

Rangatahi Information Sheet

The Trans-Tasman Internet-delivered Prevention of youth Suicide (TIPS) Study: Testing apps to reduce suicidal thoughts in young people and young adults.

We'd like you to take part in our research study! It involves using an app for 30 days and completing surveys. We are interested in your thoughts on the app. We want to make sure that apps recommended to young people are helpful, engaging and safe. We need people aged 16-to-24 years old who have experienced suicidal thoughts in the past 30 days. If you choose to take part, you will be randomly assigned one of the apps we're testing to try. We'd like the chance to tell you more about the study so you can decide if you want to take part or not.

Before you decide, you may want to talk about the study with other people, such as family, whānau or friends. Please feel free to do this. Please read all nine pages in this info sheet before you decide whether to participate or not.

What is this study about?

Young people/ rangatahi have many strengths and skills, but we know sometimes life can become challenging. When things get tough, some people sometimes think about suicide. We know that some young people prefer apps over face-to-face supports so making sure that the apps available to you are helpful and accessible is important. What we don't know is whether the apps available to young people/rangatahi help reduce suicidal thoughts.

Who are we?

We are a diverse research team based at the University of Auckland Waipapa Taumata Rau. We are passionate about supporting young people and young adults. We use a He Awa Whīria (braided rivers) bicultural collaborative approach. Please feel free to contact us! Our details are on Page 5 of this info sheet.

Who can participate in this study?

We are looking for young people and young adults to test our apps who are:

- between the ages of 16 and 24 years of age.
- have experienced suicidal thoughts in the last 30 days.
- own or have access to a smartphone.
- live in Aotearoa New Zealand or Australia.

What will happen in the study?

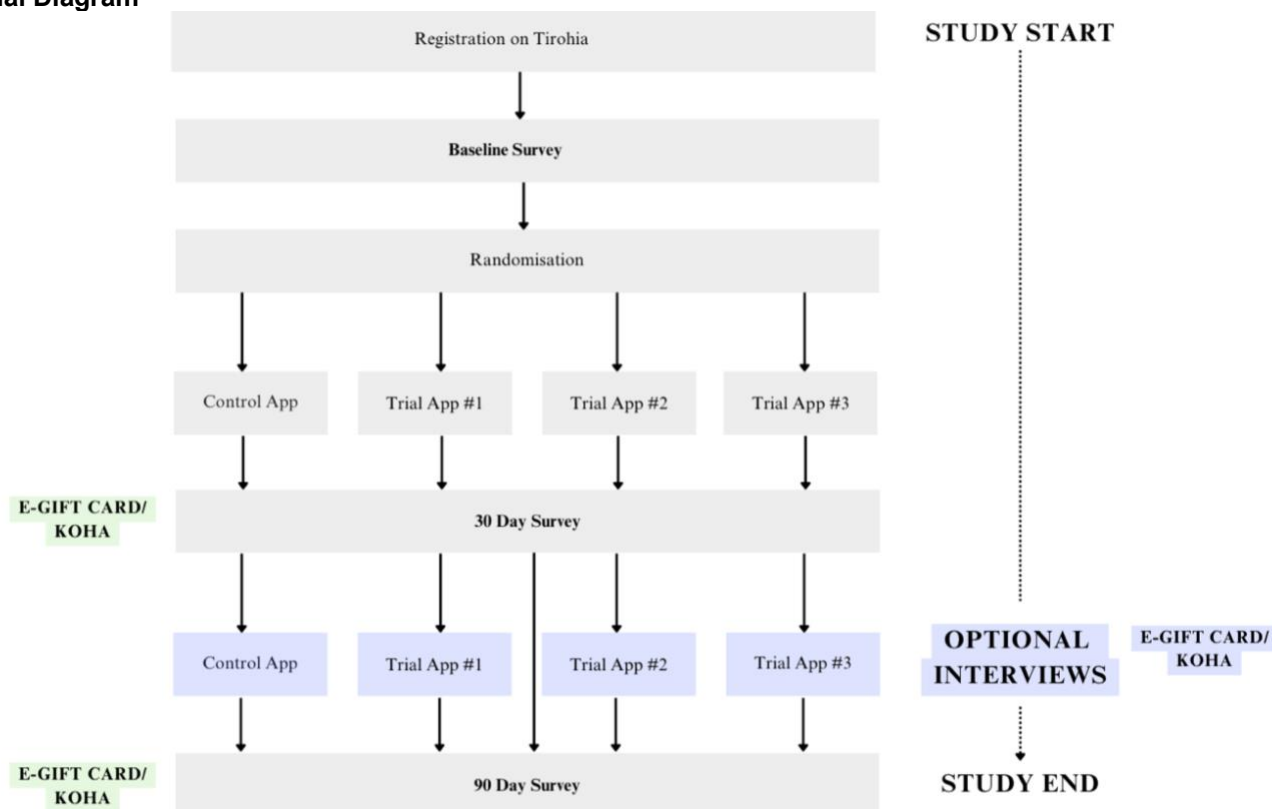
If you agree to participate in this study, you will be invited to download one of the four apps that are part of the study.

You will access our secure online research platform, Tirohia. Once you're on Tirohia, you will complete the following:

1. **Screening and registration:** You will be asked to complete a quick screening survey on Tirohia which will ask if you meet our study inclusion criteria, you'll then be asked to register.
2. **Registering to Tirohia:** We use Tirohia to communicate with you via email and/or text and this is where you will do the surveys.
3. **Survey 1 (Day 0):** Before getting access to the app, you will be asked to complete Survey 1. Survey 1 includes demographic information and questions about your wellbeing and suicidal thoughts.

4. **App allocation:** Once you have registered and completed Survey 1 you will be given a link to download your app (it will be one of the four apps that are part of the TIPS study).
5. **Using the App:** When you receive the link to the app you will be provided with an app bio and details on how to use the app. This will include an overview, how often to use the app and the goals of the app. One of the apps in the trial is considered a control app. As a participant you will be randomly assigned (by a computer) an app and you won't know if the app you are assigned in the control one (see trial diagram below). You may have used the app that is presented to you before (in another study). If this is the case, it means you can't go on to be a part of the TIPS study. Please be reminded that it is your choice to participate and you can withdraw at any time without giving a reason.
6. Some activity on the app will be recorded by the app, including the activities you access, complete, and the time(s) of your log-ins. This activity will be accessible to the research team only. These data will be used to record how much you and the other participants in the study use the app. Your name will not be connected to these usage data, they will be identified by study number only.
7. **Survey 2 (Day 30) and Survey 3 (Day 90):** We will then send you a survey to complete 30 days and 90 days after downloading the app. Each survey will be approximately 10 minutes long. The research team will contact you via email or text to remind you when to complete each survey.
8. You will have uninterrupted access to the app you have been allocated to for the duration of the trial until the final participant has completed the 90-day follow-up (you won't know this but you will receive an automated reminder ahead of the end of your access period).
9. **Invitation to Interview:** After completing your 30-day survey we may, if you agree, invite you to participate in a one-on-one interview with a researcher. You do not have to do an interview if you do not wish to. In the interview we'll ask what you think of the app you are using and your thoughts on what might improve the app. There is more detail below on the interview.
10. **Reminders:** You will be sent a maximum of two reminder notifications to complete each survey (there are 3 surveys) via email and/or text.

Trial Diagram



Are there any big risks involved?

We don't think that there are any big risks in this study, but 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. Regardless of which app you receive, we have included a "help button" that contains a directory of key sources of help such as phone lines to ensure that you have access to support 24/7.

Being part of this study should not replace usual supports in any way.

Please be aware that these apps are being studied to understand further whether they work to reduce suicidal thoughts. There is very little known about the most effective intervention for youth suicidal ideation, but the best bet so far are therapies delivered by well-trained mental health clinicians like cognitive behaviour therapy, dialectical behaviour therapy, mentalisation therapy and family therapy. If you want more support, we encourage you to seek out this professional help.

If you live in New Zealand, you can look at this website for free treatment in your area: <https://www.wellbeingsupport.health.nz/available-wellbeing-support/youth-wellbeing-services/>.

Should the research team observe distress in any of your responses, a clinical research team member will contact you to make sure you are supported.

What are the benefits?

We hope that you will gain some useful tools for your wellbeing and skills to reduce suicidal thoughts. Your participation will help us to understand whether these apps are safe and useful for other young people. To

thank you for your time and effort you will receive koha as an e-gift card (NZD \$15) when you **complete** the survey after 30 days of using the app, and after the survey at the 90 day follow up (\$15). This means that, in total, if you complete the whole study (do 3x surveys over 90 days which is about 3 months) you will receive NZD \$30 in total.

Your Privacy

- Your information is **confidential (private)**
- All information given to us will be kept **safe** and **secure on Tirohia**. We use two-factor authentication (2FA) to access Tirohia.
- Tirohia automatically assigns you (each participant) a study number. This study number is connected to your data (that we use). Study data are stored separately to your identifiable data (i.e. your details) on Tirohia.
- Consent will be **stored separately** from data.
- The information will be kept for **10 years** and then confidentially permanently destroyed. Please note your healthcare provider will **not** be notified of your participation in the TIPS study (we as researchers do not have access to any information about you other than what you supply to us).

Breach of Privacy / Confidentiality

Given the high security level of the Tirohia platform and the University's systems a breach of privacy is unlikely. A breach of privacy means unauthorised or accidental access to, or disclosure, alteration, loss, or destruction of a participant's information.

In the unlikely event of participant privacy and confidentiality being breached during the study, the following steps will be taken:

- The participant will be informed of the breach as soon as practicable and provided with support as required.
- A Sponsor quality review will be conducted to ascertain factors contributing to the breach and any corrective action required to prevent future breaches.
- The approving HDEC will be informed.
- For notifiable privacy breaches of privacy under the Privacy Act 2020, the New Zealand Privacy Commissioner will be notified in accordance with that Act.

Consent

Before accessing the app, you will be required to read and complete an online consent form on Tirohia. Please make sure you read the document carefully and read all the points on the consent form. If you have any questions or concerns, please contact us. Only those aged 16 years or older are eligible to participate in the study.

It is your choice

We don't mind if you don't take part. If you don't want to take part, you don't have to give a reason, and there will be no negative consequences to saying no.

You can also decide to withdraw from the study at any point. You can withdraw by sending an email with the subject 'Withdrawal' to TIPS_youth@auckland.ac.nz. If you choose to withdraw after completing the first questionnaire, we will not be able to withdraw your data. Choosing to participate or not, will have no effect on any relationship you may have with a member of our research team, or with any other organisation or group you belong to.

How will my data be used?

The data from this study will allow us to determine whether the apps are effective and safe to be recommended and made widely available to young people/rangatahi.

Personal information such as your age, ethnicity, and gender will be stored securely.

The data will be analysed by one of the study team who resides in Australia; the data will be encrypted and stored securely. The analysis will have oversight by Dr Tania Cargo (Ngāti Maru, Ngāti Manu, Ngāpuhi).

Results may be published in a peer-reviewed journal(s) and presented at a relevant conference(s). No identifying information will be used, only anonymous and group data will be reported. Your individual responses will not be linked to your name.

Your information is a taonga (treasure) and will be treated accordingly. Māori data sovereignty permits Māori organisations to access coded Māori data, to support Māori development aspirations. This means that iwi and hapū might request Māori data. Requests will be assessed by Dr Tania Cargo (Ngāti Manu, Ngāti Maru, Ngāpuhi) and will follow Te Mana Raraunga (Māori Data Sovereignty) recommendations. De-identified data (deidentified survey, usage and interview data) can be requested by other researchers for future studies. A 'data request committee' that is led by Dr Tania Cargo and includes other study team members will review these requests and can decline the requests if they are not appropriate.

If you wish (you can indicate on your consent form) we will send you a copy of the summary findings of this study. Please note that this may be up to two years after your participation.

After completion of the study, all confidential data, including computer data files and notes will be stored for a minimum period of 10 years to allow for publication and re-analysis, after which time it will be securely and confidentially permanently destroyed.

How will the data be stored?

This study is being run from Aotearoa/New Zealand, with participants from Aotearoa/New Zealand and Australia. Deidentified data will be shared securely from Aotearoa/New Zealand to researchers in Australia for analysis.

Your data will be collected on the online study platform Tirohia, which we use for a range of other studies as well. This is a secure platform used to store the information collected from the study for a minimum of 12 months while the study is active. All communications between your device and Tirohia are encrypted. Tirohia resides on a secure University of Auckland server that requires two-factor authentication. The University has a well-developed cybersecurity policy, including monitoring, incident management and, as appropriate, reporting. Your name will not be connected to the data set. This means that we will only report group data, not individual data, so your privacy will always be maintained.

Once we have established the integrity of the data we will download and store the data on secure University of Auckland servers, and delete the data, but not your account, from the Tirohia platform. This data server is managed by the University of Auckland for research data and access to the drives are provided only to approved study team members. After completion of the study, all confidential data, including computer data files and notes will be stored for a minimum period of 10 years to allow for publication and re-analysis, after which time it will be securely and confidentially permanently destroyed.

More about the interview

We need a smaller number of participants for this part of the study (20 per app, 80 all up). Interviews will be held in person at the University of Auckland, Waipapa Taumata Rau or online via Zoom and will take about 30 minutes. It will be one-on-one with a researcher either in person or online via Zoom. You are welcome to bring support person/whānau member to the kanoahi ki te kanoahi (face-to-face) or online interview. The support person will not be a part of the study. They will not have any data collected, nor will anything about them or anything they say be analysed. Kai will be provided to those attending in person and koha as an e-gift card (NZD \$50) will be offered to all interview participants. The interview will be audio-recorded with your permission. The audio recordings will be transcribed (all the words typed out) and deidentified, and the original recordings will be destroyed. The person who transcribes will sign a confidentiality agreement before they listen to the recording. We hope that the focus groups and interviews will be fun and give you a chance to offer your thoughts about using the app.

Participation is entirely your choice, and you are free to withdraw your consent at any time. Your information will be kept confidential.

Who has approved this study

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards. The Southern Health and Disability Ethics Committee HDEC has approved this study.

Thank you

To thank you for completing the surveys you will receive koha of NZD \$30 in total. Koha will be an e-gift card (NZD \$15) when you complete the survey after 30 days of using the app. You will be sent another e-gift card after the survey at the 90 day follow up (NZD \$15).

We will also ask whether you want a summary report of our findings.

Contacts

If you have any questions, concerns or complaints or need any additional information about this research, please contact us. Our team is co-led by Dr Tania Cargo (Ngāti Maru, Ngāti Manu, Ngāpuhi) and Associate Professor Sarah Hetrick (Pākehā).

Name	Affiliation	Role	Contact
Associate Professor Sarah Hetrick	University of Auckland	Principal Investigator (trial co-lead)	s.hetrick@auckland.ac.nz
Dr Tania Cargo	University of Auckland (Ngāti Maru, Ngāti Manu, Ngāpuhi)	Principal Investigator (trial co-lead)	t.cargo@auckland.ac.nz
Dr Sarah Fortune	University of Auckland	Co-investigator	sarah.fortune@auckland.ac.nz
Dr Hiran Thabrew	University of Auckland	Co-investigator	h.thabrew@auckland.ac.nz
Dr Michelle Tye	Black Dog Institute, UNSW Sydney	Co-investigator	m.torok@unsw.edu.au
Dr Lauren McGillivray	Black Dog Institute, UNSW Sydney	Co-investigator	l.mcgillivray@blackdog.org.au
Dr Quincy Wong	Western Sydney University	Co-investigator	quincy.wong@wsu.edu.au

Alternatively, if you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <http://www.advocacy.org.nz/>

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:

Phone: 0800 400 569 (Ministry of Health inquiries)

Email: hdec@health.govt.nz

Support

Understandably, some people may find it stressful or upsetting when dealing with suicide content. If participating in the study causes you to become upset, please stop your participation. Please contact one of our expert team or call for support (see below numbers) immediately.

If anything causes you to become upset, or you are concerned about how you feel, please talk to an adult you can trust, like a counsellor, your family doctor (GP) or family or whānau.

Please note that these phone/text numbers below connect you to a 10-20 minute conversation with a peer support worker who will try and find further assistance if needed. This contact is not considered treatment.

If you or someone else might be unsafe, call 111 in New Zealand or 000 In Australia. If you need to talk to someone right away or feel you can't cope, there are people who can help you immediately.

In **Aotearoa New Zealand** you can call or text the following numbers:

- If you are in immediate danger, please call emergency services immediately on 111
- Youthline: Call 0800 37 66 33 or text 234
- Need to Talk: Call or text 1737
- Lifeline: Call 0800 543 354
- Suicide Crisis Helpline: Call 0508 828 865 (0508 TAUTOKO)

In **Australia** you can call or text the following numbers:

1. **Lifeline Australia** (24/7) crisis support: call 13 11 14 or text to 0477 131 114
2. **Qlife** (3pm to midnight) LGBTQ+ support: call 1800 184 527 or chat online: <https://qlife.org.au/resources/chat>
3. **Kids Helpline** (24/7) for ages 5-25years: call 1800 551 800 or chat online: <https://kidshelpline.com.au/get-help/webchat-counselling>
4. **Suicide Callback** (24/7): call 1300 659 467 or chat online: <https://www.suicidecallbackservice.org.au/phone-and-online-counselling/>

If you require Māori cultural support, we encourage you to chat to your whānau. You may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext. 2324.