



Participant Information Form

Evaluation of Eating Disorders and Neurodivergence: A Stepped Care Approach

Who is conducting the evaluation?

The evaluation is being carried out by the following individuals and organisations:

Role	Name	Organisation
Workforce Development Coordinator	Dr Emma Spiel	The National Eating Disorders Collaboration (NEDC)
National Manager	Hilary Smith	The National Eating Disorders Collaboration (NEDC)
Chair and Research Lead	Laurence Cobbeart	Eating Disorders Neurodiversity Australia (EDNA)
Deputy Chair and Clinical Lead	Anna Millichamp	Eating Disorders Neurodiversity Australia (EDNA)

Funding

The evaluation is funded through NEDC's core funding.

What is the purpose of the evaluation?

You are invited to participate in the evaluation of [Eating Disorders and Neurodivergence: A Stepped Care Approach](#). We hope to learn whether this report is successful in its aims to improve knowledge, understanding, attitudes and confidence of people who have a role in the prevention, identification and/or treatment of eating disorders for neurodivergent people, and those with lived experience.

Who is being asked to participate?

People who have read [Eating Disorders and Neurodivergence: A Stepped Care Approach](#) are being asked to participate in this survey.

Do I have to participate?

Participation in the evaluation is voluntary. If you want to be part of the evaluation, 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. Non-participation will not affect your relationship with NEDC or any other listed organisation.

What does taking part involve?

If you decide to take part in this evaluation, you will be asked to complete an online survey.

The survey will ask you about:

- Your age, geographic location, gender identity, sexuality, intersectional identities, profession, and/or lived experience.
- Your knowledge, understanding and confidence regarding neurodivergence and eating disorders after reading *Eating Disorders and Neurodivergence: A Stepped Care Approach*.
- Feedback to help improve the usefulness of the report so that we can develop this content to better meet your needs.
- Your name and email address, if you wish to go into a draw for 1 of 3 x \$50 vouchers (optional)*.

**Note - this information will only be used to contact act successful participants as part of the prize draw and not for any other purposes.*

The survey will take about 10 minutes to complete. There will be one survey to complete in total.

What are the benefits?

Although there is no direct benefit to participants, information from the survey will assist us to develop materials to support clinicians to build confidence in neurodiversity and eating/body image affirming care for eating disorders and neurodivergence.

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.

This evaluation survey has been assessed as involving low or negligible risk to participants.

The survey asks participants to identify their relationship to eating disorders and neurodivergence, either as a professional or someone with lived experience. This could generate distress and we encourage participants to protect themselves from any potential harm this may cause and to seek help. Support services are listed at the end of this document.

Your right to protect yourself from harm and to seek support.

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed because of your participation in the evaluation survey, the evaluation team can link you in with supports as required. Alternatively, several free contactable support services are included below.

Name/Organisation	Position	Telephone	Email
Dr Emma Spiel	Workforce Development Coordinator	02 8456 3923	emma.spiel@nedc.com.au

What will happen to my information?

By clicking on 'I have read the Participant Information Form and consent to participate in this evaluation', you are agreeing to take part in the evaluation of *Eating Disorders and Neurodivergence: A Stepped Care Approach*.

We will **collect** information about you in ways that may identify you.

We will **store** information about you in ways that will not identify you.

We will **report** and **publish** information about you in ways that will not identify you. For example, in a publicly available evaluation report or presentation at a conference using de-identified group data.

We will keep your information for 5 years or until we no longer need it after the project is completed. After this time, we will destroy all your data. In addition, we will take reasonable steps to destroy or de-identify your information when we have been directly instructed by you to permanently remove or suppress your information.

The storage, transfer and destruction of your data will be undertaken in accordance with the [Butterfly Foundation Privacy Policy](#). Your information will be stored electronically on a secure, password-protected OneDrive only accessible by the approved research staff.

The personal information you provide will be handled in accordance with the Privacy Act 1988 (Cth) (Privacy Act), the Privacy and Data Protection Act 2014 (Vic) and other relevant Australian and state laws in relation to the management of personal information.

You have the right to access the personal information about you and the right to request correction and amendment of it. NEDC will share a summary of the findings from the evaluation at the request of the participants and provide an opportunity for feedback.

Will I hear about the results of the study?

We will let you know about the results of the study through communications sent out via NEDC's member database. Should you wish to become an NEDC member please [click here](#).

As an NEDC member, you have the opportunity to become part of an eating disorders network: a community of people with lived experience, expertise or an interest in eating disorders through which you will learn, contribute and engage in project activities. Membership is free.

Should you not wish to become an NEDC member, please contact the project team via emma.spiel@nedc.com.au with your email address and we will send you a copy of the results.

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 can only withdraw your responses if we can link who you are with your questionnaire responses (i.e., completed the items that state your name and/or email).

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

Who can I get in touch with about the research?

If you have any questions or would like to speak with the research team, please use the contact details below.

Name/Organisation	Position	Email
Emma Spiel (NEDC)	Workforce Development Coordinator	emma.spiel@nedc.com.au

Should you have concerns about your health and/or wellbeing or the health or wellbeing of a loved one who may be experiencing disordered eating, body image concerns or a suspected eating disorder as a result of participating in the evaluation you may contact the following helplines for immediate wellbeing support and information:

Eating Disorders Information:

- [The National Eating Disorders Collaboration](#)
- [Inside Out Institute](#)

Eating Disorders Information and Support:

- [Butterfly National Helpline](#)
- [Eating Disorders Families Australia](#)
- [Eating Disorders Victoria](#)
- [Eating Disorders Queensland](#)

Beyond Blue

Telephone (**1300 224 636**) 24 hours/7 days or chat online 3 pm to 12 am AEST/7 days.

For more information: www.beyondblue.org.au/get-support/get-immediate-support

Lifeline

Lifeline offers crisis support by telephone 24 hours/7 days (**13 11 14**) or chat online 7 pm to 12 am AEST/7 days.

For more information: <https://www.lifeline.org.au/gethelp/get-help-home>

Butterfly Foundation

Call (**1800 33 4673**), email the Helpline, or use the webchat between 8 am and 12 am AEST/7 days.

For more information: <https://butterfly.org.au/get-support/helpline/>

1800RESPECT

1800RESPECT provides free support for victims of sexual and/or domestic violence. Telephone (**1800 737 732**) and online chat available 24 hours/7 days.

For more information: <https://www.1800respect.org.au/>

Kids Helpline

Kids Helpline is a free and confidential 24/7 online and phone counselling service for young people aged 5 to 25 (**1800 55 1800**).

For more information: <https://kidshelpline.com.au/>

Autism Connect

Autism Connect is a free, national autism helpline, providing independent and expert information over phone (**1300 308 699**), email, and webchat.

For more information: <https://www.amaze.org.au/autismconnect/>

QLife:

QLife (1800 184 527) provides free, Australia-wide anonymous, LGBTI peer support for people wanting to talk about a range of issues including sexuality, identity, bodies, feelings or relationships.

For more information: <https://www qlife.org.au/resources>

Rainbow Door:

Rainbow Door (1800 729 367) is a free specialist LGBTQI+ helpline providing information, support and referral to all LGBTQI+ Victorians , their friends and family.

For more information: <https://www.switchboard.org.au/resources>

In case of an emergency, [call 000](#).