

ABN 15 211 513 464

Dr Kim Bulkeley
Senior lecturer

Susan Wakil Health Building
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 2 9351 9034
Email: kim.bulkeley@sydney.edu.au
Web: <http://www.sydney.edu.au/>

Project title: Intervention approaches for children with disabilities who are restricted eaters

PARENT PARTICIPANT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about interventions used with children who are restricted eaters. This study aims to identify what intervention approaches are being used with children with disabilities who are restricted eaters. This will enable a comparison to be made to what is currently being described in the literature and what is happening in daily clinical practice. The findings will inform development of resources to support high quality interventions for this group of children.

You have been invited to participate in this study because you are a parent of a child who has a disability and identifies as a restricted eater. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:

- Rene Fraser, Higher Degree by Research Student, The University of Sydney
- Dr Kim Bulkeley, Senior Lecturer, The University of Sydney
- Dr Rebecca Barton, Lecturer, The University of Sydney

Rene Fraser is conducting this study as the basis for a higher degree by research at The University of Sydney. This will take place under the supervision of Dr Kim Bulkeley and Dr Rebecca Barton.

(3) What will the study involve for me?

You must be able to give fully informed consent to participate in this study. We will ask you to provide demographic information regarding your child's age, diagnosis and description of their eating skills. You will be invited to participate in an interview that will take 45 minutes to one hour. The interview will be completed over zoom or telephone. With your permission the interviews will be recorded enabling the researchers to accurately recall what was discussed. During the interview you will be asked about your child and the support you have received around restricted eating. You may be asked about what assessments have been completed, what treatments you have been offered or received, and how clinicians have communicated with you, your child and your family. There are no right, or wrong answers and the purpose of the study is to collect information on what is currently occurring in practice. All information obtained in interviews will be stored securely in accordance with The University of Sydney procedures and deidentified for publication purposes.

(4) How much of my time will the study take?

Interviews will generally last around 45 minutes to an hour.

(5) Who can take part in the study?

Parents of children aged up to 18 years of age; are not exclusively bottle or breast fed; who have a lifelong permanent disability; and are restricted eaters. Restricted eaters are people who eat less than 30 foods, exclude whole food groups or their participation in family mealtimes is affected. You must have received support for your child's restricted eating from a health professional (speech pathologist, occupational therapist, dietitian or psychologist) in the last 5 years.

(6) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect 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 later, you are free to withdraw at any time. You can do this by emailing Rene Fraser rfra6188@uni.sydney.edu.au There will be no consequences of withdrawing from this study.

You are free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

(7) Are there any risks or costs associated with being in the study?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study. However, some participants may experience emotional discomfort. If any emotional discomfort is experienced, please raise this with the researcher by contacting Rene Fraser rfra6188@uni.sydney.edu.au. We can then discuss an appropriate action such as contacting your GP, calling [Life Line](#) on 13 11 14 or [Beyond Blue](#) 1300 22 4636 for support as needed.

(8) Are there any benefits associated with being in the study?

It is not anticipated that this research study will directly benefit you. The results arising from this research will contribute to the knowledge base around children with disabilities who are restricted eaters to develop resources to support high quality practice.

(9) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise. Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications.

(10) Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if I would like further information about the study?

When you have read this information, Rene Fraser will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact Rene Fraser, HDR Student, The University of Sydney, rfa6188@uni.sydney.edu.au or Dr Kim Bulkeley, Senior Lecturer, The University of Sydney, kim.bulkeley@sydney.edu.au.

(12) Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. This feedback will be in the form of a one page plain English summary. You will receive this feedback after the study is finished.

(13) What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (protocol #2021/540). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** human.ethics@sydney.edu.au
- **Fax:** +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep