



PARTICIPANT INFORMATION SHEET

Identifying the impact of the costs of cancer care on Victorian cancer patients

Principal Researcher: Professor Victoria White

Please keep a record of this sheet as it contains information and contact details you may want to refer to after the focus group.

After reading this form if you would like to take part in the focus group please proceed with the Eventbrite registration process.

What is this project about?

Deakin University is working with Cancer Council Victoria to conduct some focus group discussions with people diagnosed and treated for cancer in Victoria. The focus groups aim to learn about the costs of cancer care and the impact of these costs for patients and their families. The research aims to find out the extent people feel informed about the costs of care and what can be done to improve the experiences of people with cancer.

Giving consent

Participation in this research is voluntary, and you can withdraw from the study at any time. Whether you take part in the research or not will have no impact on your relationship with the Cancer Council Victoria or Deakin University.

If you decide to take part, please continue with the Eventbrite registration process. The Eventbrite registration process includes a statement of consent. You can withdraw consent at any time, even after registering through Eventbrite.

If you decide not to take part in the group that is perfectly fine. For our records we would like to know who takes part in the group, but you do not have to tell us why you do not want to take part in the group if you do not want to. Please email these reasons through to vicki.white@deakin.edu.au Lead researcher.

What will I be asked to do?

You are invited to take part in a focus group discussion about costs associated with your cancer care and information you received or wanted to receive about these costs. About 5-7 other people will also take part in the discussion. We would like to hear about your experiences relating to the costs of cancer care. We would also like to hear your thoughts about how things might be improved. The group discussion will last for about 90-120 minutes and will be audio-recorded. You will also be asked to complete a brief questionnaire to provide us with some background information such as your age, when you were diagnosed with cancer, your treatment and whether you were treated in the public or private health system. Focus group topics for discussion will cover things like what information you received



about costs of cancer care, who provided you with information, long term impact of cost of cancer care and what can be done better. You will receive a \$50 Coles/Myer gift voucher to compensate you for costs associated with attending the group.

What will happen to my information?

All information you provide will be kept private and confidential. It will be stored securely and only the researchers will be able to access it. The brief questionnaire you complete will only be identified through a research code. In the focus group your first name may be mentioned. However you will not be named in any reports that utilise the information gathered through the focus group. The focus group recording will be transcribed by an external company that specializes in this sort of work. All data will be transferred securely using password protected files. Any names that may be included in the transcripts will be removed by the researchers. All electronic data from the focus groups (recordings, transcripts and data from the brief questionnaire) will be stored in password protected documents on the Deakin University computer server. Only people associated with the project will have access to these documents.

What are the possible risks & benefits?

While the research findings from this project may not benefit you directly, you may find it interesting to reflect on your experiences. We hope that the knowledge gained from this research will improve the experiences of people treated for cancer in Victoria in the future.

The main inconvenience to you is the time it takes to participate in the discussion, including travelling to and from the discussion location. As you are one of a group of people, participating in focus groups means that the things you talk about will be heard by others. We will discuss the importance of keeping the focus group discussions confidential but we recognize that other people in the group will hear your thoughts and experiences. Talking about your diagnosis and treatment may bring up difficult feelings for some people. Some services to contact for information or support relating to cancer are provided below in the section headed: **For further information or support**

Who can I contact?

If you have any questions about this project, or if you have any problems related to your involvement, please contact Victoria White using the phone or email details below. At the focus group please talk to the facilitator at your discussion group session. Victoria and the facilitator will be able to provide you with further information.

This research project have been approved by the Human Research Ethics Committee at Deakin University. If you have any complaints or concerns about how this research is being conducted or any questions about your rights as a research participant, please contact: *The Human Research Ethics Office, Deakin University, 221 Burwood Highway, Burwood Victoria 3125,*



Telephone: 9251 7129, research-ethics@deakin.edu.au Please quote project number HEAG-H 138_2019

For further information or support

If you would like further information about cancer or want to talk to someone about how you are going, please contact Cancer Council Victoria's Cancer Information and Support Service on 13 11 20. Calling this free service will connect you to a cancer nurse trained to provide information and support people with cancer.

Researcher contact details

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