

STUDY PROTOCOL

DigiFale: A digital health literacy programme for Pacific communities.

July 2021 Version 3

Date: 16/07/2021



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Project Sponsors

The principal financial sponsor of this project is the Ministry of Health. The design, conduct, analysis, and interpretation of study results will be made independent of the study sponsor.

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1. OVERVIEW

Project Title:

DigiFale: A digital health literacy programme for Pacific communities

Study period:

April 2021 – April 2022

Research aims:

- 1. To test the acceptability and effect of a culturally contextualised mobile literacy programme among a sample of Pacific adults considered digitally excluded; and
- 2. To explore how developing digital literacy can contribute to improving health among Pacific communities.

Research objectives:

- 1. To evaluate how a contextually mobile literacy programme can build digital literacy among Pacific communities.
- 2. To enable Pacific communities to use digital literacy skills to access digital health services.

Study design and methodology:

A non-randomised study utilising <u>community-based participatory</u> approaches and focus groups utilising the *tutala*, combined with quantitative (pre-post survey) approaches. The study design and methodologies are presented in-depth in the following sections.

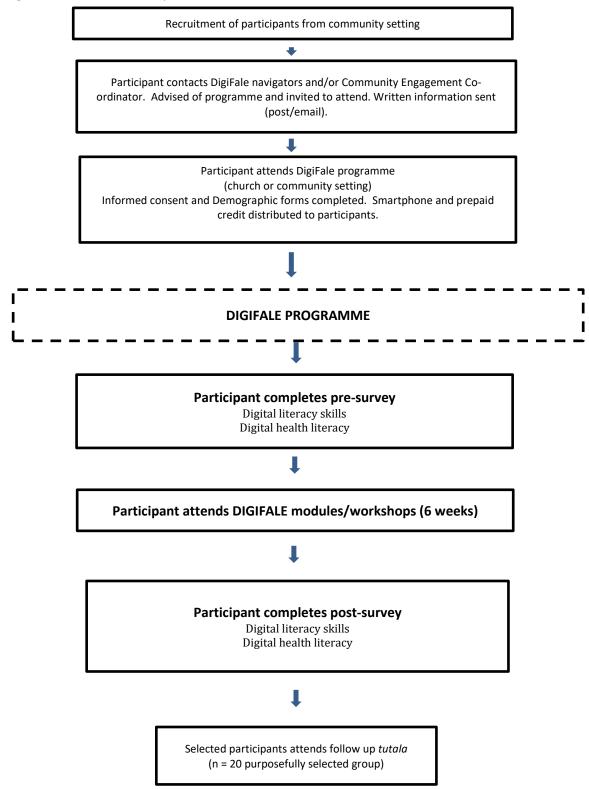
Eligibility criteria:

Participants must be a Pacific adult, considered digitally excluded (no digital device/mobile phone, used a mobile phone but stopped because it was too difficult; not confident using a mobile phone); ability to give informed consent.



2. STUDY FLOW DIAGRAM

Figure 1. Overview of study flow





3. RATIONALE

The New Zealand Government's vision for digital inclusion is that everyone in New Zealand has what they need to participate in, contribute to, and benefit from a digital world. ² COVID-19 shone a light on the need for Pacific communities to be more digitally connected. Despite the internet being identified as a vital resource for many during COVID-19, it was afforded only to those who had digital access, connectivity, and proficiency. ² In response, Moana Research developed *DigiFale* to address the digital exclusion needs Pacific communities experienced, particularly when attempting to access online health services.

Globally, digital health and mobile health (mHealth) technologies are rapidly changing the landscape of how healthcare is being delivered. The challenge for New Zealand is to ensure emerging digital health technologies benefit all population groups, and not exacerbate health inequities and the digital divide. ¹ To ensure an increasing number of Pacific people can benefit from digital health tools to cope with the impact of COVID-19 and the transition towards digitised health services, *DigiFale* (a digital health literacy programme) provides the necessary access, connectivity and skills required to overcome the obstacles of digital exclusion.

Pacific religious leaders, faith-based organisations, and faith communities have a critical role at mobilising Pacific communities and the dissemination of information and resources that is relevant to health and wellbeing. Churches act as a primary source of support, comfort, guidance, and direct health care and social service for the communities they serve. The World Health Organisation recognises that churches are often able to reach the most vulnerable with assistance and health information and identify those most in need. ³ Religious leaders provide a critical link and safety net for individuals within their faith communities to ensure they are prepared to, as seen most recently, adhere to COVID-19 New Zealand Government Alert Level guidelines.

The delivery of healthcare services via mobile communication devices offers an opportunity to reach diverse, under-served individuals and groups and affect change, particularly when traditional approaches have been consistently met with barriers such as language, cultural differences, work commitments, financial and transport difficulties. ⁴ Overall, DigiFale is a culturally contextualised mobile literacy programme that provides the necessary access, connectivity, and skills required to strengthen digital health literacy. By strengthening digital and mobile literacy within church settings, Pacific communities can build essential skills towards digital health literacy to make informed choices to improve and manage their own health more effectively.



3. STUDY OBJECTIVES

Aim

The aim of this study is to test the acceptability and effect of a culturally contextualised mobile literacy programme among a sample of Pacific adults who are considered digitally excluded; and to explore how developing digital literacy can contribute to improving health among Pacific people.

Objectives

The objectives of *DigiFale* are to:

- 1. To evaluate how a contextually mobile literacy programme can build digital literacy among Pacific communities.
- 2. To enable Pacific communities to use digital literacy skills to access digital health services.

4. STUDY DESIGN

A non-randomised study utilising <u>community-based participatory</u> approaches, focus groups utilising the *tutala*, combined with quantitative (pre-post survey) approaches.

The programme will utilise a 'train the trainer' approach using DIGIFALE navigators to deliver the sessions. The lead researcher will facilitate a workshop with DIGIFALE navigators, provide an overview of the programme, and cover core subject areas related to the programme sessions and adult learning principles. Each cohort of DIGIFALE participants (Niue, Samoa, Tonga, Cook Island) will have DIGIFALE navigators from their ethnic specific background to enable sessions to be delivered in their first Pacific language. The study researcher and a community engagement coordinator will work alongside the DIGIFALE navigators as they lead and deliver the sessions within their cohort.

Hihi framework

The *DigiFale* programme will use the Hihi Framework to:

- Palana (planning and conceptualisation of the DigiFale programme);
- Oko (DigiFale modules and programme delivered by skilled facilitators; family and group *tutala* undertaken by interviewers who know how to protect and bring out the best of the taonga/insights);
- *Tauteuteaga* (preparing insights and data from the evaluation and group *tutala*)
- Tui (weaving insights through analysis and dissemination of preliminary findings).

5. INCLUSION CRITERIA

- Self-identified as Pacific
- Aged 18 years or older
- Considered digitally excluded
 - o No mobile phone
 - Used a mobile phone but stopped using this because it was too difficult



- Not confident using a mobile phone
- Ability to give informed consent.

6. STUDY PROCEDURES

Phase One – Recruitment and Informed consent

6.1. Recruitment of eligible participants

Recruitment of participants, and family members will be undertaken within the community. Participation in the focus groups (conducted at the end of the programme) is entirely voluntary. If individuals choose not to take part, they will be free to withdraw at any time without giving a reason.

6.2. Consent, Pre-survey & Demographic Questionnaire

Before the *DigiFale* programme starts, participants will be given consent forms (CF) and a participant information sheet (PIS) outlining the aims and objectives of the programme. Identifying family members to support individuals during their programme will also be important. If individuals do not have intergenerational household support, the *DigiFale* navigators can provide this. Each participant will complete a pre-survey digital skills questionnaire which is repeated at the end of the programme (post-survey). Each *DigiFale* participant will receive a device (smartphone) and connectivity package (\$50 credit) which provides the access and connectivity required to become digitally included and participate in the programme.

<u> Phase Two – DigiFale Programme</u>

6.3. DigiFale programme

Participants will attend five group sessions with their cohort, delivered over five weeks. The mode of delivery is group sessions of no more than 15 people, delivered face-to-face in an environment that is familiar to participants such as a church setting or community hall. The trained DIGIFALE navigators (n=10) will work closely with participants during each session.

Each group session will last approximately 1.5-2-hours (face to face). Facilitation of the programme will be conducted in English and Pacific languages from the community. In the event of further COVID-19 lockdowns, sessions will be transitioned online with the assistance of their family member or *DigiFale* navigator.

The *DigiFale* modules which provide the digital skills, are designed so that each session builds on the previous one. Each training session will start with what is relevant for individuals, consisting of four main types of activity:

- 1) Explanation: Short explanations to introduce mobile literacy skills;
- 2) Activity: Practical exercises on phones;
- 3) Discussion: To encourage participants to consider the relevance in their lives;
- 4) Recap: To reinforce lessons of each module.



Figure 2 provides a brief visual overview of the key features, functions and skills covered in the DigiFale programme. Each module builds on the necessary skills that move individuals from basic mobile literacy to digital health literacy (Figure 3). Relevant learning materials will be provided in hardcopy, softcopy and other necessary materials as required.

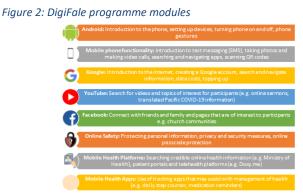
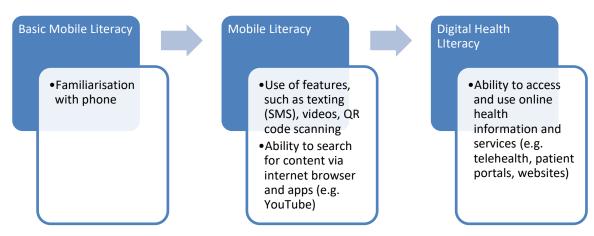


Figure 3: DigiFale digital literacy journey



The theoretical basis of the *DigiFale* is informed by:

- 1) Community participatory research principles (working in partnership with church communities and youth groups).
- 2) Pacific Fonofale model, which ensures essential elements such as family, culture and spirituality are incorporated into the approach. Pacific cultural values are embedded within the fale.
- 3) Four elements outlined in the New Zealand Digital Inclusion Blueprint movitation; access; trust; and skills.
- 4) Behaviour change techniques (BCT's) Instruction on how to perform a behaviour (4.1); Social support (general) (3.1); and Behaviour rehearsal / practice (8.1) which are incorporated in each session.
- 5) Intergenerational social support (family support and *DigiFale* navigators).

Phase Three – Outcomes Evaluation and Dissemination

6.4. Post-questionnaire

At the end of the programme, all DigiFale participants (including those that withdrew from the programme) will complete a digital skills questionnaire (which was also undertaken at the **DIGIFALE** protocol Version 3.0 Moana Research



beginning). Questions about their experience and satisfaction with the programme, its usefulness and perceived impact will be completed using a semi-structured questionnaire on paper or online. A certificate is provided for participants upon completion of the programme.

6.5. Focus Groups

Group *tutala* with a sub-sample of participants (*DigiFale* participants and family members) will discuss in detail acceptability and relevance of the programme, elements or features to improve, as well as reflections on the value and experience of the programme in achieving its goal – to improve digital health literacy among Pacific communities.

Using the four elements of digital inclusion outlined by the New Zealand Digital Inclusion Blueprint, ² insights will also include exploring inspiration and barriers around a) motivation (perceived value and awareness of mobile inclusion); b) access (device, internet connectivity, accessibility, barriers); c) skills (foundation and current levels of digital skills; online safety); and d) trust (digital understanding, trust, and confidence). The focus group will last approximately one to one and a half hours and will be recorded using a digital audio recorder and field notes.

Participation in the focus groups (conducted at the end of the programme) is entirely voluntary. If individuals choose not to take part, they will be free to withdraw at any time without giving a reason.

Sample size and data collection

The sample size of the *DigiFale* project is approximately 60 Pacific adults. The focus groups will involve approximately 20 Pacific adults. Only the focus groups will be recorded using a digital audio recorder and field notes.

Reciprocity

At the start of the *DigiFale* programme, participants will be given a mobile device which they will keep at the end of the programme. A \$50 mobile credit will also be provided for internet connectivity.

As part of the outcome evaluation, the sub-sample of participants (*DigiFale* participants and family members) will receive a \$100 *fakaalofa* (supermarket voucher) as a token of appreciation for sharing their time and insights. Individuals will also be asked if they would like to be informed of the study results which will be indicated on their consent form.

7. PROPOSED OUTCOMES

The primary short-term outcome will be reported changes in digital literacy skills (from baseline measures and at the end of the programme)

Secondary outcomes include programme attendance, participant satisfaction, and self-reported improvements with intergenerational communication and social connection.

During the programme, all *DigiFale* participants (including those that withdrew) will be asked to complete the following:

Attendance

DIGIFALE protocol Version 3.0 Moana Research



Attendance at the DIGIFALE programme will be assessed based on the number of sessions the participant attended (% of 5).

Digital skills questionnaire

Participants will complete a digital skills self-assessment survey (pre/post survey). Several questions related to digital health literacy will be included.

Participant satisfaction

All participants will be asked to complete a satisfaction survey at the end of the programme. Participants can complete the survey in paper or electronic format. This will be completed during the last workshop. The survey data will be de-identified.

Follow up interview

A purposefully selected sample of participants will be invited to a group *tutala*. Participants will be asked about their experiences and opinions of the *DigiFale* programme, elements or features to improve, as well as reflections on the value and experience of the programme in achieving its goal – to strengthen digital health literacy among Pacific communities. Using the four elements of digital inclusion outlined by the New Zealand Digital Inclusion Blueprint, ² qualitative insights will also include exploring inspiration and barriers around a) motivation (perceived value and awareness of mobile inclusion); b) access (device, internet connectivity, accessibility, barriers); c) skills (foundation and current levels of digital skills; online safety); and d) trust (digital understanding, trust, and confidence). Following the *tutala*, participants will be offered a *fakaalofa / mea alofa / koha* in appreciation of their time.

8. ANALYSIS

Qualitative data will be transcribed verbatim and entered in NVivo 12. Coding, categorising, and classifying qualitative data will be completed using a general inductive approach, ⁶ and Pacific methodological approaches appropriate for the research. Independent coding and coding consistency checks will be undertaken to ensure trustworthiness of the data analysis. Workshops to discuss the research themes cross-referenced by ethnicity, demographic or other variable will enable collective agreement of theme saturation, prioritization, and exceptions. Descriptive analysis will be undertaken with the quantitative data generated.

Sociodemographic information will be collected through a demographic form at the start of the family interview session. This will be analysed by a Senior Biostatistician utilizing SAS.

9. DATA MANAGEMENT

Generation and collection –	Data generation (source data)
how will data be generated	In this study, the following types of data will be collected:
and collected	 personal identifying information (names, contact details in the event participants request a copy of the final report);
	 sensitive information including criterion sampling questions (e.g. socioeconomic status, highest level of education);
	detailed notes taken during the interviews and focus groups;



	4. audio recordings of interviews.
	Source Document Plan The source documents for this study include the demographic questionnaire (paper); notes taken during focus groups (paper and/or digital); audio recordings of interviews (digital); and the signed PIS/CFs (paper). We will maintain a Source Document Plan that will document the source, i.e.
	original recording, for each data discrete item/category of items collected for the study. This Source Document Plan, signed and dated by the Principal Investigator, will be prepared prior to recruitment of the first participant and will be filed in the site's Investigator Site File.
Generation and collection	Data capture methods and data use, storage, access and disclosure during the study
Use Storage and access during the study	Data collection methods Potential participant contact details, along with unique participant identifier codes, will be recorded digitally in a password-protected Excel file, which will be saved on a secured Drive. Additional screening data will be collected on paper, identified by the participant code.
	Access Disclosure Interviews will be audio recorded on a secure digital recording device that does not link to the cloud. Notes will be taken digitally or in hard copy. Consent documents will be collected in hard copy and scanned.
	Use of the data Contact details will be used by the research team to organize interviews with participants who meet the sampling criteria. The data from the screening questionnaire will help guide the sampling procedure. Screening data from participants who participate in interviews will be used in the study to generate a demographic overview of study participants. The notes and audio recording data from interviews will be analysed at the end of the programme. At the end of the recruitment and data collection process, all contact details and screening questionnaires related to individuals who were not selected to participate in an interview will be destroyed. Materials related to participants will be securely stored as outlined in the protocol.
	Storage and access All study-related data will be secured in digital files only accessible by two factor authenticated password and locked physical storage facilities. All data collection will be undertaken in accordance with the National Ethical Standards for Health and Disability Research and Quality Improvement (2019) and Health Research Council Pacific Research Guidelines (2014). Files containing private or confidential data will be stored in locations accessible only by appropriate designated members of the research team.



	Specific storage and access procedures:
	 Specific storage and access procedures: Contact details will be stored digitally along with participant identifier codes, in a password-protected drive accessible only by the research team. Screening questionnaires will be digitally stored in a password protected drive accessible only by the research team. Following the conclusion of data collection, all questionnaires related to individuals who were not interviewed will be destroyed. Participant consent and receipt of reimbursement documents will be collected in hard copy by the research team at the time of interviews. Consent documents will be scanned and stored by the research team in a single password-protected file, and the hard copies destroyed. Hard copy and/or digital interview notes and audio recordings will be stored by the research team as described above. All audio recordings will be removed from recording devices as soon as they have been transferred to a secure drive. Disclosure The study protocol, documentation, data and all other information generated will be held in strict confidence. No information concerning the study, or the data will be released to any unauthorised third party. Information will not be released without written permission of the participant.
Methods to reduce identification of participants	 Data confidentiality Participant confidentiality is strictly held in trust by the Principal Investigator, and participating research staff. To preserve confidentiality and reduce the risk of identification during collection, analysis and storage of data and information, the following will be undertaken: a. The number of confidential variables collected for everyone has been minimised. The data collected will be limited to that required to address the primary and secondary objectives. b. Participant identifiers will be stored separately to the data collected from family interviews. This code will be linked only to participant names and contact details. All screening questionnaires, interview notes and recordings will be stored and linked to the participant codes. The Principal Investigator is responsible for the storage of a master-file of names and other identifiable data with the participant ID; access to this document will be restricted to the research team and authorised persons as listed previously. The master file will be stored securely, and separately, from study data in locked/ password-protected database with passwords kept separately.
	Information gathered through the interviews and focus groups will be transcribed verbatim. Field notes following the interview will be recorded and the audio



	recording will be made available, to enable researchers to refer to the interview during the analysis stage, if needed.
Analysis	Please refer to ANALYSIS section.
Storage post-study ARCHIVE	Archiving - Data and document retention
Disposal	 Archiving All data will be retained for a period of 6 years in accordance with HDEC ethics committee requirements, before being destroyed. During the archive period, the Principal Investigator will be the custodian, who will have access to the stored data and outline any procedures that may be followed to dispose of the data at the end of the archival period. Records will not be destroyed without the written consent of the Principal Investigator. Destruction Following the archive period both data and documents will be destroyed using irreversible methods to ensure that the data is no longer usable. Hardcopies will be disposed of via a confidential shredding process. For electronic data, software that permanently erases data will be utilised.
Long-term custodianship	Long-term custodianship (after archive period finished) Following the conclusion of the study, all digital data will be archived in a secure Moana Research network drive, which will be managed by the Principal Investigator (Amio Matenga Ikihele – Innovations Lead /Moana Research)

10. ETHICAL APPROVAL

Ethical Approval will be sought from The Health and Disability Ethics Committees. All research will be conducted according to the Pacific Health Research guidelines developed by the Health Research Council ⁷ and National Ethical Standards for Health and Disability Research and Quality Improvement.

11. DISSEMINATION OF RESULTS

At the end of the study, all study participants (who requested it and provided their details) will receive a brief summary of the study results, an outline of their significance, and future research plans. A presentation to communities will be offered. The findings of the pilot will also be published in a peerreviewed journal reaching a wider national and international audience who have an interest in this subject area.

In alignment with *'foaki'* in the Hihi framework, we will value this process as a 'gifting back' of the information received, in a form that is authentic and of the highest quality to the individuals involved in this project.



12. OWNERSHIP OF DATA

Individual study data will remain the property of individual participants. Moana Research has the responsibility for storage, protection, and retrieval of study data. Data will be stored securely for ten years and after this time will be safely destroyed.

13. PUBLICATION POLICY

We aim to publish the findings in one or more publications submitted to appropriate journals.

14. RESEARCH TOOLS

- A1 Participant Information Sheet
- A2 Consent Form
- A3 Demographic questionnaire
- A4 Pre-survey (DigiFale intervention)
- A5 Post-survey (DigiFale intervention)
- A6 Programme logic for focus groups
- A7 Guidelines for staff undertaking interviews
- A8 Risk Register
- A9 Koha Acceptance Form
- A10 Dissemination plan
- A11 Checklists (pre/post workshops and tutala)
- A12 Summary of Protocol Amendments

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1. Digital Inclusion Research Group. Digital New Zealanders: The pulse of our nation. Wellington, New Zealand. Digital Inclusion Research Group. 2017.

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8. National Ethics Advisory Committee. National ethical standards for health and disability research and quality improvement. Wellington. Ministry of Health. 2019.



A1 – PARTICIPANT INFORMATION SHEET

Project title:

DIGIFALE: A digital health literacy programme for Pacific communities.

FAKAALOFA LAHI ATU, TALOFA LAVA, MALO E LELEI AND KIA ORANA.

Are you interested in learning how to use a mobile phone, and how you can use this for health-related purposes?

If you have answered yes to the above, we invite you to take part in a programme exploring how a digital literacy programme for Pacific communities – DIGIFALE - can increase digital literacy and how these digital literacy skills can be used to access online and digital health services.

This project is coordinated by Moana Research and funded by the Ministry of Health. The results and learnings of this project will also be used to inform PhD research led by Amio Matenga Ikihele at the University of Auckland.

Your participation is purely voluntary, and you can withdraw at any time. Before you decide to participate, you may want to talk to other people such as family, friends, or healthcare providers about this project. Feel free to do this. To help you decide if you want to take part in the project, please read this information sheet. If you have any questions, you can contact myself or other researchers at any time.

What is the purpose of this project?

This project aims to evaluate a culturally aligned mobile literacy programme among Pacific communities considered digitally excluded; and to explore how using mobile phones can improve health.

The results of this project will assist with how we can improve digital literacy among Pacific communities. It will also help us understand how we can improve health and wellbeing, when considering the use of online health services and digital health tools. If you agree to participate, you will be asked to sign a Consent Form on the last page of this document. This copy of the Participant Information Sheet is yours to keep.

Who can participate?

We are looking for Pacific adults who self identifies as being digitally excluded. This refers to those who have 1) no mobile phone; 2) used a mobile phone but stopped using this because it was too difficult; or 3) not confident using a mobile phone. You must be able to provide consent to participate. The DIGIFALE programme will be facilitated in four Pacific languages (Niue, Samoa, Tonga, and Cook Island) including English.

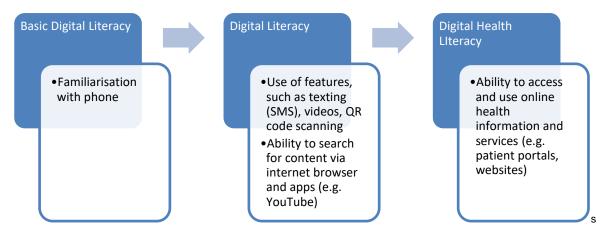
What will my participation in this project involve?

You will attend weekly group sessions over five weeks, each lasting approximately 1.5-2 hours (face to face). The DIGIFALE programme has several modules and you will work closely with a DIGIFALE navigator as they teach digital skills. Each module is designed so that each session builds on the previous one, eventually increasing digital skills so you can access digital health services. Figure 1 outlines the journey towards digital health literacy, which is defined as "the ability to seek, find, understand, and appraise health information from



electronic sources and apply the knowledge gained to addressing or solving a health problem."1





At the start of the DIGIFALE programme, you will be asked to complete a digital skills questionnaire which will be repeated at the end of the programme. You will be asked questions about your age, digital access (device ownership and internet access); and digital literacy skills (ability to undertake mobile phone functions and ability to search for information online). You will also be provided with a mobile phone and \$50 prepaid credit which you get to keep when you complete the programme.

At the end of the programme, a small number of DIGIFALE participants will be asked to provide further feedback through a group talanoa/tutala (discussion). Questions include your reflections on the value and experience of the DIGIFALE programme, how acceptable it was, and what value you have taken away from participating. Interviews with selected participants will be completed by the DIGIFALE Project Lead Amio Matenga Ikihele (details pg. 4) and a research assistant. Participants will receive a voucher in recognition of your participation and time.

If you choose to withdraw before the DIGIFALE programme finishes, you will be given a short questionnaire to complete asking for your feedback about the programme, and any improvements that could be made.

All information collected in the demographic questionnaire, surveys, and group talanoa/tutala is labelled only with your participant code, not your name, date of birth, or other things that could identify you. It will also be stored in strict confidence in a locked filing cabinet in a locked office for ten years and destroyed (shredded) after ten years.

Participation in this project is entirely voluntary: it is your choice. If you choose not to take part, you will not be affected in any way. If you agree to take part, you will be free to withdraw at any time without giving a reason. Your withdrawal from the programme will not affect you in any way or your relationship with Moana Research, the University of Auckland, your community or health provider. You are encouraged to ask questions at any time during the project.

¹ Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006;8(2):e9. DOI: 10.2196/imir.8.2.e9 **DIGIFALE** protocol Version 3.0 Moana Research



What are the discomforts and risks?

We do not anticipate any risks with this project. All workshops will be facilitated using Pacific values. The only risk involved for you taking part is the possibility that the programme could touch on culturally sensitive or personally sensitive matters related to digital skills and/or digital inclusion/exclusion.

In the event you feel uncomfortable during any of the DIGIFALE workshops, you are completely free to leave the session, with no questions asked. Please note as workshops consist of a number of people, your participation and contributions are not anonymous or confidential to the other participants in the same workshop. All participants will be asked to "agree to respect and treat as confidential the contribution of other focus group participants" when they sign their consent form.

Participation in the group *talanoa/tutala* at the end of the programme is also voluntary and you will be able to withdraw at any time. However, once the focus groups have started, we will be unable to separate the comments made by individual participants and it will not be possible for you to edit the transcripts. This information will not be personally identifiable in any material stored in writing or in audio.

How will these discomforts and risks be alleviated?

If the discussions trigger uncomfortable feelings (such as being worried), you are welcome to talk to any of the researchers who will be happy to listen to your concerns and/or refer you to specialist services that could help. We have listed below some numbers of organisations you can contact should you wish to talk to someone who is not involved in the project.

- Support from a trained counsellor Free call or text 1737 any time
- Healthline 0800 611 116
- Health & Disability Commission 0800 555 050

What happens after the programme and focus groups?

Audio will be electronically recorded and then securely stored in computers protected by passwords. Audio recordings will be transcribed by the researchers.

None of the anonymous information from audio recordings will be made publicly available. All information obtained for this project is of great value and will be stored for ten years in a secure manner in password-protected computers, information will be deleted and shredded after the ten years. No third parties other than the researchers and those conducting the focus groups will be involved.

What are the benefits?

Your experiences in the DIGIFALE programme are important and will help contribute to designing and improving digital literacy programmes, online and digital health services for Pacific communities in Aotearoa. The findings from this programme have the potential to improve the way digital health services are created and implemented for communities that are considered to have low uptake and access to digital health technology. The findings from this research will be presented to researchers, clinicians, service providers and the Ministry of Health. It may also be used within academic publications or used to develop further programmes that are suitable for Pacific communities.

How will my privacy be protected?

The programme involves several people in attendance. As such, your participation in the DIGIFALE programme is not anonymous or confidential to other participants in the same room. All participants in the DIGIFALE programme will be asked to "agree to respect, treat as confidential, and not disclose the contribution of other group participants" upon signing the consent form. All personal information/data collected during this project will be kept confidential and accessible only to the researchers.



All data will be stored on a password protected network drive at Moana Research. All electronic data will be stored for a maximum of ten years and will be destroyed safely after this time. If any information is to be published, it will not contain any personal or identifying information of individuals or families.

What are the costs of participating in this research?

The only cost to participate in this project will be your time. Each workshop takes approximately 1.5-2 hours over five weeks.

What opportunity do I have to consider this invitation?

Once you have read this information sheet, you are most welcome to contact me directly to discuss any further questions you may have before deciding to participate. Once your queries have been answered, you may then sign the consent form.

Please note that we will always be accessible if you have any questions about this project.

Will I receive feedback on the results of this research?

As highlighted in the consent form, you will receive a summary of the research findings if you have selected this as an option.

Has the project received ethical approval?

The project has received ethics approval from the Southern Health and Disability Ethics Committee on 10 May 2021, Reference Number21/STH/110.

Who do I contact for further information about this research?

Please do not hesitate to contact me should you have any queries or concerns. Should you be interested to participate in this project, please contact:

Amio Matenga Ikihele DIGIFALE Project Lead & PhD student amio@moanaresearch.co.nz 0211752087	Ane Fa'aui Community Engagement Coordinator ane@moanaresearch.co.nz 0212725673	Jacinta Fa'alili-Fidow Moana Research CEO jacinta@moanaresearch.co.nz 021748627
PhD details: Department of Epidemiology and Biostatistics School of Population Health Faculty of Medical and Health Sciences The University of Auckland		

For concerns of an ethical nature, you can contact the Chair of the Health and Disability Ethics Committee (HDEC) that approved this study on:

Phone: 0800 4 ETHIC

Email: <u>hdecs@health.govt.nz</u>



A2 - CONSENT FORM

This form will be held for a period of ten years.

Please tick to indicate you consent to the following:

I have read and I understand the Participant Information Sheet.	
I have been given sufficient time to consider my participation in this project.	
I am satisfied with the answers I have been given regarding the project, and I have a copy of this consent form and information sheet.	
I understand that my participation in this project is voluntary (my choice) and that I may withdraw from the project at any time without this affecting me in any way.	
I consent to the research staff collecting and processing the information I give in the questionnaire (such as age, address, ethnicity, and employment status).	
I consent to the research staff audio recording the focus group.	
If I decide to withdraw from the project, I agree that the information collected from me to the point when I withdraw may continue to be processed.	
I understand that my participation in this project is confidential and that no material that could identify me personally will be used in any reports on this project.	
I know who to contact if I have any questions about the project in general.	
I agree to respect, treat as confidential, and not disclose the contribution of other group participants.	
I wish/do not wish to receive a summary of findings, which can be emailed or mailed to me at this email/postal address:	

Declaration by participant:

I hereby consent to take part in this project.

Participant's name:	
Signature:	Date:



Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Participant's name:	
Signature:	Date:

(This form will be held for a period of ten years)



A3 - DEMOGRAPHIC QUESTIONNAIRE

(completed at the beginning of the programme. This form will take approximately five minutes to complete)

Age (years)	
Gender	 Male / Tāne Female / Wahine Another gender / He ira kē anō
Which ethnic group or groups do you belong to?	 New Zealand European Māori Samoan Cook Island Māori
Mark the space or spaces that apply to you.	 Tongan Niuean Indian Chinese Other (please state, eg, Dutch, Japanese, Tokelauan)
Suburb	
Employment status	Paid employee Employer Coff count of the strengthenergy
Mark the space that apply to you	 Self-employed and without employees Unpaid family worker Not elsewhere included
Household composition	 How many adults (16 years and over) live in your household? How many children (under 16 years) live in your household?
Key support person	 Do you have a nominated family member or support person that can assist you with your mobile phone and set up at home? Yes No
	What is their relationship to you? Spouse / Partner Child Grandchild Extended family member Friend Church member Other
	ACCESS – Internet and Devices
Do you own a mobile phone?	Yes No
Do you have an email address?	Yes No
Have you used the internet before?	 Yes No



If YES, where do you use the internet MOST of the time? Do you personally use any of these technology related items?	 Home Friend or family's home School Work Free WiFi spots Library Internet café Other Tablet / iPad Laptop Smartphone (e.g. iPhone or Android) Mobile phone (not smartphone – text and calls only) I do not own any of these devices
Does anyone in your household own or use any of these technology related items?	 Tablet / iPad Laptop Smartphone (e.g. iPhone or Android) Mobile phone (not smartphone – text and calls only) No one owns any of these devices
DIGITA	L HEALTH – Interest in using mobile phone for health
Where do you seek information related to HEALTH and WELLBEING for YOURSELF? <i>(Tick all that apply)</i>	 Family member Friend Church leaders Family doctor or nurse Websites (please state)
If you have a mobile phone already, do you <u>currently</u> use your mobile phone to improve your health? <i>(Tick all that apply)</i>	 I use telehealth e.g. talk to a health worker on the phone or video for advice or treatment I use text messages to communicate with health workers or have used a text messaging service for health (e.g. appointment reminders) I read posts or watch videos about health on social media I use Google to find health information I use health apps (e.g. MyFitnessPal, My Quit Buddy, Calm) I use a health tracker (e.g. steps/kms, heart rate, sleep patterns) No, I do not use my phone for health
What type of mobile health would you like to use in the <u>future</u> if available? (<i>Tick all that apply</i>)	 Phone calls to talk to a health professional Telehealth to video chat with a health professional A text messaging service (e.g. to access support from a nurse) Social media (e.g. Facebook to learn more health facts and tips) Health apps (e.g. MyFitnessPal, My Quit Buddy, Calm) Health tracker (e.g. steps/kms, heart rate, sleep patterns) No, I would not use my phone for health in the future Other



A4 - PRE-SURVEY (completed at the beginning of the programme. This form takes approximately 5 minutes to complete)

BASIC INFORMATION		
Church group	Cook Island	
*this will be	□ Niue	
updated to the	🗆 Samoa	
proper name later		
Participant code		

FOUNDATION / BASIC SKILLS		
I can turn on my mobile phone	Yes	No
I can make phone calls	Yes	No
I can send text messages	Yes	No
I can send emails	Yes	No
I can send and receive photos & videos	Yes	No
I can connect a device to a Wi-Fi network	Yes	No
I can find and open different applications (App) or programmes on a device	Yes	No
I can use different menu settings on a device to make it easier to use (e.g. change the font size to make it easier to read)	Yes	No
SKILLS TO CARRY OUT ONLINE ACTIVITY AND SERVIC	ES	
I can access and register services online including filling in forms, particularly government services	Yes	No
I can use the internet to find information that helps me to solve problems (e.g. use search engines)	Yes	No
I can use my digital skills to keep up with the change of technology	Yes	No
SOCIAL CONNECTION SKILLS		
I can communicate with others digitally (e.g. text, email or Messenger)	Yes	No
I can speak to others through video tools (e.g. FaceTime, Zoom or Skype)	Yes	No
I can use the internet to stream or download entertainment content (e.g. watching video clips. Movies, listening to music, playing games online, or reading a book)	Yes	No
SKILLS TO BE SAFE ONLINE		
I can keep the information I use to access my online accounts secure, by using different and secure passwords for websites and accounts	Yes	No
I can respond to requests for authentication (e.g. reactivate an account when I've forgotten my password)	Yes	No
I can assess the risks and threats involved in carrying out activities online and act accordingly including:	Yes	No
	Yes	No

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 I can recognise and avoid suspicious links in emails, websites, social media messages and pop ups, and know that clicking on these links is a risk Identifying secure websites by looking for the padlock and 'https' in the 	Yes	No
address bar		
I make sure not to share or use other people's data or intellectual property without their consent	Yes	No
I am careful with what I share online as I know that online activity produces a permanent record that can be accessed by others	Yes	No
SKILLS TO ACCESS DIGITAL HEALTH SERVICES		
I know how to access my patient portal	Yes	No
I can use my patient portal (e.g. booking appointments, viewing medical records)	Yes	No
I can find and download health-related applications (Apps) or programmes on a device	Yes	No
I can find helpful health related advice and information on the internet	Yes	No
I can use the internet to answer my questions about health	Yes	No
I feel confident in using information from the Internet to make health decisions	Yes	No



A5 - POST-SURVEY (completed at the end of the programme. This form takes approximately 6 mintues to complete)

Please indicate if you are confident undertaking the following tasks without any help.

BASIC INFORMATION			
Church group	Cook Island		
*this will be	□ Niue		
updated to the	🗆 Samoa		
proper name later			
Participant code			

BASIC SKILLS		
I can turn on my mobile phone	Yes	No
I can make phone calls	Yes	No
I can send text messages	Yes	No
I can send emails	Yes	No
I can send and receive photos & videos	Yes	No
I can connect a device to a Wi-Fi network	Yes	No
I can find and open different applications (App) or programmes on a device	Yes	No
I can use different menu settings on a device to make it easier to use (e.g. change the font size to make it easier to read)	Yes	No
SKILLS TO CARRY OUT ONLINE ACTIVITY AND SERVIC	ES	
I can access and register services online including filling in forms, particularly government services	Yes	No
I can use the internet to find information that helps me to solve problems (e.g. use search engines)	Yes	No
I can use my digital skills to keep up with the change of technology	Yes	No
SOCIAL CONNECTION SKILLS		
I can communicate with others digitally (e.g. text, email or Messenger)	Yes	No
I can speak to others through video tools (e.g. FaceTime, Zoom or Skype)	Yes	No
I can use the internet to stream or download entertainment content (e.g. watching video clips. Movies, listening to music, playing games online, or reading a book)	Yes	No
SKILLS TO BE SAFE ONLINE		
I can keep the information I use to access my online accounts secure, by using different and secure passwords for websites and accounts	Yes	No
I can respond to requests for authentication (e.g. reactivate an account when I've forgotten my password)	Yes	No
	Yes	No



I can assess the risks and threats involved in carrying out activities online and act accordingly including:	Yes	No
I can recognise and avoid suspicious links in emails, websites, social		
media messages and pop ups, and know that clicking on these links is a risk	Yes	No
 Identifying secure websites by looking for the padlock and 'https' in the address bar 		
I make sure not to share or use other people's data or intellectual property without their consent	Yes	No
I am careful with what I share online as I know that online activity produces a permanent record that can be accessed by others	Yes	No
SKILLS TO ACCESS DIGITAL HEALTH SERVICES		I
I know how to access my patient portal	Yes	No
I can use my patient portal (e.g. booking appointments, viewing medical records)	Yes	No
I can find and download health-related applications (Apps) or programmes on a device	Yes	No
I can find helpful health related advice and information on the internet	Yes	No
I can use the internet to answer my questions about health	Yes	No
I feel confident in using information from the Internet to make health decisions	Yes	No

PARTICIPANTS EXPERIENCE WITH DIGIFALE (completed AFTER the workshop)

1. How easy was it to for you to learn new digital skills on the DigiFale programme?

Very difficult	Difficult	Fair	Easy	Very easy
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2. How would you rate your experience on the DigiFale programme?

Very poor	Poor	Fair	Good	Excellent
-----------	------	------	------	-----------

3. How would you rate your experience with your DigiFale navigator?

Very poor Po	oor Fair	Good	Excellent
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4. How likely would you be to use the skills you have learned within the next 6 months?

Very unlikely	Likely	Don't know	Unlikely	Very likely
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5. Would you recommend the *DigiFale* programme to others? (e.g. family members, church community, friends?)

Yes	No
Why/Why not?	

6. How might we improve the *DigiFale* programme for others in the future?

Comment	:
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A6 - LOGIC FOR QUALITATIVE QUESTIONS (Groups Tutala)

This schedule is a guide only and allowances must be made for questions/discussions that naturally arise from the interview. The objectives of *DigiFale* are to:

- Generate insights on how a mobile literacy programme can improve digital health literacy among Pacific communities;
- Identify intergenerational support mechanisms (cultural, family, spiritual) that influence digital health literacy among Niue communities;
- Improve our understanding of how mobile health can engage Pacific communities in health care with the potential to improve health inequities.

Item	Objective	Guiding Questions
Introductions	<i>Folafolaaga</i> – getting to know one another	• All participants to introduce themselves, their role on the programme (participant, navigator or family member)
<i>DigiFale</i> programme	 To gain insight with how a mobile literacy programme can improve digital health literacy (includes programme acceptability, relevance and features to improve) 	 Tell me about your experience with the <i>DigiFale</i> programme? Can you provide me with an example of what you did during a <i>DigiFale</i> session? Were you supported in this programme? If so, how? What was useful about the programme? What did you look forward to with each <i>DigiFale</i> session? Would you recommend the programme to other people? How might the <i>DigiFale</i> programme be improved?
Digital Skills		 Are there any concerns or issues that prevent you from using your mobile phone or accessing the internet? Has the <i>DigiFale</i> programme had any impact on you and your family? Please explain (positive or negative)
Intergenerational support	2. Identify intergenerational support mechanisms (cultural, family, spiritual) that influence digital health literacy)	 Tell me about your experience working alongside your <i>DigiFale</i> / navigator / or family member? Did you feel supported by the person working alongside you? How did they make you feel? Has your connection with members or your community changed after the programme? If so, how? What has been the value/benefit of this approach for you personally?
Digital health literacy	3. Improve our understanding of how mHealth can engage Pacific communities in health care with the potential to improve health inequities.	 What sort of things can you do on your phone now? How confident do you feel using your phone now? How confident are you using your phone for health-related concerns or issues?



		•	Do you use your phone for health-related concerns or issues? Why/why not? How might we ensure individuals like yourselves have the ongoing support and tools to access online health information and support.
Conclusion	Any additional information	•	Is there anything else you would like to share about your experiences in the <i>DigiFale</i> programme? Conclusion



A7 – GUIDELINES FOR STAFF UNDERTAKING INTERVIEWS

Introduction

This is a summary of the Moana Research guidelines for staff undertaking interviews or other research in participant's homes. Minimising harm to both participants and researchers is an ethical consideration for everyone involved in a research study.

Interviewing people in non-public places

Some consideration should be given to research in non-public places and to appropriate methods of mitigating risks arising from this. Unless there are strong reasons for interviewing people in their own homes or other non-public places consider meeting in a safe, mutually convenient, quiet public place, where you can't be easily overheard. Some public places might not necessarily be safe, e.g., small shops.

All research in non-public places will be undertaken in pairs. A buddy system will also be implemented where a friend, colleague or line manager is informed about the fieldwork timetable, including who the researcher meets, where the meeting takes place and for how long. An updated itinerary will be communicated before each interview/fieldwork trip so that the buddy/manager is aware of any changes in plans.

If interviewing in a non-public place is essential or unavoidable, please follow the advice given below:

Preparations and basic personal safety:

- Where possible, conduct visits during daylight.
- Ensure someone knows where you are working, who you are likely to be meeting and what time you expect to get back, inform them if your plans change.
- Carefully plan your journey. Write down directions and draw a map on a separate piece of paper that you can consult inconspicuously. Getting a map out can identify you as a stranger, uncertain of the area and in some situations vulnerable.
- Wear clothing that is comfortable, appropriate for the area you are visiting, and has pockets.
- Carry only essential keys, money or cards, and a mobile phone (use a cheap handset if possible). Put aside money for your return fare if needed have an emergency "stash" hidden somewhere on your person in case your bag gets stolen.
- Before your set out make sure your phone is fully charged, has a signal where you are going and has credit.
- If you need to carry a laptop or other equipment bear in mind that computer bags are an invitation to thieves. Laptops can be carried just as easily in anonymous looking small back packs. Make copies of data just in case. Consider data security and encrypting sensitive data.
- Always carry a form of ID e.g., a laminated copy of your passport or driving license (leave originals somewhere safe) and a copy of your research permit where applicable.



Personal safety when interviewing:

- Find out as much background information about interviewees as possible. To be forewarned is forearmed. Local knowledge and contacts are crucial. Find out the local sensitivities, tensions, political landscape, topics to avoid etc.
- Always be friendly and polite and do not appear aggressive or annoyed if an interviewee is late or says they must leave early. Respect their wishes. You are taking up their time.
- Consider whether your interviewees might have expectations that you will give them something in return for their cooperation. Think about how you might handle that without compromising yourself or your research manage their expectations and find out what local customs are and what is culturally appropriate.
- If possible, conduct meetings during daylight hours in a public or neutral space, for example a café; if you are interviewing a controversial figure or someone likely to attract negative attention consider a hired room or an office environment.
- Have pre-prepared exit excuses should you need one, and neutral responses to sensitive controversial issues, in case your opinion is asked.
- Where questions might be sensitive trial your questions where possible with someone you trust who is aware of the context. Familiarise yourself with the local culture sensitivities and tensions.
- Be aware of how you might come across, particularly in a cultural environment you might not be familiar with.

When interviewing in a subject's home is necessary:

Interviewing in someone's home increases the risk to your personal safety and wherever possible arrange to visit with an additional person. If this is not possible it is particularly important to inform someone of your itinerary and check in and out with them (see section above for more information on check-ins). In addition to the measures in the above section on 'Personal safety when interviewing' consider the following:

- Research the local area and the nature of the accommodation (if it is a high crime area you need to factor this into your personal safety measures and decision to go)
- Watch out for dogs, and do not enter premises if you feel at risk from a dog or other animal.
- Keep your belongings together and try to sit nearest the door.
- Watch for changes in the person's mood, expression, and body language.
- If you feel at risk leave as soon as possible without arousing suspicion (have a pre-pared exit excuse).
- Never enter a house if you are in anyway unsure or uneasy about the occupant(s) or situation.
- Do not carry out the visit if the risks cannot be managed.

In a hostile situation or where you feel yourself threatened:

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- Remove yourself from the situation as quickly as possible (have a pre-prepared exit excuse/exit plan). Back away slowly.
- Try to remain calm and de-escalate the situation; speak gently, slowly, and clearly.
- If appropriate acknowledge their feelings (... I can see you are angry.)
- Make your body language neutral and relaxed don't mirror defensive or aggressive body language, such as crossed arms or hands-on hips.
- Maintain eye contact ... but do not stare.
- Keep your distance allow plenty of personal space.
- Do not reach out to touch or make physical contact if someone is angry or emotionally upset.
- Never raise your voice or let yourself be led into an argument.
- Do not tell them to 'calm down'!



A8 – RISK REGISTER

The risk register has been developed on an excel and will be reviewed regularly to mitigate, prevent or manage anticipated and emerging risks related to this research.

Risk register includes the following elements:

	1
Element	Descriptor.
ID #	Identification number.
Date logged	The date that the risk is logged onto the register.
Person	Person who entered the risk. The expectation is that they provide the required data and escalate, delegate and respond as needed.
Identified Risk	High level description of the risk.
Description	Brief description and summary of the risk.
Status	Open, resolved, ongoing.
Impact	Rate: 1 (LOW) to 5 (HIGH) - Suspected impact and consequences if the risk arises.
Probability	Rate: 1 (LOW) to 5 (HIGH) - How likely is it that the risk will occur?
Priority	Impact score (1-5) multiplied by the Probability score (1-5). Prioritization indicates relative importance therefore urgency to respond and can be used to determine if it is a high, medium or low risk.
Types of risk	Nature or type of risk. For example: Reputational, operational, ethical.
Response (mitigation and management)	What can be done to lower or eliminate the impact or probability of the risk.
Ownership	Who is responsible?
Notes and relevant documents	Attach relevant information and documentation pertaining to the risk.

ID	DATE LOGGED	PERSON	IDENTIFIED RISK	DESCRIPTION	STATUS	IMPACT	PROBABILITY	PRIORITY	TYPES OF RISK	OWNERSHI P	NOTES
Numbered risk & ID	Date of risk entered	Person who entered risk. Provide date and escalate, delegate and correspond as needed.	High level description of the risk	Brief description and summary of the risk.	Status – Open, resolved, Ongoing	Rate 1(Low) 5(High)	Rate 1(Low) 5(High)	Impact & Probability- Prioritised by highest	Include types of relevant risks. Eg. Reputational Operational Ethical	Who is responsible?	Attach Relevant documents



A9 – KOHA ACCEPTANCE FORM



Koha Acceptance Form

EVENT:			
DATE:			
VENUE:			

Dear Participant(s),

	Nam e	Amount	Signature
l			

On behalf of the CEO of Moana Research, we would like to thank you for your contribution.

Please accept this gift as a token of our appreciation.

Kind regards.

Jaal Tidow

Moana Research CEO

(Please ensure this form is soanned and saved in the Moana Research files under Koha – Koha Acceptance Forms)

KOHA POLICY

MOANA RESEARCH_20



A10 - DISSEMINATION PLAN

Plans for disseminating the findings of this research

There are several key audiences for this project, which include:

- Funders & Planners with District Health Boards, Primary Healthcare Organisations, Governments Agencies, Digital and Data - Ministry of Health, NGO's, New Zealand Telehealth leadership group,
- Pacific families and communities
- Academia

DigiFale is a culturally contextualised mobile health literacy intervention that provides the necessary access, connectivity, and skills required to overcome digital inequities. By strengthening digital literacy, Pacific communities can build essential skills to access digital health services and make informed choices to improve and manage their health more effectively.

Pacific communities are the considered most at risk of being digitally excluded which is concerning as they are the same population groups who experience worse social and health outcomes and poorer access to primary healthcare services. Pacific are also more likely to find it difficult accessing online Government services as highlighted in a 2019 digital exclusion report by the Citizens Advice Bureau. This project will provide new knowledge that can be used to improve the health outcomes of Pacific communities who are considered digitally excluded and what support mechanisms are necessary to enable communities to utilise online health services.

Translating findings from this project requires a range of modalities which include:

- Written summaries for participants
- Community fono
- Face to face presentation (or zoom) to funders
- Development of links with key organisations to contribute findings within their spaces
- Use of electronic media such as websites and social media
- Radio platforms
- Publications including Full, Executive Summary and Plain English summary reports of the project and in peer review journals.

This proactive dissemination strategy offers the breadth to reach out to multiple audiences and the depth to conduct more in-depth interactive work with key audiences, funders, planners, and policy makers.



A11 – CHECKLIST

PRE-WORKSHOP CHECKLIST



A12 – Summary of Protocol Amendments

Page	Section heading	Amendment		
2	Project team members	Project team and advisors updated		
2	Project sponsor	Project sponsor included		
5	Study flow diagram	Study flow diagram included		
7	Study design	The Kakala framework was replaced with the Hihi framework		
7	Inclusion criteria	Adult changed to Aged 18 years or over and 'no internet access' removed		
10	Proposed outcomes	Outcomes rewritten and categorised		
14	Dissemination of results	The Kakala framework was replaced with the Hihi framework		
14	Ownership of data	Ownership of data changed from six years to ten years		
16	Participant information sheet	Introduction rewritten. Included a definition of digital health literacy, advised participants they receive pre-paid credit and keep the mobile phone at the end of the programme.		
17	Participant information sheet	Updated paragraph on anonymous data to include sentence "is labelled only with your participant code, not your name, date of birth, or other things that could identify you" as per HDEC suggestions.		
19	Participant information sheet	Updated contact person Community Engagement Coordinator role		
20	Consent form	Updated period – six years to ten years.		
22	Demographic questionnaire	Included time it takes to complete form (5 minutes) and updated age, ethnicity, gender, and employment status to align with Statistics NZ		
24	Pre-survey	Included time it takes to complete form (5 minutes) and updated questions		
25	Post-survey	Included time it takes to complete form (5 minutes and updated questions		
4	Research aims and objectives	Research aims and objectives rewritten		
8	DigiFale programme	Changed the number of sessions from six to five sessions over five weeks.		
17	PIS	Addition of PhD student at the University of Auckland		