

Appendix S1. Participant information sheet: Views of women at high-risk of ovarian cancer towards removal of fallopian tubes for ovarian cancer prevention.

Before you decide to take part in this survey, it is important for you to understand the purpose of this and what it will involve. Please take time to read the following information carefully. Do discuss it with your family, friends, healthcare professional or others if you wish. Please ask if there is anything you do not understand or if you would like more information.

Aim of this survey

This survey is meant for women who are at high-risk of developing ovarian cancer. Some women may carry a fault/alteration in their BRCA1 or BRCA2 gene, whilst others may have a strong family history that puts them at an increased risk of developing ovarian cancer. It aims to understand what they feel about having only their fallopian tubes removed, to prevent ovarian cancer.

If you wish to take part in this survey after reading the information, please complete the enclosed consent form along with the survey, and return them to us -in the pre-paid envelope.

Background Information

Some women may have an alteration or fault in their DNA sequence or genetic code. Two such genes in which a fault may lie are known as the BRCA1 and BRCA2 genes. Pronounced “brakka-1” and “brakka-2”. Women with a strong family history of ovarian cancer or breast & ovarian cancer may also have a higher risk of developing ovarian cancer.

The currently advised practice is to offer removal of both tubes **and** ovaries to prevent ovarian cancer in such high-risk women. This is undertaken after a woman has completed her family. It is called **Risk Reducing Salpingo Oophorectomy** or **RRSO**.

It involves undergoing an operation to remove the ‘tubes **and** ovaries’ (Figure 1a). This is usually done through keyhole surgery under a general anesthetic and is available on the NHS (National Health Service). It is usually undertaken after the age of 35-40 years. In women who have not had breast cancer, RRSO may halve their risk of developing this if carried out before the menopause.

Removal of the ovaries will mean the woman will go into early menopause. Early menopause in some women is associated with side effects like hot flushes, sweats, thinning of the bones, and a higher risk of heart disease. It may also reduce libido and sexual function. Taking hormone replacement therapy can minimise these side effects. A number of women choose to decline or delay this operation to avoid the potential symptoms/problems of early menopause.

The fallopian tube is the tube that is connected to the womb. It collects the egg from the ovary and transports it to the womb. Current research suggests that a number of cancers of the ovary actually start in the fallopian tube. It is important to understand that ovarian cancers may start outside of the tube too.

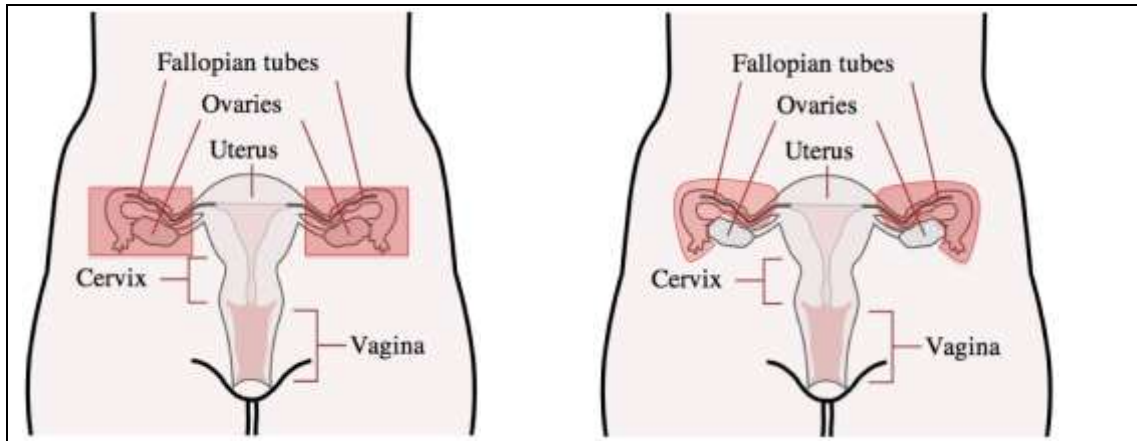


Figure 1a: Current procedure showing removal of tubes and ovaries (shaded in red).

Figure 1b: Proposed procedure showing removal of tubes alone (shaded in red)

A number of experts believe that removing the tubes alone would provide some protection from getting ovarian cancer (Figure 1b). This 'first stage' is called **Risk Reducing Early Salpingectomy (RRES)**. This may be particularly helpful for those women who wish to avoid or delay the removal of ovaries, for example, until after the menopause. Women who just have their fallopian tubes removed will need to have a *second* operation at a later date to remove their ovaries. This 'second stage' can be undertaken once they reach the menopause. This is called **Delayed Oophorectomy (DO)**. This is essential to provide optimal protection against ovarian cancer. Both operations are usually carried out by keyhole surgery (laparoscopy) under general anaesthesia. Each operation may involve an overnight stay in hospital and the recovery time is usually 1-2 weeks.

At present the precise level of benefit obtained from removing the tubes alone is not known. There are no research studies to show whether this 'two-stage procedure' is acceptable and effective for preventing ovarian cancer. Further research is needed to establish this.

This survey will help us understand your views on this 'two-stage' strategy to prevent ovarian cancer.

QUESTIONS & ANSWERS

Why have I been invited to take part in this survey?

You have been invited because your healthcare team or support group believe that you are at high risk of developing tubal/ovarian cancer. This is either because you carry an alteration/fault in the BRCA1/BRCA2 gene or you have a strong family history that puts you at higher risk of developing ovarian cancer.

What do I have to do to take part in the survey?

You will need to fill in the survey consent form. This can be done online or through a paper version which is enclosed with this information sheet.

If you are filling in a paper version, please also send the completed consent form to the research team at the address below. A prepaid envelope is provided.

Once you have completed the form it can also be posted to the research team in the pre-paid freepost envelope provided.

The online version can be accessed through the link:

<https://www.surveymonkey.co.uk/r/MCQZXWP>

Once you access the survey website you will also be able to review the information sheet online. The site will guide you through an eligibility form followed by a consent form. You will be able to access the survey questionnaire once you have completed the online consent form.

Postal address:

RRESDO Team
Barts Cancer Institute, ECMC
Queen Mary University of London
Charterhouse Square
London EC1M 6BQ

What will I be asked to do if I take part and when will this happen?

If you have decided to take part, please complete the consent form, ensuring that you follow the instructions and sign the relevant sections. You may then go on to complete the survey enclosed. This should take approximately 10 minutes to complete. You may choose to complete the survey online (see web link above).

It is important for you to understand, that should you become mentally incapacitated or in the event of your death, during the course of this project, we will continue to include your information in this research study.

Do I have to take part?

You do not have to participate in this study if you do not wish to. Your participation in this survey is entirely voluntary. You are free to withdraw from responding at any time without giving a reason. It will not affect your current or future healthcare.

How confidential is this survey?

The survey is completely confidential. You will not be personally identified from any analysis or outcomes of the survey. All the information that you provide will be treated in the strictest confidence and will comply with UK Data Protection Laws.

How will I benefit from participating in this survey?

By taking part, you will help us understand how women like yourself feel towards this new approach of preventing ovarian cancer. It will help develop future research studies for ovarian cancer prevention in high-risk women. Your participation in this survey will thus hopefully benefit the health of women at high risk of ovarian cancer in the future.

You will not personally benefit from taking part in this survey.

What will happen if I don't want to carry on with the survey?

You are free to withdraw from the survey at any time, through personal choice and without giving any reason for doing so. In addition should you change your mind after completing the consent form, you can still opt out by not completing the survey.

If you have provided contact details and subsequently change your mind, your data can be withdrawn from any analysis in the study. If you have not provided us your name or contact details then any submitted data will be anonymous. It cannot be linked to you or excluded from the analysis.

Do I need to provide my contact details?

No this is not essential.

What is the second consent form for?

The last section in the survey asks if you are happy to be contacted by the research team in the future. This is for other research studies (not linked to this survey). If you are happy to be contacted, you will need to fill in your name and contact details and sign a consent form. This is the second consent form, named '**CONSENT FORM-2**'

You are 'not' obliged to provide this information. You do '**not**' need to provide this information for the purpose of this survey. Do not provide this information if you do not wish to be contacted by the research team.

If you do elect to provide this information, the research team may contact you in the future to enquire if you are interested in taking part in future research. Any future research you are informed about will be ethically approved by an independent Research Ethics Committee. You are **not** obliged to participate in any future research studies by signing this form.

Who are the researchers involved in this project?

The project will be run by health professionals and co-ordinated by QMUL. It is the result of collaborative work of a number of individuals:

Dr Ranjit Manchanda	Consultant Gynaecological Oncologist, Royal London Hospital & Clinical Senior Lecturer, Queen Mary University of London
Dr Faiza Gaba	Clinical Research Fellow Gynaecological Oncology, Queen Mary University of London
Professor Usha Menon	Professor of Gynaecological Oncology, University College London
Mr Ertan Saridogan	Consultant Gynaecologist, University College Hospital
Professor Gareth Evans	Professor of Medical Genetics and Cancer Epidemiology, University of Manchester
Ms Vishaka Tripathi	Genetic Counsellor, Clinical Genetics, Guys Hospital

Who has reviewed the survey?

The survey has been reviewed by a number of experts and some lay people. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. The survey has been reviewed and given a favourable opinion by West Midlands – Edgbaston Research Ethics Committee. Research Ethics Committees are made up of healthcare professionals and members of the public who are not connected to the study.

What will happen to the results of the survey?

The results of this survey will be presented at conferences and published in a scientific journal. Your personal details will not be mentioned in any such publication. This will also be made available through supporting charity websites.

This survey will also contribute towards setting up a study. This future study will assess the two-step strategy to prevent ovarian cancer. This will involve removing fallopian tubes alone followed by removal of ovaries after the menopause.

If I need to contact someone about the research, whom should I contact?

If you have any questions, queries or concerns regarding the survey, please contact the study team using the contact details below.

Email: bci-rresdo@qmul.ac.uk

Write to:

Barts Cancer Institute, ECMC, Queen Mary University of London, Charterhouse Square, London EC1M 6BQ

How will my data be collected and how will it be processed?

Queen Mary University of London is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information

and using it properly. Queen Mary University of London will keep identifiable information about you for 20 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The NHS will collect information from you for this research study in accordance with our instructions.

The research team will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from QMUL and regulatory organisations may look at your research records to check the accuracy of the research study. Your NHS site will pass these details to us (Queen Mary University of London) along with the information collected from you. The only people in the research team at QMUL who will have access to information that identifies you will be people who need to contact you for the purpose of follow up or to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

You can find out more about how we use your information at <http://www.jrmo.org.uk>.

What if you have any concerns or worries?

If you have any concerns or questions you should initially contact the RRESDO team who will do their best to answer your questions. The contact details are provided at the end of this information booklet. If there is something that you are unhappy with and you wish to complain formally, you can do this through the Research Governance Sponsor of this study by writing to:

Dr Sally Burtles
Director of Research Services & Business Development
Joint Research Management Office (JRMO)
Queen Mary University of London
QM Innovation Building
5 Walden Street
London, E1 2EF, UK

Please quote reference 012048 in all correspondence. All communication will be treated in strict confidence.

For further independent information or support please contact:

BRCA Umbrella
Website: www.brcaumbrella.ning.com

Eve Appeal
Email: office@eveappeal.org.uk
Website: www.eveappeal.org.uk

Ovacome

Email: support@ovacome.org.uk

Website: www.ovacome.org.uk

Appendix S2. Survey to determine attitudes of women at increased risk of ovarian cancer towards risk reducing early salpingectomy with delayed oophorectomy for ovarian cancer prevention.

Thank you for agreeing to take part in our study. This survey is for women who are at high risk of developing ovarian cancer.

Prior to completing the survey, please ensure that you have:

- Read the patient information sheet, which explains the purpose of this survey.
- Completed consent form 1, ensuring that you have followed the instructions and signed in the relevant sections.

Please fill in this survey and return it in the enclosed envelope, along with consent form 1. You will not need to pay for postage.

Alternatively, you can complete the questionnaire online at the following website:

<https://www.surveymonkey.co.uk/r/MCQZXWP>

Your answers will be treated in strict confidence. No person will be identified individually as a result of analysis from this survey.

If you have any questions, please feel free to contact the research team.

You can write to:

RRESDO Team
Barts Cancer Institute, ECMC
Queen Mary University of London
Charterhouse Square
London EC1M 6BQ
Email: bci-rresdo@qmul.ac.uk

SECTION 1: Previous Gynaecological operation(s). Please tick the most appropriate option for each question.

Q1.1 Have you had any operations to remove an ovary or fallopian tube?

- Yes No *Go to section 2* Not Sure

If you have answered No to Q1.1 - Go to section 2

Q1.2 What was the reason for the operation? Please tick all that apply.

- To prevent developing cancer in the ovary
- To treat a problem in the ovary (non-cancerous)
- To treat a problem in the fallopian tube (non-cancerous)
- To treat a problem related to pregnancy
- Other (please specify):
- _____

Q1.3 Please specify which organs were removed.

- Both tubes and ovaries removed *Go to section 4*
- One or part of ovary/ fallopian tube removed

Please specify: _____

- Not Sure

If you have had both tubes and ovaries removed Go to section 4

SECTION 2: This section is aimed at women who have NOT had an operation to remove 'both' their tubes and ovaries (together or at separate times). Please tick the most appropriate option for each question.

Q2.1 This question relates to your periods. Please tick the most suitable option.

- I still have regular periods *Go to question 2.3*
- My periods are irregular but I have had at least 1 period in the last 12 months *Go to question 2.3*
- I have not had a period at all in the last 12 months

If you have ticked the first / second option in Q2.1 omit Q2.2 and go to Q2.3

Q2.2 If you are not having periods, what is the reason they have stopped?

- Natural menopause Surgery (eg. Removal of womb)
- Chemotherapy / radiation treatment Mirena coil/ pill/ implant/ other contraception
- Other medication Don't know

Q2.3 Are you planning to have an operation to reduce the risk of developing ovarian cancer?

(This would involve removal of your tubes and ovaries).

- Yes, I am planning to have an operation now
- Yes, I am planning to have an operation within a year
- Yes, I am planning to have an operation in 1-5 years time
- Yes, I am planning to have an operation but after 5 years time
- Yes, I am planning to have an operation but have not thought about the timing of this
- No, I am not planning to have an operation
- I am uncertain about having an operation
- Other: (Please use free text to specify)
-

Q2.4 Some women decline or delay having their tubes and ovaries removed for preventing ovarian cancer. This may be due to concerns about the effects of early menopause. Some of the effects of early menopause are listed below. How important are they in influencing

your decision to have an operation to remove your ovaries (and tubes) to prevent ovarian cancer?

Please use the scale of 1 to 5 to answer this question, where 1 is not at all important and 5 is very important.					
	Not at all important			Very important	
	1	2	3	4	5
Developing hot flushes or night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thought of looking older in appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decreased libido or other sexual side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to have any more children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of osteoporosis (brittle bones)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased risk of heart disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased risk of developing dementia or memory loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential impact on survival	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The need to take hormone replacement therapy up to the age of 50	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: (Please use free text)					

Q2.5 New research suggests that a number of cancers in high risk women start in the fallopian tube. Prior to this survey, had you heard of removing just the tubes to reduce the chance of getting ovarian cancer?

- Yes No Not Sure

Q2.6 An operation to remove BOTH tubes and ovaries is still the recommended practice to prevent ovarian cancer.

A number of experts have suggested a two-stage operation as another option. The first stage will involve removal of tubes alone. This is called risk reducing early salpingectomy (ES). The second stage will be to remove the ovaries. This will take place at a later time (after the menopause). This is called delayed oophorectomy (DO).

Leaving the ovaries behind will prevent early menopause or its symptoms and side effects. However some clinicians are concerned that this two-stage approach leaves women more vulnerable until they have completed the second stage (removal of ovaries). Details of the procedure are explained in the information sheet provided.

Would you consider having this two-stage operation to reduce the chance of developing ovarian cancer?

Yes

No

Not Sure

SECTION 3: This section is for women who have NOT had an operation to remove BOTH their tubes and ovaries. Please tick the most appropriate option for each question.

There are many issues to think about when deciding to have an operation to reduce your risk of ovarian cancer. We would like to learn more about your views on undergoing a ‘two stage’ operation to prevent ovarian cancer. The first stage involves removal of the tubes alone. This is called risk reducing early salpingectomy (ES). The second stage will be to remove the ovaries. This will take place at a later time (after the menopause). This is called delayed oophorectomy (DO).

Q3.1 We have listed some of the potential benefits of the ‘Two-Stage’ operation (RRESDO).					
Please indicate how important these factors are to you in deciding to choose to have a two-stage operation.					
Please use a scale of 1 to 5, where 1 is ‘Not at all important’ and 5 is ‘very important’. You may use free text to describe other factors that may influence your decision.					
	Not at all important		Very important		
	1	2	3	4	5
It could reduce my risk of ovarian cancer without causing early menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It gives my doctor a chance to inspect my ovaries and tubes for any abnormalities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It delays the negative effects of early menopause: specifically hot flushes, night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It delays the negative effects of early menopause: specifically thinning of bones or osteoporosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It delays the potential negative effects of early menopause: specifically potential change to sexual function.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is not associated with increased risk of heart disease linked with early menopause.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: (Please use free text)					

<p>Q3.2 How acceptable would you find the following factors, when considering to have the Two Stage operation (RRESDO)?</p> <p>You may also use free text to describe other factors.</p>			
<p>The need to undergo two separate operations. (The first operation is to remove your tubes and the second operation to remove your ovaries at the time of your natural menopause).</p>			
<input type="checkbox"/> Not at all acceptable	<input type="checkbox"/> Somewhat acceptable	<input type="checkbox"/> Very Acceptable	<input type="checkbox"/> Not Sure
<p>The first operation (to remove the tubes only) may cause some damage to your ovaries and lead to an earlier menopause.</p>			
<input type="checkbox"/> Not at all acceptable	<input type="checkbox"/> Somewhat acceptable	<input type="checkbox"/> Very acceptable	<input type="checkbox"/> Not Sure
<p>The potential risk of complications during each operation. The risk of complications is around 1 in 30 (for example, skin bruising, infection). The risk of more serious complications such as damage to other organs or major blood vessels, clots in the lungs, hernias is around 1 in 200.</p>			
<input type="checkbox"/> Not at all acceptable	<input type="checkbox"/> Somewhat acceptable	<input type="checkbox"/> Very acceptable	<input type="checkbox"/> Not Sure
<p>The possible need for further ovarian monitoring appointments, blood tests and scans until your ovaries are removed.</p>			
<input type="checkbox"/> Not at all acceptable	<input type="checkbox"/> Somewhat acceptable	<input type="checkbox"/> Very acceptable	<input type="checkbox"/> Not Sure
<p>The additional time you have to spend in hospital when you have the operation.</p>			
<input type="checkbox"/> Not at all acceptable	<input type="checkbox"/> Somewhat acceptable	<input type="checkbox"/> Very acceptable	<input type="checkbox"/> Not Sure

The additional time you have to take off work for the operation and recovery. (Each procedure would usually require around 1-2 weeks off work).

Not at all
acceptable

Somewhat
acceptable

Very
acceptable

Not Sure

The level of protection against ovarian cancer provided by removing the tubes alone is not yet known.

Not at all
acceptable

Somewhat
acceptable

Very
acceptable

Not Sure

The possible chance of developing ovarian cancer in between the first and second operations.

Not at all
acceptable

Somewhat
acceptable

Very
acceptable

Not Sure

For women who are at high risk for ovarian cancer, delaying removal of ovaries until menopause may not provide any protection against breast cancer compared to early removal of the ovaries, which may reduce the chance of getting breast cancer by up to 50% (relevant for those who have not had breast cancer).

Not at all
acceptable

Somewhat
acceptable

Very
acceptable

Not Sure

Other: (Please use free text to state other factors)

Q3.3 At present we do not know precisely how much protection a woman may get from the removal of tubes alone. Further research is needed to see if the two-stage operation is acceptable and effective at preventing ovarian cancer. This research will be looking at removing tubes alone, followed by removal of ovaries after the menopause.

Would you be interested in participating such a study?

- Probably Maybe Probably not Definitely not

Please go to section 5

SECTION 4: This section is only for women who have already had both their tubes and ovaries removed. Please tick the most appropriate option for each question.

Q4.1 How old were you when you had an operation to remove both your tubes and ovaries? (Please state your age (in years) at the time of the operation).

Q4.2. This question relates to your periods at the time of the final operation to remove your tubes and ovaries.

- I was still having regular periods
 My periods are irregular but I have had at least 1 period in the last 12 months I had not had a period at all in the last 12 months

Q4.3 If you did not have a period for 12 months, was this due to contraception or medication?

- Yes No

Q4.4 How would you describe yourself just before your operation to remove your tubes and ovaries.

- Pre menopausal (not gone through the menopause)
 Peri menopausal (getting some symptoms but not completed the menopause)

Post menopausal (definitely gone through the menopause) **Go to Q4.7**

Q4.5 Did you take HRT (hormone replacement therapy) after your operation?

Yes

No

Q4.6 If you took HRT how many years did you take it for?

4.7 Some women decline or delay having their tubes and ovaries removed for preventing ovarian cancer. This may be because of concerns about the effects of early menopause. Some of the effects of early menopause are listed below. How important were they in influencing your decision to have an operation to remove your ovaries?

Please use the scale of 1 to 5 to answer this question, where 1 is not at all important and 5 is very important.

	Not at all important			Very important	
	1	2	3	4	5
Developing hot flushes or night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thought of looking older in appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decreased libido or other sexual side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to have any more children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk of osteoporosis (brittle bones)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased risk of heart disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased risk of developing dementia or memory loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Potential impact on survival	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The need to take hormone replacement therapy up to the age of 50	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: (Please use free text)					

--

Q4.8 How much did the following aspects of menopause affect you soon after the removal of your tubes and ovaries?				
	Not much at all	Somewhat	Very much indeed	Not sure
Hot flushes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vaginal dryness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reduced libido or other sexual side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to have any more children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Osteoporosis (brittle bones)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leaking urine (urinary incontinence)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue / tiredness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having to take hormone replacement therapy till age 50	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mood alterations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Impact on relationship with partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: (Please use free text)				

Q4.9 We would like you to think back on your decision to remove your tubes and ovaries. Please indicate how strongly you agree or disagree with the following statements.

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
It was the right decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I regret the choice that was made	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would make the same decision if I had to do it over again	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decision did me a lot of harm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The decision was a wise one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was directly influenced by the expressed wishes of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was influenced by the unexpressed wishes of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q4.10 New research suggests that a number of cancers in high-risk women start in the fallopian tube. Prior to this survey, have you heard that removing just the tubes alone may reduce the chance of getting ovarian cancer?

Yes

No

Not Sure

Q4.11 This question is for those who had their tubes and ovaries removed before the menopause.

If the option had been available, would you have opted for a two stage operation instead? The first stage would have involved removal of tubes alone. This is called risk reducing early salpingectomy (ES). The second stage would have been to remove the ovaries. This would have taken place at a later time (after the menopause). This is called delayed oophorectomy (DO).

Probably

May be

Probably not

Definitely not

Not Applicable

Please go to section 5

SECTION 5-10: For all Participants

SECTION 5: Your Children

Q5.1 Do you have any children of your own?

No Yes

If yes, how many? (Please state a numerical digit e.g. 2) _____

5.2 Have you completed your family?

Yes No Not Sure

SECTION 6: Genetic Screening

Q6.1 Is there a known mutation (alteration) in your family in the BRCA1 or BRCA2 gene?

Yes No

No, another genetic mutation has been detected in my family (please specify):

Q6.2 Have you undergone a genetic test to detect a fault in the BRCA1 or BRCA2 gene?

Yes No Not Sure

If you did not answer 'Yes' to Q6.2, go to Section 7

Q6.3 If you answered yes to question 6.2, what did your test result show? Please tick all that apply.

- | | |
|--|---|
| <input type="checkbox"/> BRCA 1 positive | <input type="checkbox"/> BRCA 2 positive |
| <input type="checkbox"/> Variant of Uncertain Significance | <input type="checkbox"/> BRCA1 and BRCA2 negative |
| <input type="checkbox"/> Waiting for test results | <input type="checkbox"/> Unsure of my test result |
| <input type="checkbox"/> Other (please specify): | |

SECTION 7: Breast Surgery

Q7.1 Have you had an operation to remove your breast or part of your breast?

Yes No Not Sure

If you did not answer 'Yes' to Q7.1, go to Section 8

Q7.2 What was the reason for the operation? Please tick all that apply.

- To reduce the risk of breast cancer For treatment of breast cancer
 To remove a benign breast lump For cosmetic reasons
 Other (please specify):

SECTION 8: Cancer

Q8.1 Have you ever been diagnosed with cancer?

Yes No Not Sure

If you did not answer 'Yes' to Q8.1, go to Section 9

Q8.2 If you answered yes to the previous question, please tick all that apply, state how old you were at the time of diagnosis.

Cancer	Yes	Age at Diagnosis (in Years)
Breast		
Ovary/Fallopian tube/ Peritoneal		
Other cancer (please specify):		

SECTION 9: Your Family

Q9.1 Do you have any close relatives in your family who have been diagnosed with cancer of the breast, ovary, fallopian tube, peritoneal, prostate, pancreas or other cancers?

Yes

No

Not Sure

If you did not answer 'Yes' to Q9.1, go to Section 10

Q9.2 If you answered yes to above question, which family members were affected by these cancers? Please state your relation to the person, the type of cancer, the age at which the cancer was diagnosed and age at death (if applicable).

	Relation	Type of cancer	Age at diagnosis	Alive Yes/No	Age at death (if applicable)
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					

Free text comments:

SECTION 10: Questions about yourself

Q10.1 What was your age at your last birthday? _____

Q10.2 What is your marital status?

- Single Married Divorced/ separated
 Cohabiting/living with partner Widowed

Q10.3 Which of these best describe your ethnic group?

- White Indian Black - Caribbean
 Jewish Pakistani Black – African
 Chinese Bangladeshi Black - other
 I do not wish to disclose my ethnic group
 Other ethnic group (Please specify):

Q10.4 What is your highest level of educational qualification?

- No formal qualifications NVQ4
 GCSE / O-level / CSE Bachelors degree
 NVQ1 /NVQ2 Masters
 A-level /NVQ3 PhD

Q10.5 Of the following income groups, which best describes your total household income in the last 12 months?

- Less than £10, 000 £30,000 - £39,000
 £10,000 - £19,999 £40,000 or more
 £20,000 - £29,000

**Thank you for completing this survey.
We appreciate your time and participation in our research.**