

Supplementary document 1: Methods elaboration

This was an open voluntary survey, with no incentives offered; potential responders were contacted on social media and in BRCA1/2 mutation carriers' medical clinics. The questionnaire was generated for this specific study, developed in collaboration between a gynecologist specialist (OL) and a BRCA1 mutation carrier (CN), based on their professional experience and relevant literature search. Prior to fielding the questionnaire was functionally and technically tested.

Before replying to the survey, an introduction describing the purpose of the study, inclusion criteria for the responders (any female BRCA1/2 mutation carrier at any age, marital or cancerous disease status) was given. Prior to consenting to answer the survey, potential responders were explained that answering the questionnaire takes approximately 5-10 minutes, the data is summarized anonymously and details on the principal investigator. Lastly, it was explained to the potential responders that the data is to be analyzed for publication in a scientific journal.

The questions were prearranged, and no adaptive questioning processes were used. Non-response options were not included in the analysis. No cookies were used, and IP addresses of responders were not collected, thus unique site visitor, view rate, participation rate and completion rate were not calculated.

The questionnaire was built into 7 pages, with an average of 12 items per page. Items provided a non-response option. Responders were able to review and change their answers through a Back button.

Supplementary document 2: English Translated questionnaire

Dear Participant,

My name is Dr. Chen Nahshon, a physician in the gynecology department of Carmel Medical Center.

I would be happy for your help in filling out a short questionnaire, designed to evaluate and quantify the opinions about dilemmas of carriers of mutations in the BRCA gene, mainly in the field of risk reduction approach.

The questionnaire is intended for women who are carriers of mutations in the BRCA1/2 genes.

The questionnaire is anonymous, takes about 5-10 minutes, and you can stop filling it out at any time. The results will be summarized and published as a scientific summary in order to promote knowledge about the carriers approaches on issues that are important to all of us.

We believe that the conclusions from the survey can help improve the medical staff's approach to patients, the information about what carriers in Israel think, and enable discussion of the specific therapeutic and preventive options for BRCA carriers.

If you agree to fill out the questionnaire, please click on the link.

Of course, we will be happy to keep you updated on all the results and conclusions of this anonymous study.

Thank you so much for your contribution!

Demographics:

Age _____

Weight _____

Height _____

Relationship: (choose one)

1. Married
2. In a relationship
3. Single
4. Divorced
5. Widower
6. Other

Ethnic: (multiple possible)

1. Ashkenazi
2. Sephardi
3. Arab
4. Ethiopian
5. Bedouin
6. Russian non-Jewish
7. Other

Religion:

1. Religious
2. Traditional
3. Secular
4. Rather not define

Education:

1. Less than 12 years
2. High school

3. Diploma studying
4. BA
5. Master's degree and above

Carrier of a mutation in:

1. BRCA1
2. BRCA2

Year of mutation carrier status discovery: _____

Mutation carrier status detection age: _____

Carrier detection due to personal malignancy: yes / no

Carrier detection due to family history: Yes / No

Carrier detection due to population survey: yes / no

Personal and family history:

Have you been diagnosed with ovarian malignancy? Yes / No

If yes –

At what age? _____

What year? _____

Have you been diagnosed prior to being diagnosed with a BRCA mutation? Yes / No

Have you been diagnosed prior to performing prophylactic oophorectomy and fallopian tube surgery? Yes / No

Have you been diagnosed with uterine malignancy? Yes / No

If yes –

At what age? _____

What year? _____

Have you been diagnosed prior to being diagnosed with a BRCA mutation? Yes / No

Have you been diagnosed prior to performing an oophorectomy and fallopian tubes with or without prophylactic hysterectomy? Yes / No

Have you been diagnosed with breast malignancy? Yes / No

If yes –

At what age? _____

What year? _____

Have you been diagnosed prior to being diagnosed with a BRCA mutation? Yes / No

Have you been diagnosed prior to performing prophylactic oophorectomy and fallopian tube surgery? Yes / No

Have you been diagnosed after performing a prophylactic bilateral mastectomy? Yes / No

Family history of ovarian malignancy: yes/no

If yes:

First degree (mother, sister, daughter)? Yes / No

If yes, at what age? _____

Family history of uterine malignancy: yes/no

If yes:

First degree (mother, sister, daughter)? Yes / No

If yes, at what age? _____

Family history of breast malignancy: yes/no

If yes:

First degree (mother, sister, daughter)? Yes / No

If yes, at what age? _____

Prevention of malignancy:

If you have been diagnosed as a BRCA carrier due to a family history / population survey (and not due to personal malignancy) please answer the following questions:

Were you discussed regarding surgery to remove the ovaries and fallopian tubes to reduce the risk of ovarian malignancy? Yes / No / Irrelevant

Have you performed prophylactic oophorectomy and fallopian tube surgery? Yes / No / Irrelevant

If yes –

At what year? _____

At what age? _____

Are you planning to have a prophylactic oophorectomy and fallopian tube surgery?

Yes / No / I Don't Know

What is your position regarding prophylactic oophorectomy and fallopian tubes in carriers?

1- Totally agree

2- Partially agree

3- I'm not sure

4- I partially disagree

5- I disagree

Is the possibility of hormone replacement therapy discussed after an oophorectomy? Yes / No

Have you taken/taken/would you like to take hormone replacement therapy after an oophorectomy? Yes / No / I Don't Know

Please mark whether you identify with the following statements regarding prophylactic oophorectomy and fallopian tubes:

	Totally agree	Partially agree	I'm not sure	I partially disagree	I disagree	Irrelevant
I was not/would not be interested in performing this surgery because there is a high surgical risk						
I was not/would not be interested in performing this surgery due to fear of complications such as infection, bleeding, etc.						
I was not/would not be interested in performing this surgery due to fear of anesthesia complications						
I was not/would not be interested in						

performing this surgery due to fear of a long recovery period						
I was not/would not be interested in performing this surgery because the imaging and clinical follow-up is satisfactory						
I was not/would not be interested in performing this surgery because I don't want to take out part of my body						
I was not/would not be interested in performing this surgery due to fear of post-menopausal symptoms						
I was not/would not be interested in performing the surgery because I do not to block the possibility of future pregnancy						
I would like to perform						

this surgery because it lowers the risk of malignancy						
I will recommend others to perform this procedure						

Additional comments:

Were you discussed regarding the addition of hysterectomy to the planned preventive surgery for oophorectomy and fallopian tubes? Yes / No / Irrelevant

Have you performed a hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal? Yes / No / Irrelevant

If yes –

At what year? _____

At what age? _____

Are you planning to perform a hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal? Yes / No / I Don't Know

What is your position regarding hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal?

1- Totally agree

2- Partially agree

3- I'm not sure

4- I partially disagree

5- I disagree

Please mark whether you identify with the following statements regarding prophylactic oophorectomy and fallopian tubes:

	Totally agree	Partially agree	I'm not sure	I partially disagree	I disagree	Irrelevant
I was not/would not be interested in						

performing this surgery because there is a high surgical risk						
I was not/would not be interested in performing this surgery due to fear of complications such as infection, bleeding, etc.						
I was not/would not be interested in performing this surgery due to fear of anesthesia complications						
I was not/would not be interested in performing this surgery due to fear of a long recovery period						
I was not/would not be interested in performing this surgery because the imaging and clinical follow-up is satisfactory						
I was not/would not be interested in						

performing this surgery because I don't want to take out part of my body						
I would like to perform this surgery because it lowers the risk of malignancy						
I will recommend others to perform this procedure						

Additional comments:

Were you discussed regarding the risk reduction bilateral mastectomy? Yes / No

Have you performed a hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal? Yes / No

If yes –

At what year? _____

At what age? _____

Are you planning to perform a hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal? Yes / No / I Don't Know

Have you undergone a biopsy from a suspicious lesion that was discovered under surveillance?

Yes / No

If yes, how many? _____

If yes, were the result benign? Yes/No

What is your position regarding hysterectomy in addition to prophylactic oophorectomy and fallopian tubes removal?

1- Totally agree

2- Partially agree

3- I'm not sure

4- I partially disagree

5- I disagree

Please mark whether you identify with the following statements regarding prophylactic oophorectomy and fallopian tubes:

	Totally agree	Partially agree	I'm not sure	I partially disagree	I disagree	Irrelevant
I was not/would not be interested in performing this surgery because there is a high surgical risk						
I was not/would not be interested in performing this surgery due to fear of complications such as infection, bleeding, etc.						
I was not/would not be interested in performing this surgery due to fear of anesthesia complications						
I was not/would not be interested in performing this surgery due to fear of a long recovery period						

I was not/would not be interested in performing this surgery for fear that the result would not have an aesthetic result						
I was not/would not be interested in performing this surgery because the imaging and clinical follow-up is satisfactory						
I was not/would not be interested in performing this surgery because I don't want to take out part of my body						
I would like to perform this surgery because it lowers the risk of malignancy						
I will recommend others to perform this procedure						

Additional comments:
