

## Participant Information Sheet

Study title:	Determining the acceptability, safety, and feasibility of a self-management memory reconsolidation program in the Zealand context.
Lead investigator:	Dr Kelly Jones (phone 021 246 0587)
Locality:	Auckland, Hamilton, Waikato and Bay of Plenty areas, New Zealand
Ethics committee:	This study has been approved by the Auckland University of Technology Ethics Committee on 08/04/2024, AUTEK Reference number (23/344)

### AN INVITATION

You are invited to take part in a study looking at an alternative way to help people who have experienced an emotional event in the past and who would like to stabilise their emotions and enhance their well-being. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. When we next speak, we will go through this information with you and answer any questions you may have. We will also ask you some questions over the phone to check that you are able to take part in this study. You do not have to decide today whether (or not) you will participate in this study. Before you decide you may want to talk about the study with other people, such as family/whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to provide your consent. There are three ways that you can consent to take part in this study. If you meet with a researcher in-person, then you can provide your consent by signing a hard copy consent form. You will be given a copy of this Participant Information Sheet and the Consent Form to keep. Or, if you prefer, you can tell us by phone or online (via Zoom or similar) that you consent to take part. In this case, the conversation will be recorded, either by video or audio. Any video and audio recordings of consent will be stored in a password-protected file. You will be emailed a copy of the video or audio recording for your consent using a password-protected zip-file.

This document is 9 pages long. Please make sure you read and understand all the pages.

## WHO ARE WE AND WHAT IS THE PURPOSE OF THE STUDY?

We are a team of people who work at the Auckland University of Technology. The purpose of the study is to learn about a potential alternative way to help people support their well-being following an emotional event/s in the past. There is evidence to show that emotions are stored with our memories and can affect the health of our bodies and our physical, mental, and emotional well-being, even long after the emotional event. Examples of an emotional event that may impact our well-being might include recent or childhood changes in health, relationships, moving away from family and friends and losing loved ones.

Some people find that directly talking about emotional experiences can be helpful. However, not everyone will feel comfortable talking with others about their experiences that led to having these emotions. In this study, you will not be asked to talk about any past emotional event/s. Instead, we are looking at a different way that might help people to support their well-being without having to directly talk about past emotional events. This approach examines the potential of gaining new unexpected perspectives on past emotional events that may help to reduce the intensity of emotions (e.g., anger, frustration, fear, etc) stored with particular memories.

The main aim of the research is to find out how to study an online program called 'Your Hidden Mind'. We would like to know if it is feasible for people to complete the online program and the study questionnaires. To find out more about the program, it is also important to consider the online program alongside other things that people might do to manage their well-being (e.g., walking, reading, counselling, talking with a friend, etc). This study will help planning for further research to test whether the program might help people improve their general well-being.

This study has been approved by the Auckland University of Technology Ethics Committee on 08/04/2024, AUTEK Reference number (23/344).

## WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY AND HOW WAS I IDENTIFIED?

You have been invited to participate because you have heard or read about the study and told us that you would like to know about this study.

We are looking for adults who live in the community and have experienced an emotional event/s in the past that is/are impacting their well-being, but who are otherwise well. You may be able to take part in this study if you are:

- are aged 18 years or older
- have experienced an emotional event/s in the past
- living in the community in Auckland, Hamilton, Waikato or Bay of Plenty areas
- able to converse in English
- able to provide informed consent
- have access to a home computer and internet, and
- you would like to stabilise your emotions to enhance your well-being

You will not be able to take part in this study if you:

- have a serious medically unstable condition or other health condition that would make it difficult to fully take part in the study
- are currently under the care of community mental health services or experiencing a mental health crisis
- have been hospitalised in the past year due to mental health crisis, self-harm or suicide
- have significant disability that would interfere with cellular health (e.g., Parkinson's or Alzheimer's disease, heart disease, diabetes)
- have significant cognitive or behavioural impairments (e.g., agitation, major depression), and/or
- are currently participating in a clinical trial.

### WHAT IS THE 'YOUR HIDDEN MIND' PROGRAM?

'Your Hidden Mind' is an online program for mind-body health and personal well-being. The program uses unique rhythmic combinations of words specifically written to invoke thoughts and memories from your past, often held subconsciously (or hidden in your mind). These combinations of words are designed to help people trigger and reprocess their memories (known as memory reconsolidation) and feelings to gain more insights, perspective, and closure. These word combinations, called Rhythmical Activating Prose (or RAPs) are a little like reading or listening to short ditties or poetry (but a little bit different as they focus on common life events and challenges by helping you to see relationships between different situations). Each RAP aims to stimulate hidden (or subconscious) thoughts and memories of past emotional events that might be driving unwanted behaviours and pains and impacting your well-being.

Here is a short example of part of a RAP –

*"I've been on a journey since the day I was conceived, a fabulous, amazing, exhilarating... Exciting trip, but also at times a tedious, dramatic, traumatic, stressful or depressing odyssey! What a time I've had, so many ups & downs, ins & outs, so many unexpected twists & turns What would my life have been without all that?...Well, I can't possibly imagine, as this is all I know".*

### WHAT WILL HAPPEN IN THIS RESEARCH?

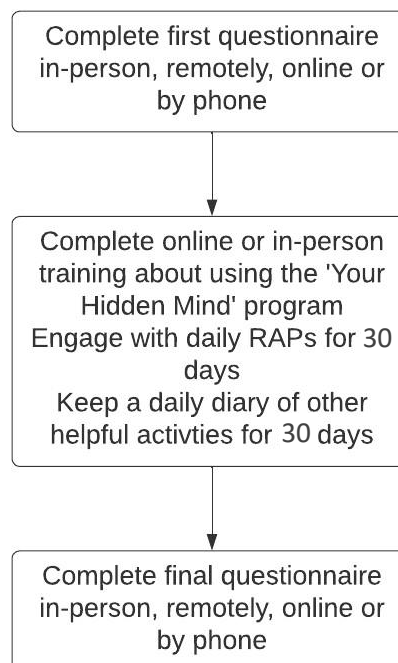
When a researcher speaks with you again by phone, you will have the opportunity to ask any questions you may have about the study. If you would like to take part, you will then be asked some questions to check that you are eligible to participate in the study. If you are interested and eligible, a time will be arranged for a member of the study team to meet with you in-person or online or by phone. Once your consent to take part has been recorded, in writing or online or by phone, you will be asked to complete the first study questionnaire. This first questionnaire will ask some questions about your current circumstances (such as living arrangements, employment), and about your health and well-being and will take about 20-30 minutes to complete. This questionnaire can be self-completed online using a computer and internet. Alternatively, you can make a time to meet with a researcher online or on the phone or in-person to talk through the questionnaire together. All researchers who

will be asking these questions have been specially trained for this study. If you like, you are welcome to have a support person/s with you while you complete the questionnaire. It is up to you whether (or not) you wish to read any further information about the program and its development. You will also complete a **Comparison Record** to track any changes in your thinking and memories over time. The researcher will provide you with a hard copy of this record. This record is for your information only and will not be shared with the study team.

### Initial training (~30 minutes)

After you complete the first questionnaire, the researcher will provide you with a username and password and show you how you can use your own computer or phone to access the 'Your Hidden Mind' program. Once you have logged into the program, the researcher will go through the '**Introduction**' section with you, including a section on '**How to Use the System**'. The researcher will also introduce you to a section on the website called '**How are you feeling? – YHM Dudes & Darlings**'. This section of the website

includes some graphics to help prompt you to think about how you are feeling before listening to or reading RAPs.



Then, the researcher will introduce you to the '**YHM RAP selector**' to show you how you can select RAPs to read or listen to. If you like, you can also watch a short YouTube video that is available on the website about how to use the program. There is also plenty of additional reading available on the website.

If the researcher meets with you in-person, they can help you to add a link to the program on the desktop of your computer, if that would be helpful. If you meet with the researcher online or on the phone, they can send you some instructions on how to do this if that might be helpful. Access to the program is free of charge for you throughout the study period.

### Daily RAPs (~20 minutes per day)

Once you are familiar with how to access the program, you will be invited to read or listen to 1-2 randomly selected RAPs two times each day for 5-days per week over the following 30 days. You can decide which 5 days per week you will be reading or listening to RAPs and which 2 days per week that you would like to take days off each week. RAPs can be read or listened to on your home computer or phone at a time that suits you. This will take about 20 minutes each day. You may also like to make some notes after listening to the RAPs about what you learned about new perspectives on your memories. If you choose to make notes, these will be for your information only and will not be shared with the research team.

### Diary (~5 minutes per day)

During the 30 days of listening or reading RAPs 5 days per week, you will also need to complete a brief diary each day of the types of things you have done each day to actively support your well-being and the duration of each activity. This might include, for example, going for a walk, meeting with a friend, reading, going to a counselling session, etc. We will give you a simple diary for recording this information.

### Total time (~13 hours over 4 weeks)

Taking part in the study will require about 13 hours of your time. This will include a total of 6-8 hours reading or listening to RAPs (20 minutes per day for a total of 20 days over a 30 day period), around 2.5 hours keeping a diary, and 2 hours for initial training on how to access and use the program and the two study questionnaires and Comparator Records.

About 6-weeks after you join the study, you will be asked to answer similar questions to those you answered at the start of the study. You will also be asked about how often you used the program during the study. Like the first questionnaire, these questions can be answered online or in-person or by using the phone or a computer. In total, you will be asked to complete two study questionnaires. The second questionnaire will also take about 20-30 minutes to complete. You will also complete another Comparison Record to track any changes in your thinking and memories over time.

Your responses to both questionnaires will be recorded using your unique participant number and stored in a secure way. All your responses can be linked using your participant number. Your data will not be used for any other purpose than for what has been specified in this information sheet. We aim to finish collecting data by the end of 2024.

## WHAT ARE THE POSSIBLE BENEFITS OF THIS STUDY?

You may not benefit directly from taking part in this study. Possible benefits are that you may understand more about associations between your memories and emotions. This insight may help to improve your general well-being. You may also learn about how to access relevant support services that may be helpful for supporting your well-being. Your participation and feedback will also help the developers of the program to make changes and improvements of the program and will help to inform future studies in this area.

## WHAT ARE THE POSSIBLE RISKS OF THIS STUDY?

There are some risks to taking part in this study. You may find it tiring or time consuming taking part in the daily activity and/or completing the questionnaires. You can take a break if you need to.

All our researchers receive training in asking sensitive questions and working with different types of people. Some of the questions asked in the study may make you feel upset about some aspects of your life, and/or may make you feel uncomfortable or embarrassed in some way. You do not have to answer any questions you do not wish to. If you need extra support during or at any time after the study, you may find it helpful to contact the following services:

**AUT Student Counselling and Mental Health** is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in

the research and are not for other general counselling needs. To access these services, you will need to:

- drop into our centre at WB203 City Campus, email [counselling@aut.ac.nz](mailto:counselling@aut.ac.nz) or call 921 9292.
- let the receptionist know that you are a research participant, and provide the title of the study and the name and contact details of the lead investigator that are stated on the first page of this Information Sheet.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

### **Mental Health Support & Counselling – Lifeline**

To speak to a counsellor please phone free 24/7 helplines:

Freephone 0800 LIFELINE (0800 543 354) or Freetext HELP (4357)  
Suicide Crisis Helpline 0508 828 865

### **National Depression Helpline**

Provides support 24/7, 365 days a year. Callers can talk to a trained counsellor who can discuss their situation and offer information, and if necessary, advice on local services:

Freephone 0800 111 757 or Free text 4202

### **Shine’s Domestic Violence Helpline**

Provides 24/7 helpline for adults and children to support safety & wellbeing

Freephone 0508 744 633 or access their chat service

### **Women’s Refuge Crisis Line**

Largest nation-wide organisation that supports and helps women and children experiencing family violence:

Freephone 0800 REFUGE (0800 733 843) or access their chat service

### **OutLine**

Rainbow mental health organisation providing support services across Aotearoa:

Freephone 0800 OUTLINE (0800 688 5463) or access their chat service

If any concerns about your general well-being arise during the study, then these will be discussed with you. We can provide support by making a referral to your family doctor on your behalf. If you or others are considered to be in immediate danger of harm, we will support your/their safety by phoning the emergency services (111) or the Crisis Assessment Team. If we are with you in-person or on the phone or computer with you, this phone call will be made while we are with you.

You will continue to receive care from your doctor and other health services. Your usual medical care will not be affected in any way by participating in the study, or by declining to participate or withdrawing from the study at any stage. Your participation in this study will be stopped in the unlikely event that any harmful effects appear or if the doctor feels it is not in your best interests to continue. Similarly, your doctor may at any time provide you with any other treatment he/she considers necessary.

If you are concerned about any aspects of the study you are free to contact the lead investigator or the Auckland University of Technology Ethics Committee to discuss any concerns. Contact details are available at the end of this information sheet.

## WHAT WILL HAPPEN TO MY INFORMATION?

During this study, the research team will record information about your study participation. This includes the answers you provide to our questions. You cannot take part in this study if you do not consent to the collection of this information.

### Identifiable Information

Identifiable information is any data that could identify you (e.g., your name, year of birth, or address). The following groups may have access to your identifiable information:

- Research staff (to contact you about the study).
- University study monitors, to make sure the study is being run properly and that the data collected is accurate.
- The ethics committees or government agencies from New Zealand if the study or site is audited. Audits are done to make sure that participants are protected, the study is run properly, and the data collected is correct.
- Your usual doctor, if any questionnaire responses provide any unexpected result that could be important for your health. This allows appropriate followup to be arranged.

Rarely, it may also be necessary for the study researcher to share your information with other people – for example, if there is a serious threat to public health or safety, or to the life or health of you or another person OR if the information is required in certain legal situations.

### De-identified (Coded) Information

To make sure that your personal information is kept confidential, information that identifies you will not be included in any report generated by the research team. Your information will be stored in a coded way using a participant study number that will be unique to you. Any survey responses that you provide will be stored in the same way. You may also be invited to take part in an interview. If you consent to take part in an interview, your responses will also be recorded in the same way (using your unique participant number). All your responses can then be linked using your participant number. The researcher will keep a list linking your code with your name, so that you can be identified by your coded data if needed. The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

### Security and Storage of Your Information

Your identifiable information will be held at the Auckland University of Technology (AUT University) during the study. Your coded information will be entered directly into electronic case record forms and stored on a REDCap secure database that is maintained by the University. All electronic information will be stored in password protected files. All storage will comply with local and/or international data security guidelines.

### Risks

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded information, there is no guarantee that

you cannot be identified. The risk of people accessing and misusing your information (e.g., making it harder for you to get or keep a job or health insurance) is currently very small, but may increase in the future as people find new ways of tracing information.

### Rights to Access Your Information

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected. Please ask if you would like to access any of your information, including any screening information, during the study. If you have any questions about the collection and use of information about you, you should ask the lead researcher, Dr Kelly Jones phone 021 246 0587.

### Rights to Withdraw Your Information

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

## **WHO PAYS FOR THE STUDY?**

The cost to you will be your time. That will include time for training on the program, daily activities for 28 days and completing two study questionnaires (one at the start and one near the end of the study). There will be no cost to you in accessing the program during the study period. There will be no travel costs to you as the questionnaires, any training and daily online program can be completed from your home.

Each participant will receive a \$20 food/fuel voucher (koha) each time you complete a questionnaire as a token of appreciation (total \$40). The online program will be freely available to you for 28 days.

## **WHAT ARE MY RIGHTS?**

The study files and all other information that you provide will remain strictly confidential, unless information is revealed that indicates you or someone else is at risk. No material that could personally identify you will be used in any reports or discussions about this study.

You will be able to access information collected about you as part of the study if you wish to do so. If any information that may be of benefit to you emerges during the study, we will contact you to let you know.

## **WHAT HAPPENS AFTER THE STUDY?**

Upon completion of the study your records will be stored for 10 years. Paper records will be stored by University personnel in a locked cabinet at AUT University in Auckland. All electronic information will be stored in password protected files. Any identifying information will not be shared outside of the research team without seeking your permission.

After 10 years all your electronic information will be deleted and paper forms will be shredded and destroyed with the university confidential waste.



## CAN I FIND OUT THE RESULTS OF THIS STUDY?

After we have looked at all data, we will send you a plain English summary of study results, if requested.

## WHO IS FUNDING THIS STUDY?

This study is being funded by a private Funder named Lavanya Nadarajah and is being undertaken by researchers at the Auckland University of Technology. There are no conflicts of interest to declare.

## WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns, or complaints at any stage, you can contact:

### Lead investigator

Any concerns regarding the nature of this project should be notified in the first instance to the lead investigator, Dr Kelly Jones, by emailing [kelly.jones@aut.ac.nz](mailto:kelly.jones@aut.ac.nz) or telephoning 021 246 0587

### Ethics Committee

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz) , 0921 9999 ext 6038.

### Cultural support

If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team Auckland and Waitematā District Health Boards Māori Research Committee) by telephoning 09 486 8324 ext 2324

Or,

**Te Puna Oranga** (Waikato DHB Māori Health Unit),  
Hockin Building, Level 1, Pembroke St, P.O. Box 934, Hamilton.  
Phone: 07 834 3644. Fax: 07 834 3619

***Please keep this for your information.***

***Thank you for interest in this study.***