PARTICIPANT INFORMATION SHEET

Full Project Title: Exploration of the communication, comprehension and decision making in the paediatric oncology relapse setting

Participants: Healthcare professionals- Questionnaire

Primary Investigator: A/Prof Tracey O’Brien  
Associate Investigators: Dr Claire Wakefield  
Dr Nicole Cousens  
Dr Frank Alvaro  
Dr Luciano Dalla-Pozza  
Dr Geoff McCowage  
Ms Kate Lenthen  
Ms Donna Drew

Study Coordinator: Dr Nicole Cousens

1. Introduction

We would like you to consider participating in a research study that will be conducted to learn more about the communication and decision-making processes occurring once a child has been diagnosed with a relapse of cancer.

This Participant Information Sheet tells you about the research project. It explains what is involved to help you decide if you want to take part.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about.

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 form. By signing it you are telling us that you:

- understand what you have read;
- consent to take part in the research project
- consent to be involved in the procedures described
- consent to use your personal information and health information as described

You will be given a copy of the Participant Information Sheet and Consent Form to keep.
2. **What is the purpose of this study?**
This project aims to further understand communication, comprehension and decision-making processes occurring for paediatric cancer relapse treatments (including early phase clinical trials). This is an important step in improving the care of children with relapsed cancer and their families, as little is currently known about the communication and decision making processes occurring, therefore a greater understanding is required.

3. **Why have I been invited to participate in this study?**
You are invited to participate in this study because:

You are a paediatric oncology healthcare professional

4. **What does participation in this study involve?**
The study involves the completion of a questionnaire which explores your practice and opinion regarding early phase paediatric clinical trials, including decision making and informed consent processes. This questionnaire can be carried out online or as a written questionnaire. The questionnaire should take approximately 15 minutes to complete.

5. **How is this study being paid for?**
The study is being supported by the Kids Cancer Centre, Sydney Children’s Hospital and by a Kids Cancer Alliance research grant awarded to the Study Investigators by the Cancer Institute NSW.

6. **What are the possible benefits?**
This study may not directly benefit you; however the completion of the questionnaire will assist in the assessment of the communication and decision making processes taking place in relation to oncology treatment options for children. The findings from this study may help to further understand the current medical practice carried out with cancer relapse patients and determine whether healthcare professionals are satisfied with the current practice.

7. **What are the possible risks?**
There are no risks associated with participation in this study.

8. **Do I have to take part in this research project?**
Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time this will not otherwise affect your employment or current and future relationship with your hospital. This information sheet is for you to keep. We will also give you a copy of the signed consent form.

9. **Will taking part in this study cost me anything, and will I be paid?**

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Participation in this study will not cost you anything. Reply-paid envelopes will be included for you to return your questionnaire back to the researcher if you are completing a written questionnaire. Otherwise it can be done online. You will not be paid for your participation.

10. **What happens to the results?**
We plan to share the results of the study with the ethics committee for ethical monitoring purposes, in peer-reviewed journals and at conferences or other professional forums for the promotion of knowledge in the health services. When published, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

11. **What will happen to information about me?**
Any information obtained in connection with this research project that can identify you will remain confidential and will only be used for the purpose of this research project. It will only be disclosed with your permission, except as required by law.

In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

Data collected in this study will be stored in locked cabinets and on password-protected network computer drives which can only be accessed by the study investigators. Data will be coded so that it cannot be individually identifiable. All data collected will eventually be disposed of, after it has been stored for approximately 5 years. Data collected will only be used for this specific project.

12. **Can I access research information kept about me?**
In accordance with relevant Australian privacy laws, you have the right to access the information collected and stored by the researchers about you. Please contact one of the researchers named at the end of this document if you would want to access your information.

In addition, in accordance with regulatory guidelines, the information collected in this research project will be kept for at least 5 years. Access to information about you after this point will not be possible.

13. **What should I do if I want to discuss this study further before I decide?**
When you have read this information, the Study Coordinator, Dr Nicole Cousens, will be happy to discuss it with you and answer any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on (02) 9385 9867.
14. Who should I contact if I have concerns about the conduct of this study?

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 14/03/19/4.01. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email Hnehrec@hnehealth.nsw.gov.au.