

Participant Information Sheet

Short Title	Boost wellbeing with read-aloud programs during cancer fog
Title	<i>An exploration of the potential benefits of read aloud programs to the wellbeing of cancer patients undergoing treatment: A mixed methods study.</i>
Project Number	204027
Principal Investigator	Elizabeth Wells
Supervisor	Dr Diane Velasquez

Introduction – What does my participation involve?

You are invited to take part in this research project, which is called **Boost wellbeing with read-aloud programs during cancer fog**. You have been invited because you are about to commence, are currently undergoing, or recently completed your cancer treatment.

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker/your doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent for your family to be contacted for an interview if you provide their details
- Consent to the use of your information as described.
- You will be given a copy of this Participant Information Sheet to keep.

What is the purpose of this research?

This research came about from observations that people affected by cancer who had previously read for pleasure were denied that activity (and all the benefits that go with it) because of cancer fog affecting their concentration. This research aims to restore that love of reading to regular readers and introduce the joy of reading to those who don't read regularly, with all the known therapeutic benefits that reading provides. In particular we aim to explore the potential improvement in the emotional wellbeing of participants as a result of taking part in the reading program. There has been no research to date in this area, and it is hoped this research will lead to reading programs in cancer centres. This research is being conducted as a PhD research project.

Do I need to be an avid reader to take part?

No! We are hoping to recruit both people who don't currently read for pleasure, as well as those with a regular reading habit who may be struggling to keep reading because of cancer fog.

What does participation in this research involve?

Interested potential participants will be screened for eligibility according to the following criteria:

- Over 18 years of age
- Confidently able to read, write and speak English
- About to receive, currently receiving, or have recently completed cancer treatment
- No currently diagnosed mental health issue

A consent form will need to be signed prior to any assessments being performed.

After completing an initial demographic questionnaire (asking about general demographic information and briefly about your cancer and treatment) and reading habits and attitudes questionnaires, the researcher will source suitable reading material based on your responses, and organise a weekly day, time and place for you to come along and relax, listening to stories being read aloud. You will be able to choose your preferred venue for the reading program: your home, your usual cancer centre (if available), a UniSA campus or your local library. Each reading session will run for about 30-40 minutes, weekly for 6 weeks. At the start of the first session, you will need to complete two short questionnaires designed to measure your emotional wellbeing (which will take less than 10 minutes to complete). Reading material will be fiction, narrative non-fiction or poetry, based on your reading preferences. This is a one-to-one program. You will not be required to do any preparatory reading, read aloud during sessions, nor participate in any discussions about the meaning of the stories, although you will be welcome to comment if you wish. This is to be an immersive experience, where you can simply lose yourself in the story and enjoy the pleasure of being read to. Mid-way through the program, a very short survey will be conducted to gauge your enjoyment of the material being read. At the conclusion of the program, you will need to complete the wellbeing and reading attitude questionnaires again and we will schedule a short (half-hour) interview about your experiences with the research program. Relatives of participants (where nominated by you) will also be asked to participate in a short (half-hour) interview about the program, as will nursing staff if you are an inpatient during the reading program and you consent for us to speak to them. All interviews will be audio-recorded then transcribed.

The researcher will take every care to remove any identifying material from the responses you provide as early as possible. Likewise, individuals' responses will be kept confidential by the researcher and will (or participants will) not be identified in the reporting of the research. However, the researcher cannot guarantee the confidentiality or anonymity of material transferred by email or the internet.

What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include relaxing and enjoying stories being read to you, without any pressure to maintain concentration, while enjoying the face-to-face contact with an experienced reader. You might discover new authors you enjoy. New readers may discover a love of stories. You might experience a boost in your emotional wellbeing.

What are the possible risks and disadvantages of taking part?

It is not anticipated that there are any risks to participation in this study beyond those encountered in everyday life.

Do I have to take part in this research project?

Participation in this research is voluntary. If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will ask you to provide us with feedback.

What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using information about/from you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Information collected or used will be stored electronically as re-identifiable via an identification number.

All information that may be used to identify you will be removed from all written documents and survey data and replaced with an identification number. Information about you (i.e. your name and contact details) will be stored separately from the survey data, in a locked cabinet in D-building at University of South Australia's Mawson Lakes campus. We will only use your information to contact you about the study.

All audio files and transcriptions will be stored and backed up according to University of South Australia's policies.

Access to data will only be available to the researcher and her supervisors.

Data will be kept for a minimum of 5 years on a password-protected computer connected to a secure network and will be securely destroyed thereafter. At this point, all consent forms will be shredded and electronic data permanently deleted.

All records containing personal information will remain confidential and no information which could lead to identification of any individual will be released, unless required by law.

What if something goes wrong?

Whilst all reading material will be chosen based on your existing reading interests, or perceived interests for new readers, and reading material of a distressing nature will be actively avoided, we understand that a cancer diagnosis is distressing, and unforeseen issues may arise. If you need support at any time please call the Cancer Council on 13 11 20 (Mon-Fri 9am-5pm) or Lifeline on 13 11 14 (24-hour / 7 days/week).

What happens when the research project ends?

A summary of project results will be available January 2023 from the researcher.

Who is organising and funding the research?

This research project is being conducted by Elizabeth Wells.
It is being funded by the University of South Australia.

Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the University of South Australia as required by the Australian government research requirements, specified in the National Statement on Ethical Conduct in Human Research (2007 - updated 2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on (08) 8302 3737 or any of the following people:

Research contacts

Name	Dr Diane Velasquez
Position	Program Director – Information Management
Telephone	+618 8302 3074
Email	diane.velasquez@unisa.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, please contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	University of South Australia Human Research Ethics Committee
HREC Executive Officer	Human Ethics Officer
Telephone	+618 8302 6330
Email	humanethics@unisa.edu.au