Sunshine Coast Eating Disorder Access Trial

Information sheet

Participants

Principal investigator

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

Introduction

You are 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 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. 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, 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 three year 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 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 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 you filled out regarding things like your mood, level of concerns about your weight, and dieting behaviour. Your name and any identifying details are removed from your data.

2. Taking part in a 15-30 minute survey (or telephone interview if you prefer) after you finish treatment to give us feedback. Questions ask about things like whether the Medicare rebates were acceptable, whether you were happy with the team approach and treatment outcome, and any obstacles you had to accessing or completing treatment. You may decline to answer particular questions without needing to give any reason. Interviews (if you choose this option) will be audiorecorded to allow accurate transcription of information. Your name and any identifying details are removed from your data.

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 I change my 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 data (which is collected by the Department of Health as part of your treatment), to be used for research. However, should you have any concerns, please do not hesitate to contact the following free services :

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.*

Eating Disorders Queensland

- *Free face-to-face, phone or skype individual counselling. Book an appointment online https://eatingdisordersqueensland.org.au/individual-counselling/*
- *Eating Disorders Queensland is funded by Qld Health to provide information and referral, free counselling, therapeutic groups, and peer support for people with eating issues, and their loved ones throughout Queensland.*

Lifeline ***13 11 14***

- *Operating hours: 24/7 (available from landline, payphone or mobile)*
- *About: A nation-wide phone counselling crisis service, face-to-face service, & information & referral service for people with mental health difficulties.*

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 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 I 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 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)
College of Education, Psychology & Social Work
Flinders University
GPO Box 2100 Adelaide 5001
Tel: 82013736
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 to taking part in this research as follows

(please tick those to which you agree)

☐ Use of my 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, or emailed to arrange a time to undertake a confidential phone interview, if you chose this option.

I declare that

- I have had the opportunity to read the information sheet provided
- All questions have been answered to my satisfaction.
- I have been given the opportunity to take the information sheet home to discuss with other members of the family or another person before providing consent if desired

I 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 identity
- I are free to withdraw consent at any stage without needing to give a reason and without affecting future treatment.

NAME _____

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 I believe the participant has understood that explanation.

NAME _____

SIGNATURE _____ DATE: _____

ROLE_____