2	3	4	5	X
40. Cancer does not make me feel inadequate.	1	2	3	4	5	X
41. I will never be self-sufficient enough to make me happy.	1	2	3	4	5	X
42. I think people are often uncomfortable being around me because of cancer.	1	2	3	4	5	X

Section 4: Questions about fertility

43. Were you concerned about fertility **BEFORE** the cancer diagnosis? *(please put a 'X' on the line below)*

	Not at all concerned								Very concerned

Please comment

44. Were you concerned about fertility **AFTER** the cancer diagnosis? *(please put a 'X' on the line below)*

	Not at all concerned								Very concerned

Please comment

45. Did your concerns about fertility affect the decision(s) you made about cancer treatments?

Yes
 No

Please comment

The following (Q.46-Q.73) are experiences that some people have with fertility and parenthood, please tick the box which best answers that item for you. *Note: Please use 'Non-Applicable (N/A)' for experiences that are not relevant to you.*

	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree	N/A
46. Pregnancy and childbirth are the two most important events for a person.							
47. It doesn't bother me when I'm asked questions about children.							
48. People without a child are just as happy as those with children.							

	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree	N/A
49. For me, being a parent is a more important goal than having a satisfying career.							
50. Family members don't seem to treat me any differently.							
51. I could see a number of advantages if I didn't have a child (or another child).							
52. Relationships need a child.							
53. The holidays are especially difficult for me.							
54. I could visualise a happy life without a child (or another child).							
55. It's hard to feel like a true adult until you have a child.							
56. Family get-togethers are especially difficult for me.							
57. At times, I seriously wonder if I want a child (or another child).							
58. A future without a child (or another child) would frighten me.							
59. I can't help comparing myself with friends who have children.							
60. Not having a child (or another child) would allow me time to do other satisfying things.							
61. I feel empty because of fertility issues.							
62. I still have lots in common with friends who have children.							
63. Having a child (or another child) is not necessary for my happiness.							
64. Having a child (or another child) is not the major focus of my life.							
65. I find it hard to spend time with friends who have young children.							

66.	I could have a long, happy relationship without a child (or another child).							
67.	I have often felt that I was born to be a parent.							
		Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree	N/A
68.	When I see families with children I feel left out.							
69.	There is a certain freedom without children that appeals to me.							
70.	As long as I can remember, I've wanted to be a parent.							
71.	I feel like friends or family are leaving us behind.							
72.	I will do just about anything to have a child (or another child).							
73.	It doesn't bother me when others talk about their children.							

74. Have fertility issues affected your relationship(s) or your ability to form a new relationship?

- Yes No

Please comment

75. Have fertility issues affected your feelings about your body?

- Yes No

Please comment

76. Have fertility issues affected your feelings about yourself as a man or a woman?

- Yes No

Please comment

Section 5: Questions relating to information & support about cancer & fertility

77. Since receiving the cancer diagnosis, have issues about fertility been discussed with a health care professional?

- Yes
- No

If YES,

a) Which health care professional(s)?

b) Who raised the issues?

- Health care professional
- Yourself
- Your partner
- Both you and your partner
- Other (please specify)

c) How satisfied were you with the discussion?

- Satisfied
- Dissatisfied
- Neither satisfied nor dissatisfied

Please tell us more about your response

78. If issues about fertility have not been discussed, would you have liked a health care professional to raise the issues? (Please go to Q.79 if you had responded 'Yes' to Q.77)

- Yes
- No

If YES, which health care professional(s) would you like to raise the issue?

79. When do you think issues relating to cancer and fertility should be discussed by a health care professional?

- At the time of diagnosis
- At the commencement of treatment
- Post-treatment and during recovery
- At each stage
- Never
- Other (Please specify)

80. Have you used or received information/resources on cancer and fertility?

- Yes
- No

If YES,

a) What were the information/resources?

b) How were the information/resources helpful or unhelpful?

81. Would you like to receive information about the effects of cancer and treatments on fertility?

Yes No

a) If YES, and this were available, how would you like to receive this information? (please tick as many as appropriate)

- Booklet/Leaflet
- Newsletter
- Telephone Helpline
- Websites
- Group/Information Sessions
- Face-to-face, individual consultation
- Other (please specify)

82. Have you had any fertility investigations or fertility preserving procedures (e.g., sperm banking, embryo cryopreservation, trachelectomy)?

Yes No

If YES, please describe your experience of these investigations and/or undergoing these procedures both BEFORE (if appropriate) and AFTER (if appropriate) the cancer diagnosis.

83. Have you attempted to become pregnant since the cancer diagnosis?

Yes No

a) If YES, have you been successful in becoming pregnant?

Yes No

Please comment

b) If NO, do you currently have any plans to attempt to become pregnant?

Yes No

Please comment

84. Have you spoken with someone about fertility issues?

Yes No

If NO, please comment

If YES, please continue to Q.85.

If NO, please go to Section 6 – Q.90.

85. If you have spoken with someone about fertility issues, who have you spoken to? (Tick all that apply)
Also, please indicate how satisfied you were with the discussion.

	Have spoken to	Satisfied	Neither satisfied or dissatisfied	Not satisfied
Partner (husband, wife, boyfriend, girlfriend)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friend / Relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical oncologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation oncologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fertility Specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious / pastoral care worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Person affected by cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support Group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer support helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1. _____				
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. _____				

86. Please explain what was satisfying, or dissatisfying, about discussing fertility issues with your partner, family and friends.

87. Please explain what was satisfying, or dissatisfying, about discussing fertility issues with people who have, or have had, cancer.

88. Please explain what was satisfying, or dissatisfying, about discussing fertility issues with health care professionals (e.g., specialists, doctors, nurses, social workers, psychologists) who are caring or have cared for you or your partner.

89. Do you have any other comments you would like to make about your experience in talking about fertility issues with others?

Section 6: Questions about your relationship with your intimate partner

The following sections are about how fertility issues caused by cancer can affect a person's intimate and sexual relationship with his/her partner. If you are under 18 years old, not sexually active or not in an intimate couple relationship, some of these sections might not be relevant for you.

The following questions (Q.90-Q.111) concern your feelings about the relationship with your partner. Please circle the number which best answers that item for you. Please use 'Non-Applicable (N/A)' for experiences that are not relevant to you.

Note: If all these questions are irrelevant to you, please go to Q.112.

90.	How well does your partner meet your needs?	1 Poorly	2	3 Average	4	5 Extremely well	0 N/A
91.	In general, how satisfied are you with your relationship?	1 Unsatisfied	2	3 Average	4	5 Extremely satisfied	0 N/A
92.	How good is your relationship compared to most?	1 Poor	2	3 Average	4	5 Excellent	0 N/A
93.	How often do you wish you weren't in this relationship?	5 Never	4	3 Average	2	1 Very often	0 N/A
94.	To what extent has your relationship met your original expectations?	1 Hardly at all	2	3 Average	4	5 Completely	0 N/A
95.	How much do you love your partner?	1 Not much	2	3 Average	4	5 Very much	0 N/A
96.	How many problems are there in your relationship?	5 Very Few	4	3 Average	2	1 Very many	0 N/A

Most people have disagreements in their relationships. Please tick the box which best answers that item for you.

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never	N/A
97.	How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
98.	How often do you or your partner leave the house after a fight?						
99.	In general, how often do you think that things between you and your partner are going well?						
100.	Do you confide in your partner?						
101.	Do you ever regret that you married/have a partner (or lived together)?						
102.	How often do you and your partner argue?						
103.	How often do you and your partner "get on each other's nerves?"						

How would you rate the following? Please tick the box which best answers that item for you.

	Every day	Almost every day	Occasionally	Rarely	Never	N/A

104. Do you kiss your partner?						
	All of them	Most of them	Some of them	Very few of them	None of them	N/A
105. Do you and your partner have outside interests together?						

How often do the following occur between you and your partner? Please tick the box which best answers that item for you.

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often	N/A
106. Have a stimulating exchange of ideas							
107. Laugh together							
108. Calmly discuss something							
109. Work together on a project							

110. The following table represents different degrees of happiness in a relationship. Please tick the box that you think represents your relationship.

Extremely unhappy	Fairly unhappy	A little unhappy	Happy	Very happy	Extremely happy	Perfect

Not in a relationship

111. Please circle the number next to the statement that best describes how you feel about the future of your relationship.

5	I want desperately for my relationship to succeed and would go to almost any length to see that it does.
4	I want very much for my relationship to succeed and will do all I can to see that it does.
3	I want very much for my relationship to succeed and will do my fair share to see that it does.
2	It would be nice if my relationship succeeded, and I can't do much more than I am doing now to help it succeed.
1	It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
0	My relationship can never succeed, and there is no more that I can do to keep the relationship going.
N/A	Not in a relationship.

The following statements (Q.112-Q.129) are about how concerns over fertility issues can affect a person's sexual and intimate relationship with his/her partner, please tick the box which best answers that item for you. Please use 'Non-Applicable (N/A)' for experiences that are not relevant to you.

Note: If all these statements are irrelevant to you, please go to Q.130.

	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree	N/A
112. I can't show my partner how I feel because it will make him/her feel upset.							
113. When I talk about our fertility issues, my partner seems comforted by my comments.							
114. My partner doesn't understand the way fertility issues affect me.							
115. I find I've lost my enjoyment of sex because of fertility issues.							
116. My partner and I work well together handling questions about our infertility.							
117. I feel just as attractive to my partner as before.							
118. It bothers me that my partner reacts differently to our fertility issues.							
119. I don't feel any different from other members of my sex.							
120. My partner is quite disappointed with me.							
121. I feel like I've failed at sex.							
122. My partner and I <i>could</i> talk more openly with each other about our fertility issues.							
123. During sex, all I can think about is wanting a child (or another child).							
124. I couldn't imagine us ever separating because of fertility issues.							
125. Having sex is difficult because I don't want another disappointment.							
126. When I try to talk about fertility issues, it seems to lead to an argument.							
127. If I miss a critical day to have sex, I can feel quite angry.							

	Strongly Disagree	Disagree	Mildly Disagree	Mildly Agree	Agree	Strongly Agree	N/A
128. Because of infertility, I worry that my partner and I are drifting apart.							
129. Sometimes I feel so much pressure, that having sex becomes difficult.							

130. Do you have any other issues around cancer and fertility that you would like to comment upon?

**This is the end of the survey.
Thank you very much for your time and contribution to the study.**

If you have some discomfort or experience any strong emotions after completing the survey, and feel as though you would like to talk to someone, please feel free to contact a member of the research team (☎ 1800 19 20 02). Alternatively, please see below for some numbers that you can call for help, trained staff are ready to take your call and provide the appropriate service to you.

- Cancer Council Helpline (☎ 13 11 20) – Monday to Friday, 9am-5pm
- Lifeline Australia (☎ 13 11 14) – 24 hour service
- The Kids Helpline (☎ 1800 55 1800) – this is a telephone service for young people aged 5-25 years

If you are a Member of CanTeen, you can talk to your Member Liaison Officer (MLO).