

Participant Information Sheet

This form will be held for a period of six years

Research Project: Toto kona: Exploring the Lived Experiences of Sepsis in the Tongan Community Residing in Aotearoa New Zealand.

Student Researcher: Fai'ana Moala Tu'ipulotu Armitage

Academic Supervisor: Louise Carrucan-Wood

Academic Supervisor: Dr Ema Wolfgramm-Foliaki

Academic Supervisor: Dr Rachael Parke

Head of School: Dr Julia Slark

Research Introduction My name is Fai'ana Moala Tu'ipulotu Armitage, and I am completing a research project at the School of Nursing at the University of Auckland. I am interesting in exploring the experiences and perspectives of adults of Tongan ethnicity about sepsis to inform efforts to raise awareness of sepsis amongst Pasifika communities. The term toto kona is a Tongan phrase related to sepsis.

Project Description and Invitation

This research aims to explore with Tongan individuals, and their family members if they choose to participate, their experiences and perspectives of sepsis and to propose a Tongan term or language that describes sepsis. From the data, key themes will inform the design of health information to share with Pasifika people.

You are invited to participate in a virtual talanoa session if you are an adult living in Aotearoa New Zealand and you are Tongan and have access to technology to participate in a talanoa session held on Zoom. You must be aged 16 years or older, and can freely provide written informed consent to share your experience and perspectives about sepsis. You will be able to share your experiences during a virtual talanoa session speaking the English language and occasional use of Tongan terms that have no literal translations into the English language.

Project Procedures

This research involves voluntary participation in one virtual talanoa session via Zoom at a mutually agreed day and time and will take no longer than one hour. The talanoa session will be audio-visually recorded and centre around what the perspectives and experiences of Tongan individuals about sepsis.

The talanoa session can occur when a person meets with me online on Zoom for one interview, or can occur when members of a family meet together with me on Zoom for one focus group discussion. If you wish family members to be present, you can indicate this on the Consent Form and I will send you an email for you to forward to them.

If you choose to participate, I will provide you with a Zoom Information Guide that will include a password-protected digital link to the allocated virtual talanoa session and a method to test the online meeting software functionality (i.e. internet stability, vision and sound on your local device in the days preceding the focus group), links to technical support options and information regarding the digital security of Zoom. From the Zoom recording, I will prepare transcription files for data analysis.

If you choose to participate in an individual interview, you can choose to indicate on the Consent Form if you wish to have an opportunity to edit the transcription file before data analysis begins. I will provide you with an opportunity of two weeks for you to review the transcription file before data analysis begins.

Participants contributing data from a virtual family talanoa session as a focus group discussion will not be able to review and edit transcriptions and data cannot be removed as it could impact the integrity of the data that other participants have contributed.

If you wish to receive a summary of the study findings by email, you can indicate this on the Consent Form.

Data storage /Retention/Destruction/ Future Use

Digitally recorded files and transcriptions files will be securely stored on a password protected service and backed up at the server at the University of Auckland. Any paper records will be secured in a locked filing cabinet, which only myself as student research and my academic supervisors will have access. After six years all electronic data files and paper files will be securely destroyed. The results of this research will be included in my research project for the course HealthSci 789 and will also be written up in academic journals and used in professional forums. The study findings will inform recommendations when designing health information about sepsis for Pasifika people.

You have the right to receive a copy of the study findings, and you can indicate an email address where you would like these to be sent on the written consent form.

Right to Withdraw from Participation

You can withdraw at any time without needing to explain why. As a participant, you can choose not to answer particular questions or leave Zoom without needing to provide a reason.

Participants taking part in the virtual talanoa session as an interview with me will be able to withdraw their data up to the point of which data analysis has begun.

Participants taking part in a virtual family talanoa session as a family focus group will not be able to withdraw their data once the talanoa session has begun because of other focus group members' information on the same recording. If participants withdraw during the talanoa session as a family focus group, any information contributed up to that point cannot be withdrawn as it will be difficult not to transcribe their data once the focus group has begun.

Anonymity and Confidentiality

No information that might identify an individual or service will be used in any of the written or oral presentations. Any content that identifies a participant or services will be replaced with a pseudonym, which will be a letter of the Tongan alphabet.

Focus group participant confidentiality cannot be guaranteed due to the presence of other participants during the focus group discussion. However, all participants will be asked to respect the confidentiality of other participants and not to disclose the content of focus group conversations to non-participants.

Any persons involved in the research, such as attending to provide cultural support or preparing transcription files for data analysis will sign a Confidentiality Agreement Form to ensure the privacy and confidentiality of participants are protected.

Please take the time to read this information and carefully consider whether you wish to participate in the study or not. Please do not hesitate to contact me or any of my academic supervisors directly if you have any questions about the study, or if any of the following information is unclear and requires clarification.

If you decide to participate in this study, you will be asked to provide your written consent to do so. You will be asked to complete a consent form prior to your talanoa session being arranged, and to send a digital copy of this to the student researcher. Although discussions are recorded, your identity will be protected. Data will be anonymised before analysis begins, and any direct quotes will be assigned a pseudonym.

Cultural Support

If you wish a person or persons to attend the virtual talanoa to provide cultural support, please indicate this on the Consent Form so this can be arranged with you. We will respect your preferences for cultural support. You may wish to have a member of your family or community with you. Persons or people attending for cultural support will be required to complete a Confidentiality Agreement before attending the virtual interview or family focus group discussion.

Contact Details

It is not expected that taking part in this study will cause harm, however, should participating in this research raise any issues or concerns that you would like to discuss with someone you can contact any member of the research team and any of the following free and confidential counselling services:

- Sepsis Trust New Zealand Support - Freephone helpline 0800 76 49 15
- Samaritans – 0800 72 66 66
- Lifeline Aotearoa 0800 54 33 54 or mobile text 4357.

Thank you for taking the time to read this information. If you have any questions about the research or would like to discuss the study further, please email me or my academic supervisors as shown below:

- **Academic Supervisor:** Louise Carrucan-Wood, Professional Teaching Fellow, School of Nursing
Email: l.carrucan-wood@auckland.ac.nz
- **Academic Supervisor:** Dr Ema Wolfgramm-Foliaki **Email:** ea.wolfgramm@auckland.ac.nz
- **Academic Supervisor:** Dr Rachael Parke **Email:** r.parke@auckland.ac.nz
- **Head of School:** Dr Julia Slark. **Email:** j.slark@auckland.ac.nz

UAHPEC Chair Contact Details :For any queries regarding ethical concerns, you may contact the Chair, The University of Auckland Human Participants Ethics Committee, Office of Research Strategy and Integrity, The University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373- 7599 ext 83711. Email humanethics@auckland.ac.nz

Approved by the Auckland Health Research Ethics Committee for three years on 21/06/24. Reference Number AH27731.