

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: Modelling Cancer Treatment

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2018-010

PRINCIPAL INVESTIGATOR: Dr LK Hallo

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project is about visualisation of the treatment journey of cancer patients. Through this visualisation we aim to improve cancer treatment through collaboration among various stakeholders

Who is undertaking the project?

This project is being conducted by Dr Leone Hallo, Prof Alex Gorod, Dr Sue Merchant

Why am I being invited to participate?

You are being invited because you are a member of Cancer Voices SA

What will I be asked to do?

You are being asked to attend a focus group at the nexus building at the University of Adelaide, corner of North Terrace and Polly Street. You will be asked to participate in a discussion which will be audiotaped.

How much time will the project take?

It is anticipated that the focus group will last for about one hour

Are there any risks associated with participating in this project?

While this project is about obtaining generalised information about cancer treatment, it is possible that it may cause you to reflect upon your own cancer treatment journey. If anyone feels the need, we will have a break and you can chat to 1 of the researchers if you need support.

What are the benefits of the research project?

The benefits of this research project may include a better understanding of how patients experience the treatment of cancer which may lead to better treatment protocols

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from the study at any time.

What will happen to my information?

Your details are not required: you will not be named in any publication. We will not refer to your individual story: the information is generalised. There is no way for anyone to be able to identify you individually. The transcripts from these focus groups and the audio records will be stored securely at the University for five years after the results of any publication. The results may be published in a journal article or conference paper.

Who do I contact if I have questions about the project?

Dr Leonie Hallo, leonie.hallo@adelaide.edu.au ph 0416155269

Prof Alex Gorod, alex.gorod@adelaide.edu.au 1 9174058097

Dr Sue Merchant, sue.merchant@gmail.com, 0408832219

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2018-010). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding a concern or complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you would like to participate, please respond to Leonie Hallo via email or phone

Yours sincerely,

Dr Leone Hallo, Adjunct Senior Lecturer

Dr Alex Gorod, Prof

Dr Sue Merchant, Researcher