



Sunshine Coast Eating Disorder Access Trial

Information sheet

Participants and Parent/carer(s)

SECTION 1: Participants under 18 years

Introduction

You are being invited to take part in a research study testing the best ways to treat eating disorders. This Information Sheet tells you about the research project. Knowing what is involved will help you decide if you want to take part. **Ask questions about anything that you don't understand or want to know more about.** There is also a section in this information form for you parent/carer to read so you can discuss this together. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

Purpose of the study

The rate of eating disorders in Australia is increasing, but most people do not receive the best treatment for their condition, and don't receive the full number of treatment sessions.

The Australian Government is trialling a project to allow more people with eating disorders to get access to the best treatment. For example, more professionals are being trained in the best methods of treatment, and treatment will cost less. Our study is measuring whether these changes improve things for people with eating disorders.

What will I be asked to do? Will it be confidential?

We are inviting your participation in two aspects of the research study:

1. Allowing us to use your anonymous treatment information for research purposes. This includes things like the type of treatment and how many sessions you received, plus questionnaires you filled out about whether you are feeling sad, or concerned about your weight. Your name is removed before we analyse this information. No identifying information is included in the combined, group results that we share with other researchers and the public (e.g., in reports, at conferences, and in scientific journals).
2. We are also inviting you to take part in a survey (or telephone interview if you prefer) after you finish treatment to give us your feedback re this new approach. Depending on how much information you want to share, this will take between 15-30 minutes. Your parent/carer can help you if you don't want to do this on your own. They can also do the survey or interview themselves to give us their own thoughts on how things went.

Questions ask about things like whether you were happy with the team approach and treatment outcome, and any difficulties you had getting treatment. Your answers are given an anonymous code. You don't have to answer any questions you don't want to, and don't need to give a reason for this. Interviews will be recorded to allow us to write down your full answers.

What if I change my mind later?

You can withdraw consent at any time without needing to give a reason - simply let your psychologist, dietician or GP know. Your future data will then not be used. Data already collected and merged with other people's anonymous information may continue to be used, however.

Are there any risks or discomforts involved in participation?

The researchers anticipate no discomfort from allowing your data to be used for research. However, should you have any concerns, you discuss these with your treating professional or you can contact the free support services.

Kids' Helpline

- 1800 55 1800
- Operating hours: 24/7
- About: A free confidential phone and online counselling and information service for ages 5-25

Butterfly's National Helpline

- Call 1800 ED HOPE (1800 33 4673)
or email support@thebutterflyfoundation.org.au
or access online counselling or an online support group from our website www.thebutterflyfoundation.org.au
- Operating Hours: 8am-12am AEST, 7 days a week (except national public holidays)
- The Butterfly Foundation's National Helpline, ED HOPE, is a free and confidential service which provides information, counselling and treatment referral for eating disorders, disordered eating, body image and related issues.

Possible benefits

You may not personally benefit from taking part in this research, however this study will allow us to improve treatments for eating disorders being used in Australia in the future.

Questions about this project?

If you have any questions or concerns about any aspect of this project, you can ask your parent/carer(s), your treating professional (e.g., psychologist or GP), or the lead researcher Professor Tracey Wade by phone or email (see details at the bottom of this form). Please also feel free to take the form home to discuss with others before deciding whether or not to take part.

How do I agree to take part or not?

If you don't wish to take part, simply let your treating practitioner know. If you are happy that you understand what is involved and do wish to take part, please read and sign the following consent form together with your parent/carer.

Many thanks for your time.



Professor Tracey Wade (Psychology)
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The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) – incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies. Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Operations Manager, Bellberry Limited on 08 8361 3222. The project number for this study is 2018-09-728



Sunshine Coast Eating Disorder Access Trial

Information sheet

Participants under 18

SECTION 2: Parents/Carers

Principal investigator

Professor Tracey Wade
College of Education, Psychology & Social Work
Flinders University
Tel: 82013736

Introduction

Your child is being invited to take part in a research study testing the best approach for managing eating disorders, and measuring the effects. This Information Sheet and Consent Form tells you about the research project. Knowing what is involved will help you discuss this with your child so they can decide if they 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 your child doesn't wish to take part, they don't have to. They will receive the best possible care whether or not they take part.

Purpose of the study

The rate of eating disorders in Australia is increasing, however the majority of people with eating disorders do not receive treatment designed specifically for their condition, nor for the recommended duration of treatment.

The Australian Department of Health has commissioned and funded a project on the Sunshine Coast to improve access to "gold standard" treatment. This includes training more teams of eating disorder professionals for early, accurate diagnosis and best-evidenced treatment, and increasing Medicare rebates to cover the full recommended duration of treatment. Our study is measuring the effects of these changes on the treatment experience and outcomes for participants with eating disorders.

What will my child be asked to do? Will it be confidential?

We are inviting your child's participation in two aspects of the research study:

1. Allowing us to use their deidentified (anonymous) assessment and treatment data for research purposes. This data includes information such as the type of treatment provided and number of sessions, and also questionnaires your child filled out regarding things like their mood, level of concerns about their weight, and dieting behaviour. Their name and any identifying details are removed from their data.

2. We are also inviting your child to take part in a survey (or telephone interview if they prefer) after the completion of treatment to give us their feedback. Depending on how much information they want to share, this will take between 15-30 minutes. Your child may like to do this on their own or with your assistance. You can also do the survey or interview yourself to give us your own feedback on how things went. Questions ask about things like whether you were happy with the team approach and treatment outcome, and any difficulties you had accessing treatment. You don't have to answer any questions you don't want to, and don't need to give a reason for this. Interviews will be recorded to allow us to write down your full answers.

When data from all participants has been analysed, the group results will be shared with other researchers and the public via journal publications, conferences, and workshops. No identifying information is included in these results.

What if we change our mind later?

If you consent but change your mind later, you can withdraw consent for future use of data with no disadvantage to continuing treatment, and without needing to give a reason - simply let your treating practitioner know. Data already collected and merged into deidentified group sets before withdrawal of consent may continue to be used, however.

Are there any risks or discomforts involved in participation?

The researchers anticipate no discomfort from allowing your child's data (which is collected by the Department of Health as part of their treatment), to be used for research. However, should you have any concerns, please do not hesitate to contact the following free support services:

Kids' Helpline

- 1800 55 1800
- Operating hours: 24/7
- About: A free confidential phone and online counselling and information service for ages 5-25

Butterfly's National Helpline

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Possible benefits

Your child may not personally benefit from taking part in this research, however this study will allow us to improve treatments for eating disorders being used in Australia in the future.

Questions about this project?

If you have any questions or concerns about any aspect of this project, you can raise them with the lead researcher (Professor Tracey Wade; email and phone number below) before agreeing to take part (i.e., take this form home with you rather than consenting now). You are also welcome to discuss taking part with family members, friends or your GP before deciding.

How do we agree to take part or not?

If you don't wish to take part, simply let your treating practitioner know. Participation is completely voluntary. If you are happy that you and your child understand what is involved and wish to take part, please read the following consent form carefully before signing it and handing back to your treating practitioner (or emailing it to the lead researcher if you took it home). Keep this information sheet for your records. You will also be given a copy of the signed consent form.

Many thanks for your time in considering this invitation.



Professor Tracey Wade (Psychology)
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Email: tracey.wade@flinders.edu.au

The Bellberry Human Research Ethics Committee has reviewed and approved this study in accordance with the National Statement on Ethical Conduct in Human Research (2007) – incorporating all updates. This Statement has been developed to protect the interests of people who agree to participate in human research studies. Should you wish to discuss the study or view a copy of the Complaint procedure with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Operations Manager, Bellberry Limited on 08 8361 3222. The project number for this study is 2018-09-728

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Consent Form – Participants’ Data

I, the undersigned, being over the age of 18 years, hereby freely consent to my child participating in the above study as follows (please tick those to which you agree)

- Use of my child’s deidentified (anonymous) treatment data
- Taking part in a survey OR interview (please circle your choice) to give feedback

If you consent to take part in a survey or interview, you will be contacted by email after your treatment has finished with a link to an anonymous survey for you and/or your child, or emailed to arrange a time to undertake a confidential phone interview, if you chose this option.

We declare that

- We have had the opportunity to read the information sheet provided
- We have been given the opportunity to take the information sheet home to discuss with others before providing consent if desired
- All questions have been answered to our satisfaction.

We understand that

- Involvement in this study may not be of any personal direct benefit
- No information will be published or shared so as to reveal my child’s identity
- We are free to withdraw consent at any stage without needing to give a reason and without affecting future treatment.

NAME (Parent/carer) _____

SIGNATURE _____ **DATE:** _____

NAME (Participant under 18 years) _____

SIGNATURE _____ **DATE:** _____

Declaration by Principal Researcher or representative

An explanation of the research project, its procedures and risks have been given to the participant and their parent/carer, and I believe they have both understood that explanation.

NAME _____ **ROLE** _____

SIGNATURE _____ **DATE:** _____