OvQuest

Ovarian cancer survivorship survey

Living after the diagnosis and treatment of ovarian cancer

Approval number HC13316

Participant selection and purpose of study

You are invited to take part in a study supported by the Australia New Zealand Gynaecological Oncology Group (ANZGOG) and Ovarian Cancer Australia, to better understand the concerns and challenges faced by women who have been treated for ovarian cancer.

We know that after finishing treatment for ovarian cancer, most people have a number of unique health needs. In the short term, they are often troubled by side-effects of their treatment and worried about the risk of their cancer coming back. For some women, side-effects may persist or new health problems might arise in the longer term. We also know that many women experience psychological and practical problems after cancer that can affect their quality of life.

We would like to better understand how common these types of issues are in order to assist in developing interventions and treatments to address the needs and concerns of women who have completed ovarian cancer treatment. It would be very helpful if you could take the time to complete a short survey to share your thoughts on all these important issues.

We are inviting all women who were diagnosed with ovarian cancer at least six months ago and who also have received chemotherapy to take part in the study.

Description of study and risks

If you agree to participate you would be asked to complete the online survey that follows. It should take approximately 20-30 minutes of your time.

It is unlikely that completing the survey will cause any harm to you as a participant. If you find that you would like to talk to someone about any problems or concerns that you may have about your follow-up care, please discuss these with your treatment team as they would know your particular situation best. You can also contact the research team by telephone or email on the details below.

Confidentiality and disclosure of information

All information you give us will be kept strictly confidential and will be stored according to strict privacy guidelines. Only authorised research staff, who understand that it must be kept confidential, will have access to the information. Data will be stored on secure computer servers for a minimum of five years on completion of the project, and will be destroyed thereafter. The information we collect from you will be identified by a code number only. The results of the research will be published in scientific journals and presented at scientific meetings. All information published will be grouped information only, so you will not be able to be identified in any reports about the project.

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, Sydney 2052 Australia (phone 02 9385 4234, fax 02 9385 6648, email ethics.gmo@unsw.edu.au). Any complaint you make will be investigated promptly and you will be informed out the outcome.

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Feedback to participants
At the end of the study, a summary of the results will be sent to all participants who request this information. You will be given the option to provide your contact details for this purpose at the conclusion of the survey.

Your consent
Participation is entirely your choice. If you decide not to take part, your decision will not affect your cancer care in any way, or your relationship with the hospital where you received your treatment. Your completed survey will be submitted directly to ANZGOG, so your cancer care team won't be aware of your responses. Participation in this study will not cost you anything. If you do decide to participate, you may withdraw from the study at any time without giving a reason. You may also refuse to answer any questions that you are asked in the survey.
Please read this Information Statement and make sure you understand it before you agree to take part. If there is anything you do not understand, or you have questions, please contact ANZGOG by telephone on +61 2 8071 4880 or by email: enquiries@anzgog.org.au. Feel free to discuss it with your family, friends or General Practitioner if you wish.
Your help with this important research work would be most appreciated.

YOUR ELIGIBILITY FOR THIS STUDY

The following questions are to confirm that you are eligible to participate in this study.

Please confirm that the following statements are true:

- ☐ I am 18 years of age or older
- ☐ I was first diagnosed with ovarian cancer at least 6 months ago
- ☐ I have received treatment with chemotherapy

Unfortunately you are not eligible to participate in this research study. Thank you for your interest in contributing to ovarian cancer research. For more information about ovarian cancer and ways in which you can help, go to www.ovariancancer.net.au .

ABOUT YOU

What age group do you belong to?

- ○ 18-30
- ○ 31-40
- ○ 41-50
- ○ 51-60
- ○ 61-70
- ○ 71-80
- ○ over 80

Which of the following best describes the place where you live?

- ○ Capital city
- ○ Other city
- ○ Regional centre
- ○ Rural or remote

What is your current marital status?

- ○ Single
- ○ Married
- ○ De facto or living with a partner
- ○ Separated or divorced
- ○ Widowed

What is the highest level of education that you have completed?

- ○ Primary school
- ○ Secondary school
- ○ Trade certificate or diploma
- ○ University degree
- ○ Postgraduate

Which of the following best describes your employment situation?

- ○ in full time paid work
- ○ in part time paid work
- ○ self-employed
- ○ looking after home/family
- ○ studying
- ○ retired
- ○ not working due to illness or disability
- ○ unemployed

Were you born in a non-English speaking country?

- ○ No
- ○ Yes

If yes, where were you born?

....

Do you speak a language other than English at home?

- ○ No
- ○ Yes

If yes, what language do you speak?

....

Are you an Aboriginal or Torres Strait Islander?

- ○ No
- ○ Yes

What is your height?

in cm?

....

OR

....

in feet...

....

...and inches?

....

What is your weight?

in kg?

....

ABOUT YOUR CANCER AND ITS TREATMENT

In what year...

...were you first diagnosed with ovarian cancer?

....

...did you first have surgery for ovarian cancer?

....

...was your most recent dose of chemotherapy?

....

What stage was your ovarian cancer at the time that you were diagnosed?

- ○ I
- ○ II
- ○ III
- ○ IV
- ○ I don't know

When have you received chemotherapy?
Select as many of the following options as are true for you.

- ☐ I received chemotherapy when I was first diagnosed with ovarian cancer
- ☐ I have received chemotherapy for recurrent ovarian cancer (if the cancer came back)

Are you currently receiving chemotherapy?

- ○ Yes
- ○ No

If you have had chemotherapy for recurrent ovarian cancer, how many lines of chemotherapy have you received?

For example, if you had chemotherapy after your surgery, then again if the cancer came back, you have received 2 lines of chemotherapy.

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ more than 6
- ○ I don't know

Which of the following chemotherapy drugs have you received?
Mark as many options as necessary.

- ☐ Carboplatin
- ☐ Cisplatin
- ☐ Paclitaxel (Taxol)
- ☐ Docetaxel (Taxotere)
- ☐ Gemcitabine (Gemzar)
- ☐ Liposomal doxorubicin (Caelyx/Lipodox/Doxil)
- ☐ Topotecan
- ☐ I don't know the name of one or more of the drugs

other

....

Did you receive intraperitoneal chemotherapy (given directly into the abdomen rather than into a vein)?

- ○ Yes
- ○ No
- ○ I don't know

Have you participated in a clinical trial for treatment of your ovarian cancer?

- ○ Yes
- ○ No
- ○ I don't know

ABOUT YOUR FOLLOW-UP CARE

In the past year, approximately how many times did you visit:

	Never	Once	2-4 times	More than 4 times
a general practitioner (GP)?	○	○	○	○
an oncologist (medical oncologist or gynecologic oncologist)?	○	○	○	○
other medical specialist(s)?	○	○	○	○
a psychologist, psychiatrist or counsellor?	○	○	○	○
an alternative or complementary medicine therapist (eg naturopath, acupuncturist, chiropractor)?	○	○	○	○

If you saw an alternative or complementary therapist in the past year, what kind of therapist(s) were they?

- ☐ naturopath
- ☐ acupuncturist
- ☐ chiropractor
- ☐ herbalist
- ☐ homeopath
- ☐ osteopath
- ☐ massage therapist

other

....

How important is it for you to:

	A	B	C	D	E
visit a specialist for cancer follow-up?	○	○	○	○	○
have a CT scan as part of your follow-up?	○	○	○	○	○
have a CA125 blood test at your follow up visits?	○	○	○	○	○

Legend for rank grid table: How important is it for you to:

Columns:

A - Not at all important

B - Somewhat unimportant

C - Neutral

D - Somewhat important

E - Extremely important

FACT-O (Version 4)

Below is a list of statements that other people with your illness have said are important.

Please mark one answer per line to indicate your response as it applies to the past 7 days.

PHYSICAL WELL-BEING

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	○	○	○	○	○
I have nausea	○	○	○	○	○
Because of my physical condition, I have trouble meeting the needs of my family	○	○	○	○	○
I have pain	○	○	○	○	○
I am bothered by side effects of treatment	○	○	○	○	○
I feel ill	○	○	○	○	○
I am forced to spend time in bed	○	○	○	○	○

SOCIAL/FAMILY WELL-BEING

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	○	○	○	○	○
I get emotional support from my family	○	○	○	○	○
I get support from my friends	○	○	○	○	○
My family has accepted my illness	○	○	○	○	○
I am satisfied with family communication about my illness	○	○	○	○	○
I feel close to my partner (or the person who is my main support)	○	○	○	○	○

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please go to the next section.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am satisfied with my sex life	○	○	○	○	○

EMOTIONAL WELL-BEING

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	○	○	○	○	○
I am satisfied with how I am coping with my illness	○	○	○	○	○
I am losing hope in the fight against my illness	○	○	○	○	○
I feel nervous	○	○	○	○	○
I worry about dying	○	○	○	○	○
I worry that my condition will get worse	○	○	○	○	○

FUNCTIONAL WELL-BEING

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home)	○	○	○	○	○
My work (include work at home) is fulfilling	○	○	○	○	○
I am able to enjoy life	○	○	○	○	○
I have accepted my illness	○	○	○	○	○
I am sleeping well	○	○	○	○	○
I am enjoying the things I usually do for fun	○	○	○	○	○
I am content with the quality of my life right now	○	○	○	○	○

ADDITIONAL CONCERNS

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have swelling in my stomach area	○	○	○	○	○
I am losing weight	○	○	○	○	○
I have control of my bowels	○	○	○	○	○
I have been vomiting	○	○	○	○	○
I am bothered by hair loss	○	○	○	○	○
I have a good appetite	○	○	○	○	○
I like the appearance of my body	○	○	○	○	○
I am able to get around by myself	○	○	○	○	○
I am able to feel like a woman	○	○	○	○	○
I have cramps in my stomach area	○	○	○	○	○
I am interested in sex	○	○	○	○	○
I have concerns about my ability to have children	○	○	○	○	○

FACT/GOG-NTX (Version 4)
Please mark one answer per line to indicate your response as it applies to the past 7 days.

ADDITIONAL CONCERNS

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have numbness or tingling in my hands	○	○	○	○	○
I have numbness or tingling in my feet	○	○	○	○	○
I feel discomfort in my hands	○	○	○	○	○
I feel discomfort in my feet	○	○	○	○	○
I have joint pain or muscle cramps	○	○	○	○	○
I feel weak all over	○	○	○	○	○
I have trouble hearing	○	○	○	○	○
I get a ringing or buzzing in my ears	○	○	○	○	○
I have trouble buttoning buttons	○	○	○	○	○
I have trouble feeling the shape of small objects when they are in my hand	○	○	○	○	○
I have trouble walking	○	○	○	○	○

FALLS

	Never	Once	2-4 times	More than 4 times
I have fallen over	○	○	○	○

INSOMNNIA SEVERITY INDEX

The Insomnia Severity Index has seven questions. For each question, please choose the number that best describes your answer.

Please rate the CURRENT (i.e. LAST 2 WEEKS) SEVERITY of your insomnia problem(s).

INSOMNIA PROBLEM

	None	Mild	Moderate	Severe	Very Severe
Difficulty falling asleep	○	○	○	○	○
Difficulty staying asleep	○	○	○	○	○
Problems waking up too early	○	○	○	○	○

How SATISFIED/DISSATISFIED are you with your CURRENT sleep pattern?

- ○ Very Satisfied
- ○ Satisfied
- ○ Moderately Satisfied
- ○ Dissatisfied
- ○ Very Dissatisfied

.

	Not at all	A little	Somewhat	Much	Very much
How NOTICEABLE to others do you think your sleep problem is in terms of impairing the quality of your life?	○	○	○	○	○
How WORRIED/DISTRESSED are you about your current sleep problem?	○	○	○	○	○
To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, mood, ability to function at work/daily chores, concentration, memory, mood, etc.) CURRENTLY?	○	○	○	○	○

SPHERE-12 QUESTIONNAIRE For ALL questions, please choose the option that most closely matches your response.

Over the past few weeks have you been troubled by:

	Never or some of the time	A good part of the time	Most of the time
Muscle pain after activity	○	○	○
Needing to sleep longer	○	○	○
Prolonged tiredness after activity	○	○	○
Poor sleep	○	○	○
Poor concentration	○	○	○
Tired muscles after activity	○	○	○
Feeling nervous or tense	○	○	○
Feeling unhappy/depressed	○	○	○
Feeling constantly under strain	○	○	○
Everything getting on top of you	○	○	○
Being unable to overcome difficulties	○	○	○
Losing confidence	○	○	○

INTERNATIONAL PHYSICAL ACTIVITY QUESTIONNAIRE
We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The questions will ask you about the time you spent being physically active in the last 7 days.

Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

Physical activities can be classified as follows:

Type of activityDefinitionExamplesVigourous activityActivities that take hard physical effort and make you breathe much harder than normalHeavy lifting, digging, aerobics, or fast bicyclingModerate activityActivities that take moderate physical effort and make you breathe somewhat harder than normalCarrying light loads, bicycling at a regular pace, or doubles tennis.
Does not include walking.WalkingWalking at work and at homeWalking to travel from place to place, and any other walking that you might do solely for recreation, sport, exercise, or leisure

Think about all of the activities that you did in the last 7 days. Think only about those physical activities that you did for at least 10 minutes at a time.

If you did not do any of a particular type of activity, leave that box blank.

	Vigorous activity	Moderate activity	Walking
On how many days did you do this kind of activity?	.....	.....	.....
How many minutes did you usually spend doing this activity on one of those days?	.....	.....	.....

The last question is about the time you spent sitting on weekdays during the last 7 days.

Include time spent at work, at home, while doing course work and during leisure time. This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television.

During the last 7 days, how much time did you spend sitting on a week day?

Hours per day

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SUPPORTIVE CARE NEEDS SURVEY - SF-34

We are interested in whether your needs, which you may have faced as a result of being diagnosed with cancer, have been met in the last month.

For every item, please select the answer that best describes whether you have needed help with this in THE LAST MONTH

INSTRUCTIONS: There are four possible answers:NO NEED: This was not a problem for you, or if you did need help with this, your need has been satisfied.LOW NEED: The item was of minor concern. You had a low need for help with the problem or issue.MODERATE NEED: The item caused you some concern or discomfort. You had a moderate need for help with the problem or issue.HIGH NEED: The item was of major concern or importance to you. You had a strong need for help with the problem or issue.
EXAMPLE:
If you answered as we have (i.e. ‘moderate need’), it means that you had not received as much information about the side-effects of your treatment as you wanted, and therefore needed some more information.

SUPPORTIVE CARE NEEDS SURVEY - SF-34

In the last month, what was your level of need for help with:

	No need	Low need	Moderate need	High need
Pain	○	○	○	○
Lack of energy/ tiredness	○	○	○	○
Feeling unwell a lot of the time	○	○	○	○
Work around the home	○	○	○	○
Not being able to do the things you used to do	○	○	○	○
Anxiety	○	○	○	○
Feeling down or depressed	○	○	○	○
Feelings of sadness	○	○	○	○
Fears about the cancer spreading	○	○	○	○
Worry that the results of treatment are beyond your control	○	○	○	○
Uncertainty about the future	○	○	○	○
Learning to feel in control of your situation	○	○	○	○
Keeping a positive outlook	○	○	○	○
Feelings about death and dying	○	○	○	○
Changes in sexual feelings	○	○	○	○
Changes in your sexual relationships	○	○	○	○
Concerns about the worries of those close to you	○	○	○	○
More choice about which cancer specialist you see	○	○	○	○
More choice about which hospital you attend	○	○	○	○
Reassurance by medical staff that the way you feel is normal	○	○	○	○
Hospital staff attending promptly to your physical needs	○	○	○	○
Hospital staff acknowledging, and showing sensitivity to your feelings and emotional needs	○	○	○	○
Being given written information about the important aspects of your care	○	○	○	○
Being given information (written, drawings, diagrams) about aspects of managing your illness and side-effects at home	○	○	○	○
Being given explanations of those tests for which you would like explanations	○	○	○	○

Being adequately informed about the benefits and side-effects of treatments before you choose to have them	○	○	○	○
Being informed about your test results as soon as feasible	○	○	○	○
Being informed about cancer which is under control or diminishing (that is, remission)	○	○	○	○
Being informed about things you can do to help yourself to get well	○	○	○	○
Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you/family/friends need it	○	○	○	○
To be given information about sexual relationships	○	○	○	○
Being treated like a person not just another case	○	○	○	○
Being treated in a hospital or clinic that is physically pleasant as possible	○	○	○	○
Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	○	○	○	○

Do you have any other comments or concerns related to your ovarian cancer experience that you would like to share with the research team?Please comment below.

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If you would like to receive a summary of the findings of this study when it is completed, please enter your contact details below.

This information will be used only to contact you as requested. The researchers will not link your identifying details to your survey responses.

Name

....

Email address

....