Participant Information Statement

Research Study: livED – A web platform for collecting varied format survey data about experiences from people with eating disorders

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1. What is this study about?

People have different experiences of eating, exercise, and body image, different experiences about seeking help and treatment, and different journeys through it all.

livED is a new uniquely designed web-based platform and is a place to share your journey, in the way you want to share it, to help us understand your experience, what has been helpful, and what you think should be different, to help inform health systems and research.

livED is the first of its kind in mental health research and provides the opportunity for many people to contribute to the research conversation in an open, ongoing, inclusive and creative way, to share past and current experiences while engaging in regular progressive data collection, with the intention to better inform our understanding, clinical awareness and health care practices.

In this study, we aim to trial the livED, to test the user experience, to connect with people in the community not usually involved in clinical research, and to consider novel and creative ways to capture health experiences.

A second part of this study will ask participants to consider whether they would consent to their experiences being linked to their health system data so researchers can gain more insights into health system usage, efficiency and effectiveness.

Additionally, people will be asked whether they would like to find out about more research opportunities in the field of eating disorders with the aim of linking people to innovative, progressive, engaging studies aimed at improving the lives of people with lived and/or living experiences of eating disorders, and that of their carers, families and supports.

We are inviting anyone who has a lived experience of disordered eating behaviours, body shape or weight concern, excessive exercise, eating disorders, or related experiences, past or present, to participate and share their story.

Please read this participant information sheet to find out more. Contact information is at the end of the sheet if you would like to know more or ask questions. Taking part is voluntary.

2. Who is running the study?

The researchers conducting this study are:

- Prof Sarah Maguire (Chief Investigator), Director at InsideOut Institute, University of Sydney & Sydney Local Health District
- Dr Jane Miskovic-Wheatley (Principal Investigator, PhD student), Research Stream Lead at InsideOut Institute, University of Sydney & Sydney Local Health District
- Mr Daniel Rogers (Co-investigator), Digital Stream Lead at InsideOut Institute, University of Sydney & Sydney Local Health District
- Dr Sabina Vatter (Co-investigator), Research Officer at InsideOut Institute, University of Sydney & Sydney Local Health District
- Dr Shu Hwa Ong (Co-investigator), Research Officer at InsideOut Institute, University of Sydney & Sydney Local Health District
- Ms Emma Bryant (Co-investigator), Research Officer at InsideOut Institute, University of Sydney & Sydney Local Health District
- Dr Patrick Eades (Co-investigator), Digital Consultant at InsideOut Institute, University of Sydney & Sydney Local Health District
- Dr Morgan Sidari (Co-investigator), Postdoctoral Researcher at InsideOut Institute, University of Sydney & Sydney Local Health District & QIMR Berghofer Medical Research Institute

Dr Jane Miskovic-Wheatley is doing this study as part of her PhD at The University of Sydney supervised by Professor Sarah Maguire.

This study is funded by the Australian Government Department of Health and Aged Care National Health and Medical Research Council MRFF Million Minds Mission as part of MAINSTREAM: The Australian Centre for health system research and translation in eating disorders project.

3. Who can take part in the study?

We are seeking people who:

- Are 16 years or over
- Have a self-reported past or current lived experience of eating disorder symptoms, whether formally diagnosed or not
- Have access to a computer, mobile or tablet device via internet connection,
- Able to read and respond in the English language.

It is not important whether you have (or have had) eating disorder symptomatology that is mild or not causing you any issues, your experiences are very valuable.

4. What will the study involve for me?

To take part in this study, please head to the study website (www.lived.org.au) and click '***Participate***'. This will lead you to the livED study platform where you will be asked to consider the details of the study and consent.

Consent to take part in the livED study (required)

This will include creating a user profile, completing a brief background survey, and consent to receive ongoing communications from the research team inviting you to complete an update survey every 6 months. You will also have access to the livED platform where you can share your experiences in different ways, when and how you like, including journal entries, verbal entries, short surveys, images, and more.

If you would like some time to consider your involvement and ask questions, you can enter your email address and we will send you a reminder 7 days later, at which time you can decide to participate, consider at a later stage, or not participate. Either way, we thank you for your consideration.

In addition, you will be invited to join a mailing list to find out about other innovative research opportunities. There are many other studies aimed at improving the lives of people with a lived experience of an eating disorder, and the lives of their communities, which could be of interest to you. Please note you are only consenting to being notified about future research opportunities, whether or not you engage with or participate in any research study or studies will be a matter for you at the time. Further, consenting to joining the mailing list is optional and if you decide not to consent to it, you may still proceed to profile creation and access the livED platform.

Consent for your data to be linked with health services (optional, open to those living in Australia only).

Research has shown that many people with a lived experience of an eating disorder, whether formally diagnosed or not, may access a variety of healthcare services for a variety of physical and mental health reasons, and this study aims at understanding and improving both access to and the experiences people with eating disorders have in health services.

By consenting to data linkage, the research team will work with national and state-based Data Linkage Units to connect your health records to your shared experiences on the livED platform. These records include but are not limited to: Pharmaceutical Benefits Scheme records, Medicare Benefits Schedule records, hospital admissions, emergency department presentations, death and disease registers, and aged care datasets.

If you consent to data linkage, the only additional step you need to take is to enter your current residential address and date of birth on the livED platform. This information will be kept separate to any of your responses moving forward and is purely for data linkage processes. Your confidentiality and privacy will be protected at all times. Please note the

Data Linkage is optional and if you decide not to consent to it, you may still participate in the livED study.

After consent

Once you have completed the consent process, you will be invited to complete basic demographic information (e.g., month/year of birth, postcode/geographical area type, gender identity, etc.). Completing consent and demographics should take approximately 5-10 minutes.

You will then be directed to complete a set of short, standardised measures asking about mental health, quality of life and eating behaviours, which should take about 20-30 minutes.

We will kindly ask you to complete this set of measures every 6 months at which time you will be sent an invitation via email. You will receive up to two reminder emails if we notice that you have not completed the set within three weeks.

On occasion, no more regularly than 3-month period, we will invite you to complete other measures that may capture more of your experiences, however, these are optional.

5. Can I withdraw once I've started?

Participating in this study is entirely voluntary and you do not have to take part in it.

If you decide to participate in the study and then change your mind you can withdraw at any time and choose to withdraw the information you have already provided by sending a written request within 1 month of the date of this correspondence to the study team on livedstudy@sydney.edu.au (please note, once data analysis has commenced, the data will be locked and can no longer be withdrawn, nor it can't be withdrawn if the de-identified group data has been included in presentations or publications).

If you decide to withdraw, we will stop collecting information from you. Any information that we have already collected will be kept in our study records and may be included in the study results in de-identified format.

Your decision will have no impact on your current or future relationship with the researchers or anyone else from the InsideOut Institute for Eating Disorders, The University of Sydney, or any health district within NSW Health.

6. Are there any risks or costs?

We do not anticipate any discomforts or risks associated with participation in this study. Because the livED platform addresses personal circumstances and experiences, the main risk is that some participants may experience emotional discomfort or distress when answering the study questions or completing other entries on the platform. In addition, there may be risks associated with this study that are presently unknown and unforeseeable.

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 Mental Health Access Line for NSW at 1800 011 511, QLife 1800 184 527, or Lifeline at 13 11 14 for crisis support. If you live outside of Australia, please make sure you are aware of your local support and crisis organisations.

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

7. Are there any benefits?

There will be no direct benefits for you as a participant in this study as there are no study interventions. However, we hope that by conducting this study we will get a deeper understanding of the lived and living experiences of people with eating disorder symptomatology, which will be supported by the health records helping us to get a better understanding of the usage of health care systems including community care, emergency department or hospital admissions. We acknowledge the time and effort it takes to complete the entries on the livED platform. We hope this study will provide valuable insight into the experiences and needs of people with eating disorders and provide us with much needed feedback from users of the system to improve it.

We do foresee some indirect benefits from participating in the livED project, as previous studies have reported benefits from the experience of recalling and sharing personal experiences in a regular and engaging way. As livED can be accessed at any time and people can contribute their past and present experiences in ways that they choose, livED can be used as a tool to connect personal stories together. It also provides an opportunity to learn about other research opportunities which may novel treatments and innovations aimed at improving the lives of people with lived experience of eating disorders and which participants in these studies may benefit from.

8. What will happen to information that is collected?

By giving your consent, you agree to us gathering information about you for this study.

Any identifiable information you share with us will be securely stored on the University of Sydney’s secure web-based data management platform designed to meet all requirements for online privacy and confidentiality of user data and will only be disclosed with your consent unless we are legally required to release information. Data is secured, and privacy and confidentiality of your data is maintained at all times. All the information collected from you for the study will be treated confidentially. Unique identification codes will be used to protect your identity when storing data.

Data collected for research purposes will be stored in a separate table with no personal identifying information and only re-identifiable by a unique identification code. Researchers will only receive anonymous data with no identifiers. Access to the database which links identifiers to identification code will require a pre-authorised login and password, known only to the Chief Investigator and a select number of researchers nominated by the Chief Investigator. Data will be retained indefinitely and not destroyed.

The data you provide on the platform, including diary entries, short response format, Likert scales, standard health measures, recordings and images, and links responses to the user profile, will be analysed by the investigators at the InsideOut Institute. We plan to publish the findings of this study. All data for use in reports, journal publications and presentations will be deidentified (meaning that you/your information will not be identifiable in these reports, publications, or presentations). The deidentified data collected will be stored for 7 years in a secure network data management system compliant with the University of Sydney Research Data Management Policy and then all files will be permanently destroyed in accordance with University's policy.

9. Will my data be used in future studies?

Sharing research data is important for advancing knowledge and innovation. A de-identified set of the data collected in this study may be made available for use in future research. Any stored data that is used for related or future research, defined in the National Statement on Ethical Conduct in Human Research (2023), will first be reviewed and approved by an appropriately constituted Ethics Committee. The results of this study and de-identified data may be shared in the future with national and international collaborators. Please be assured that your identity will not be revealed at any time and that details of individual participants will not be identifiable if data is pooled with other institutions.

10. Will I be told the results of the study?

You have the right to hear the results of this study. Please indicate in the consent form if you would like to receive the study results once the study has been finalised by providing your contact details on the consent form. This feedback will be provided as a plain language summary.

11. What if I would like further information?

After reading this information, a Researcher will be available to discuss it with you further and answer any questions you may have. If you would like to know more now or at any stage during the research program, please feel free to contact researchers Jane or Sabina at livedstudy@sydney.edu.au.

12. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [HREC Approval No. 2023/895] in accordance with the *National Statement on Ethical Conduct in Human Research (2023).*

If you have any concerns about the study's procedures or would like to make a complaint to someone not involved in the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

Thank you for your consideration
This information is for you to keep