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| **PLAIN LANGUAGE STATEMENT AND CONSENT FORM** | Deakin University logo |

TO: Participant

**Plain Language Statement**

Date: March 2025

Full Project Title: Who and what helps people with intellectual disability manage obesity?

**Principal Researcher:** Associate Professor Joanne Watson

**Student Researcher:** Samantha Lilly

**Associate Researcher(s):** Professor Angela Dew, Professor Adrian Cameron

**This research project is part of a PhD study by Deakin University student, Sam Lilly. Sam is being supervised by Associate Professor Jo Watson, Professor Angela Dew and Professor Adrian Cameron.**

# Your consent

This document, which is called a ‘Plain Language Statement’ contains detailed information about what you will be asked to do in this research project. The purpose of this document is to explain to you as clearly as possible what being part of this project means so that you can make a fully informed decision about joining or not. Your participation in this activity is voluntary. This means you don’t have to do it if you don’t want to.

We will ask you throughout the project whether you still consent to be involved. This is called ongoing consent.

You can ask questions about any information in this document. You can talk about being part of this project with a relative, friend or support worker. Once you understand what the activity is about and if you agree to take part in it, you can consent to participate by signing and returning this form to the research team using the contact details provided.

You are encouraged to download and keep a copy of this document for your records. You can do this by downloading the document and saving it on your computer.

Someone you trust might be helping you decide whether to participate. This kind of support is important. However, only you should decide if you want to participate in this study. No one else can force you to participate.

# Purpose and background

The purpose of this research is to hear from you about who affects your choices about what you eat and your exercise. We also want to know how these people affect these choices.

# What you will be asked to do

If you decide to be part of this research project you will be asked to come to 1 or 2 in-person meetings with Sam. The meetings will be in a place that is best for both you and Sam. You will not need to bring anything with you to the interview. You may bring a support person if you like. These meetings will be audio recorded on a recording device and will take no longer than an hour for each interview. Please allow an additional hour to read and understand the documentation and questions if you have any

During the session, we can include some arts-based activities such as body mapping. Body mapping involves tracing your body outline onto a large sheet of paper. We then decorate the outline with things that are important to us. I will then ask you questions about what you have drawn, and you can tell me. During this interview you will be asked about who influences what you eat and your physical activity. You will also be asked how these people influence these activities – in a helpful or unhelpful way.

If you decide to stop being part of the research project, that is ok. You just need to tell us.

# Data and privacy

Your privacy is very important. All the information you tell us about will be kept confidential, except where we must tell someone else because you have told us something that is illegal.

Your name and email address will be recorded by researchers at Deakin University only so we can contact you. These details will not be shared with anyone else. The research team will also ask you some questions such as your age, living arrangements, why you think you have an intellectual disability and why you think you are obese. After your interview we will send a video summary of what you told us. You can add or delete any information you want to.

All the information you give us will be kept in a secure place. Only the research staff working on this project will be able to see it. Deakin University must keep the information you give us for five years after we write about it. This is a rule set by Deakin University. Identifiable data will be kept in a separate folder on the Deakin RDS to the de-identifiable data.

We will not use your real name or any other identifying details about you when we write or talk about the research. You can choose a fake name (pseudonym) which we will then use instead of your real name. You can ask us to send you a copy of any articles we publish about the research.

# Risks and potential benefits

You are not expected to receive any direct benefit from being part of this project (eg, health advice or health care). Being part of this project will help us to better understand who influences eating and exercise choices for people with intellectual disability who are obese and how these people influence these choices.

If you become upset while talking about obesity and intellectual disability, we can stop the interview, and you can choose whether to continue with the interview or not. If you wish, we will give you the names and contacts for organisations that you can talk to (e.g., BeyondBlue and Lifeline). The research team will also be in touch with you between the interviews in case you require any support or refer you to services.

The research activity follows the National Statement on Ethical Conduct in Human Research. This means that we respect you in every part of the research and follow ethical guidelines. We have procedures to uphold the rights, safety, and well-being of all research participants. We will make sure we explain to you what we are doing and why we are doing it.

This research project will be monitored in accordance with the National Statement and Deakin University is required to monitor all human research which it conducts. All projects must submit annual and final reports. The following information must be included in annual reports: Progress to date, or outcome in the case of completed research; Maintenance and security of records; Compliance with the approved proposal; and compliance with any conditions of approval.

# Expected benefits to the wider community

It is hoped that this study will provide insight into what role other people play in your food choices and exercise you do. This will inform policy decisions and health information for those living with obesity and intellectual disability.

# Reimbursement and funding

Deakin University has received funding from a non-government organisation, Impact Obesity to support this research to the value of $20,000. You will receive a gift card valued at $50 for each interview you undertake.

# Withdrawal

Being part of this project is entirely your choice, and you may withdraw prior to data analysis. However, once all the information has been analysed and your name removed, we cannot withdraw the information you give us, as we won’t know who said what.

To withdraw from this project, you can email or phone the researchers and they can help you complete the withdrawal form. Withdrawing from this project will not have any bad effect on your relationship with Deakin University or your support services.

# Data sharing

At the conclusion of the research, the results will be shared via a full project written summary sent to participants. The de-identified results will also be presented at relevant conferences, and in peer-reviewed publications. No identifying information will be shared in any of these formats.

# Contact

**Principal Investigator:** Associate Professor Joanne Watson
Email: joanne.watson@deakin.edu.au
Phone: +61 3 925 17189

**Research Student:** Samantha Lilly, PhD Candidate
Email: slilly@deakin.edu.au

Deakin University, Melbourne Burwood Campus
School of Health and Social Development
221 Burwood Highway, Burwood, VIC 3125

# Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Human Research Ethics Office, Deakin University,

221 Burwood Highway, Burwood Victoria 3125,

Telephone: 9251 7129

Email: research-ethics@deakin.edu.au

Please quote project number [2024/HE000837]***.***

If you wish to read more about ethical conduct in human research, please see here: [National Statement on Ethical Conduct in Human Research 2023 | NHMRC](https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023)

 **PLAIN LANGUAGE STATEMENT AND CONSENT FORM** 

**TO:** Participant

**Consent Form**

**Date:** March 2025

Full Project Title: Who and what helps people with intellectual disability manage obesity?

**Reference Number:** 2024/HE000837

[ ]  I understand and have a copy of the attached Plain Language Statement *and I agree to participate.*

I consent to participate in the following:

[ ]  One interview

[ ]  Two interviews

[ ]  I understand my name will not be used in any publication or presentation of the research.

[ ]  I understand I will be audio recorded.

[ ]  I understand I can review the interview transcripts or recording.

Participant’s Name (printed) …………………………………………………………………………………………………

Signature ……………………………………………………… Date …………………………………………………….

**Please post or email this form to:**

**Research Student:** Samantha Lilly, PhD CandidateEmail: slilly@deakin.edu.au

Deakin University, Melbourne Burwood Campus
School of Health and Social Development
221 Burwood Highway, Burwood, VIC 3125

**PLAIN LANGUAGE STATEMENT AND CONSENT FORM** 

**TO: Participant**

**Withdrawal of Consent Form**

*(To be used for participants who wish to withdraw from the project)*

**Date:** March 2025

Full Project Title: Who and what helps people with intellectual disability manage obesity?

Reference Number: 2024/HE000837

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[ ] I hereby wish to WITHDRAW my consent to participate in the above research project and understand that such withdrawal WILL NOT change my relationship with Deakin University or my service provider*.*

Participant’s Name (printed) …………………………………………………………………………………………………

Signature ………………………………………………………………. Date ……………………………………………………..

**Please post or email this form to:**

**Research Student:** Samantha Lilly, PhD CandidateEmail: slilly@deakin.edu.au

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