

Plain Language Statement

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Project: Is less more? Exploring consumer and clinician perspectives on de-intensification strategies in melanoma

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Introduction

Thank you for your interest in participating. Please read the information below so that you can decide if you would like to take part in this research. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

De-intensification or de-escalation of cancer therapies aims to reduce the amount of treatment a person receives without harming their chances of getting better. Reducing unnecessary treatments may lead to fewer side effects and treatment burden for people with cancer and their carers.

This study aims to explore the perspectives of people with melanoma, their carers, and their clinicians on de-intensification approaches in melanoma. We use an online voting platform, Polis, that provides real-time visual feedback to participants, and allows participants to contribute their own views.

What will I be asked to do?

If you agree to participate, there will be two parts. First, you will be asked to complete an online survey on your age group, gender, location, and brief details about your melanoma history, carer experience, or clinical role. Upon completion, a personalised link will be emailed to you.

You will access the second part by clicking on the emailed link. This will bring you to the Polis platform. You will be able to participate anonymously in the Polis conversation by voting "agree" or "disagree" or "pass" on comments on de-intensification in melanoma. You will have the opportunity to add your own comments to generate conversation and

present your opinions. You will be able to view, in real-time, where you lie on the opinion landscape.

You will be able to participate in the Polis conversation on any internet-enabled device with your personalised link at any time over a three-week period. We encourage you to interact with Polis several times during this time. We will email you prompts to participate, however you can participate as little or as much as you want.

What are the possible benefits?

To date, there is no published research on the perspectives on melanoma patients and carers on de-intensification strategies in melanoma. This is an opportunity for you to contribute towards the conversation in this space using Polis, a platform that has not been applied in healthcare research previously.

There are unlikely to be any direct material benefits for you. Data collected in this study will be used to inform health economic modelling, relevant stakeholders, and policy makers of the opinions of melanoma consumers and clinicians. This may indirectly benefit participants through improved, consumer-informed health planning.

What are the possible risks?

There are minimal risks to participating, however some of the survey questions or Polis comments may cause distress. To minimise this risk, participant-submitted Polis comments will be strictly moderated. Participation in this study is voluntary, and you can skip any questions or comments you do not want to answer or stop at any time.

If you require more information or support, you can contact:

Melanoma Patients Australia: 1300 88 44 50
Cancer Council: 13 11 20
Lifeline: 13 11 14
Beyond Blue: 1300 22 4636

Please do not include any potentially identifiable information in your comments. To minimise this risk, all participant-contributed comments will undergo strict moderation.

Do I have to take part?

No. Participation is completely voluntary. You can withdraw at any time, however due to technical reasons, we will be unable to withdraw any data already collected on the Polis platform. At your request, any data collected via the initial online survey can be withdrawn.

Will I hear about the results of this project?

We will share a summary of our findings on our website for participants. We aim to publish our findings in academic journals and present them at national and international conferences. It is possible the results of this study may also be communicated or discussed in the media.

What will happen to information about me?

You will not be personally identifiable in any results published from this study. Any identifiable information collected will be delinked from the dataset and stored separately from responses. Data will be stored securely on a server at the University of Melbourne for the duration of the project, and for a further five years after the final publication, as per University of Melbourne guidelines. De-identified raw data may be shared upon request with other researchers for the purposes of scientific transparency and rigor.

Who is funding this project?

This project does not receive any funding. Dr Jennifer Soon is supported by a Melbourne Research Scholarship and this project will form part of her doctoral studies.

Where can I get further information?

If you would like more information about the project, please contact Dr Jennifer Soon (Jennifer.Soon@unimelb.edu.au).

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne (Project ID: 29429). If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team and/or the name or ethics ID number of the research project.