

**PARTICIPANT INFORMATION SHEET: Patients**

Making decisions about seeking or not seeking Complimentary and Alternative Medicine (CAM) during and after conventional cancer treatment: A qualitative investigation.

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Flinders University & Flinders Medical Centre

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We are currently conducting a study looking at how and why people with cancer decide whether or not to use a range of health strategies known as Complementary and Alternative Medicine (CAM). You are invited to participate in this research project but you do not have to be involved, whether you wish to or not is entirely up to you. Whether you take part or not, your medical care will not be affected in any way.

**Aims of the project**

The ultimate aim of this project is to develop a resource that can help people with cancer decide whether they are interested in using CAM or not. We will do this by exploring with you how you made your decision about seeking or not seeking CAM, and then use this information to help create the resource. We will not be trying to convince people to either use or not use CAM, we are simply trying to help people explore all the potential choices as part of their decision making.

**Summary of procedures**

If you choose to participate, you will be asked to attend a discussion group of six to eight individuals to talk about your experiences with CAM: what helped you decide whether or not to use CAM, what benefits and costs have come from this decision, whether you have changed your mind about using CAM throughout your treatment, and what additional help would you have liked in terms of making decisions about CAM. Prior to attending the discussion group you will be given a topic guide to help you think about your ideas and opinions. The discussion groups will take place in the seminar room of the Oncology Ward at Flinders Medical Centre and refreshments will be provided. Upon development of a web-based resource, you may also be invited to read through it and provide feedback on any improvements required.

As the discussion will be tape recorded, the researcher will seek your consent on the attached form, to record the interview, to use the recording or a transcription in preparing publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions.

**Commitments**

Every effort will be made to arrange the discussion groups at a time convenient to you, but they may be scheduled during work hours and you will be required to travel to Flinders Medical Centre. The discussion group will last approximately 90 minutes. You will be reimbursed for travel and car parking expenses.

**Outcomes**

You will not be informed of the outcomes of this study, unless requested.

**Risks and adverse effects**

While there are no direct benefits to you associated with this study, it is anticipated that the web-based self-help program will assist the cancer community in the future. There are no risks from participating in the discussion groups, however research shows that dealing with issues in health crises can lead to short-term emotional discomfort. If any of the topics discussed in the groups cause you distress, the researcher will refer you to a counselling service.

**Confidentiality**

All records containing personal information will remain confidential and no information that could lead to your identification will be released, except as required by law.

**Compensation**

If you suffer injury as a result of participation in this research or study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

**Publication**

You should be aware that the results may be published in conference papers, scientific journals or other venues at a later date.

**Withdrawal**

Your participation in this study is entirely voluntary and you have the right to withdraw from the study at any time without giving a reason. If you decide not to participate in this study, or if you withdraw from the study, you may do so freely, without affecting the standard care or treatment you will receive.

**Contact**

Should you require further details about the project, either before, during or after the study, you may contact Dr Lisa Beatty, 8201-2506.

**Complaints**

*This study has been reviewed by the Flinders Clinical Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the executive officer on 8204 4507 or email [research.ethics@health.sa.gov.au](mailto:research.ethics@health.sa.gov.au)*

**CONSENT TO PARTICIPATION IN RESEARCH**

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I, ..... request and give consent to my  
(first or given names) (last name)  
involvement in the research project *(short title)*: **Making decisions about seeking or not seeking Complementary and Alternative Medicine (CAM) during and after cancer treatment: A qualitative investigation**

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by .....  
(first or given names) (last name)  
and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. Participation in a discussion group on deciding whether or not to use CAM .....
2. My information and participation will be recorded on audio-tape .....
3. Review and provide feedback about a web-based resource module on decision making and CAM .....

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

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Signature of Research Participant : ..... Date: .....

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I, ..... have described to .....  
the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: ..... Date: .....

Status in Project: .....