

PARTICIPANT INFORMATION STATEMENT

HOW SHOULD WE TALK ABOUT EATING DISORDERS? A DELPHI EXPERT CONSENSUS STUDY.

My name is Joanna Doley, and I am currently studying for the Doctor of Philosophy at La Trobe University under the supervision of Prof. Susan Paxton, Dr. Laura Hart and A/Prof Arthur Stukas. I am looking for persons with expertise in eating disorders (i.e. clinicians, researchers, recovered persons in advocacy positions) to participate in a study looking at how we should talk about eating disorders in the community.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to gather expert opinion on ways to talk about eating disorders in community settings (i.e. schools, universities, workplaces, sports clubs) that a) reduce eating disorder stigma, b) increase knowledge about eating disorders, and c) do not cause or worsen any disordered eating/body image problems. The results will form the basis for a document of guidelines on how to talk about eating disorders in the community, which will be available to the public.

WHY HAVE I BEEN CONTACTED?

You have expertise in eating disorders. We are recruiting through eating disorder support or advocacy organisations in English-speaking countries (including speakers' banks associated with these organisations), and online presence (researchers' or clinicians' web pages, blogs of persons who work in an advocacy role).

WHO CAN PARTICIPATE IN THIS STUDY?

You are invited to participate in this study if you have expertise in eating disorders and are 18 years of age or over. Your expertise might be from working in the field of eating disorders (for instance, a clinician or researcher), or from working/volunteering in an advocacy role as someone recovered from an eating disorder (fully recovered for at least two years with no significant eating disorder thoughts or behaviours). You are asked not to participate if you believe that responding to a questionnaire about eating disorders will cause you distress, even if you are fully recovered.

WHAT DOES PARTICIPATION INVOLVE?

You are being asked to complete three rounds of an online questionnaire over a period of approximately four months. The first round will be the longest and will take approximately 60-90 minutes to complete. Specifically, you will be asked to rate items that describe what a talk about eating disorders for community groups should include and how likely this content is to contribute to reduced stigma, increased knowledge, or risk for an increase in

eating disorder symptoms in the intended audience. You will also be given the option to elaborate on the reasons for your answers. You will also be asked to complete demographic information (occupation/role within the field, whether you have lived experience of ED, age, gender, country of residence).

After the first round questionnaire, each item will be categorised as endorsed as a guideline (if 80% of all participants agree the item is important), re-rating required (70-79% of participants agree the item is important) or rejected as a guideline (less than 70% of participants agree the item is required in the guidelines).

You will then be emailed a report that will show the outcome for each item. For each of the items requiring re-rating, your report will show how your responses compare to that of the group. You may then decide to change or maintain your rating in the subsequent round. This process is repeated in subsequent rounds until only items with a high level of agreement between participants remain. There will be fewer items in each subsequent round, requiring less participation time for each questionnaire.

WHAT IF I CHANGE MY MIND ABOUT PARTICIPATING?

Your participation in the study is entirely voluntary, and you do not have to participate. You are also free to withdraw from the study at any time. If you wish to withdraw after commencing the questionnaire during any round, do not submit the questionnaire. There are no consequences or penalties for withdrawing from the study. You may also request the withdrawal of any responses previously submitted to the research team, while data collection is ongoing. Simply email any member of the research team to request withdrawal of your data. Once the three questionnaires are completed, the data will be stored in a de-identified format and we will be unable to extract your personal responses.

WHAT ABOUT CONFIDENTIALITY?

During the data collection phase, your responses to questionnaires will be linked to your email address so we can track when questionnaires have been completed and prepare personalised feedback. Questionnaires will be administered electronically using the online survey software, Qualtrics.com, which uses Transport Security Level (TSL) encryption. Your data will only be identifiable to the researchers for the duration of data collection. After this time, data will be downloaded and de-identified (your email address will be deleted from data files), and kept in a password protected file on a La Trobe University project specific network drive accessible only to the research team. Consent forms and personalised feedback reports will be stored in separate password protected files on the same research network drive. After the study is complete, all data will be stored for a minimum of for 5 years.

HOW WILL RESULTS OF THIS RESEARCH BE MADE AVAILABLE

The results of this research will be published in a publically available guideline document. You will be emailed a copy of this document at the conclusion of this study. In addition, we will encourage eating disorder advocacy and other community-based organisations to use the guidelines and publicise them on their website. In addition, results of this research

may be used for publications in academic journals, at conference presentations, and in official documents submitted towards the completion of the Doctor of Philosophy degree. All results will be published in group average format and no individual identifying information will be published.

ARE THERE ANY RISKS?

This study deals with subject matter that could be sensitive for some individuals. If you have recovered from an eating disorder, there is a chance you may experience psychological distress from responding to some questions. If you feel distressed about any of the issues that arise from participation in this research, please immediately contact one of the services in your local area. There is a comprehensive list of support services provided at the bottom of this document.

WHAT ARE THE BENEFITS

If you are a person with lived experience of ED, you will be contributing to guidelines that are aimed at reducing eating disorder stigma, also intended to decrease any stigma associated with being a person recovered from an eating disorder. People who work in the field of eating disorders will also benefit from participation. They will gain insight into others' reasoning for how to talk about eating disorders and this may improve communication with clients or members of the general public.

WHERE CAN I GET MORE INFORMATION?

If you would like more information about the study before deciding to participate, please contact any member of the research team.

Ms Joanna Doley

Is a PhD candidate who is conducting this research.

Email: 18349097@students.latrobe.edu.au, Phone: +61 3 9479 1906

Professor Susan Paxton

Is a Clinical Psychologist and senior researcher who is the lead investigator of this research.

Email: susan.paxton@latrobe.edu.au, Phone: +61 3 9479 1736

Dr. Laura Hart

Is a Post-doctoral Research Fellow with experience in conducting Delphi studies.

Email: l.hart@latrobe.edu.au, Phone +61 3 9479 6495

A/Prof Arthur Stukas

Is a senior academic with experience in social psychology research.

Email: a.stukas@latrobe.edu.au, Phone +61 3 9479 1515

If you have any complaints or concerns about your participation in the study that the researcher has not been able to answer to your satisfaction, you may contact:

Senior Human Ethics Officer

Ethics and Integrity, Research Office

La Trobe University, Victoria, 3086
Email: humanethics@latrobe.edu.au, Phone: +61 3 9479 1443.
Please quote the application reference number 15-062

CONFIDENTIAL SUPPORT SERVICES

AUSTRALIA

Nationwide

The Butterfly Foundation

Telephone support line and web counselling service
(Open 8am-9pm, Mon-Fri)

Phone: 1800 33 4673

Email: support@thebutterflyfoundation.org.au

Website: www.thebutterflyfoundation.org.au/web-counselling

Lifeline Australia

24 hour telephone crisis support

Phone: 13 11 14

New South Wales

The Butterfly Foundation

Support line: 1800 33 4673

Phone: 02 9412 4499

Fax: 02 8090 8196

Email: support@thebutterflyfoundation.org.au

Website: www.thebutterflyfoundation.org.au

Centre for Eating and Dieting Disorders (CEDD)

Service support centre based in Sydney.

Phone: 02 9515 6040

Website: www.cedd.org.au

Northern Territory

Top End Mental Health Services (TEMHS)

First point of contact for people seeking a mental health service in the Northern Territory

Phone: 08 8999 4988

Fax: 08 8999 4999

Website: www.health.nt.gov.au

Queensland

Eating Disorders Association Inc Queensland

Provides information, support and referral services.

Telephone: (07) 3394 3661

Website: www.eda.org.au

Email: admin@eda.org.au

South Australia

Centacare: PACE

Services include telephone support, face to face counselling and referral pathways.

Telephone: 08 8159 1400

Website: <http://www.centacare.org.au/OurServices/HealthWellbeing/PACE.aspx#>

Tasmania

Tasmania Recovery from Eating Disorders

Support group – can also assist individuals with information about ED

Website: <http://www.tred.org.au/>

Mental Health Service Helpline

24 hour mental health crisis helpline

Phone: 1800 332 388

Victoria

Eating Disorders Victoria (EDV)

The EDV helpline operates from Monday to Friday from 9.30am to 5pm.

Telephone: 1300 550 236

Website: www.eatingdisorders.org.au

Email: help@eatingdisorders.org.au

Western Australia

Women's Health Works

Provides information and support for a range of issues to do with women's health, including eating disorders.

Telephone: (08) 9300 1566

Website: www.womenshealthworks.org.au

Email: info@womenshealthworks.org.au

UNITED STATES OF AMERICA

(Nationwide)

National Eating Disorders Association

Telephone helpline is a first point of contact for referral and information. Open Mon-Thurs 9am-9pm, Fri 9am-5pm

Phone: **1-800-931-2237**

Website: <http://www.nationaleatingdisorders.org/find-help-support>

The National Suicide Prevention Lifeline

24 hour crisis helpline available to anyone in suicidal crisis or emotional distress

Phone: 1-800-273-8255

Website: <http://www.suicidepreventionlifeline.org/>

UNITED KINGDOM

(Nationwide)

Beat UK

A helpline for those with eating disorders, open to anyone over 18. Open Mon - Wed,
2pm-4pm
Phone: 0345 634 1414
Website: <http://www.b-eat.co.uk/>

Samaritans

24 hour telephone support line.

Phone: 0845 7 90 90 90,

Email: jo@samaritans.org

Website: www.samaritans.org

IRELAND**(Nationwide)****Bodywhys**

First point of contact to access local ED support services, also provide telephone support counselling (Mon, Wed, Sun – 7:30pm-9:30pm, Tue, Thu, Fri 10:30am-12:30pm)

Helpline: 1890 200 444

E-Mail Support Service alex@bodywhys.ie

Website: <http://www.bodywhys.ie/supportServices/helpline/>

Samaritans

24 hour telephone support line.

Phone: 0845 7 90 90 90,

Email: jo@samaritans.org

Website: www.samaritans.org

CANADA**(Nationwide)****National Eating Disorder Information Centre**

Helpline for people with eating disorders open Mon-Fri 9am-9pm EST

Phone: 1-866-NEDIC-20 (1-866-633-4220)

416-340-4156 in Toronto/GTA

Website: <http://www.nedic.ca>

The National Suicide Prevention Lifeline

24 hour crisis helpline available to anyone in suicidal crisis or emotional distress

Phone: 1-800-273-8255

Website: <http://www.suicidepreventionlifeline.org/>

NEW ZEALAND**(Nationwide)****Eating Disorders Association of New Zealand**

Group run by carers of people with eating disorders, point of contact to recommend services local to people with an eating disorder.

Helpline: 0800 2 EDANZ

Website: <http://www.ed.org.nz/>

Lifeline Aotearoa

24 hour telephone crisis support

Phone: 0800 543 354 (within Auckland: 09 5222 999)

Website: <http://www.lifeline.org.nz/>

Otago/Southland and Central Otago

The Southern Support Eating Disorder Service

Free help to anyone who has questions, concerns or symptoms and/or behaviours consistent with an eating disorder. Open Mon-Fri during business hours.

Phone: 0800 EAT RIGHT (0800 328 744)