# Participant Information Statement

## *Research Study: Chemotherapy and Sources of Side-effect Information*

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### 1. What is this study about?

We are conducting a research study investigating how the different sources of information people encounter prior to undergoing chemotherapy can influence expectation and subsequent experience of side effects arising from chemotherapy. During this study you will be asked about the sources of information you used to understand your treatment (e.g., doctors, family, social media) as well as what side-effects you expected and experienced as a result of chemotherapy. Taking part is optional.

Please read this sheet and feel free to email researchers to ask about anything that is not clear or you want to know more about.

### 2. Who is running the study?

The researchers conducting this study are:

- Prof Ben Colagiuri, Head of School and Professor of Psychology, University of Sydney
- Cosette Saunders, PhD Student, University of Sydney
- A/Prof Haryana Dhillon, Co-investigator, University of Sydney
- Prof Robert Zachariae, Co-investigator, Aarhus University
- Dr Alice Munk, Co-investigator, Aarhus University
- A/Prof Ali Amidi, Co-investigator, Aarhus University
- Prof Andrew Geers, Co-investigator, University of Toledo

Cosette Saunders is conducting this study as the basis for the degree of Doctor of Philosophy (Science) at The University of Sydney.

### 3. Who can take part in the study?

We are seeking English speaking adults aged 18 and over who have undergone their first experience with chemotherapy for cancer in the last 12 months. This includes combined

chemoradiation therapy or if you have undergone radiation therapy post-chemotherapy. Both neoadjuvant or adjuvant chemotherapy is acceptable.

People that received their chemotherapy in Australia, New Zealand, The United Kingdom, Canada or the United States are eligible.

Adults who have undertaken Immunotherapy and other targeted treatments are **not** eligible for this particular study.

## 4. What will the study involve for me?

If you decide to participate in this study, you will be asked to complete a survey online which should take between 20-25 minutes to complete.

You will be asked to answer questions concerning:

- Demographics (e.g., age, gender, socio-economic status).
- Your cancer diagnosis and treatment.
- What information sources you used to inform yourself of the side effects of chemotherapy and what information those sources contained.
- What side-effects you expected and subsequently experienced.
- Your perceptions of potential strategies to reduce chemotherapy side effects.
- At the end of the survey, you will have the option to add any additional thoughts you would like to share via audio recording.

## 5. Can I withdraw once I've started?

Participating in this study is optional and you do not have to take part.

Your decision will have no impact on your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind, you can withdraw by simply exiting the survey. If you would like to withdraw once you have submitted, email the researchers to let them know you would like to withdraw and what you would like us to do with information we have collected about you. If the data has already been deidentified or published we will be unable to withdraw your data.

## 6. Are there any risks or costs?

The focus of this research concerns your experience with cancer, and some people may find this topic emotional. Therefore, if you anticipate this to be an issue, we advise you do not participate.

## 7. Are there any benefits?

Participating in this research will allow us to better understand the sources of information people with cancer use and rely upon. This will provide a basis for future

research to improve communication strategies with cancer patients and reduce the burden of chemotherapy side effects.

## 8. What will happen to information that is collected?

By giving your consent, you agree to us gathering information about you for this study.

Any identifiable information you share with us will be securely stored and will only be disclosed with your consent unless we are legally required to release information. We plan to publish the findings of this study. You will not be identifiable in these publications.

Sharing research data is important for advancing knowledge and innovation. A de-identified set of the data collected in this study may be made available for use in future research.

## 9. Will I be told the results of the study?

You have the right to hear the results of this study. You can tell us that you wish to receive feedback by ticking the appropriate box on the Participant Consent From. This feedback will be provided as a plain language summary.

## 10. What if I would like further information?

After reading this information, the researcher/s will be available to have further discussions with you and answer any questions you may have:

- Miss. Cosette Saunders via email, cosette.saunders@sydney.edu.au

## 11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney 2024/070 in accordance with the *National Statement on Ethical Conduct in Human Research (2007).*

If you have any concerns about the study's procedures or would like to make a complaint to someone not involved in the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

***This information is for you to keep***