

ED-Care Evaluation: Community Views on the Eating Disorder Medicare Benefit Schedule Items		
The research is being carried out by the following researchers:		
Role	Name	Organisation
Chief Investigator	Dr Siân McLean	La Trobe University
Co-Investigator	Dr Deborah Mitchison	Western Sydney University
Co-Investigator	Associate Professor Susan Hart	Western Sydney University
Co-investigator	Prof Matthew Fuller-Tyszkiewicz	Deakin University
Co-investigator	Associate Professor Genevieve Pepin	Deakin University
Co-investigator	Elyse O’Loughlen	La Trobe University
Co-investigator	Alexandra Aulich	La Trobe University
Co-investigator	Courtney McLean	La Trobe University
Research funder	This research has received funding from the Australian Government Department of Health and Aged Care.	

1. What is the study about?

You are invited to participate in a survey study that is seeking opinions and feedback on the Medicare supported Eating Disorder Treatment and Management Plan (Medicare Eating Disorder Plan). The Medicare Eating Disorder Plan was first introduced in November 2019 and we want to learn what individuals with a lived experience of an eating disorder, as well as the carers of a person with an eating disorder, think about this new type of support.

In Australia, people experiencing an eating disorder are eligible for mental health and dietetic support through Medicare. People living with an eating disorder can access mental health treatment either through a Medicare Eating Disorder Plan or a Mental Health Treatment Plan (MHTP) through Better Access. Dietetic treatment can be accessed through the Medicare Eating Disorder Plan or a Chronic Disease Management Plan.

A Medicare Eating Disorder Plan provides up to 40 sessions of evidence-based psychological treatment from a mental health professional and up to 20 sessions of dietetic services from an accredited practicing dietitian over a 12-month period. People with a clinical diagnosis of anorexia nervosa, or with severe presentations of bulimia nervosa, binge eating disorder, or other specified feeding and eating disorders (OSFED) are eligible for this type of plan.

This online survey is part of a larger formal Evaluation Project of the Medicare Eating Disorder Items, which has been commissioned by the Australian Government. Your opinions and feedback will be contributing to a timely and important review of this important health service.

2. Do I have to participate?

Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. Who is being asked to participate?

You have been asked to participate because you identify as being one of the following:

- You have a lived experience of an eating disorder (either currently or in the past)
- You are or have been a support/carer for someone with an eating disorder (either currently or in the past)

4. What will I be asked to do?

If you want to take part in this study, we will ask you to complete an online questionnaire, that includes multiple choice and free text questions to help us understand what you think about this topic. It will take up to 20 minutes of your time. Your responses are completely anonymous.

At the end of the survey, you will have the option of clicking on a new and separate survey link. We will ask you to provide your name and email address. You may then choose to accept our offer of a Coles digital \$20 voucher, as a thank you for your time. You may also agree to be contacted about further research on this topic, which would be in the format of an online interview to ask for any additional feedback you may have about the Medicare Eating Disorder Plan.

5. What are the benefits?

We expect no immediate benefit to participants involved in this study - aside from the value of having the opportunity to share your opinion on this important topic. We expect this study to benefit larger society by gathering diverse perspectives from the very community the Medicare Eating Disorder Plan seeks to support. The information that is collected in this study is an important part of the formal evaluation, that can then inform decisions about the future direction of the Medicare Eating Disorder Plan.

6. What are the risks?

With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. It is possible that participants may feel some discomfort as they complete the survey questions as this is a sensitive topic which might prompt participants to think about their personal experiences. If you do become upset or distressed while completing this survey, we suggest you contact your regular mental health care provider or general practitioner.

You can also receive support from the following hotlines:

- Lifeline (general mental health support): 13 11 14 / chat-online @ www.lifeline.org.au/crisis-chat
- The Butterfly Foundation Helpline (eating disorder or body image specific support): 1800 ED HOPE / 1800 334 673 / chat-online @ butterfly.org.au/get-support/chat-online
- ConnectOed to find support from a Credentialed Eating Disorder Clinician <https://connected.anzaed.org.au>

The contact details for these hotlines will also be available at the end the survey.

You may also contact the Chief Investigator to provide feedback about your experience.

Name/Organisation	Position	Telephone	Email
Siân McLean, La Trobe University	Senior Lecturer	03 9479 2949	s.mclean@latrobe.edu.au

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- You may become upset or distressed when answering questions due to the personal and sensitive nature of this topic.

7. What will happen to information about me?

By clicking on the 'I agree, start questionnaire' button, this tells us you want to take part in the study.

We will **collect** information about you in ways that will not reveal who you are.

We will **store** information about you in ways that will not reveal who you are.

We will **publish** information about you in ways that will not be identified in any type of publication from this study.

We will **keep** your information for 7 years after the project is completed. After this time we will destroy all of your data.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Research Data Management Policy](https://policies.latrobe.edu.au/document/view.php?id=106/) <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). All data collected is non-identifiable.

8. Will I hear about the results of the study?

The results will be published by the Australian Government Department of Health and Aged Care, as part of the Final Evaluation Report. The findings of this study will therefore be made publicly available.

9. What if I change my mind?

If you no longer want to complete the questionnaire, simply close the web browser. If you change your mind after clicking on the 'Submit' button, we cannot withdraw your responses because we cannot link who you are with your questionnaire responses. This is an anonymous survey.

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Alexandra Aulich	Project Manager		eatingdisorders@latrobe.edu.au

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC23130	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

Consent Form – Declaration by Participant

By continuing to complete the online survey I acknowledge that I, (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know that, because this survey is anonymous, I cannot withdraw from the study once I have completed and submitted my responses. I agree information provided by me or with my permission during the project may be included in presentations, published in journals and made publicly available on a data-sharing platform, on the condition that I cannot be identified.

I would like my information collected for this research study to be:

- Only used for this specific study
 Used for future related studies;

I agree, start questionnaire