

EXPLANATORY STATEMENT

Lived Experience Advocates

Project ID: 37721

Project title: The co-creation of health professional education with lived experience advocates with lived experience of an eating disorder in a larger body.

Chief investigators:

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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone numbers or email addresses listed above.

What does the research involve?

Eating disorders are often misunderstood and misrepresented by the media, which in turn impacts health professional perceptions. Atypical anorexia shares the medical risk of anorexia nervosa but is often overlooked because the clients exist in larger bodies. This leads to the worsening of the eating disorder, despite the client reaching out for treatment because their symptoms were dismissed. Therefore, there is a need to educate health professionals and health professionals in training.

The aim of this study is to investigate the lived experience of those with atypical anorexia and those that live in a larger body with and eating disorder to develop educational material to help health professionals better recognise and treat the condition. It will aim to break stereotypes, build empathy and clinical capability.

You will be asked to complete a one-hour interview with a researcher. This will be conducted at a time convenient to you. The interviewer will ask you to describe your experience getting a diagnosis and interaction with the medical system through treatment. You will be asked to consider what barriers you faced and whether there were elements that could have been improved. This interview will then be used (audio, transcript and/or video) in a package for health professional education. You will have the opportunity to choose whether you would like to be identified (name, audio and image), use a pseudonym or remain anonymous. Your interview will then be used to develop educational material which might include theatre, poem, artwork or other artistic representations along with traditional educational material.

We respect your knowledge and wisdom in this area. You will have the opportunity to view your contribution before it is released to medical professionals to maintain your autonomy.

Why were you invited for this research?

You were invited to be part of this study as you have a lived experience with atypical anorexia.

Consenting to participate in the project and withdrawing from the research

Explanatory Statement and Consent Form tell you about the research project. You will be given a copy of this Explanatory Statement to keep. It explains what will be expected of you, if you choose to take part in the research. Please read this Explanatory Statement in full before deciding. Ask questions about anything that you don't

understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or family member. Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide to take part in the study you will be asked to sign a consent form. By signing it you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to participate in the research processes that are described;
- Consent to the use of your personal and health information as described below.

You have the right to withdraw from the study, at any time. At this point you will have the option to withdraw your data, if necessary.

Possible benefits and risks to participants

Although we do not expect that this research will cause you any distress and anything more than minor inconvenience, it should be noted that difficult topics such as mental health, body image and relationship to food. Should you become concerned about issues that arise throughout or after the study, we can provide you with a list of counselling services (below) and advise you to seek medical advice from your General Practitioner.

Services on offer if adversely affected:

If you are adversely affected by the interview you are encouraged to reach out to your treatment team and/or the following services

Eating Disorders Victoria - <https://www.eatingdisorders.org.au/find-support/> or 1300 550 236 (Mon-Fri 9.30-4.30)

The Butterfly Foundation - <https://butterfly.org.au/get-support/helpline/> or 1800 33 4673 (8am- midnight, 7 days)

Lifeline - <https://www.lifeline.org.au/> or 13 11 14 (Available 24 hours)

Confidentiality

We respect your confidentiality and therefore you will have the option to remain anonymous. The final educational package provided has the ability to utilise your audio, video or just your words. Therefore, on the consent form you will have the ability to select what level of anonymity you would like from fully identifiable, a pseudonym used or anonymous. Please note if you choose the option for your data to remain anonymous and you choose to withdraw from the study you will not be able to withdraw your data. The audio of the interview will be provided to a third-party transcription service. No identifying information will be provided with the audio file to maintain confidentiality.

Storage of data

During these five years of data storage, the principal researchers may use the collected data in future, related projects following review and approval of the project from Monash Health Human Ethics Committee. After this period the electronic and paper data will be deleted and/ or destroyed. This project will form part of a higher research degree theses and possible academic publications. No personal or identifiable data will appear in any publication or dissemination of results. In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. You also have the right to request that any information, with which you disagree, be corrected. Please contact one of the researchers named at the end of this document if you would like to access your information.

Results

The results of this study will be used to help develop education material for health professionals. You will have an opportunity to review your contribution before this is released. Further, this material will be evaluated for efficacy. The results of this evaluation are planned to be submitted to a peer reviewed journal and appropriate conferences. These outputs will be made available to participants upon request.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Chancellery Building D,
26 Sports Walk, Clayton Campus
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Thank you,
Dr Christie Bennett
Chief Investigator