

Men's attitudes toward forming and maintaining romantic relationships with

All relationships can be challenging. Relationships with BRCA1 or BRCA2 mutation carriers can be especially challenging. While BRCA1 or BRCA2 positive women's thoughts on romantic relationships have been studied, no one has looked at the relationship from the man's perspective. In this study, we hope to do just that. We're interested in hearing your side about what it's like to be in a relationship with a woman who is facing these issues. We hope the data collected for this study will be beneficial for both men and BRCA1 or BRCA2 positive women.

To participate, we ask that you are currently in a relationship with a BRCA1/2 positive woman. We also ask that you are a male age 18 or older. Participation in this survey is optional, and we hope to hear as many perspectives as possible. If at any point in the survey you are made to feel emotional discomfort, please exit from the survey. Your identity will remain anonymous and your answers confidential. As a thank you, you will be eligible to participate in a raffle to win one of five \$25 Visa gift cards after completion of the survey. Thank you for your participation.

If you have any questions about this survey, please contact Caitlin Mauer (caitlinmauer2012@u.northwestern.edu).

1. Are you currently a male partner of a woman with a BRCA 1 or BRCA2 mutation age 18 or older?

- Yes
- No

These next questions focus on the timing of when you learned about your partner's BRCA mutation. However, we know relationships develop on their own timetable and don't always follow a straight line. If your experience doesn't fit neatly into one of the categories, please fill in the details where you see "Other/More Information."

2. What is the nature of your relationship with your partner?

- We are "hooking up"
- We are dating
- We are co-habiting
- We are engaged
- We are married
- Other/More Information

Men's attitudes toward forming and maintaining romantic relationships with

3. How long have you been in a relationship with your partner?

- 0-5 months
- 6-11 months
- 1-2 years
- 3-4 years
- 5 years or more

4. Did you know your partner had a BRCA1/2 mutation before you started dating?

- Yes
- No

5. Were you in a relationship with your partner when she initially found out she was BRCA1/2 positive?

- Yes
- No

6. In what stage of your relationship did your partner disclose her BRCA1/2 mutation status to you?

- On the first date
- During the beginning dating phase
- After we got more serious
- After we were engaged
- After we were married
- Other/More Information

7. How long had you been together when she disclosed her BRCA1/2 mutation status?

- 0-5 months
- 6-11 months
- 1-2 years
- 3-4 years
- 5 years or more

Men's attitudes toward forming and maintaining romantic relationships with

8. Would you have preferred to be informed about her mutation status at a different time than you were?

- Earlier
- Later
- Timing was appropriate
- Would prefer not to know
- Other/More Information

9. How much distress did her test result cause you personally?

No distress

Some distress

A lot of distress

Amount of distress

10. How much information did your partner tell you during that first conversation when she disclosed her mutation status? (Check all that apply)

- Her family history of breast and/or ovarian cancer
- The inheritance of BRCA1/2 mutations
- Breast cancer risks
- Ovarian cancer risks
- Cancer risk-reducing surgeries
- Early menopause
- Possible shortening of her childbearing years
- The potential for her children to inherit or have inherited the mutation
- Other/More Information

11. Did you feel you needed to do more research after your partner disclosed her mutation status for the first time?

No additional research

Some additional research

A lot of additional research

Amount of research

Men's attitudes toward forming and maintaining romantic relationships with

12. If you did more research, did you do it independently or with your partner?

- Independently
- With my partner
- Both independently and with my partner
- I did not do more research

13. When a woman discloses her mutation status, it often can cause a change in the dynamic of her relationships. How did your partner's disclosure of her mutation status change your relationship with her? (Check all that apply, but please add other changes in your relationship not mentioned here.)

- We became more intimate
- We became less intimate
- I became more attracted to her
- I became less attracted to her
- I became more involved in her family
- I became less involved in her family
- The way we communicated changed
- The nature of our conversation topics changed
- We discussed the future more
- We discussed the future less
- Other changes:

Because of the high chance of developing breast cancer over the course of their lifetime, some women choose to have mammograms and regular breast screening to detect breast cancers early. Other women choose to have mastectomies (have both breasts surgically removed) before they actually develop cancer (prophylactic mastectomies). Breast reconstruction, or surgery to rebuild a breast after a mastectomy, is available and optional.

14. Has your partner been diagnosed with breast cancer?

- Yes
- No

Men's attitudes toward forming and maintaining romantic relationships with

15. When during your relationship was your partner initially diagnosed with breast cancer? (Check all that apply)

- Before our relationship started
- After our relationship started
- Before her mutation testing was performed
- After her mutation testing was performed

16. Has your partner undergone (a) mastectomy(ies)?

- Yes
- No

17. Were you involved in your partner's decisions about what type of surgery she chose?

- Yes
- No

18. Did she have reconstruction of her breast(s) following her mastectomy(ies)?

- Yes
- No

19. Did this change your views on a future with her? (Check all that apply)

- I have/had concerns about sexual relations with her after surgery
- I have/had concerns with her loss of sensation in her breast tissue
- I have/had concerns about her appearance after surgery
- I have/had concerns about what others would think about her appearance
- I have/had concerns I would be less attracted to her physically
- I have/had concerns about her ability to breast feed
- I have/had concerns about her health/lifespan
- I have/had no concerns
- Other (please specify)

Men's attitudes toward forming and maintaining romantic relationships with

20. How did this surgery change your views of her attractiveness?

	Less attractive	Same attractiveness	More attractive
Attractiveness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. (Optional) Please list the reasons why you think your attractiveness toward her may or may not have changed.

22. Breast reconstruction surgery following mastectomy has the same results as cosmetic breast implants.

- True
- False

23. If your partner were to have her breasts reconstructed, would this change your views on a future with her? (Check all that apply)

- I would have concerns about sexual relations with her after surgery
- I would have concerns with her loss of sensation in her breasts
- I would have concerns about her appearance after surgery
- I would have concerns about what others would think about her appearance
- I would have concerns I would be less attracted to her physically
- I would have concerns about her ability to breast feed
- I would have concerns about her health/lifespan
- I would have no concerns
- Other (please specify)

24. Have you seen reconstructed breasts or photographs of reconstructed breasts?

- Yes
- No

Men's attitudes toward forming and maintaining romantic relationships with

25. Breast reconstruction surgery following mastectomy has the same results as cosmetic breast implants.

- True
- False

26. If your partner were to consider a prophylactic mastectomy, would this change your views on a future with her? (Check all that apply)

- I would have concerns about sexual relations with her after surgery
- I would have concerns with her loss of sensation in her breasts
- I would have concerns about her appearance after surgery
- I would have concerns about what others would think about her appearance
- I would have concerns I would be less attracted to her physically
- I would have concerns about her ability to breast feed
- I would have concerns about her health/lifespan
- I would have no concerns
- Other (please specify)

27. If your partner chose to have a prophylactic mastectomy, would you want your partner to have her breasts reconstructed?

- Yes
- No
- I don't care
- I don't know
- Other (please specify)

Men's attitudes toward forming and maintaining romantic relationships with

28. Have you seen reconstructed breasts or photographs of reconstructed breasts?

- Yes
- No

29. Breast reconstruction surgery following mastectomy has the same results as cosmetic breast implants.

- True
- False

30. Has your partner undergone prophylactic mastectomies?

- Yes
- No

31. Has your partner undergone breast reconstruction after her surgery?

- Yes
- No

32. Breast reconstruction surgery following mastectomy has the same results as cosmetic breast implants.

- True
- False

33. Did your partner's surgery(ies) change your views on a future with her? (Check all that apply)

- I have/had concerns about sexual relations with her after surgery
- I have/had concerns with her loss of sensation in her breasts
- I have/had concerns about her appearance after surgery
- I have/had concerns about what others would think about her appearance
- I have/had concerns I would be less attracted to her physically
- I have/had concerns about her ability to breast feed
- I have/had concerns about her health/lifespan
- I have/had no concerns
- Other (please specify)

Men's attitudes toward forming and maintaining romantic relationships with

34. How did this surgery change your views of her attractiveness?

Less attractive Same attractiveness More attractive

Attractiveness

35. (Optional) Please list the reasons why you think your attractiveness toward her may or may not have changed.

36. Have you and your partner discussed her risk of developing breast cancer?

- Yes
- No

37. How much does this risk of your partner developing breast cancer worry you?

Not worried Worried Very worried

Worry

38. If your partner were to consider a prophylactic mastectomy, would this change your views on a future with her?

- I would have concerns about sexual relations with her after surgery
- I would have concerns with her loss of sensation in her breasts
- I would have concerns about her appearance after surgery
- I would have concerns about what others would think about her appearance
- I would have concerns I would be less attracted to her physically
- I would have concerns about her ability to breast feed
- I would have concerns about her health/lifespan
- I would have no concerns
- Other (please specify)

Men's attitudes toward forming and maintaining romantic relationships with

39. If your partner chose to have a prophylactic mastectomy, would you want your partner to have her breasts reconstructed?

- Yes
- No
- I don't care
- I don't know
- Other (please specify)

40. Have you seen reconstructed breasts or photographs of reconstructed breasts?

- Yes
- No

41. Do you equate reconstructive surgery with cosmetic breast augmentation?

- Yes
- No

42. I have a close family member or friend that has been diagnosed with: (Check all that apply)

- Breast cancer
- Ovarian cancer
- Neither type of cancer

Women with BRCA1/2 mutations have an increased chance of developing ovarian cancer during their lifetime. Ovarian cancer in BRCA carriers typically appears after the age of 35. Ovarian cancer is difficult to detect early and is often not found until it is in later stages. Hence, some women with BRCA mutations choose to remove their ovaries after child-bearing age to reduce the risk of ovarian cancer. This is called a prophylactic oophorectomy. Prophylactic oophorectomies performed on a woman before natural menopause can result in menopausal symptoms for her.

43. Has your partner been diagnosed with ovarian cancer?

- Yes
- No

Men's attitudes toward forming and maintaining romantic relationships with

44. Had she been diagnosed after you entered into a relationship with her?

- Yes
- No

45. Has your partner had her ovaries removed?

- Yes
- No
- I don't know

46. Has this changed your views on a future with her?

- I had/have concerns that we can no longer conceive biological children naturally together
- I had/have concerns that menopausal symptoms will affect our relationship
- I had/have concerns about her ability to respond sexually
- I had/have not had concerns about my future with her
- Other (please specify)

47. Have you and your partner discussed her risk of developing ovarian cancer?

- Yes
- No

48. Does this risk of your partner developing ovarian cancer worry you?

	Not worried	Worried	Very worried
Level of worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Men's attitudes toward forming and maintaining romantic relationships with

49. If your partner with the BRCA1/2 mutation were to consider prophylactic oophorectomy, would this change your views on a future with her?

- I had/have concerns that we will need to have children before we would otherwise start
- I had/have concerns that her menopausal symptoms will affect our relationship
- I had/have concerns about her ability to respond sexually
- We are done with child-bearing
- We are not planning to have children
- Other (please specify)

An individual with a BRCA1/2 mutation has a 50% chance of passing on the BRCA1/2 mutation to each of their children.

50. Do you have any children with your current partner? (Check all that apply)

- I have daughter(s) only
- I have son(s) only
- I have daughter(s) and son(s)
- I don't have any children with my current partner
- I have children from another relationship
- I want to have (more) children with my current partner
- I do not want to have (more) children with my current partner
- I am unsure if I want to have (more) children with my current partner

Men's attitudes toward forming and maintaining romantic relationships with

51. Have you had concerns that children from your current relationship could have inherited or will inherit this predisposition to cancer?

- Yes
- No
- We do not have children
- We do not plan to have children

Comments

52. How old are you?

Age (in years)

53. How old is your partner?

Age (in years)

54. What is your ethnicity? (Check all that apply)

- American Indian or Alaskan Native
- Asian
- Black or African American
- Hispanic or Latino
- Caucasian
- Prefer not to respond
- Other (please specify)

55. In which state do you reside (Please spell out the name. ex: California)?

Men's attitudes toward forming and maintaining romantic relationships with

56. How many years of school have you completed?

- Eight or less
- Some high school
- High school graduate, or GED
- Some college
- College graduate
- Post-bachelors degree
- Prefer not to respond

57. Are you a health care provider (including nurse, physician, genetic counselor, etc.)?

- Yes
- No

58. What is your religious background?

- Catholic
- Protestant (Baptist, Presbyterian, etc.)
- Jewish
- Islamic
- Buddhist
- Hindi
- Agnostic
- Atheist/None
- Prefer not to respond

59. Is there anything else you feel is important about your experience that was not asked in this survey?