Participant Information Sheet

PROJECT TITLE: 'CHEMOBRAIN': THE SUPPORT EXPERIENCES OF YOUNG ADULT CHILDHOOD CANCER SURVIVORS

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2024-009

PRINCIPAL INVESTIGATOR: Dr Alexandra Whittaker

STUDENT RESEARCHER: Miss Ines Semendric

STUDENT'S DEGREE: Ph.D in Medicine

Dear Participant,

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

What is the project about?

This research project is about young adult survivors of childhood cancer who experience 'chemobrain'. 'Chemobrain' can include effects on everyday functions such as memory, learning and decision making. The aim of this research is to explore the experiences of young adult survivors of childhood cancer who experience 'chemobrain' and explore the past and current impacts it has had. Importantly, we want to know where supportive care is done well or where more attention needs to be directed. It does not aim to assess any correlation between chemotherapy and cognition nor is the interview diagnostic in any capacity. Through this research, we look to improve our understanding of how young people are affected and whether adequate support is being implemented and, if not, what factors may be contributing to this to direct future supportive care.

Who is undertaking the project?

This project is being conducted by Miss Ines Semendric. This research will form the basis for the degree of Ph.D in Medicine at the University of Adelaide under the supervision of A Prof Lyndsey Collins-Praino and Dr Alexandra Whittaker.

Why am I being invited to participate?

You are being invited as you,

- Are between the age of 18 and 25 years old
- Have a previous diagnosis of childhood cancer under the age of 18
- Completed chemotherapy treatment, of any type or any duration, at least 6 months ago
- Currently in remission
- Experience self-reported or clinically diagnosed cognitive issues following treatment (e.g., memory or attention issues)
- Reside in Australia and speak English fluently

You will not be eligible to participate if you,

- Have a diagnosed learning disability **prior** to cancer diagnosis and treatment
- Have a diagnosis of a neurological disorder
- Are not fluent in English

What am I being invited to do?

You are being invited to participate in a one-on-one online Zoom interview with a member of the research team (Miss Ines Semendric). An appointment will be made for a day and time that suits you for the interview. If you require any personal accommodations, we are able to take frequent breaks and/or split the interview into sessions.

Prior to the interview, you will be asked to complete a short demographic form about your age, sex at birth, gender, and details of your past diagnosis and treatment. A copy of the interview themes will be provided to you ahead of time. During the interview you will be asked about your past and current experiences of 'chemobrain', your experience with accessing support, and, if provided, where you believe more support needs to be implemented. Participants may choose to have a support person, such as family or a friend, present during the interviews for support.

The interview will being audio-recorded and transcribed into text. You are not required to share a videofeed if you do not want to. The interview transcription will be sent to you to look over and approve. A pseudonym will be allocated to your transcription to de-identify the data for analysis and any reporting of results, however this data will be re-identifiable by Miss Ines Semendric who will store this data on a secure server accessible only by Miss Ines Semendric, Dr Alexandra Whittaker and A Prof Lyndsey Collins-Praino.

How much time will my involvement in the project take?

This interview will take approximately 45-90 minutes. You are welcome to take any breaks throughout the process which may add to the allocated time. Additionally, we will do our best to accommodate for any necessary personal accommodations.

Are there any risks associated with participating in this project?

Risks of participation may include feeling distress from thinking about your prior health status or fatigue (cognitive or physical). Members of the research team will be available to contact at any given time if you have concerns or queries regarding the study or participation, although responses may not be immediate. If you feel distressed or concerned prior to, or during, the interview, please cease immediately and speak to your GP or healthcare professional for appropriate support. If you are prone to fatigue, we are able to accommodate by splitting the interview session into multiple shorter sessions. If you require a break at any point, please let us know.

Emergency contacts

Triple zero (000)

Mental Health emergencies – SA Health (13 14 65)

Lifeline Australia (13 11 14)

Beyond Blue Australia (1300 22 4636)

Cancer Council (13 11 20)

What are the potential benefits of the research project?

Participating in this study is unlikely to directly benefit you. The potential broader benefits of participating in this interview may include:

- Contributing to furthering our understanding of 'chemobrain' in childhood cancer survivors and how this may impact their lives short- and long-term
- Providing you with an outlet to express any concerns
- Providing up-to-date and primary information that may aid in informing and improving current survivorship care for childhood cancer survivors particularly around support needs

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 point prior to completion of data analysis.

What will happen to my information?

Participants will be individually identifiable by the research team from initial contact to transcribing of the recorded audio from the interview sessions. Following this, the data will be re-identifiable. All personal identifiers will be removed and a pseudonym will be randomly allocated to the data. There will be private record of what participant is associated with what psuedonym, this data will be

securely stored as described below and only available to the referenced research members. Any publicly shared research findings (as described below) will not be identifiable.

Collected data will be stored on a University of Adelaide server with a password protection for a minimum of seven years following the completion of the research project. Only members Dr Alexandra Whittaker, A/Prof Lyndsey Collins-Praino and Miss Ines Semendric of the research team will be able to directly access this data. The remaining members of the research team will only be exposed to already de-identified data.

The findings of this survey will be recorded and published in a scientific journal publicly. The researchers may also opt to publish research findings in news blogs or media posts. Only summary data will be published and discussed; all individuals responses will remain anonymous.

As this study is expected to inform future research projects extended consent is sought in this study for the use of participant's de-identified data in future research projects including an extension of, or closely related to, the original project and/or projects in the same general area of research.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

Can I see the results of the research project?

If you wish to find out the aggregate results of the study as they might appear in professional publications, please feel free to contact Miss Ines Semendric at ines.semendric@adelaide.edu.au. You may also wish to follow the involved laboratories official twitter pages - @CANDL_neuro and @AWCAN_UA for updates on this and related research. Please note that publications will not include any information that could be used to identify any individual.

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

If you would like more information or have any futher questions regarding this project, please contact our study email below:
cc_survivors@adelaide.edu.au

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-2024-009). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018). 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 concerns or a 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 3, 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?

Please email **cc_survivors@adelaide.edu.au** to express your interest in participating and you will be provided with all relevant information (participant information sheet, consent form, and a copy of the interview questions). After reviewing the participant information sheet, please return a signed copy to **cc_survivors@adelaide.edu.au** to provide your consent to participate. A team member will be in touch shortly to find an appropriate time for you to hold your interview. Thank you for your interest in participating.

Yours sincerely,

Miss Ines Semendric
A Prof Alexandra Whittaker
A Prof Lyndsey E. Collins-Praino
Dr Danielle Pollock
Dr Kate Obst