

The Shared Table Program Evaluation

PARTICIPANT INFORMATION STATEMENT

The Shared Table: Fostering Eating Disorder Recovery at Home Evaluation

(1) What is this study about?

You are invited to take part in an evaluation study about The Shared Table hosted by Eating Disorders Queensland (EDQ). The Shared Table was created by EDQ, Queensland Eating Disorder Service (QuEDS), and Child Youth and Mental Health Service (CYMHS). The Shared Table is an online training program designed for carers of individuals affected by eating disorders. Collectively, we have launched this program for carers to address the lack of support and accessible resources for carers interested in providing Supportive Meal Therapy (SMT). We hope by improving access to appropriate knowledge and resources, carers will feel more confident to care for their loved ones.

This study aims to evaluate how useful and practical The Shared Table is for Carers. We would like to see how the program supports carers in experiencing less burden and stress, and how it impact's carer's knowledge, willingness, confidence and skill-level in providing care to those they are supporting. We would also like to use the feedback and information gained to inform ongoing development and improvement of the program's content and delivery, and to provide some insight into how suitable online programs and resources for carers are more broadly.

Australia's Institute for Eating Disorder Research and Clinical Excellence, The InsideOut Institute, and QIMR Berghofer Medical Research Institute are assisting to evaluate The Shared Table. Your participation in this research study is voluntary. This Participant Information Statement tells you about the evaluation study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and if you have any questions, the contact details of the research team are below.

(2) Who is running the study?

This study is being carried out by the following researchers:

- Professor Nick Martin, QIMR Berghofer Medical Research Institute
- Dr Morgan Sidari, QIMR Berghofer Medical Research Institute & InsideOut Institute
- Amy Hannigan, Queensland Eating Disorder Service (QuEDS)
- Belinda Chelius, Eating Disorders Queensland (EDQ)
- Dr Tania Withington, Child Youth and Mental Health Service (CYMHS)

(3) What will the study involve for me?

The Shared Table is structured into 7 program modules organised into various topics, such as *Planning*, *Pre-meal Support*, and *The Role of Nutrition in Eating Disorder Recovery*.

For the evaluation, we will ask that you complete three questionnaires at different times:

Pre-questionnaire – Presented at the start of The Shared Table program, this questionnaire should take about 10 minutes to complete and include questions on your demographic and general

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information, your sense of wellbeing and burden and your general experiences, skill-level, willingness, confidence and knowledge. It will also ask you about some techniques you may already use at meal times and your preferences for these techniques. This questionnaire must be completed to gain access to the program.

Post-questionnaire – A questionnaire will be presented upon completion of The Shared Table, or one month after you first access The Shared Table and will ask you about your skill-level, willingness, confidence and knowledge surrounding caregiving, as well as program feedback, and should take approximately 5-10 minutes to complete.

1-month follow up - You will be invited via email to complete a follow up questionnaire to evaluate the long-term impact of the program on carer's skill-level, wellbeing, confidence, willingness, knowledge and sense of burden. It will also ask you about techniques you use at meal times and your preferences for these techniques. This questionnaire should take approximately 10 minutes to complete.

For the questionnaires, you will be emailed two reminders for the respective due dates for each questionnaire if questionnaires have not already been completed on invitation.

Program usage

Throughout the study we will also collect analytic information regarding your usage of the program, namely how much of the program you complete, time taken, and completion pattern. This information will allow us to understand whether completing more of the course and/or particular parts of the course results in better outcomes on the questionnaires. By consenting to the study, you agree for us to use this de-identified information in the current evaluation study.

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

Each questionnaire is anticipated to take around 10 minutes to complete. The Shared Table online modules are self-paced, so the amount of time it will take you will depend on how you use it. It includes text-based content, reflective exercises, and 40 minutes of videos.

(5) Who can take part in the study?

To take part in this study you need to be a carer for a person with an eating disorder, defined as an individual who provides ongoing personal care, support and assistance to someone else who needs it because that other individual is suffering from an eating disorder, and be at least 18 years of age.

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

Participation in this study is entirely voluntary and you do not have to take part. Your responses, or your decision not to participate, will not impact your current or future relationship with your service provider or any of the researchers.

If you decide to take part in the study and then change your mind later, you are free to withdraw your pre-questionnaire, post- questionnaire data anytime within one month of your accessing the program. You can withdraw your 1-month follow up questionnaire data up until the point of submitting the responses. After this period, all data will be locked for analysis. If you withdraw, we will not collect

additional personal information from you. Please note that data generated from you until the time of withdrawal will not be deleted, and will be used for legitimate scientific purposes.

You do not have to give a reason for withdrawal and your withdrawal will not affect your relationship with the research team, QIMR Berghofer Medical Research Institute, or any other participating organisation. You can withdraw by emailing Dr Morgan Sidari at morgan.sidari@sydney.edu.au.

(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. If at any time you feel distressed, you can call the Butterfly Foundation at 1800 33 4673 to get support from an eating disorder specialist, the Carer Gateway at 1800 422 737 for carer specific support or LifeLine at 13 11 14 for crisis support. You can also call EDQ at (07) 3844 6055 or enquire on EDQ's website (<https://eatingdisordersqueensland.org.au/contact/>) to be linked with a carer coach or other carer services. Please note that you will not be connected directly to a carer during that call, so the other phone numbers are more appropriate if you need immediate support.

Participating in this study will not cost you anything, nor will you be paid.

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

We cannot guarantee that you will receive any direct benefits from being in the study. However, we hope that that The Shared Table program may assist you to feel more confident to care for your loved one. We hope that findings from this study will confirm the effectiveness of The Shared Table support program and provide directions for improvement of the program in the future.

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

Your responses from the training program and questionnaires will be collected via LearnDash, a Learning Management System (LMS) that ensures all data is encrypted and stored behind a hardware firewall, all accounts are password protected and data is transferred over a secure SSL (HTTPS) secure connection and keyed with a private certificate to ensure all information is fully protected. The only identifiable data that will be collected is your email address, which we need to be able to email you the follow-up questionnaire. This email address will only be stored in the LearnDash database, it will *not* be provided to QIMR with your other responses. To maintain your privacy and confidentiality, you will be assigned a unique participant code that will be used throughout the study on all documents (known as de-identification). Only authorised project staff from EDQ will be able to link this code to you. Only de-identified data will be transferred to QIMR Berghofer researchers for analysis. Once received, your de-identified data will be stored on the internal network at QIMR, which is password protected and requires Multi-factor Authentication. All electronic data and study materials will be stored for 5 years and then all files will be permanently destroyed in accordance with QIMR policy.

Your information will be kept strictly confidential, except as required by law.

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

Before you decide to take part in the study, you can talk about it with your friends and family regarding participation.

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

When you have read this information, Dr Morgan Sidari will be available to discuss it with you further and answer any questions you may have. Dr Sidari is a postdoctoral researcher and study investigator who is undertaking the current evaluation study as part of her role with MAINSTREAM at the InsideOut Institute. If you would like to know more at any stage during the study, please contact Morgan by email at morgan.sidari@sydney.edu.au.

(12) What happens when the research project ends?

At the end of this project, we would like to use your de-identified data, including sharing with collaborators for future research into supporting eating disorder recoveries. Any future research projects that use your de-identified data must first be approved by a Human Research Ethics Committee or another appropriate ethical review body. We will only do this with your agreement, however we will not contact you again to obtain your permission. Please let the research team know if you do not want us to use your de-identified data for future research.

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

It is anticipated that the results of this research study will be published in academic journals and policy documents and be presented at local and international scientific conferences. Results will also be communicated to the wider community through public talks, social media networks and print media as well as via the EDQ website. In any publication and/or presentation, information will be provided in such a way that you cannot be identified as we will not use any of your personal information as part of this research study.

(14) How is this study funded?

The development of this program was funded by LINK Innovation Fund Metro North Hospital and Health Service. The Leading Innovation through Networking and Knowledge-sharing (LINK) initiative is an opportunity to work with partners to improve patient experiences, outcomes, continuity and quality of care. The focus of the initiative is to collaboratively address the areas of hospital admission and discharge practices, and avoidance of unnecessary hospital admissions and readmissions.

The evaluation of this study is not directly funded and will be conducted by Dr Sidari as part of her role in The InsideOut Institute's MAINSTREAM project.

(15) 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). This study has been approved by the Human Research Ethics Committee – QIMR Berghofer Medical Research Institute. 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, updated 2018). This statement has been developed to protect people who agree to take part in research studies.

If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (+617) 3362 0117 and quote protocol number 2022/P3814. The conduct of this study at QIMR Berghofer Medical Research Institute and Queensland Eating Disorder Service (QuEDS) has been authorised by QIMR Berghofer Medical

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Research Institute. Any person with concerns or complaints about the conduct of this study may contact the study coordinator on (+617) 3362 0117 and quote the protocol number 2022/P3814.



Participant Consent Form

Project Title: The Shared Table: Fostering Eating Disorder Recovery at Home Evaluation

Project Number: P3814

Principal Investigators: Prof Nicholas Martin, Dr Morgan Sidari

Declaration by Participant

By progressing to complete the questionnaires, I agree that I have:

- a) Reviewed and understood the contents of this Participant Information and Consent Form.
- b) Been informed that I may discuss the project with the Investigators by contacting the QIMR Berghofer investigator via the contact details on page 4 of the participant information sheet.
- c) Given permission for the use of personal information collected as described for the purposes of this project.

Please tick a box below to indicate your wishes regarding the use of your data in future research:

I agree to my de-identified data to be used in future research projects involving eating disorder. I understand that all future research will first be approved by a human ethics committee or an appropriate ethics review body and will abide by the required guidelines and regulations.

OR

I agree to my de-identified data to be used in any future research project. I understand that all future research will first be approved by a human ethics committee or an appropriate ethics review body and will abide by the required guidelines and regulations.

OR

I do not agree to the use of my de-identified data obtained during this study for use in future research projects.

I understand that I can download a copy of this Participant Information and Consent Form to keep. I voluntarily agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

Participant Name (please print)

Date

