



# COUNTING OURSELVES

AOTEAROA NEW ZEALAND TRANS AND NON-BINARY HEALTH SURVEY

## Participant Information Sheet

**Principal Investigator:** Dr Jaimie Veale +64 7 837 9216 or [jveale@waikato.ac.nz](mailto:jveale@waikato.ac.nz)

**Ethics committee ref:** 2022 FULL 12683

Kia ora, mālō e lelei, talofa lava, namaste, kia orana, nisa bula vinaka, nín hǎo, welcome.

Thank you for your interest in taking part in Counting Ourselves, the Aotearoa New Zealand Trans and Non-binary Health Survey.

Participation in this study is voluntary and it is important you read this information so you can decide whether you want to participate. Before you decide, you may want to talk about the study with other people, such as friends, family, whānau, or healthcare providers. Feel free to do this. You may contact us if you have any questions about the survey by emailing [kiaora@countingourselves.nz](mailto:kiaora@countingourselves.nz) or by phoning us on **07 837 9216**. You may also contact us if you want a **paper copy** of the survey to fill out, instead of doing this online. We will post out a paper copy and a return prepaid envelope.

If you agree to take part in this survey, you will be asked to consent at the bottom of this page. Please make sure you have read and understood all the information.

### Who are we?

We are a research team based at the Transgender Health Research Lab at the University of Waikato who work to improve the health and wellbeing of trans and non-binary people.

Our research team is led by our Principal Investigator Dr Jaimie Veale and our Co-Principal Investigator Jack Byrne. Both Jack and Jaimie are trans and have many years' experience conducting trans health and human rights research, including the first Counting Ourselves survey in 2018. Our core project team and associate investigators are listed below with further information available on our website [countingourselves.nz](http://countingourselves.nz)

#### Principal Investigator

- Dr Jaime Veale

#### Co-Principal Investigator

- Jack Byrne

#### Co-Investigators

- Dr Kyle Tan

#### Lab Manager

- Ashe Yee

#### Associate Investigators

- Ahi Wi-Hongi
- Phylesha Brown-Acton
- Dr Elizabeth Kerekere
- Prof Gareth Treharne
- Dr George Parker
- Dr John Fenaughty
- Dr Rona Carroll

#### Students

- Ryan Bentham (PhD)
- Sofia Gonzalez (Masters)
- Harry Jones (Masters; University of Canterbury)
- Taine Polkinghorne (Masters; University of Auckland)

## **Voluntary participation and withdrawal from this study**

Participation in the survey is voluntary. The only questions that we require you to answer are in the first section, where we check you can participate in the study by asking if you are trans or non-binary, live in Aotearoa, and are at least 14 years old. Otherwise, you can skip any other questions, for any reason.

You can withdraw from the survey at any time for any reason. If you start the survey and then wish to withdraw, you can return to this page at any time using the "Previous" button and click on the option asking for all your responses to be erased. Because the survey is anonymous, once you have submitted your response you cannot withdraw from the study.

## **What is the purpose of the study?**

Counting Ourselves is an anonymous survey asking about trans and non-binary people's health and wellbeing. This is the second wave of Counting Ourselves - we conducted the first survey in 2018. We are asking some of the same questions from 2018 to see what changes may have happened since then. Other questions are new, based on feedback about issues important to our communities.

We hope that this survey can collect information that will improve the lives of people in our communities, by showing us:

- how well trans and non-binary people are doing in our mental health and physical health compared to the rest of the population
- the stigma, discrimination, and violence we experience as trans and non-binary people, as well as how racism and others forms of discrimination impact us
- our experiences in doctors' clinics, hospitals, and other healthcare settings; this could be for gender affirming care, such as hormones or surgeries, or when we see someone about our general health
- how support from our friends, family, whānau, and others might protect us against the impacts of stigma, discrimination, and violence that trans and non-binary people face

## **How is the study designed?**

The study is designed as an anonymous survey with many questions taken from large Aotearoa New Zealand surveys so we can compare our experiences against the wider population. Some of the questions were the same as Counting Ourselves 2018 so that we can keep track of changes over time.

## **Who can take part in the study?**

This survey is for trans and non-binary people. This means anyone whose gender is different from their sex assigned at birth, whatever term you use to describe your identity. We want to hear from all of you!

You are eligible to take part in this survey if you are:

- trans or non-binary
- aged 14 years or older and
- currently living in Aotearoa New Zealand

If you do not meet these eligibility criteria, you cannot take part in this survey.

It does not matter whether you use the specific terms 'trans' or 'non-binary' to describe yourself, whether you have taken medical steps to affirm your gender, or plan to do so. There are many terms that people in our communities use. For example, these include:

- trans, transgender, transsexual, takatāpui, or irawhiti
- trans woman, transfeminine, or whakawahine
- fa'afafine, fakaleiti or leiti, fakafifine, akava'ine, or vakasalewalewa
- trans man, transmasculine, tangata ira tāne, fa'atama, or akatāne
- non-binary, tāhine, genderqueer, irakē, gender fluid, irahuri, gender diverse, irahuhua, bi-gender, cross-dresser, pangender, demi-gender, agender or irakore
- trans people filling out the survey might also identify as simply a woman or as a man.

### **What will my participation in the study involve?**

We expect the survey to take about 70 minutes for you to complete, but this may be less if you skip some sections or more if you decide to write more about your experiences.

During the survey, you will be asked for your responses to questions on a broad range of topics. For most questions, you just need to tick boxes to indicate your response, but some questions allow you to write in more details.

### **What are the possible risks of this study?**

Due to the survey length, you might be at risk of fatigue. To help you manage this risk, you can take a break from the survey and return at a later time to complete it. If you need to take a break, you can complete the survey in multiple sessions by exiting the survey and returning within 3 months and before the survey closes. This function works provided you use the same computer and browser, have allowed cookies in your browser, and haven't cleared or deleted the cookies in the browser before you return to the survey. Click [here](#) to see further information about cookies and how to enable them.

We only ask questions about things that are important for our communities to know. Some of these questions are about difficult topics that might be hard for you to answer. For example, there are questions about hurting yourself, suicide, and experiences of being treated badly by other people, including emotional, physical, sexual violence and conversion practices. This means that you might be at risk of emotional harm or discomfort. To help you manage this risk:

- Before we ask you these sensitive questions, we will ask you if you would like to skip them.
- We provide you with a list of support services you can contact if you need help.
- We undertook extensive consultation about our questions to ensure that they are really necessary for achieving the study objectives and are beneficial to our communities.

Remember, it is your choice whether you answer these or any other questions.

### **What are the possible benefits of this study?**

By taking part in the survey, you are helping us understand the health and wellbeing of trans and non-binary people in Aotearoa New Zealand. Your experiences, no matter how ordinary or extraordinary, are valuable. The study is unlikely to provide individual benefits to you, though we hope it improves the situation for our communities.

### **What if something goes wrong?**

You can contact the research team by emailing [kiaora@countingourselves.nz](mailto:kiaora@countingourselves.nz) or by phoning us on **07 837 9216**.

If you want to talk to someone about some of the sensitive issues raised in the survey, you can text or call **1737** to reach a counsellor 24 hours a day through the National Telehealth Service. You can also contact OutLineNZ's confidential Rainbow helpline every evening from 6pm-9pm (Phone: **0800 688 5643**; Email: [info@outline.org.nz](mailto:info@outline.org.nz)).

We have listed some other helplines next to specific questions too. You can see a full list of other support services on our website at: [countingourselves.nz/support/](https://countingourselves.nz/support/).

## **What will happen to my information?**

The information you provide in this survey is anonymous. We do not collect your name or any other information that might be able to identify you as an individual.

### Future research using your information

If you consent to participate in this study, your anonymous data will be used by the research team for research on the health and wellbeing of trans and non-binary people. We may make parts of our anonymous data available to other researchers on request for them to conduct their own studies. Before granting other researchers access to the data, the Counting Ourselves team must be satisfied that appropriate data management plans are in place and that ethical approval for its use has been obtained in accordance with local laws and regulations.

### Security and storage of your information

- Everyone's individual anonymous responses will be stored on two-factor authenticated password-protected University of Waikato accounts and computers. Only the research team, including staff, students, and Co-Investigators, will have access to these. All storage will comply with local data security guidelines.
- Data will be kept until it is no longer required. The PI and Co-PI (Dr Jaimie Veale and Mr Jack Byrne) will be responsible for deleting the data.
- We will collect your IP address, which is a unique number based on your internet connection. It does not identify you or your current physical address. We will only use IP addresses to double check for multiple responses from the same person, and then will delete all IP addresses.
- We will not publish any information where the number of responses is so small or the comments made are so specific that someone could possibly guess who made them. When making these decisions, we keep in mind that the sizes of trans and non-binary communities are small.
- If you contact us asking for a printed copy of the survey, we will delete your contact details once we have posted the survey to you. If you fill out the paper copy of the survey, we will put your answers into the computer anonymously and then shred your paper survey.

### Risks

- All efforts will be made to protect your privacy. However, absolute confidentiality of information cannot be guaranteed, even with anonymous information. There is a very small risk that if someone who already knew you accessed your full survey response, they may guess your identity from all the information you supplied. Because our team includes experienced researchers and we have data management protocols in place, the risk of people accessing your information, identifying you, and misusing your information is currently very small, especially as this is an anonymous survey. This risk may increase in the future as people find new ways of tracing information. All our survey responses are kept on secure, password-protected university servers and we will continue to work with the university technical experts to reduce any risks that might emerge in the future.
- The 2018 Counting Ourselves survey results have been used successfully to advocate for the health, wellbeing and human rights of trans and non-binary people. However, it is also possible that others may use the research findings inappropriately to support negative stereotypes, stigmatise, or discriminate against parts of our communities, including those that you identify with. The Counting Ourselves project team takes our responsibility to minimise this risk very seriously when deciding what findings to publish and whether we will collaborate with other researchers to analyse our survey data.

### Rights to access or withdraw your information

Because the survey is anonymous, once you have submitted your responses you will not be able to access, correct or withdraw your information, even if you change your mind about it being used.

If you have any questions about the collection and use of information about you, you should contact Dr Jaimie Veale.

### Data-linking

Some survey participants have completed the 2018 Counting Ourselves survey or the 2021 identify survey ([www.identifysurvey.nz](http://www.identifysurvey.nz)). We give those people the option of allowing us to link their responses to those surveys to their answers in this second Counting Ourselves survey. This is called 'data-linking'.

Data-linking in this study is optional and only occurs if people provide non-identifying details by responding to three optional questions asking the day of the month you were born on, the first letter of the town you were born in, and the first two letters of your first pet. These details will help us to determine which, if any, responses are from the same person across the data sets from these three surveys. We will confirm this match using demographic details such as age, gender, and ethnicity. These details and this process will still keep your individual identity anonymous.

You can agree to your data being linked by completing the relevant questions.

### Māori data sovereignty

Māori data sovereignty is about protecting information or knowledge that is about (or comes from) Māori. We recognise the taonga of the data collected for this study. To help protect this taonga:

- We have consulted with our Māori Investigators about the collection, ownership, and use of study data.
- We welcome Māori researchers and organisations requesting access to our anonymous data, including access to responses from Māori participants. Any requests for access to this data will be considered in consultation with our Māori Associate Investigators.

### **What happens after the study**

When the data collection period is complete, we will analyse the data and make the results available in a community report, academic journal articles, fact sheets, conferences and community presentations, and other publications.

### **Can I find out the results of the study?**

We will keep the community informed about the results of the study through our website, [countingourselves.nz](http://countingourselves.nz), and our Facebook and Twitter pages. If you would like to receive email updates, then you can subscribe to our mailing list by visiting our website [countingourselves.nz](http://countingourselves.nz).

### **Who is funding the study?**

We have received funding from the Royal Society Te Apārangi to do this research.

### **Who has approved the 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 HDEC has approved this study (Approval no: 2022 FULL 12683).

### **Who do I contact for more information or if I have concerns?**

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

Dr Jaimie Veale (Principal Investigator)  
+64 7 837 9216 or [jveale@waikato.ac.nz](mailto:jveale@waikato.ac.nz)

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](mailto:advocacy@advocacy.org.nz)  
Website: <https://www.advocacy.org.nz/>

You can also contact support services or community groups for help, support and information including those supporting Māori, Pasifika people, and other specific groups. We have a list of contacts available on our website at: [countingourselves.nz/support/](https://countingourselves.nz/support/). These include Gender Minorities Aotearoa, the national trans organisation that operates within the kaupapa Māori public health framework, Te Pae Māhutonga

Phone: 04 385 0611

Email: [support@genderminorities.com](mailto:support@genderminorities.com)

Website: <https://genderminorities.com/>

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHIC (0800 438 442)

Email: [hdecs@health.govt.nz](mailto:hdecs@health.govt.nz)

I have read the information above and agree that I understand my rights and what the survey involves and I agree to take part in the study.

I do not agree to participate in this study and would like any information I have already provided to be erased.