

APPENDIX A

PARTICIPANT INFORMATION SHEET – CHILD

(for users 12-13 years of age)

Title: An Online CBT-based Self-Help Program For Eating Disorders: Skilled Pilot Evaluation

Principal Investigator: A/Prof Sarah Maguire, Director, InsideOut Institute for Eating Disorders

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This information page has been put together to help you choose if you would like to take part in our research.

(1) What is this study about?

We are researchers at the InsideOut Institute for Eating Disorders. We are trying to see how an online self-help program, *Skilled*, that is based on a therapy called Cognitive Behavioural Therapy (CBT) can help people with eating difficulties. We also want to understand whether people with eating difficulties find *Skilled* helpful and easy to use.

Finding out these things will help us to understand why people with eating difficulties may find it hard to use and access online. This can tell us how we can improve *Skilled* to make it easier for people with eating disorders to get the help they need.

(2) Do I have to be in the study?

No, you don't. If you say no, that is okay. You and your parents/carers will decide if being in this study is the right thing for you.

Even if you take part at the start of this study and change your mind later and don't want to part of the research anymore, that is okay too. All you need to do is tell the researcher or your parents/carers that you don't want to take part anymore. We will still look after you in the best way possible.

(3) What will happen to me in the study?

To see if you are suitable to take part in the study, we will give you a few online questions (around 5 minutes long) and a researcher will talk to you on the phone (around 30-60 minutes long) about your eating patterns, and your previous and current mental health experiences. If you are hurting yourself or plan to hurt yourself, we will encourage you and your parents to take you to a counsellor and will not ask you to take part in the study. If you are okay to do the study, we will give tell you how to sign up to the study and start the program.

Before you start the program, we will need a General Practitioner (GP) to check your physical and medical health and return a signed form to the researchers. This form will tell us that the GP thinks you are okay to take part in the study, and they will keep checking on your health. Please ask your parents/carers to give us the contact details of the GP that you see.

Once we see that you are okay to participate and you agree to take part in the study, we will give you some online questionnaires before you start the *Skilled* program.

You can choose between two options for how you would like to complete *Skilled*, which has 11 modules. Everyone who takes part in the study must complete the first 5 modules, but for the other 6 modules, you can choose to: (1) do the **full program**, that is all 6 modules in order, or (2) **choose your own adventure**, where you can complete as many of the 6 modules as you'd like, in any order. Every week, the module that comes after the one you previously completed will be unlocked – whether you pick the first, or second, option.

Once you choose how you want to complete the modules, you will be randomly placed into one of two groups: 1) **engagement help**: If we notice you're having trouble staying involved, a clinician will reach out to offer support, or 2) **no engagement help**: we don't track how you're engaging and therefore we won't take any action or contact you.

Just so you know, the engagement help will be offered before you stop taking part in the program. It's different from what happens if someone actually stops. No matter which group you're in (with or without engagement help), if you don't complete any tasks in the *Skilled* program for two or three weeks, someone will reach out to check in and offer support.

We will ask you questions at different times in the study:

Baseline – Before you start the program, we will ask you some questions (around 20 minutes long) about your background and general health, before you can start the program.

Weekly – Before starting each module, you will be asked to complete questionnaires (5-10 minutes long) that check your safety and eating behaviours.

Mid-treatment – When you finish the first 5 modules, you will be asked to complete questionnaires about your eating behaviours and symptoms, as well as overall wellbeing, mood and stress levels.

Post-program – When you finish modules, you will again be asked about eating behaviours and symptoms, as well as overall wellbeing, mood and stress levels. You can also choose to take part in a 45-minute interview that helps us know how we can improve *Skilled*.

3-month, 6-month, & 12-month follow-up – After you finish *Skilled*, we will ask you using email if you would like to complete some follow-up questions (~ 20 minutes long) at different times. These questions ask about how the program has impacted your eating patterns, psychological distress, and quality of life over time.

You will be sent two email reminders for each questionnaire.

To make sure you're safe and well, your doctor (GP) will get a report every two weeks about your health based on the most recent questionnaires you've filled out. If there are any worries about your safety, your doctor might talk to the research team, or they might contact your doctor. We'll also reach out to your parent or guardian if we're concerned. If we're ever worried about your safety, we'll always try to talk to you first.

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

The weekly questionnaires will take you around 5-10 minutes, while the remaining questionnaires may take you around 20 minutes to complete. This means that over the 12-month period of the study, it may take around 6.5 hours.

(5) Who can take part in the study?

People who show eating difficulties, which will be checked by researchers when they call you before the study, can take part in the research. To take part, you will also need to access a computer or device (like a phone) that has internet connection, live in Australia, not be pregnant, not plan to harm yourself in any way, not have recently lost or gained weight quickly, or be very underweight. You also should be medically stable,

not be seeing someone at the moment to help your eating difficulties, not be using any stimulant medication, not been diagnosed with Avoidance/Restrictive Food Intake Disorder, Pica, Rumination Body Dysmorphia, or Psychosis, and be at least 12 years old.

If you are not sure what some of these terms means, or whether you have any of these features, feel free to ask your parents/carers or the research team.

(6) Is there anything that could make me upset if I take part in the study?

We do not expect that being part of this research will upset you. You will be asked for your GP to complete a standard medical test on you, like checking your heart rate, and doing a blood test. It is not likely to that you will be physically uncomfortable or upset from this, or the questions we ask you in the study.

If anything you talk about during the study makes you upset, you can stop the study. Your parents/carers will be told and you will be given the names of people you can talk to about what is making you upset, if that is what you want to do. The researchers can help you to do that. You can talk to your GP if you feel upset at any time in the study. There are some other professionals who you can call if you feel upset, which are:

- Kids Helpline - 1800 551 800
- Butterfly Foundation (they specialise in helping people with eating difficulties – 1800 334 673
- The Mental Health Access Line for NSW – 1800 011 511
- Lifeline (if you feel very distressed) – 13 11 14

(7) Are there any benefits of taking part in the study?

We hope this study can provide evidence that *Skilled* is helpful in improving people's eating difficulties and show ways that we can improve the information and access to *Skilled*.

If you finish the study and complete the 3-month follow-up questions, you could win one of 10 gift cards which are worth \$100 each. When you start the study, you will be given a participant code number, which will go into a draw that we randomly pick from 10 times. The people whose numbers that were drawn will be given gift cards.

(8) What will happen to my information?

Your information will only be used by the researchers. You can tell them whatever you want and no one will know that it came from you. The only time the researchers would have to tell someone is if anyone hurt you or upset you in any way. The researchers would also have to tell someone if you said you might hurt yourself or someone else.

(9) Who can answer my questions?

If you have any questions, you can call the research team on 02 8627 5690 or email them on skilledstudy@sydney.edu.au.

You can also ask your parents/carers to talk to us.

This information sheet is for you to keep.