



**Health**  
South Eastern Sydney  
Local Health District



Faculty of Medicine and Health  
School of Clinical Medicine  
Randwick Clinical Campus  
T: (02) 9382 3114 (Direct line: Dr Ursula Sansom-Daly)  
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Investigator: Rhea Felton

Supervisory Team: Dr Ursula Sansom-Daly, Dr Jordana McLoone and Dr Melvin Chin

### **Understanding Children's Experiences of Parental Cancer Study Participant (PARENT/CARER) Information Sheet**

#### **What is this study about?**

Growing research recognises the importance of hearing children's voices directly in the field of oncology. This study is an effort to allow children to express their views on how they understand and experience life when their parent/carer has been newly diagnosed with cancer. The key aim of this research is to investigate how children understand, experience and make meaning of their parents/carers cancer.

#### **Who is doing the study?**

This study is being carried out by Rhea Felton as part of her PhD candidature under the supervision of Dr Ursula Sansom-Daly, Dr Jordana McLoone and Dr Melvin Chin from UNSW, Department of Medicine and Health, School of Clinical Medicine in the Discipline of Paediatrics.

#### **What does the study involve?**

You are being invited as a parent to participate in one conversation about how you believe your child has made-meaning of your / your spouses' cancer. Your child is being asked to take part in one conversation, with the use of games including drawing and writing. During the conversation, your child will be asked some prompting questions about what is important to them, what makes them happy and how they understand their mum/dad's illness.

#### **What is my role as the parent/carer during the child interview?**

The study's focus is to hear from children about their experiences of having a parent/carer who has been diagnosed with cancer. This information aims to guide understanding on how children can be supported during this challenging life event in their life. We also understand that talking about



experiences can be challenging for many people at all ages. As such, we recognize the importance for children to feel supported during the interview and acknowledge that parental presence can provide comfort for children. As a parent/carer, we value your presence of being a passive support figure for your child, allowing free-flow of dialogue from your child.

**How much time will it take?**

The conversation will be conducted at a location convenient for you and the participating children and should not take longer than 1 hour each, one with yourself AND/OR partner and one with your child/ren.

**Can I AND/OR my child withdraw from the study?**

Participation in the study is entirely voluntary. You and your child are not obliged to participate and even if you decide to participate, you are free to withdraw at any time without having to give a reason and without consequence.

**Will the study benefit me?**

The study intends to build knowledge and understanding on how children experience life when their parent/carer has been diagnosed with cancer, from a child's perspective. Their contribution to this study will be for research purposes only.

**Are there any risks involved in this study?**

This study poses minimal risks to participants. The greatest risk is that some questions may raise uncomfortable feelings for you and your child. Should you or your child become distressed we will provide you with an option to stop being involved in the research study. We also have developed a resource kid that we will make available that can help you provide support to your child and yourself, should that be appropriate. It is also not an obligation for your child to answer the questions we ask as part of the research. Your child can also choose not to answer a question or not take part in a discussion.

**How will my and my child's confidentiality be protected?**

We intend to protect yours and your child's anonymity and the confidentiality of all responses to the fullest possible extent, within the limits of the law. No individuals will be identified in any publication of the results. In the final report, you and your child will be referred to by a pseudonym. We will remove any references to personal information that might allow someone to guess you and your child's identity. Electronic data will be kept securely by the researchers for 15 years or until the youngest participant turns 25 years (whichever later), Following this time period, electrical data will be destroyed by rewriting or reformatting, as per University Policy.



The only time we will be required to breach confidentiality is if we suspect, on reasonable grounds, that a child or young person is at risk of being neglected, physically, sexually or emotionally abused. In that event we will be required to inform the appropriate child protection authority.

**Can I review and/or edit my responses prior to data analysis and publication?**

You can review and/or edit your responses prior to data analysis and publication. If you or your child are seeking to do this, please contact Investigator Rhea Felton on [r.felton@unsw.edu.au](mailto:r.felton@unsw.edu.au).

**Will I be reimbursed for my time?**

There is no instant monetary reimbursement this study will provide for your participation. However, Cl Felton intends to publish a children’s book series capturing the findings of this research study in the format of children’s literature and would like to gift this series to participating families. Please indicate if you would like to receive this series in the below consent page.

**Has this project received funding?**

This project has not received any funding.

**How will I receive feedback?**

Once the research has been completed, a brief summary of the findings will be available to you on request. The results will be presented at academic conferences and in academic journals and children’s literature.

**Where can I get further information?**

Should you require any further information, or have any concerns, please do not hesitate to contact the Chief Investigator, Dr Ursula Sansom-Daly or Co-Investigator, Rhea Felton on the below details:

Dr Ursula Sansom-Daly <a href="mailto:Ursula@unsw.edu.au">Ursula@unsw.edu.au</a> (02) 9382 3114	Rhea Felton <a href="mailto:r.felton@unsw.edu.au">r.felton@unsw.edu.au</a> +61 0403 857 715
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**Who can I contact for support outside usual business hours?**

There is a list of support services you can contact after usual business hours (before 9am and after 5pm) on the final two pages of the Resource Toolkit.

**If I wish, how do I agree to participate?**

If you would like to participate, please indicate that you have read and understood this information by signing the accompanying consent form.



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The ethical aspects of this study have been approved by the South Eastern Sydney Local Health District (SESLHD) Human Research Ethics Committee 2023/ETH01697.

Dr Melvin Chin is the Chair of the SESLHD Ethics Committee but was not involved in the review of this project.

Should you have any concerns about the conduct of this project, you are welcome to contact the SESLHD research support office on 02 9382 3587 or [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au)

*This information sheet is for you to keep.*



**Consent Form - Participant (Parent/Carer)**

**Project Title: Understanding Children’s Experiences of Parental Cancer**

Name of Parent/Carer: \_\_\_\_\_

Name of Child: \_\_\_\_\_

Name of Investigator: Rhea Felton

Supervisory Team: Dr Ursula Sansom-Daly, Dr Jordana McLoone and Dr Melvin Chin

1. I consent to participating in this project, the details of which have been explained to me, and I have been provided with a written information sheet to keep.
2. I can review and/or edit my responses prior to data analysis and publication. I can contact the researcher, Rhea Felton on [r.felton@unsw.edu.au](mailto:r.felton@unsw.edu.au) to do this.
3. I understand that my participation will involve participation in discussion with the researcher and I agree that the researcher may use the results as described in the plain language statement.
4. I consent to participating in a discussion with the researcher and I agree that the researcher may use these results as described in the plain language statement.
5. I acknowledge that:
  - a. The possible effects of participating in the workshops have been explained to my satisfaction. I understand that a resource kit is available that can help me provide support to my child and myself, should that be appropriate;
  - b. I have been informed that my child and I are free to withdraw from the workshop at any time without explanation or prejudice and to withdraw any unprocessed data provided;
  - c. The project is for the purpose of research;
  - d. I have been informed that the confidentiality of the information provided will be safeguard subject to any legal requirements;
  - e. I have been informed that with my consent the interview will be audio-taped and I understand that audio-taps will be stored securely on the UNSW OneDrive Folder and will be destroyed after 15 years or when the youngest participant turns 25 years.
  - f. The name of my child and I will be referred to by a pseudonym in any publications arising from the research;

I consent my child’s and my voice to be recorded during our conversation **yes**  **no**

I wish to receive a short report about the research findings **yes**  **no**

I wish to receive the children’s book series once published **yes**  **no**

Parent/Carer signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigators signature: \_\_\_\_\_ Date: \_\_\_\_\_

**(PARTICIPANT’S COPY)**



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I consent my child’s and my voice to be recorded during our conversation yes  no

I wish to receive a short report about the research findings yes  no

I wish to receive the children’s book series once published yes  no

Parent/Carer signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigators signature: \_\_\_\_\_ Date: \_\_\_\_\_

**(INVESTIGATOR’S COPY)**