Appendices

Appendix 1 – Growin' Up Healthy Jarjums Aboriginal research governance

Aboriginal Research Governance

An Aboriginal Research Governance is established to oversee the research process including research design, implementation, analysis and reporting.

The Research Team
This research is co-led by three academics, three Aboriginal community researchers, and one PhD student.

Name	Affiliations	Positions	Responsibilities
Professor Billie Bonevski	The University of Newcastle	Chief Investigator	Oversee all aspects of project. Expertise on smoking cessation and health behaviour change. Provide primary supervision to PhD candidate Perkes.
Professor Joerg Mattes	The University of Newcastle	Investigator	Expertise on child respiratory health. Provide co-supervision to PhD candidate Perkes.
Dr Kerry Hall	Griffith University	Investigator	Expertise on Indigenous child respiratory health. Co-supervision to PhD candidate Perkes and cultural oversite on research.
Noelene Skinner	MNCLHD; The University of Newcastle	Aboriginal community researcher; Gumbaynggirr woman	Recruitment, data collection, analysis, dissemination, and cultural protocols in the Gumbaynggirr community.
Bernice Leece	HNELHD; The University of Newcastle	Aboriginal community researcher; Gomeroi woman in the Kamilaroi Nation	Recruitment, data collection, analysis, dissemination, and cultural protocols in the Kamilaroi Nation.
Belinda Huntriss	The University of Newcastle	Aboriginal community researcher; Worimi woman	Recruitment, data collection, analysis, dissemination, and cultural protocols in the Awabakal community.
Sarah Perkes	The University of Newcastle	PhD Student	Co-ordinate all aspects of the study including ethics, intervention co-design and data analysis.

The organisations involved in this project include:

1. Awabakal Aboriginal Medical Service (AMS)
2. Galambila AMS
3. Armajun AMS
4. Muloobinba
5. Kulai Preschool
6. Aboriginal Maternal Infant Health Services and Child and Family Health, NSW Health (Newcastle, Coffs Harbour and Inverell)

Existing Aboriginal advisory process

Aboriginal community researchers lead the Aboriginal advisory process for this research, guided by participating organisations. Aboriginal community researchers lead communications with organisations and community members, and advise the research team on local protocols. This process has worked well to date, allowing for flexibility of involvement among organisations. Most of the research team and organisations have worked together in some way since 2017, as part of a previous study. We continue to build on these solid working relationships. An Aboriginal advisory group will solidify this process and add greater transparency and accountability. The '8 steps in the research journey' from 'Keeping research on track II' (NHMRC, 2018) will help continue to guide this process.

Objectives

Growin' up Healthy Jarjums project acknowledges that Aboriginal and Torres Strait Islander people have the right to make decisions about research that is affecting them. It is paramount that the research conducted ensures Aboriginal and Torres Strait Islander communities are fully informed about, and agree with, the purposes and conduct of the project.

Terms of Reference

The role of the Aboriginal Advisory group will be to provide cultural consultation, advice and direction to ensure that the research project developed and the implementation of the research is appropriate and meaningful to the communities involved.

The Aboriginal Advisory Group will be instrumental guiding the development of:

- Research design and methodologies
- Research plan implementation and conduct
- Analysis of findings ensuring appropriate reflection of community and ways of doing in the organisations
- Guidance of future research
- Knowledge translation strategy

Duration of operation

The Aboriginal Advisory group is currently being established. The first official meeting will occur August 2020.

Membership

The Aboriginal advisory group will include:

1. Aboriginal community researchers on the research team (currently Noelene Skinner, Belinda Huntriss and Bernii Leece).

2. Aboriginal investigator (currently Dr Kerry Hall)

3. Representatives (1 or more) from participating communities. A representative may include, but not limited to; midwife, Aboriginal health worker/practitioner, general practitioner, community member, and community Elder.

The membership of the Aboriginal advisory group will commit to:

- Attending all scheduled meetings (face to face or via zoom weblink)
- Provide cultural and community guidance for the development and implementation of the project.
- Share all communications and information across group members and relevant staff and/or community within organisation.
- Notifying members of the advisory group, as soon as practical, if any matter arises which may be deemed to affect the development of the project.

Meetings

Advisory group members are required to participate in meetings every third month, members can use zoom weblink for meetings.

Responsibilities of Advisory group

- Representing their Aboriginal community and advising on all aspects of the proposed research including research design, ownership of data, data interpretation and publication of research findings.
- To ensure cultural appropriateness is upheld with the development and delivery of the research within their community.
- Record minutes of meetings and present to research team either via email or in a team meeting.

Responsibilities of research team to Advisory group

- Providing the Advisory group with all the relevant information and explanations on the intent, process, methodology, and evaluation of the project.
- Comply with requests for further information as requested from the Advisory group.
- Respect the Advisory group member's decision making, acknowledging that each Aboriginal community will have different decision-making processes reflecting their particular social and cultural values; and ensure that appropriate cultural protocols and procedures are in place at each stage in the development, conduct, and reporting of the research.

Contribution & Acknowledgement

All partnering sites are currently consulting on the appropriate practices for contribution and acknowledgement in line with their organisations policies. At the least. each site will be acknowledged on all promotional materials and research reporting including peer reviewed journals. Each site will be offered authorship on all publications in line with authorship guidelines.

Reference

National Health and Medical Research Council (NHMRC, 2018), Keeping research on track II: A companion document to *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (2018), Commonwealth of Australia: Canberra.

Appendix 2 – Co-design interview guide: women

Interview Guide with Women

Study title: The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child

Setting up

- Make sure room is comfortable and welcoming (and refreshments available)
- Introduce yourself and attend to issues of cultural safety
- Yarning to break ice and make participant feel comfortable and secure
- Explain study, issues of confidentiality, anonymity and get informed consent
- Explain and get permission for audio recording
- The demographic questionnaire may be completed at the start or end (optional)

Introducing the topic

We are interested in hearing about your experiences and usage of mobile apps for health and wellbeing. We are also interested in your ideas and opinions for a new mobile health app that we are developing specifically for Aboriginal women and children.

You can tell your stories in your own way and I can help by asking some questions along the way. You may share any story that you are comfortable in doing so, and what you say will be confidential.

Questions

1. How would an mHealth intervention designed for healthy living for Aboriginal and Torres Strait Islander people differ from other mHealth interventions?
2. Are you more interested in mHealth for your own health or your child's health? What topics and features interest you?
3. What do you think stops or prevents some women from accessing health information and services for themselves and their children?

Follow up questions by app developer

1. What are you favourite apps? What do you like about them?
2. How often and for how long (frequency and duration) do you normally use these apps?
3. What makes you come back to the apps on subsequent days?
4. How do you use notifications? Do you check notifications often or not use them at all? What app notifications do you use the most?
5. Do you mind getting reminders via SMS? Do you prefer SMS to app notifications?
6. Do you communicate mainly via text or voice or a mix of both? What is the mix?
7. Do you use a calendar, alarms, or alert reminders?
8. Do you share their phone? If so, with who? (Would this be an issue with sharing stress factors, moods, health info, secrets?).

9. Do you or have you ever video-conferenced with someone using your phone, e.g. Facetime, Skype, Facebook video, etc? Who with? Family, friends, health professional?
10. If an app for child health, would you prefer an app you can share with partners/family or just for yourself to use?
11. If you have completed a challenge with an app relating to your health or your child's health, would you like to share this progress with your friends and family?
12. What features of an app would motivate you to keep using an app relating to your or your child's health?

* explain that most people use apps a lot when they get them, but then use drops off. Provide examples to facilitate discussion

How likely or unlikely would you be to use this app once it's finished?Ending the interview

Complete demographic questionnaire if not completed at the start

- Thank participants for their time – offer voucher for expenses
- Explain that if the participants wish, a copy of the report can be sent to them as individuals or to an organisation to access
- Ask participants how they are feeling – debrief and refer if needed for further support/counseling

Appendix 3 – Co-design interview guide: staff

Interview Guide with staff

Study title: The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child

Setting up

- Make sure room is comfortable and welcoming (and refreshments available)
- Introduce yourself and attend to issues of cultural safety
- Yarning to break ice and make participant feel comfortable and secure
- Explain study, issues of confidentiality, anonymity and get informed consent
- Explain and get permission for audio recording

Introducing the topic

We are interested in your ideas and opinions for a new mobile health app that we are developing specifically for Aboriginal women and children. You can tell your stories in your own way and I can help by asking some questions along the way. You may share any story that you are comfortable in doing so, and what you say will be confidential.

Questions

1. What do you think are the most important health and well-being topics to include for Aboriginal or Torres Strait Islander women, children, and family?

2. What are the barriers for Aboriginal or Torres Strait Islander families to having good health?

3. What types of mobile technology do you think could support Aboriginal or Torres Strait Islander women's and children's health?

4. How would an app designed for healthy living for Aboriginal and Torres Strait Islander women differ from other apps?

Ending the interview

Complete demographic questionnaire if not completed at the start

- Thank participants for their time
- Explain that if the participants wish, a copy of the report can be sent to them as individuals or to an organisation to access

Appendix 4 – Pilot interview guide: women

Appendix 4

Participant number
__ __

The pre-test of a mobile health programme with Aboriginal women
for postnatal health of woman and child (birth to five years)

Interview Guide

(Women participants)

Interview completed by:

		| | | | 2 | 0 | |
signature	*printed name*	*day* *month* *year*

Study coordinator to complete:

	Sarah Perkes	| | | | 2 | 0 | |
signature	*printed name*	*day* *month* *year*

Hi, my name is ___ and I am ringing from the The University of Newcastle. We would just like to ask you a few questions about your experience with the mobile health programme that you have been trialling Is now a good time? {If not confirm a suitable time and call back}

The interview is going to be split into 2 sections. The first will look at what you thought about the programme and the second part will ask you a few questions about yourself.

Section 1: Interview schedule - TextMATCH

1.01	Date of interview	20 day month year
1.02	What did you think about the message and app programme?	
1.03	Did you find the messages and app useful?	○ Yes ○ No --> go to 1.05
1.04	How useful?	○ 1 (a little useful) ○ 2 ○ 3 ○ 4 ○ 5 (extremely useful)
1.05	Did you find the messages and app content relevant to you? (please comment)	○ Yes ○ No
1.06	Were the messages and app culturally appropriate to you?	○ Yes ○ No
1.07	Did you find the messages and app easy to understand?	○ Yes ○ No

1.08	Were the activities and information in the messages and app appropriate?	○ Yes ○ No
1.09	Was there any part of message, or app, that you found irrelevant or inappropriate? If yes please provide detail	○ Yes ○ No
1.10	What did you think about the frequency of the messages i.e. how often you received them? NOTE: depending on stage of the programme they receive 1-3 messages per week	○ Too often ○ Just right ○ Not often enough
1.11	We would like to know if the message or app programme has had any impacts on you, your family and/or your child. Do you think the programme has had any impacts?	
1.12	Do you think that the programme has resulted in improvements to your smoking habits (if a smoker)?	○ Yes ○ No NA
1.13	Do you think that the programme has resulted in improvements to your family's or friend's smoking habits (if a smoker)?	○ Yes ○ No NA
1.14	Do you think that the program has resulted in improvements to your child's exposure to second hand smoke?	○ Yes ○ No
1.15	Do you think that the messages have resulted in positive changes to your eating habits?	○ Yes ○ No
1.16	Do you think that the messages have had a positive impact on your exercising (or physical activity)?	○ Yes ○ No
1.17	Do you think that the messages have resulted in improvements to your knowledge or understanding of women's health?	○ Yes ○ No
1.19	Do you think that the messages have resulted in improvements to your knowledge or understanding of child health?	○ Yes ○ No
1.20	Did the messages make you feel more supported when caring for your child?	○ Yes ○ No
1.21	Are there any other impacts that receiving the messages have had on you or your family? Please specify:	

1.22	We would like to know if you have any suggestions for how we could improve the programme.	
1.23	Would you recommend the programme to other people a child under 5 years of age? Why/why not?	○ Yes ○ No
1.24	Do you have any final comments or feedback on the app or message program?	

Appendix 5 – Pilot interview guide: staff

Appendix 5

Participant number

__ __

The pre-test of a mobile health application with Aboriginal women
for postnatal health of woman and child (birth to five years)

Interview Guide

(Staff participants)

Interview completed by:

		| | | | 2 | 0 | |
signature	*printed name*	*day month year*

Study coordinator to complete:

	Sarah Perkes	| | | | 2 | 0 | |
signature	*printed name*	*day month year*

Hi, my name is ___ and I am ringing from the The University of Newcastle. We would just like to ask you a few questions about your experience with the mobile health programme that you have been trialling. Is now a good time? {If not confirm a suitable time and call back}

The interview is going to be split into 2 sections. The first will look at what you thought about the programme and the second part will ask you a few questions about yourself.

Section 1: Interview schedule

1.01	Date of interview	_ _ | _ _ | 2 0 _ _ day month year
1.02	What did you think about the Jarjums mobile health program?	
1.03	Do you think the program would be useful for women with children under five years of age?	○ Yes ○ No --> go to 1.05
1.04	How useful?	○ 1 (a little useful) ○ 2 ○ 3 ○ 4 ○ 5 (extremely useful)
1.05	Did you think that the content is relevant to women you see in your work place? (please comment)	○ Yes ○ No
1.06	Do you think that the program is culturally appropriate?	○ Yes ○ No
1.07	Do you think that the program is easy to understand?	○ Yes ○ No
1.08	Were the activities and information appropriate?	○ Yes ○ No

1.09	Was there any part that you found irrelevant or inappropriate? If yes please provide detail	○ Yes ○ No
1.10	What did you think about the frequency of the messages	○ Too often ○ Just right ○ Not often enough
1.11	. Do you think that the program is likely to have any impact on women's or children's health? How?	
1.12	Do you think that the program may result in improvements to women's knowledge or understanding of own health?	○ Yes ○ No
1.13	Do you think that the program may result in improvements to women's knowledge or understanding of a child's health?	○ Yes ○ No
1.14	We would like to know if you have any suggestions for how we could improve the program	
1.15	Would you recommend the program to women with children under 5 years of age? Why/why not?	○ Yes ○ No
1.16	Do you have any final comments or feedback?	

Appendix 6 – Survey: women

The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

Sociodemographic survey

This study is being conducted by:

Chief Investigator/PhD supervisor: Professor Billie Bonevski[1]

Aboriginal Researchers: Noelene Skinner[1,3]
Bernise Leece [1, 2]
Belinda Huntriss[1]

PhD Candidate: Sarah Perkes[1]

Affiliations:
1. University of Newcastle, Newcastle, NSW, Australia
2. Mid North Coast Local Health District, NSW, Australia
3. Hunter New England Local Health District, NSW, Australia

Contact details:
Sarah Perkes
Centre for Brain & Mental Health Research
The University of Newcastle, Callaghan, 2308
0451 994 827
Sarah Perkes@newcastle.edu.au

The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

Please complete all questions below

1. What is your age? __________

2. Indigenous Status:

Child/Children: ☐Aboriginal ☐Torres Strait Islander ☐Both ☐NI

Mother: ☐Aboriginal ☐Torres Strait Islander ☐Both ☐NI ☐Declined ☐Unknown

Father**:** ☐Aboriginal ☐Torres Strait Islander ☐Both ☐NI ☐Declined ☐Unknown

3. Who is your mob/tribe/nation?
1) ___________________________
2) ___________________________
3) ___________________________
☐ Unknown
☐ Declined

4. Do you identify with an Aboriginal and/or Torres Strait Islander community?
0. No
1. Yes
2. Unknown
3. Declined

If yes, which community do you identify with? ________________________________

5. Do you maintain cultural connections at home?
(eg Art Music/Dance Storytelling Food Traditional medicine)
0. No
1. Yes
2. Unknown
3. Declined

If yes, specify:

☐Art ☐Music/Dance ☐Storytelling ☐Food ☐Traditional medicine

☐Indigenous television ☐Indigenous radio ☐Indigenous newspapers

☐Indigenous internet sites ☐ Other (specify) _________________

6. Are any members of your family from the stolen generation?
0. No
1. Yes
2. Unknown
3. Declined

The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

7. Employment (labour force) status of parent/guardian:

	Mother	Father	Guardian
Employed full time			
Employed part time			
Employed casual			
Not in paid employment			
Not applicable			
Unknown			
Declined to answer			

8. Highest education level of parent/guardian

	Mother	Father	Guardian
Did not finish high school			
High school			
Certificate			
Diploma			
Bachelor degree			
Post graduate degree			
Not applicable			
Unknown			
Declined to answer			

9. Are you currently pregnant?

0. No
1. Yes

10. How many people live in your household (including adults, children, and yourself)? __

11. How many children (under 18 years) live in your household? _________

12. Please complete the table below for each child living in your house

Age of child (under 18 years) living in house	____mths/ yrs
Has your child had wheezing or whistling in the chest in the last 12 months?	☐ yes ☐ no
Has your child had a cough that has lasted more than 4 weeks in the past 12 months? If yes, How many times has the child had a cough that has lasted more than 4 weeks? Did you see a doctor about this cough?	☐ yes ☐ no __________ ☐ unknown ☐ yes ☐ no

The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

Has your child been diagnosed by a doctor with a respiratory illness?	☐ yes ☐ no
If yes,	
- Asthma/Reactive airways disease	☐ yes ☐ no
- Pneumonia (confirmed by chest xray)	☐ yes ☐ no
- Influenza (confirmed by laboratory test, eg NPA or blood test)	☐ yes ☐ no
- Bronchiolitis	☐ yes ☐ no
- Bronchitis	☐ yes ☐ no
- Croup	☐ yes ☐ no
- Whooping cough (laboratory confirmed)	☐ yes ☐ no

13. Do you currently smoke any tobacco products?
0. No, not at all
1. Yes, less often than once a week
2. Yes, at least once a week
3. Yes, daily

If yes, How many cigarettes do you usually smoke per day (on the days you smoke)?

14. Do you have a partner?
0. No
1. Yes

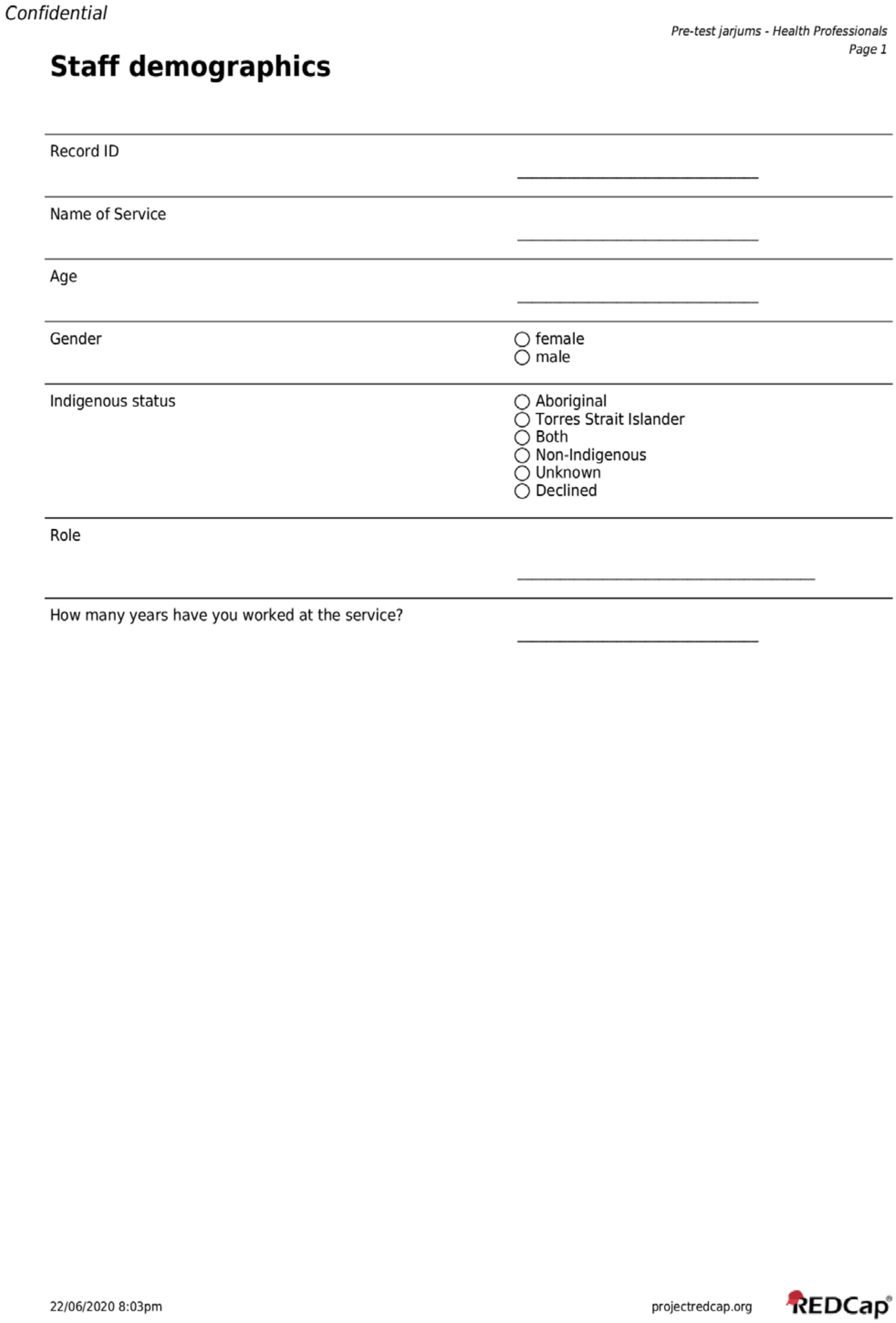
If yes – does your partner currently smoke?
0. No
1. Yes

15. How many tobacco smokers (include yourself if you still smoke) usually live in your household?
0. 0
1. 1
2. 2--3
3. More than 3

16. Child exposure to tobacco smoke

Indoor household exposure	Yes	No	Mother	father	other
Outdoors household exposure	Yes	No	Mother	father	other
Is child exposed whilst in the car	Yes	No	always	sometimes	rarely

Appendix 7 – Survey: staff



Confidential

Pre-test jarjums - Health Professionals
Page 1

Staff demographics

Record ID ______________________________

Name of Service ______________________________

Age ______________________________

Gender
○ female
○ male

Indigenous status
○ Aboriginal
○ Torres Strait Islander
○ Both
○ Non-Indigenous
○ Unknown
○ Declined

Role ______________________________________

How many years have you worked at the service? ______________________________

22/06/2020 8:03pm

projectredcap.org REDCap

Appendix 8 – Information sheet: women

Professor Billie Bonevski
Chief Investigator and PhD supervisor
University of Newcastle
billie.bonevski@newcastle.edu.au
02 4033 5710

Participant Information Sheet

The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

Invitation: You are invited to share your opinion on trial phone apps for Aboriginal women. The app is for women's and child's health after having a baby until the child is five years old.

You are invited to join two ninety-minute focus groups/interviews and complete a questionnaire. The focus groups/interviews will be approximately four weeks apart.

What is the purpose of the research?

- Your opinions will help us develop a phone app for Aboriginal women to have healthy lifestyles for themselves and their children.

Why have I been invited to participate in this research?

- We are interested in the opinions of Aboriginal and Torres Strait Islander women 16 years and up. Women that are pregnant (30+ weeks gestation) or a mother/main carer of a child 0 to five years, and own a mobile phone are eligible to participate.

What does participation involve?

- Two Focus groups: Participation in each focus group will involve talking with an Aboriginal research assistant, app developer and a student in a group with other Aboriginal women and answering a questionnaire (in first group only). Each group will go for up to ninety minutes. The purpose of the first group will be to gather your ideas and concepts for an mHealth app. The purpose of the second group will be to gather feedback on a provisional mHealth app.

  Or Two Interviews: If you are unable to attend the focus groups you can choose to undertake the above processes in one on one interviews with an Aboriginal research assistant or student researcher.

- 16 item Questionnaire: The questionnaire will involve answering questions in writing or on a tablet on your age, education, smoking history, and child respiratory health. The researchers can help you to fill out the form. It will take approximately 10 minutes. You will only complete the questionnaire one time if you attend both focus groups or interviews.

- The focus groups and/or interviews will take place in a community place e.g. playgroup, Aboriginal Medical Service or other place chosen by the research assistant and participant.

- The Aboriginal research assistant and app developer will ask questions to start discussion on different topics including social media and app/phone usage, health and wellbeing and may ask your opinion on designs for a trial mobile phone app What you talk about will be taped so the researcher can listen to it again, and we will also write the questions and your answers down. At a later date you will be offered a copy of the report with findings if you provide an email contact. Any names you have talked about (and your own name) will be blacked out or the names changed if you prefer. You will be also asked to give your consent to participate in the study.

- You may recommend a family member or friend to participate in the study by providing them a study flyer or by passing on the research assistants contact details

Will taking part in the study cost me anything, and will I be paid?

- You will be given a $30 shopping voucher to reimburse you for any costs incurred to attend each focus group/interview and complete one questionnaire. If you attend two focus groups/interview and complete the questionnaire you will receive $60 shopping vouchers in total.
- Childcare will be provided during the focus group if required, please advise the research assistant if needed

What will happen if I become distressed or upset in the focus group/interview?

- If you would feel more comfortable, you may bring a female family member or friend for support. Though this person will not be reimbursed unless participating also.
- If you become distressed during the focus group/interview for any reason we will stop and ask if you are okay. You will have the option of continuing in the focus group/interview or stopping. If required, we will refer you to an appropriate health provider within the nearest medical service such as your GP and/or social worker and/or Aboriginal Health Worker.
- If required, the contact details of local Aboriginal health services are:

1. Galambila (Coffs Harbour) - (02) 6652 0800
2. Awabakal (Newcastle) - (02) 4907 8555
3. Armajun (Inverell) – (02) 6721 9777

How will my confidentiality be protected?

- Your name will not be kept attached to what you say in the focus group/interview or any other information you give, nor used when we report the results.
- Any information collected about you will be kept confidential and secure and only seen or heard by the research team except as required by law.
- A transcription service may be used to write down the text from what people said in the audio recordings of the focus groups/interviews. The transcription service will

bound by a confidentiality agreement.

- All written information will be secured in a locked filing cabinet in Prof Bonevski's office or at the University of Newcastle. Only authorised personnel in the research team will have access. Audio data will be stored electronically on a password protected computer file.

What happens with the results of the research?

- Your information along with information from others will form the results of this research.
- These results may be used to inform the development of a phone App or social media platform specifically for Aboriginal women to support better health including quitting smoking after having a baby and child health
- Results will also be used to write a report but you will not be identified in any way.
- The results will be presented to Aboriginal communities and more widely though articles and at a conference.

What if I don't want to take part in the research, or if I want to drop out later?

- It is your choice whether or not you choose to participate.
- Whether you participate, or not, will not affect the care you receive from any health professionals, medical services or health services you attend.
- If you choose to participate, you can also later drop out from the research without penalty.
- If you decide to drop out and wish to withdraw your data (questionnaire and verbal) we will make our best attempt to do so prior to publishing data or providing final reports to funding bodies (approximately 3 months after completion of study)

What should I do if I want more information about the study before I decide to participate?

- You can ask any questions you like. Please talk to any of the following researchers:

Professor Billie Bonevski
Chief Investigator and PhD supervisor
University of Newcastle
billie.bonevski@newcastle.edu.au
02 4033 5710

Professor Joerg Mattes
Co-Investigator and PhD supervisor
joerg.mattes@newcastle .edu.au

Professor Billie Bonevski
Chief Investigator and PhD supervisor
University of Newcastle
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Dr Kerry Hall
Co-Investigator and PhD supervisor
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Bernise Leece
Aboriginal Research Assistant and Cultural Liaison (Inverell)
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Noelene Skinner
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Belinda Huntriss
Aboriginal Research Assistant and Cultural Liaison (Newcastle)
University of Newcastle
Belinda.Huntriss@newcastle.edu.au

Sarah Perkes
PhD Candidate
University of Newcastle
sarahjane.perkes@uon.edu.au
0451 994 827

The study is being conducted by:

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02 4033 5710
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Co-Investigators and PhD supervisors:
Professor Joerg Mattes
Dr Kerry Hall

Professor Billie Bonevski
Chief Investigator and PhD supervisor
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billie.bonevski@newcastle.edu.au
02 4033 5710

Aboriginal Research Assistant:
Bernice Leece
Noelene Skinner
Belinda Huntriss

PhD Candidate:
Sarah Perkes

This study will contribute to the student researcher's PhD thesis.

The study is funded by the Mid North Coast Local Health District (MNCLHD), Commonwealth Scientific and Industrial research Organistaion (CSIRO), National Health and Medical Research Council (NHMRC) and the University of Newcastle (UoN) (research student support funds).

Complaints about this research:

If at any stage you have complaints or concerns about this research, you may contact: The Chairperson AH&MRC Ethics Committee Aboriginal Health & Medical Research Council of NSW PO Box 1565 STRAWBERRY HILLS NSW 2012 Phone 02-9212 4777 or email: ethics@ahmrc.org.au

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

Appendix 9 – Information sheet: organisations

Professor Billie Bonevski
Centre for Brain & Mental Health
The University of Newcastle
+61 2 40335710
billie.bonevski@newcastle.edu.au

Organisational Information Sheet

The Co-design of a Mobile Health App with Aboriginal Women for Postnatal Health of Women and Children (birth to five years)

What the research project is about

The purpose of this research is to co-design a mobile health app for Aboriginal women's and child's health. The app will be a resource for women to access reliable health information and tools, and communicate with a range of health services about their child's health from birth to five years. The app will focus on child respiratory health but may also include other health topics for women and children such as physical activity, nutrition and social and emotional wellbeing. How the app looks, what features it has and exactly what health topics it covers will be up to women and health services to decide.

What will be involved in participation for:

Women:

- Co-design workshops – Up to 24 women in total (four to six women per workshop) will be welcomed to join in two workshops between May and August in three regions (Coffs Harbour, Inverell and Newcastle). In the first workshop, women will be asked about their current app use, shown a series of designs, sort health topics, and participate in drawing activities. The same women will be invited back to a second workshop approximately one month later to provide feedback on the design, content, and features of the provisional app. Workshops will be run by an Aboriginal researcher and app developer. Women will be reimbursed with a $30 shopping voucher for attending each workshop.
- Pre-test - Once we have developed a basic app, we will test the app with approximately 45 women (10 to 15 women from each region) between October and December 2019. More information to follow on this part of the research.

Services:

- Interviews with health staff - health staff working with families and children (0 to five years) will be welcomed to tell us about their ideas and concepts for an app, and again to gain feedback on the provisional app. Further details provided in the participant information sheet for health professionals.
- Pre-test - Once we have developed a basic app, we will test the app with approximately 15 health staff (3 to 5) from each region between October and December 2019. More information to follow on this part of the research.

Expected Benefits

- Short term:
    1) A basic mobile health app co-designed by Aboriginal women and health services for health of women and children (0 to 5 years)
    2) Research data to understand if the app is accepted and used by Aboriginal women; if/how the app impacted health behaviour/outcomes, and if is feasible for health staff to use in daily practice
- Long term:
    1) If the pre-test shows the app may be useful and effective we will aim to continue to develop the app with women and services and complete a larger trial
    2) If found to be effective and if it's feasible the app will be provided free of charge to LHDs and ACCHOs for use

Professor Billie Bonevski
Centre for Brain & Mental Health
The University of Newcastle
+61 2 40335710
billie.bonevski@newcastle.edu.au

How a service can participate

We know services are busy providing clinical care and so we welcome services to participate in any way that suits them. Some ways to participate may include:

- Provide a letter of support and receive updates on the study
- Assist with recruitment of women to join the co-design workshops
- Permit us to interview health staff at your health service
- Participate in the pre-test (once further information is provided)
- Other ____________________

Withdrawal from study, confidentiality and data storage

- Participation of the organisation in this research is voluntary. The organisation has the right to withdrawal at any time throughout the study up to the point of publication.
- The names of participants and organisations will not be kept attached to what is said during interviews or any other information provided, nor used when we report the results.
- Any information collected about participants and organisations will be kept confidential and secure and only seen or heard by the research team except as required by law.
- A transcription service may be used to write down the text from what people said in the audio recordings of the interviews. The transcription service will bound by a confidentiality agreement.
- All written information will be secured in a locked filing cabinet in Prof Bonevski's office or at the University of Newcastle. Only authorised personnel in the research team will have access. Audio data will be stored electronically on a password protected computer file.

Our Team

Name	Positions	Contact
Professor Billie Bonevski	Chief Investigator and PhD supervisor	02 4033 5710 billie.bonevski@newcastle.edu.au
Professor Joerg Mattes	Co-Investigator and PhD supervisor	joerg.mattes@newcastle .edu.au
Dr Kerry Hall	Co-Investigator and PhD supervisor	kerry.hall@griffith.edu.au
Noelene Skinner	Aboriginal Researcher Coffs Harbour	0403 196 123 Noelene.Skinner@health.nsw.gov.au
Bernice Leece	Aboriginal Researcher Inverell	0434 789 915 Bernice.Leece@hnehealth.nsw.gov.au
Belinda Huntriss	Aboriginal Researcher Newcastle	0400 121 630 belinda.huntriss@gmail.com
Sarah Perkes	OT/ PhD student	0451 994 827 Sarah.perkes@newcastle.edu.au
VastPuddle	App developer	https://www.vastpuddle.com.au/

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Funding of study:

The study is funded by the Mid North Coast Local Health District (MNCLHD), Commonwealth Scientific and Industrial research Organistaion (CSIRO), National Health and Medical Research Council (NHMRC) and the University of Newcastle (UoN) (research student support funds).

Complaints about this research:

If at any stage you have complaints or concerns about this research, you may contact: The Chairperson AH&MRC Ethics Committee Aboriginal Health & Medical Research Council of NSW PO Box 1565 STRAWBERRY HILLS NSW 2012 Phone 02-9212 4777 or email: ethics@ahmrc.org.au

*This study will contribute to the student researcher's PhD thesis.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.

Appendix 10 – Ethics approval: Aboriginal Health and Medical Research Council of NSW

Aboriginal
Health & Medical
Research Council
of NSW

Office address
Level 3, 66 Wentworth Ave
Surry Hills NSW 2010
www.ahmrc.org.au

Postal address
PO Box 1565
Strawberry Hills NSW 2012

T +61 2 9212 4777
F +61 2 9212 7211
E ahmrc@ahmrc.org.au

17th April 2019

AH&MRC Ethics
Committee
02 9212 4777
ethics@ahmrc.org.au

Professor Billie Bonevski
University of Newcastle
Room 5017, Level 5, McAuley Centre,
Mater Hospital, Waratah 2298
Ph: 02 4033 5710

Dear Professor Bonevski,

HREC Reference number: 1485/19
Project title: The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)

Thank you for submitting the above research project for ethical review. This project was considered by the AH&MRC Ethics Committee at its meeting held on 5th February 2019.

I am pleased to advise you that the above research project meets the requirements of the *National Statement on Ethical Conduct in Human Research (2007)* and ethical approval for this research project has been granted by AH&MRC Ethics Committee.

The nominated participating site/s in this project is/are:

1. *Coffs Harbour & District Local Aboriginal Land Council*
2. *Kulai Aboriginal preschool*
3. *Durri Aboriginal Medical service*
4. *Armajun Aboriginal Health Service – Inverell, Armidale, Tingha*
5. *Coffs Harbour Aboriginal maternal Infant Health Service*
6. *Mid North Coast Local Health District*

Note: If additional sites are engaged prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the AH&MRC HREC. Notification of withdrawn sites should also be provided to the AH&MRC HREC in a timely fashion.

The approved documents include:

Document	Version	Date
SP02995_1_Documents (7).zip AH&MRC Ethics-Cover-Sheet-five-Key-Prin_Postnatal_app_study.doc.docx		

Approval of this project from AH&MRC Ethics Committee is valid from 16th April 2019 to 16th April 2020 subject to the following conditions being met:

Aboriginal
Health & Medical
Research Council
of NSW

Office address
Level 3, 66 Wentworth Ave
Surry Hills NSW 2010
www.ahmrc.org.au

Postal address
PO Box 1565
Strawberry Hills NSW 2012

T +61 2 9212 4777
F +61 2 9212 7211
E ahmrc@ahmrc.org.au

- The Coordinating Principal Investigator will immediately report anything that might warrant review of ethical approval of the project.
- The Coordinating Principal Investigator will notify the AH&MRC Ethics Committee of any event that requires a modification to the protocol or other project documents and submit any required amendments in accordance with the instructions provided by the HREC. These instructions can be found at www.ahmrc.org.au/ethics .
- The Coordinating Principal Investigator will submit any necessary reports related to the safety of research participants in accordance with AH&MRC Ethics Committee policy and procedures. These instructions can be found at www.ahmrc.org.au/ethics .
- The Coordinating Principal Investigator will report to the AH&MRC Ethics Committee annually in the specified format and notify the HREC when the project is completed at all sites.
- The Coordinating Principal Investigator will notify the AH&MRC Ethics Committee if the project is discontinued at a participating site before the expected completion date, with reasons provided.
- The Coordinating Principal Investigator will notify the AH&MRC Ethics Committee of any plan to extend the duration of the project past the approval period listed above and will submit any associated required documentation. Instructions for obtaining an extension of approval can be found at www.ahmrc.org.au/ethics .
- The Coordinating Principal Investigator will notify the AH&MRC Ethics Committee of his or her inability to continue as Coordinating Principal Investigator including the name of and contact information for a replacement.
- The Coordinating Principle Investigator will submit the final draft report from the research, and any publication or presentation where data or findings are presented, to the AH&MRC Ethics Committee to be reviewed for compliance with ethical and cultural criteria prior to:
- Any submission for publication; and/or
- Any dissemination of the report

Should you have any queries about the AH&MRC Ethics Committee's consideration of your project please contact Tania Skerry. The AH&MRC Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from www.ahmrc.org.au or from the Ethics Coordinator.

The AH&MRC Ethics Committee wishes you every success in your research.

Yours faithfully,

Ms Val Keed
Chairperson
AH&MRC Ethics Committee

Appendix 11 – Ethics approval: The University of Newcastle

Appendix 11

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	**Professor Billie Bonevski**
Cc Co-investigators / Research Students:	**Dr Kerry Hall** **Professor Joerg Mattes** **Miss Belinda Huntriss** **Miss Sarah Perkes** **Ms Noelene Skinner** **Mrs Bernii Leece**
Re Protocol:	**The co-design and pre-test of an mHealth app with Aboriginal women for postnatal health of woman and child (birth to five years)**
Date:	**09-May-2019**
Reference No:	**H-2019-0076**
Date of Initial Approval:	**09-May-2019**

Thank you for your **Response to Conditional Approval** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Ethics Administrator.

We are pleased to advise that the decision on your submission is **Approved** effective **09-May-2019**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2019-0076**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants You may then proceed with the research.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress*, *Reporting of Adverse Events*, and *Variations to the Approved Protocol* as detailed below.

PLEASE NOTE:
In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

- ***Monitoring of Progress***

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

- ***Reporting of Adverse Events***

1. It is the responsibility of the person **first named on this Approval Advice** to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of completion of the research, must be reported by the person first named on the Approval Advice to the (HREC) by way of the Adverse Event Report form (via RIMS at https://rims.newcastle.edu.au/login.asp) within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
4. Serious adverse events are defined as:
    - Causing death, life threatening or serious disability.
    - Causing or prolonging hospitalisation.
    - Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
    - Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
    - Any other event which might affect the continued ethical acceptability of the project.

5. Reports of adverse events must include:
    - Participant's study identification number;
    - date of birth;
    - date of entry into the study;
    - treatment arm (if applicable);
    - date of event;
    - details of event;
    - the investigator's opinion as to whether the event is related to the research procedures; and
    - action taken in response to the event.

6. Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

- ***Variations to approved protocol***

If you wish to change, or deviate from, the approved protocol, you will need to submit an *Application for Variation to Approved Human Research* (via RIMS at https://rims.newcastle.edu.au/login.asp). Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation. **Variations must be approved by the (HREC) before they are implemented** except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Human Research Ethics Committee

For communications and enquiries:

Human Research Ethics Administration

Research & Innovation Services
Research Integrity Unit
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 17894
Human-Ethics@newcastle.edu.au

RIMS website - https://RIMS.newcastle.edu.au/login.asp

Linked University of Newcastle administered funding:

Funding body	Funding project title	First named investigator	Grant Ref

Appendix 12 – Chapter 8 manuscript

Original Paper

Aboriginal and Torres Strait Islander Women's Access to and Interest in mHealth: National Web-based Cross-sectional Survey

Sarah Jane Perkes[1], BA, MPH; Billie Bonevski[1], PhD; Kerry Hall[2], PhD; Joerg Mattes[3,4], MBBS, PhD; Catherine Chamberlain[5], PhD; Jessica Bennett[3], BA; Robyn Whittaker[6], MBBS, PhD; Kerrin Palazzi[4], BBiomedSc, MPH; David Lambkin[4], MBiostat; Michelle Kennedy[3,4], PhD

[1]College of Medicine and Public Health, Flinders University, Bedford Park, Australia
[2]First Peoples Health Unit, Griffith University, Southport, Australia
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Abstract

Background: Health programs delivered through digital devices such as mobile phones (mobile health [mHealth]) have become an increasingly important component of the health care tool kit. Aboriginal and Torres Strait Islander women of reproductive age are likely to be caring for children and family members and needing health care, but little is known about their access to and interest in mHealth.

Objective: The objectives of this study were to investigate Aboriginal and Torres Strait Islander women's ownership of digital devices, access to the internet, current mHealth use, and interest and preferences for future mHealth. We examined the factors (age, remoteness, caring for a child younger than 5 years, and level of education) associated with the ownership of digital devices, use of internet, and interest in using a mobile phone to improve health. This study also examines if women are more likely to use mHealth for topics that they are less confident to talk about face-to-face with a health professional.

Methods: A national web-based cross-sectional survey targeting Aboriginal and Torres Strait Islander women of reproductive age (16-49 years) was performed. Descriptive statistics were reported, and logistic regressions were used to examine the associations.

Results: In total, 379 women completed the survey; 89.2% (338/379) owned a smartphone, 53.5% (203/379) a laptop or home computer, 35.6% (135/379) a tablet, and 93.1% (353/379) had access to the internet at home. Most women used social media (337/379, 88.9%) or the internet (285/379, 75.2%) everyday. The most common modality used on the mobile phone for health was Google (232/379, 61.2%), followed by social media (195/379, 51.5%). The most preferred modality for future programs was SMS text messaging (211/379, 55.7%) and social media (195/379, 51.4%). The most preferred topics for future mHealth programs were healthy eating (210/379, 55.4%) and cultural engagement (205/379, 54.1%). Women who were younger had greater odds of owning a smartphone, and women with tertiary education were more likely to own a tablet or laptop. Older age was associated with interest to use telehealth, and higher educational attainment was associated with interest for videoconferencing. Most women (269/379, 70.9%) used an Aboriginal medical service and overall reported high rates of confidence to discuss health topics with a health professional. Overall, women showed a similar likelihood of selecting a topic in mHealth whether they were or were not confident to talk to a health professional about that.

Conclusions: Our study found that Aboriginal and Torres Strait Islander women were avid users of the internet and had strong interest in mHealth. Future mHealth programs for these women should consider utilizing SMS text messaging and social media modalities and including content on nutrition and culture. A noteworthy limitation of this study was that participant recruitment was web-based (due to COVID-19 restrictions).

(J Med Internet Res 2023;25:e42660) doi: 10.2196/42660

KEYWORDS

mHealth; Aboriginal; Torres Strait Islander; public health; health literacy; digital literacy; Australia; native; cross-sectional; national survey; technology use; technology ownership; digital device; mobile device; usage; adoption; acceptance; digital divide

Introduction

Aboriginal and Torres Strait Islander people experience inequitable health burden due to the continuing impacts of colonization, intergenerational trauma, and systemic racism experienced in Australia [1]. A number of health outcomes for Aboriginal and Torres Strait Islander people have remained steady or worsened over the past decade [2], including rates of mental illness [3], psychological distress [3], asthma [4], diabetes [5], cardiovascular disease [3], and chronic obstructive pulmonary disease [3], although gains have been made in other areas such as decreased smoking during pregnancy [6], antenatal visits [6,7], year 12 completion [8], and university attendance [8]. The life expectancy gap between Aboriginal and Torres Strait Islander women and non-Indigenous women is 7.6 years. Although the life expectancy of Aboriginal and Torres Strait Islander women has improved in recent decades, the gap still remains [9]. Addressing the social, cultural, and political determinants of health will lead to the greatest improvements in Aboriginal and Torres Strait Islander health outcomes [10]. A large-scale systemic reform that positions Aboriginal and Torres Strait Islander people as the decision makers for Aboriginal and Torres Strait Islander people is required [10].

Aboriginal and Torres Strait Islander women are “healers, storytellers, keepers of our kids, and truth-seekers” [11]. Aboriginal and Torres Strait Islander women have been instrumental in driving the change for Aboriginal and Torres Strait Islander people, including leading the mandate for Uluru Statement from the Heart [11]. Aboriginal and Torres Strait Islander women not only look after their own health but also the health of the collective: their community, grandchildren, parents, grandparents, children, and other family members [12]. The positive experiences of and role modeling by Aboriginal and Torres Strait Islander women to their children and others influence their development and behavior and often lead to better health outcomes for all of their community [13]. Health promotion programs targeting women’s health inevitably have important positive impacts on children and other community members.

There is strong evidence that health promotion programs developed by and for Aboriginal and Torres Strait Islander women are the most successful [10,14,15]. Aboriginal and Torres Strait Islander women can seek health care from Aboriginal Community Controlled Health Organizations (ACCHOs) or a mainstream public health service. Specific services for Aboriginal and Torres Strait Islander women’s and children’s health exist in both ACCHOs and mainstream services, though ACCHOs tend to outperform mainstream services in health and well-being outcomes [16]. One such exemplar of a women’s and children’s health promotion program developed by an ACCHO is the Waminda Dead or Deadly program [17]. This program has been running for over 10 years and aims to enhance cultural connection and health and well-being through a range of activities, including cooking groups with local ingredients, exercise groups (prenatal and postnatal), yarning groups, and lifestyle medicine. This program was designed by and for local Aboriginal and Torres Strait Islander women and therefore operates in a flexible way to meet local women’s needs [16]. Locally developed programs achieve positive health outcomes for Aboriginal and Torres Strait Islander women [16]. To supplement these programs and to reach women who may not have access, alternative modes of delivery could be beneficial.

The potential of technology in promoting health and well-being in general is significant, with low cost and wide reach, high acceptability, and equitability if digital inclusion is considered carefully. Telehealth, health websites, social media campaigns, web-based patient portals, health apps, SMS text messaging programs, and wearable devices are becoming important daily tools for health care nationally and internationally. The COVID-19 experience has reinforced how important it is to have alternatives to face-to-face health care. Global evidence suggests mobile health (mHealth) to be effective and acceptable to populations underserved by traditional primary health and public health campaigns [18,19]. mHealth may be particularly important for Aboriginal and Torres Strait Islander communities, given the high rate of mobile phone use [20,21] and barriers to accessing mainstream primary health care [22]. An important first step to developing and delivering effective mHealth interventions is gathering information about the population, including context, digital access, and interest in mHealth [23]. This information is critical to designing interventions that have sustained engagement [23], which many mHealth solutions fall short of [24]. To date, there is little information on the access, interest, and preferences in mHealth among Aboriginal and Torres Strait Islander women.

The aims of this study were as follows:

1. To describe Aboriginal and Torres Strait Islander women’s ownership of digital devices and access to the internet.
2. To describe Aboriginal and Torres Strait Islander women’s current use, interest, and preferences for future mHealth programs.
3. To examine factors (age, remoteness, caring for a child younger than 5 years, and level of education) associated with Aboriginal and Torres Strait Islander women’s access to digital devices and the internet and interest in using a mobile phone to improve health.

4. To examine if Aboriginal and Torres Strait Islander women are likely to be interested in using mHealth for health topics that they are not confident talking to a health professional about.

Methods

Study Design

A web-based cross-sectional survey design was selected, as we were interested in the experiences and views of a large sample of women at one point in time and to compare different variables at that point in time. We had planned to complete a portion of the surveys face-to-face; however, due to COVID-19 restrictions, web-based data collection was the most feasible approach. This study is reported according to the Checklist for Reporting Results of Internet E-Surveys [25].

The Which Way? Study

This study is part of a larger study, the Which Way? study, a co-designed and co-owned research study with urban and regional Aboriginal and Torres Strait Islander communities [26-31]. The Which Way? study aims to improve care relating to smoking cessation by developing an Indigenous-led evidence base for smoking cessation to support Aboriginal and Torres Strait Islander women to be smoke-free during pregnancy and beyond. Detailed information on the larger study research prioritizations, governance, relationships, and methodologies can be found in the protocol paper [30].

Study Participants

Aboriginal and Torres Strait Islander women of reproductive age (16-49 years) who were smokers or ex-smokers (any level of consumption) were invited to participate in this study. Smokers and ex-smokers were the eligibility criteria, as this study is a substudy of a large study on Aboriginal and Torres Strait Islander women's preference for nonpharmacological approaches to smoking cessation.

Procedures

Consent was obtained via a digital consent sheet using a tick box at the beginning of the survey. A copy of the Participant Information Sheet was provided via a hyperlink; progression through the survey was not granted until consent was provided. Participants were also informed of the approximate time required to complete the survey in the opening page of the survey. The survey was hosted on REDCap [32]. The database was accessible by authorized team members only. On completion of the survey, women were eligible to go in a draw for a chance to win an iPad. Women were recruited over a 3-month period between July 10, 2020 and October 10, 2020 inclusive. Participants were recruited via snowballing and targeted Facebook and Instagram paid advertising. The survey was promoted through social media by using both organic and paid advertisements. A Facebook page and an Instagram account were developed for the Which Way? study. The survey link was shared by the research team through professional contacts and by Aboriginal partner organizations via organizational social media pages and accounts. Paid advertising was used to increase reach on social media accounts. Advertising was specified for "location: Australia" and "Aboriginal peoples' television network-Aboriginal title-smoking." It was an open survey; all participants who accessed the link to the website were able to participate in the survey.

Survey Instrument

Instrument Items

The survey included 36 items, of which 17 items are reported here. Branching logic was used to present questions that were relevant for each participant based on their previous responses. Generally, there was 1 survey item per page. The full survey took 10 minutes to complete. Women were required to complete each response to progress through the survey and were unable to return to their responses. Survey items and questions were developed in partnership with the partnering services. A draft survey was discussed among the research team, and partners then pretested with 15 Aboriginal and Torres Strait Islander women and community members known to the research team.

Participant Characteristics

The characteristics that were analyzed were (1) Aboriginal and Torres Strait Islander status, (2) age, (3) smoking status, (4) rurality (Accessibility and Remoteness Index of Australia), (5) use of Aboriginal Health Services, (6) education, (7) pregnancy status, (8) number of children living in the household, and (9) number of children younger than 5 years.

Access to Digital Devices and the Internet

1. Device ownership was determined by asking "What device(s) do you own?" (response options: iPad/tablet, laptop, or home computer; smartphone [iPhone or Android]; mobile phone [calls/text only]; I do not have access to any of these) [33].
2. Internet access was determined by asking "Where do you have internet access?" (response options: home, workplace, commuting/travel, community center, I don't have internet access anywhere, somewhere else) [33].
3. Frequency of social media use was determined by asking "In the last 12 months, how often have you accessed social media?" (response options: not at all, about once a week, a few times per week, everyday) [34].
4. Frequency of internet use was determined by asking "In the last 12 months, how often have you accessed the internet for other things?" (response options: not at all, less than once a week, about once a week, a few times per week, everyday) [35].

Using Your Phone to Improve Health

1. Women were asked to indicate how they currently used their mobile phone for their health by responding to the following: "Do you currently use your mobile phone for anything to do with your health? (multiple selections allowed)" (response options: I use Google to find health information; I read posts or watch videos about health on social media; I use a health tracker; I use health apps; I use telehealth, eg, talk to a health worker on the phone for advice or treatment; I use text messages to communicate with health workers or have used a text messaging service for health; Other; No, I don't use my phone for health) [34].

2. Women were asked to indicate what mHealth modalities they would be interested in using in the future by responding to "What type of mobile health would you like to use in the future if available? (multiple selections allowed)" (response options: text messaging service, eg, to help quit smoking or exercise or remind me to do something for my health; social media; health apps; health tracker; phone calls to talk to a health worker; videoconferencing to video call with a health worker; other; no, I wouldn't use my phone for health in the future) [34].
3. Women were asked to indicate which 3 health topics they would be most interested in by responding to, "Pick 3 health topics that would be of most interest to you if using a mobile phone for your health" (response options: help me improve what I eat, engage with Aboriginal and Torres Strait Islander culture, show/teach me exercises, improve my mental health, help me to stop smoking, women's health, help me limit or quit cannabis or other drugs, child's health, help with family violence, help me limit drinking) [34].
4. To determine the participant's confidence to talk to a health professional about different health topics in person, women were asked to respond to "Do you feel confident to talk with a doctor/health worker about the following health topics (women's health, eating/diet, exercise, child's health, mental health, quitting smoking, reducing alcohol, family violence, cannabis, or other drug use)?" (response options: yes, no, not relevant).

Exclusion Criteria

Women were excluded from all analyses if they did not meet the inclusion criteria (ie, self-identifying as an Aboriginal or Torres Strait Islander woman, aged 16-49 years, and a current or ex-smoker) or if their survey was incomplete.

Ethics Approval

Ethics approvals were granted by Aboriginal Health and Medical Research Council New South Wales (14541662), University of Newcastle (H-2020-0092), and the local health district ethics committee (2020/ETH02095).

Analyses

The data were analyzed in SAS v9.4 (SAS Institute). Descriptive statistics are presented as count (%), mean (SD), and median (range). Age was categorized as <21 years, 21-34 years, and >34 years for descriptive statistics. Logistic regressions were used to examine the associations of age, remoteness, caring for a child younger than 5 years, and level of education with device ownership, mHealth modalities of interest, and mHealth topics of interest (top 3 selections only). A chi-squared test was used to examine the relationship between women's interest in using mHealth for a health topic if they were not confident to discuss it in person with a health professional. An α level of .05 was specified for all tests and CIs.

Logistic regressions are presented as odds ratio (OR) (95% CI). For the logistic regressions, age was treated as continuous and ORs reported for increments of 5 years. Rurality was dichotomized into "major cities," "regional," and "remote" Australia. "Caring for a child younger than 5 years" was recoded as a binary response for the purposes of analysis. Level of education was collapsed into 3 categories and was presented as an overall Wald type-III *P* value and pairwise OR (95% CI) and *P* values for each level comparison with the reference (completed high school). "Education" was recoded into "did not complete high school," "completed high school," and "completed tertiary education" for the purpose of analysis. Complete case analysis was used for this study, given the relatively low number of participants being excluded due to missing data.

Results

Data were collected for 865 women. Of these, 607 were eligible, 228 were excluded due to incomplete surveys, leaving 379 women included in the analyses.

Participant Characteristics

Participant demographics are presented in Table 1. The mean age of the women was 31 years. More than half of the women lived in cities (194/379, 51.2%), 42.7% (162/379) in a regional area, and 6.1% (23/379) in a remote area. Most women used an Aboriginal health service (269/379, 70.9%).

Table 1. Demographic characteristics of Aboriginal and Torres Strait Islander women who were included in the survey (N=379).

Characteristics	Values
Age (years)	
<21, n (%)	43 (11.3)
21-34, n (%)	196 (51.7)
>34, n (%)	140 (36.9)
Mean (SD)	31.0 (7.7)
Median (min, max)	32 (16, 49)
Remoteness, n (%)	
Major city	194 (51.2)
Regional	162 (42.7)
Remote	23 (6.1)
Level of education, n (%)	
Up to year 9	37 (9.8)
Year 10-11	102 (26.4)
Year 12	73 (19.3)
Current student at University/Technical and Further Education/apprentice	77 (20.3)
Trade certificate	40 (10.6)
University degree	50 (13.2)
Aboriginal and Torres Strait Island status, n (%)	
Aboriginal	357 (94.2)
Torres Strait Islander	7 (1.8)
Aboriginal and Torres Strait Islander	15 (3.9)
Use of Aboriginal Health Service, n (%)	
Yes	269 (70.9)
No	110 (29)
Children living in household, n (%)	
1-2	159 (42)
3 or more	129 (34)
None	91 (24)
Children living in household younger than 5 years, n (%)	
None	237 (63.5)
1 or more	142 (37.5)

Access to Digital Devices and the Internet

Approximately 89.2% (338/379) of the women owned a smartphone, 53.6% (203/379) a laptop, 35.6% (135/379) a tablet, and 16.4% (62/379) a mobile phone (calls and text only) (Table 2). Approximately 93.1% (353/379) of the women had access to the internet at home, and 88.9% (337/379) of the women used social media everyday.

Table 2. Device and internet access and frequency of social media and internet use (N=379).

Characteristics	Values, n (%)
Device ownership	
Smartphone (iPhone or Android)	338 (89.2)
Laptop or home computer	203 (53.6)
iPad/tablet	135 (35.6)
Mobile phone (calls/text only)	62 (16.4)
I do not own any of these	2 (0.5)
Access to the internet	
Home	353 (93.1)
Workplace	165 (43.5)
Commuting/travel	90 (23.7)
Community center	48 (12.7)
Somewhere else	17 (4.5)
I don't have access to the internet	8 (2.1)
Use of social media in the last 12 months	
Everyday	337 (89)
A few times per week	33 (8.7)
Not at all	5 (1.3)
About once a week	4 (1.1)
Use of internet for other things in the last 12 months	
Everyday	285 (75.2)
A few times per week	70 (18.5)
About once a week	16 (4.2)
Less than once a week	7 (1.8)
Not at all	1 (0.3)

Using the Phone to Improve Health

Current mHealth Modalities Used

The most common function used on the mobile phone for health was Google (232/379, 61.2%), followed by social media (182/379, 48%), health trackers (130/379, 34.3%), health apps (124/379, 32.7%), telehealth (116/379, 30.6%), and text messages (69/379, 18.2%) (Table 3).

Table 3. Mobile phone use and preferences for mobile health topics and functions (N=379).

Characteristics	Values, n (%)
Current mobile health modalities used	
I use Google to find health information	232 (61.2)
I read posts or watch videos about health on about health on social media	182 (48)
I use a health tracker	130 (34.3)
I use health apps	124 (32.7)
I use telehealth	116 (30.6)
I use text messages	69 (18.2)
Other	8 (2.1)
No, I do not use my phone for health	51 (13.5)
Future mobile health modalities of interest	
A text messaging service	211 (55.7)
Social media	195 (51.5)
Health apps	184 (48.5)
Health tracker	164 (43.3)
Phone calls to talk to a health worker	152 (40.1)
Videoconferencing to video call with a health worker	100 (26.4)
Other	5 (1.3)
No, I would not use my phone for health in the future	20 (5.3)
Mobile health topics of interest	
Help me improve what I eat	210 (55.4)
Engage with Aboriginal and Torres Strait Islander culture	205 (54.1)
Show/teach me exercises	162 (42.7)
Improve my mental health	155 (40.9)
Help me to stop smoking	122 (32.2)
Women’s health	61 (16.1)
Help me limit or quit cannabis or other drugs	48 (12.7)
Child’s health	45 (11.9)
Help with family violence	28 (7.4)
Help me limit drinking	23 (6.1)
Other	9 (2.4)
None of these topics interest me	5 (1.3)

Future mHealth Modalities of Interest

The most preferred mHealth modality for future health care was text messages (211/379, 55.7%), followed by social media (195/379, 51.5%), health apps (124/379, 48.5%), health trackers (164/379, 43.3%), telehealth (152/379, 40.1%), and videos (100/379, 26.4%) (Table 3).

mHealth Topics of Interest

The most preferred topic for future mHealth programs was healthy eating (210/379, 55.4%), followed by cultural engagement (205/379, 54.1%), exercise (162/379, 42.7%), mental health (155/379, 40.9%), stop smoking (122/379, 32.2%), women’s health (61/379, 16.1%), limit or quit cannabis or other drugs (48/379, 12.7%), child’s health (45/379, 11.9%), family violence (28/379, 7.4%), and limit unsafe drinking (23/379, 6.1%) (Table 3).

Confidence to Talk With a Health Professional About Different Health Topics

Women reported high rates of confidence to discuss all health topics with a health professional (Table 4).

Table 4. Confidence talking with a doctor/health worker about different health topics (N=379).

Health topics	Yes, n (%)	No, n (%)	Not relevant, n (%)
Women's health	328 (86.6)	36 (9.5)	15 (4)
Eating/diet	314 (82.8)	51 (13.5)	14 (3.7)
Exercise	307 (81)	51 (13.5)	21 (5.5)
Child's health	305 (80.5)	12 (3.2)	62 (16.4)
Mental health	285 (75.2)	50 (13)	44 (12)
Quitting smoking	265 (70)	49 (13.2)	65 (17.2)
Reducing alcohol	162 (42.7)	47 (12.4)	170 (44.9)
Family violence	135 (35.6)	79 (20.8)	165 (43.5)
Cannabis or other drug use	111 (29.2)	68 (17.9)	200 (52.7)

Association Between Participant Characteristics and Device Ownership

For every 5-year increase in age, the odds of owning a smartphone decreased by 35% (OR 0.723, 95% CI 0.509-0.834; *P*<.001). Of those aged 16 to 21 years, 100% (43/43) owned a smartphone; of those aged 21-34 years, ownership was 90.8% (178/196); and of those aged 34-49 years, ownership was 83.6% (117/140). There was no association between owning a smartphone and level of education attainment or caring for a child younger than 5 years (Tables S1 and S2 in Multimedia Appendix 1).

Women who had completed tertiary education were almost twice as likely (OR 1.916, 95% CI 1.095-3.354; *P*=.02) to own an iPad or tablet compared to those whose highest education was high school completion. No other characteristics (age, remoteness, child younger than 5 years) were associated with ownership of an iPad or tablet (Tables S3 and S4 in Multimedia Appendix 1).

There was a statistically significant overall association with the level of education and ownership of a laptop or computer. Individuals who had completed tertiary education were more than twice as likely (OR 2.176, 95% CI 1.180-4.012; *P*=.01) to own a laptop or home computer compared to those who had completed high school. Those who had not completed high school were 69% less likely to own a laptop or computer compared to those who had completed high school (OR 0.310, 95% CI 0.190-0.506; *P*≤.001). No other characteristics (age, remoteness, or caring for a child younger than 5 years) were associated with ownership of a laptop or computer (Tables S5 and S6 in Multimedia Appendix 1).

The likelihood of owning a mobile phone (text and calls only) increased as age increased (per 5-year increase in age; OR 1.222, 95% CI 1.006-1.484; *P*=.04). No other characteristics (education, remoteness, or caring for a child younger than 5 years) were associated with ownership of an iPad or tablet (Tables S7 and S8 in Multimedia Appendix 1).

Association Between Participant Characteristics and Future mHealth Modalities of Interest

For every 5-year increase in age, the odds of selecting telehealth as a future mHealth modality of interest increased by 22% (per 5-year increase in age; OR 1.232, 95% CI 1.065-1.425; *P*=.005). No other characteristics (education, remoteness, or caring for a child younger than 5 years) were associated with selecting telehealth as a preferred mHealth modality (Tables S9 and S10 in Multimedia Appendix 1). Women who had completed high school were more likely than those who did not complete high school to select videoconferencing as a future mHealth modality of interest (OR 0.497, 95% CI 0.284-0.872; *P*=.01). No other characteristics (tertiary education, remoteness, or caring for a child younger than 5 years) were associated with selecting videoconferencing as a preferred mHealth modality (Tables S11 and S12 in Multimedia Appendix 1). No statistically significant associations between participant characteristics and the selection of text messaging (Tables S13 and S14 in Multimedia Appendix 1), social media (Tables S15 and S16 in Multimedia Appendix 1), health apps (Tables S17 and S18 in Multimedia Appendix 1), or health tracker as preferred mHealth modalities (Tables S19 and S20 in in Multimedia Appendix 1) were found.

Relationship Between Participant Characteristics and Preferred mHealth Topics

Women living in regional and remote areas were 43% less likely than those in urban areas to select cultural engagement as a topic (OR 0.437, 95% CI 0.287-0.666; *P*≤.001) (Tables S21 and S22 in Multimedia Appendix 1). No statistically significant associations were found between participant characteristics and the selection of healthy eating (Tables S23 and S24 in Multimedia Appendix 1) or exercise (Tables S25 and S26 in Multimedia Appendix 1).

Relationship Between Confidence to Discuss a Health Topic With a Health Professional and Selecting That Topic for Future mHealth Interventions

Overall, women showed a similar likelihood of selecting a topic in mHealth whether they were or were not confident to talk to a health professional about that topic (Table S27 in Multimedia Appendix 1). Topics that showed a similar likelihood of being selected included diet, exercise, family violence, quitting smoking, cannabis and other drug use, mental health, women's health, and children's health. Reducing alcohol was the only topic that showed significance (*P*=.002). Notably, for most women (170/379, 44.9%), reducing alcohol was not a relevant health topic, and 42.7% (162/379) of the women were confident to discuss with a health provider. The number of women not confident to discuss reducing alcohol with a health provider was low (47/379, 12.4%) as such, and the number of women selecting alcohol reduction as an mHealth topic who were not confident to discuss with a health professional was also low (11/379, 2.9%).

Discussion

Principal Results

The findings of our study suggest that Aboriginal and Torres Strait Islander women have high access to smartphones and social media and their interest in using technology for health care is high. SMS text messaging was the most preferred mHealth modality.

Strengths and Limitations

A strength of this study is that it was led and governed by Aboriginal researchers. MK, the senior author and lead investigator of the larger study, is a Wiradjuri woman working with a team of Aboriginal and Torres Strait Islander researchers. Aboriginal Health Services are full partners and co-owners of this research. The full details of the governance are available in the protocol for the larger study [30]. As a non-Indigenous researcher (SJP) leading the mHealth portion of the survey, it was important to be guided by Aboriginal leadership and partnership to ensure cultural safety and best practice of ethical standards of research with Aboriginal and Torres Strait Islander people [36,37].

A key limitation of this study is that all recruitments were conducted online and it is therefore biased toward people who have access to digital devices and the internet. We planned to complete a portion of the surveys in person; however, due to COVID-19 restrictions, this was not possible. Unsurprisingly, due to the recruitment strategy, access to devices and the internet was much higher in this study than in other available data. In this study, 99.5% (377/398) of the women owned either a smartphone or a mobile phone. It is unlikely that this proportion reflects all Aboriginal and Torres Strait Islander people, particularly people living in remote locations or in poverty. Two recent studies [38,39] with Aboriginal and Torres Strait Islander people reported lower access to mobile phones. In 1 study, 12.9% (39/301) of the women did not have access to a phone [38], and the other study reported frequent sharing of phones (rather than individual ownership), as is common practice in low-resource settings [39]. In this study, 93.1% (353/379) of the women had access to the internet at home compared to 72% of the Aboriginal and Torres Strait Islander people reported in the 2016 census [40]. Further, as this survey was embedded in a larger study on nonpharmacological smoking support, only current or former smokers were included, possibly creating further bias. Lastly, the usage of complete case analysis further limits the generalizability of this study to people with similar characteristics. Although these weaknesses may limit generalization, overall, these results offer useful insights into the type of mHealth modalities and topics of interest for the future development of mHealth programs.

Comparison With Prior Work

In this study, SMS text messaging was found to be the most desired modality, with 55.7% (211/379) of the women reporting an interest in using SMS text messaging for future health care. Interestingly, SMS text messaging was the least currently utilized mHealth modality for health care at 18.2% (69/379). There were no significant associations found between participant characteristics and women selecting SMS text messaging as the desired modality; as such, SMS text messaging appears to be equally desirable by women of different ages (16-49 years), women living in cities and in regional or remote areas, women with and without young children, and women with different levels of educational attainment. Two studies using SMS text messaging with Aboriginal and Torres Strait Islander women in remote settings found high acceptability for SMS text messages but no difference in the clinical outcomes, including attendance for appointments for otitis media [41] and postpartum screening following gestational diabetes [39]. In a randomized controlled trial with Aboriginal and Torres Strait Islander families in urban and remote settings, SMS text messages were used to retain women; over 96.7% (180/186) of the children remained in the randomized controlled trial until their clinical end point at day 21 [38]. There is great potential for more effectively using SMS text messaging to reach Aboriginal and Torres Strait Islander women to improve health outcomes.

Social media was the second most preferred modality, with 51.5% (195/379) of the women selecting social media as an mHealth modality of interest for the future. Daily social media use among the women was high at 88.9% (337/379)—much higher than that reported in the rest of the population. A web-based survey in 2021 with 2000 Australians reported that 55% of the population used social media daily [42]—similar to the trend in a 2014 survey with 400 Aboriginal and Torres Strait Islander people, wherein 69% used Facebook compared with 40% of the other Australians [20]. The "Social Media Mob: Being Indigenous Online" report suggests that social media uptake is higher among Aboriginal and Torres Strait Islanders than the rest of the nation, including in remote and very remote areas [21]. Carlson and Frazer [21] outlined that Aboriginal and Torres Strait Islander people use social media for a range of positive reasons—to connect with friends and family, share jokes, seek love, find information, seek help, and political activism—but that ensuring psychological and cultural safety should be a priority.

Several Aboriginal and Torres Strait Islander–led social marketing campaigns for health promotion, such as Tackling Indigenous Smoking and Deadly Choices, create posts that appeal to positive emotions, photos and (short) videos, simple content, and real-time support, among other strategies [43]. In an ethnographic study of Deadly Choices, the 5 important principles for the success of the campaign were outlined: (1) create a dialogue, (2) build communities online and offline, (3) incentivize healthy web-based engagement, (4) celebrate Indigenous identity and culture, and (5) prioritize partnerships [44]. Future health initiatives on social media for Aboriginal and Torres Strait Islander women should lean on these findings.

The most preferred topics for future mHealth programs were healthy eating (210/379, 55.4%), followed by cultural engagement (205/379, 54.1%), exercise (162/379, 42.7%), and mental health (155/379, 40.9%). A recent qualitative study examined the types of health content that were shared among Aboriginal and Torres Strait Islander people through social media networks as well as how people engage with and are influenced by it [45]. They found that posts on mental health and nutrition were more commonly shared than posts on health topics where there is concern about stigma and shame, such as smoking and alcohol consumption [45]. The findings in our survey somewhat reflect those findings. Most of the topics associated with shame and stigma, including limiting or quitting cannabis or other drugs, family violence, and reducing alcohol, were in the bottom 4 (out of 9) health topics of interest. Although quitting smoking was the fifth (out of 9) popular choice, the difference may be due to most of the 20 participants in the qualitative study being smokers [45] compared to 37.5% (141/379) of the participants in our study being nonsmokers.

For topics that have concern for shame and stigma, it is suggested that negative messages that have been successful at a whole population level, such as quitting smoking, may need to be adapted for Aboriginal and Torres strait Islander mHealth initiatives [45]. The importance of centering positive cultural identity and narratives in mHealth initiatives is evident [43-45]. This was highlighted in a recent qualitative study that found Facebook posts celebrating culture and cultural achievements as well as challenging racism were mostly posted by women [45]. The popularity of embedding culture in mHealth programs was shown in the results of that study [45], with "culture" as the second most popular topic. The existing evidence suggests that future mHealth programs must integrate culturally relevant content. Further research to determine its effect on engagement and health outcomes is warranted.

Although smartphone ownership was relatively high at 89.2% (338/379) (similar to national figures of 92% [42]), ownership of other digital devices, including laptops, was low at 53.6% (203/379) (national figure is 78% [42]). Access to devices (as well as the internet and data), alongside affordability and digital ability are combined to provide a digital inclusion score (out of 100) [46]. The digital inclusion gap between Aboriginal and Torres Strait Islander people and the rest of the nation is 7.9 (55.1 compared to 63) [46]. Aboriginal and Torres Strait Islander people are less likely to have access to consistent, fast, and large amounts of data, more likely to be mobile-only users, and more likely to use prepaid data; these factors all decrease digital inclusion [46]. Digital inclusion facilitates efficient delivery and uptake of critical services, including health care, as well as employment and education opportunities [46]. Digital inclusion remains in The National Agreement on Closing the Gap as part of the Access to Information target (Target 17)—by 2026, Aboriginal and Torres Strait Islander people will have equal levels of digital inclusion. It is imperative that we seek to advance mHealth solutions developed for and by Aboriginal and Torres Strait Islander people.

Conclusions

Aboriginal and Torres Strait Islander women are avid users of technology and have a strong interest in mHealth. New mHealth initiatives should consider having strong partnerships with ACCHOs and be designed by and for Aboriginal and Torres Strait Islander women to meet their digital and health needs. Nutrition and culture should be considered as topics of particular interest. Social media and SMS text messaging may be the most currently accessible and preferable modalities.

Acknowledgments

We acknowledge the partnering services and staff for their time and commitment to this long-term project, including the Dhanggan Gudjagang team, Yerin Eleanor Duncan Aboriginal Health Centre, Tamworth Aboriginal Medical Service, Nunyara Aboriginal Health Clinics, and Waminda South Coast Women's Health and Welfare Aboriginal Corporation. We also acknowledge all the Aboriginal and Torres Strait Islander women who contributed to this research project—thank you for sharing your experiences with us; it is our honor to privilege your voices. This study was funded by the National Heart Foundation Aboriginal and Torres Strait Islander Award grant 102458.

Data Availability

The data sets generated during and analyzed during this study are not publicly available in line with Aboriginal and Torres Strait Islander health research ethical guidelines but are available from the corresponding author on reasonable request.

Authors' Contributions

MK conceptualized the larger study, led data collection, acquired funding, designed the methodology, and reviewed and edited the manuscript. SJP, BB, KH, JM, CC, JB, RW, and MK contributed to the conceptualization of the study or design of the survey instrument. SJP wrote the original draft, and BB, KH, JM, CC, JB, RW KP, DL, and MK reviewed the manuscript. BB, KH, and JM provided PhD supervision to SJP. KP and DL completed the statistical analysis.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary tables.
[DOCX File , 86 KB-Multimedia Appendix 1]

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Abbreviations

ACCHOs: Aboriginal Community Controlled Health Organizations
mHealth: mobile health
OR: odds ratio

Edited by R Kukafka, T Leung; submitted 12.09.22; peer-reviewed by M Galani, K Biswas, N Vu; comments to author 16.01.23; revised version received 22.01.23; accepted 31.01.23; published 06.03.23

Please cite as:
Perkes SJ, Bonevski B, Hall K, Mattes J, Chamberlain C, Bennett J, Whittaker R, Palazzi K, Lambkin D, Kennedy M
Aboriginal and Torres Strait Islander Women's Access to and Interest in mHealth: National Web-based Cross-sectional Survey
J Med Internet Res 2023;25:e42660
URL: https://www.jmir.org/2023/1/e42660
doi: 10.2196/42660
PMID:

Appendix 13 – Co-authorship approval for Chapter 8 manuscript

Student Name: Sarah Jane Perkes
Student ID: 2264590

CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 1

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	Perkes SJ, Bonevski B, Hall K, Mattes J, Chamberlain C, Bennett J, Whittaker R, Palazzi K, Lambkin D, Kennedy M. Aboriginal and Torres Strait Islander womenȇ access to and interest in mHealth: national web-based cross-sectional survey. Journal of Medical Internet Research. 2023;25:e42660. https://doi.org/10.2196/42660
Section of thesis where publication is referred to	Chapter 8

Student's contribution to the publication

70	%	Research design
50	%	Data collection and analysis
90	%	Writing and editing

Outline your (the student's) contribution to the publication:

Authors contribution to the publication:
MK led the conceptualisation of the larger study, acquired funding, design of the methodology, and reviewed & edited the manuscript. SP, BB, KH, JM, CC, JB, & RW contributed to the conceptualisation of the study and/or design of the survey instrument SP led the design of the survey items for mHealth, contributed to data analysis and led the writing of drafts and final manuscript. BB, KH, JM, CC, JN, RW KP, DL and MK reviewed the manuscript. KP and DL completed the statistical analysis.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1	Dr Michelle Kennedy	Signed	Michelle Kennedy Digitally signed by Michelle Kennedy Date: 2022.10.31 09:21:06 +11'00'	Date	31-Oct-2022
Name of Co-Author 2	Prof Billie Bonevski	Signed		Date	27/10/2022
Name of Co-Author 3	Dr Kerry Hall	Signed		Date	31-Oct-2022

Appendix 14 – Chapter 9 manuscript

Original Paper

Development of a Maternal and Child mHealth Intervention With Aboriginal and Torres Strait Islander Mothers: Co-design Approach

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Abstract

Background: Despite their growing popularity, there are very few mobile health (mHealth) interventions for Aboriginal and Torres Strait Islander people that are culturally safe and evidence based. A co-design approach is considered a suitable methodology for developing health interventions with Aboriginal and Torres Strait Islander people.

Objective: The aim of this study was to co-design an mHealth intervention to improve health knowledge, health behaviors, and access to health services for women caring for young Aboriginal and Torres Strait Islander children.

Methods: Aboriginal researchers led engagement and recruitment with health services and participants in 3 Aboriginal and Torres Strait Islander communities in New South Wales, Australia. Focus groups and interviews were facilitated by researchers and an app developer to gather information on 3 predetermined themes: design characteristics, content modules, and features and functions. Findings from the co-design led to the development of an intervention prototype. Theories of health behavior change were used to underpin intervention components. Existing publicly available evidence-based information was used to develop content. Governance was provided by an Aboriginal advisory group.

Results: In total, 31 mothers and 11 health professionals participated in 8 co-design focus groups and 12 interviews from June 2019 to September 2019. The 6 design characteristics identified as important were credibility, Aboriginal and Torres Strait Islander designs and cultural safety, family centeredness, supportive, simple to use, and confidential. The content includes 6 modules for women's health: Smoke-free families, Safe drinking, Feeling good, Women's business, Eating, and Exercising. The content also includes 6 modules for children's health: Breathing well; Sleeping; Milestones; Feeding and eating; Vaccinations and medicines; and Ears, eyes, and teeth. In addition, 6 technology features and functions were identified: content feed, social connection, reminders, rewards, communication with health professionals, and use of videos.

Conclusions: An mHealth intervention that included app, Facebook page, and SMS text messaging modalities was developed based on the co-design findings. The intervention incorporates health behavior change theory, evidence-based information, and the preferences of Aboriginal and Torres Strait Islander women and health professionals. A pilot study is now needed to assess the acceptability and feasibility of the intervention.

(JMIR Form Res 2022;6(7):e33541) doi: 10.2196/33541

KEYWORDS

mHealth; co-design; Aboriginal and Torres Strait Islander; mother; baby; young children; mobile phone

Introduction

Background

The health and well-being of Aboriginal and Torres Strait Islander people have been significantly affected by dispossession, interruption of culture, and intergenerational trauma since the colonization of Australia [1]. The ongoing impact has resulted in an unequal opportunity for good health. The life expectancy of Aboriginal and Torres Strait Islander women is 8 years less than that of non-Indigenous Australian women [2]. In the 2018-2019 National Aboriginal and Torres Strait Islander Health Survey, the majority of women aged ≥15 years were not meeting guidelines for physical activity, vegetable intake, or fruit intake; 36% reported that they smoked tobacco daily; and 35% reported that they experienced high or very high levels of psychological distress [3]. Infant mortality continues to be unacceptability high for Aboriginal and Torres Strait babies at 2.1 times the rate of non-Indigenous infants (6.3 and 3.1 per 1000 live births, respectively) [4]. Mothers and babies getting the best possible care and support for a good start to life is 1 of 12 health priorities of the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 [1].

Aboriginal and Torres Strait Islander people make up 3.3% (798,400/24,193,939) of the Australian population [5] and include many distinct groups with their own language and culture. In total, 44% of Aboriginal and Torres Strait Islanders live in regional areas, 37% in cities, and 18% in remote or very remote areas [5]. Those living in regional and remote areas have less access to primary health care and overall poorer health [6]. Nationally, Aboriginal and Torres Strait Islander people have less access to the internet at home (75.3% compared with 85.8% of all Australians); there are significant differences based on location: 82.8% in cities, 73.2% in regional areas, 61.3% in remote areas, and 49.9% in very remote areas [7]. More than 1 in 3 (35%) Aboriginal and Torres Strait Islander people are mobile-only users compared with a national rate of 1 in 5 (19.9%); these figures are linked to socioeconomic factors [8]. Using only a mobile is likely to incur more costs for data, less capability, and less access to more sophisticated digital health information and tools [8]. It is of importance that mobile health (mHealth) interventions are developed with a goal to increase digital inclusion.

mHealth is the use of mobile technology to improve health. Functions include SMS text messaging, multimedia messaging service, voice, internet access, and software apps, which range in complexity. mHealth is used for a variety of purposes, including health education, health behavior change, sensors and point-of-care diagnostics, registries and vital-event tracking, and data collection [9]. mHealth is being used increasingly for health promotion because of its reach, with >7 billion mobile phone subscriptions globally [10]; the Be He@lthy, Be Mobile initiative by the World Health Organization has reached >3.5 million people [11]. There are limited recent national figures on smartphone ownership among Aboriginal and Torres Strait Islander people, although available data indicate that ownership is high; a survey with 400 Aboriginal and Torres Strait Islander people in 2014 reported that 70% of Aboriginal and Torres Strait Islander people owned a smartphone and 69% used Facebook compared with 66% and 40% respectively for non-Indigenous Australians [12]. The top reason for using a mobile phone in this group was to send SMS text messages [12].

Studies focused on Aboriginal and Torres Strait Islander people using SMS text messaging to improve health show high acceptability of the modality [13-15]. SMS text messaging has the advantage of being accessible on all mobile phones and not requiring access to a data service. There are few technical barriers to SMS text messaging and high acceptability of the modality among new mothers [16,17]. In a metareview (23 systematic reviews, 371 studies, and 79,665 participants) on the impact of mHealth on a range of outcomes, including clinical outcomes, adherence to treatment and care, health behavior change, disease management, and attendance rates, SMS text messaging was the most frequently examined function and reported to be the most successful overall [18]. SMS text messaging seems to be particularly effective at increasing smoking cessation rates (in adult smokers from mostly high-income countries) [19]. The evidence for SMS text messaging helping to improve nutrition and physical activity is not as strong; however, SMS text messaging used in conjunction with other mHealth functionality has shown significant positive effects for healthy eating [18].

Health apps continue to be popular, although the evidence suggests that apps have limited effectiveness on changing health behaviors [18,20-22]. Some studies have found that apps can be effective at changing behavior among some clinical groups [18], although overall there is limited evidence to date. Of the few trials focused on Indigenous populations, app use has been reported to be low [23,24]. A recent pilot randomized controlled trial of a smoking cessation app with 49 Aboriginal people in Australia reported low to moderate level of app use, and at 6-month follow-up, only 1 participant was abstinent [24]. The authors concluded that although there was broad acceptability for the app, mHealth interventions should be designed with functions that are commonly used, including social media platforms [24]. A co-designed mHealth app developed in New Zealand with Māori and Pacific Islander people was tested in a cluster randomized controlled trial in 2019 (n=1451) [23]. Adherence to health-related–behavior guidelines increased at 12 weeks in both groups, with no difference between the groups. Engagement with the app overall was low, although those who did engage with the app as it was designed saw greater benefit. The co-design approach was reported to have drawn a very positive response from the community, as was reflected in the high participation and follow-up rates [23].

Social media is a form of mHealth, with potential to support health. The Aboriginal and Torres Strait Islander health sector was an early adopter of social media networks to promote health

[25,26]. Social media campaigns on COVID-19 by Aboriginal and Torres Strait Islander health organizations is a recent example [27]. A recent Cochrane review on behavioral interventions delivered through social media for health behavior change, health outcomes, and health equity (88 studies; n=871,378) reported varied effects; overall, social media was found to improve physical activity, weight loss, and general well-being, and small to no effects were found for other outcomes [28]. No studies focusing on Aboriginal and Torres Strait Islander people were included in the review.

Objectives

In response to the limited mHealth interventions available for Aboriginal and Torres Strait Islander women and children, we aimed to co-design a prototype focused on the needs and ideas of Aboriginal and Torres Strait Islander mothers. Co-design is a partnership approach where end users are actively involved from conception to dissemination [29]. Using co-design methodologies is one of the guiding principles of the Aboriginal Health and Medical Research Council of New South Wales (NSW) Ethical Guidelines for conducting health research with Aboriginal people [30]. In this paper, we describe the co-design processes and findings, as well as provide a description of the mHealth prototype.

Methods

Study Design

In total, 8 focus groups and 12 interviews were conducted from June 2019 to September 2019. Surveys were used to collect demographics at the start of focus groups and interviews. An Aboriginal advisory group that included Aboriginal team members who were also members of the participating communities met quarterly to oversee design, implementation, analysis, and reporting. An expert mHealth research group was consulted for opinion on research and intervention design.

Ethics Approval

Human research ethics approval was received from the Aboriginal Health and Medical Research Council (1485/19) and the University of Newcastle (H-2019-00760).

Co-design Framework

A co-design framework for an mHealth intervention with Māori and Pacific communities in New Zealand [29] based on work by Bratteteig et al [31] was used to guide the methods used in this study. Co-design is a coherent methodology with a range of tools and techniques used to favor the preferences of end users [31]. The co-design methods used included focus group and interview discussions, card sorting, storyboarding, design activities, survey, guidance from expert groups, and an iterative design phase with the research team.

Setting

Focus groups and interviews were held at 3 regional NSW locations: Newcastle, Coffs Harbour, and Inverell. In total, 5 Aboriginal organizations (including 3 Aboriginal health services, an Aboriginal preschool, and an Aboriginal corporation) and 3 NSW Health sites participated. Venues for focus groups and interviews were decided in consultation with participants.

Participants

Women aged ≥16 years who were either mothers or primary carers of an Aboriginal or Torres Strait Islander child aged 0 to 5 years or were pregnant (≥30 weeks gestation), owned or regularly used a smartphone, and had accessed a participating service (Aboriginal health service or NSW Health service) were eligible to participate. Health professionals at participating services who worked with women or children were eligible.

Procedures

Convenience sampling was used to recruit participants. Aboriginal researchers (BH, NS, and BL) who worked within the participating communities used their personal networks. In addition, participants were asked if they would like to recommend a friend or family member to the study. Potential participants were screened for eligibility when they contacted the researcher on the telephone. The researcher explained the study and gained informed consent over the telephone initially and again in person before the start of the focus group or interview. Participants were reimbursed with a shopping voucher worth Aus $30 (US $21.6) for attending focus groups and interviews and provided with refreshments. Health professionals were recruited using a snowball methodology through the participating services. Health professionals were not reimbursed.

Mothers and health professionals participated in separate focus groups and interviews. Focus groups and interviews were cofacilitated by a combination of Aboriginal researchers (NS and BH), a PhD student (SJP), and an app developer. Interviews and focus groups were 20 to 90 minutes in length. The number of participants in focus groups ranged from 2 to 6. Focus groups and interviews were recorded and transcribed, and field notes were taken.

Measures

Different surveys and discussion guides were used with mothers and health professionals. Discussions and activities were used to identify (1) design characteristics, (2) content modules, and (3) features and functions.

Mothers

Survey

The survey comprised 16 items, including demographic, cultural, and socioeconomic items. The items were selected from a previous study [32], with all items having been tested with Aboriginal and Torres Strait Islander mothers previously.

Discussion Guide

In all focus groups and interviews with mothers, 3 main questions were asked. Follow-up questions were asked depending on responses. Additional questions about mobile phone use to inform features and functions were asked in focus groups cofacilitated by the app developer. The three main questions were as follows:

How would an mHealth intervention designed for healthy living for Aboriginal and Torres Strait Islander people differ from other mHealth interventions?

Are you more interested in mHealth for your own health or your child's health? What topics and features interest you?

What do you think stops or prevents some women from accessing health information and services for themselves and their children?

Activities

Card-sorting activities were used to identify current mobile phone use (functions used, frequency of use, and reasons for use). Storyboarding activity was used to elicit creative descriptions of the mHealth intervention using drawings and words on what the intervention should include. Design activity was used to gain feedback on potential designs.

Health Professionals

Survey

The survey comprised 5 items related to demographic and professional practice characteristics.

Discussion Guide

In all focus groups and interviews with health professionals, 3 main questions were asked. Additional follow-up questions were asked depending on the response. The three main discussion questions were as follows:

1. What do you think are the most important health and well-being topics to include for Aboriginal or Torres Strait Islander women, children, and family?
2. What are the barriers for Aboriginal or Torres Strait Islander families to having good health?
3. What types of mobile technology do you think could support Aboriginal or Torres Strait Islander women's and children's health?

Co-design Analysis

A generalized thematic analysis was completed. An Aboriginal researcher (BH) and a PhD student (SJP) independently coded themes. NVivo software (version 12.0; QSR International) was used to complete independent coding and comparison by the 2 coders. In total, 3 predetermined codes were used based on a similar co-design study [29]. These codes included (1) design characteristics, (2) content modules, and (3) features and functions. The coders met to agree on subcodes and definitions. Survey findings are presented using descriptive statistics.

Intervention Development

The findings from the co-design stage were subsequently used to develop a prototype intervention incorporating an app, SMS text messaging, social media, and videos. The intervention development was an iterative process, with meetings held among the team members to decide the final features and functionalities. Not all ideas could be adopted because of various reasons, such as time, funding, and technology constraints. We used a combination of building new functions (app) and using existing functions (Facebook page and SMS text messaging).

The intervention was grounded in behavior change theory. The Health Belief Model was used to underpin the app portion of the intervention. The Health Belief Model is considered to be well suited to mHealth interventions with use of the *cue to action* component [33]. The basic constructs are perceived threat of illness, perceived benefits of health behavior change, perceived barriers to change, cues to action, and self-efficacy [34]. Behavior change techniques were used to formulate SMS text messages. The SMS text messages were coded for behavior change techniques by 2 coders (Sam McCrabb and SJP) using behavior change technique taxonomy (version 1) [35] and the process outlined by Michie et al [36]. Of the 2 coders, 1 was experienced in coding behavior change techniques (Sam McCrabb) and the other was a PhD student (SJP). Disagreements were resolved through discussion and key messages adapted to include further effective behavior change techniques.

Key messages were developed on health topics identified from the focus groups and interviews. Content was formulated from publicly available evidence-based health resources. Key messages were adapted to SMS text messages, small pieces of written information for the app, and Facebook posts.

The prototype intervention included an app, videos, Facebook page, and SMS text messaging (Textbox 1).

Textbox 1. Components of the prototype intervention.

App

- A web-based prototype app was developed. Rapid iterative cycles between the app developer and research team were used to refine the design. An Aboriginal graphic designer developed graphics for each module and logo.

Videos

- A total of 12 short videos were captured on a Canon camera. All presenters were health professionals from participating sites or contacts of the research team. Short scripts were provided to health professionals based on key messages. Staff were encouraged to use their own knowledge and expertise on each topic. Videos were filmed by a videographer and professionally edited. Captions were completed by Rev, and voiceovers were completed by 2 Aboriginal researchers (BH and NS). The videos ranged from 112 to 300 seconds in length. Vimeo was used as the platform to host the videos.

Facebook page

- A Facebook group was developed and administrated by 2 Aboriginal researchers (BH and NS). Both researchers were regular Facebook users and had significant networks and knowledge of Aboriginal and Torres Strait Islander organizations, events, and health services. Key messages were predeveloped in text and video format. Other content shared was decided by the administrators, including sharing posts from their personal accounts if they were suited to the broad aim of the intervention.

SMS text messaging

- SMS text messages were developed based on the processes described by Abroms et al [37]. Steps include choosing a behavior change goal, choosing communication objectives and behavioral techniques, designing a framework, and writing an SMS text message library [37]. SMS text messages were written to allow tailoring using the mother's and child's names, child's age, and topic interest of the mother. Tailoring SMS text messages around the timing of key behaviors, such as after a baby is born, can improve saliency and likelihood of behavior change [38]. SMS text messages were written by an Aboriginal researcher (BH) and a PhD student (SJP). A web-hosted SMS text messaging server (SMS Express) will be used to send all SMS text messages.

Results

Overview

A total of 42 participants were recruited to the study: 31 mothers and 11 health professionals. Demographics and cultural characteristics of mothers are presented in Table 1, and demographics of health professionals in Table 2.

Table 1. Demographic and cultural characteristics of mothers (N=31).

Characteristics	Values
Age (years), mean (SD; range)	31.17 (7.69; 19-50)
Indigenous status, n (%)	
Aboriginal	21 (68)
Torres Strait Islander	2 (7)
Nonidentified	7 (23)
Did not answer	1 (3)
Identified with an Indigenous community, n (%)	
Yes	25 (81)
No	1 (3)
Unknown	4 (13)
Did not answer	1 (3)
Maintain cultural connections at home, yes, n (%)	25 (81)
Ways of connecting to culture, n (%)	
Music or dance	19 (61)
Storytelling	19 (61)
Indigenous television	18 (58)
Art	15 (48)
Food	14 (45)
Indigenous internet sites	10 (32)
Indigenous newspapers	7 (23)
Traditional medicine	6 (19)
Indigenous radio	5 (16)
Other	1 (3)
Family members from Stolen Generations[a], n (%)	
Yes	6 (19)
No	12 (39)
Unknown	13 (42)
Education of mother, n (%)	
Did not finish high school	6 (19)
High school	6 (19)
Certificate	10 (32)
Diploma	2 (7)
Bachelor’s degree	4 (13)
Postgraduate degree	1 (3)
Did not answer	2 (7)
Currently pregnant, yes, n (%)	1 (3)
Partner, yes, n (%)	16 (52)
Number of people living in household, mean (SD; range)	4 (1.31; 2-7)
Number of children (aged <18 years) living in household, mean (SD; range)	2.39 (1.41; 1-5)
Smoking status of mother, n (%)	
Nonsmoker	21 (68)
Yes, daily	5 (16)

Characteristics	Values
Yes, at least once a week	2 (7)
Yes, less often than once a week	1 (3)
Did not answer	2 (7)
Number of cigarettes smoked per day (on the days smoking), mean (SD; range)	8.5 (3.21; 4-12)
Number of smokers in household, n (%)	
0	14 (45)
1	10 (32)
2 to 3	4 (13)
>3	1 (3)
Child exposure to indoor tobacco smoke, yes, n (%)	1 (3)
Child exposure to outdoor tobacco smoke, yes, n (%)	15 (48)
Child exposure to tobacco smoke in the car, yes, n (%)	0 (0)

[a]The Stolen Generations refers to a period in Australia's history when Aboriginal children were removed from their families through government policies. This happened during the period from the mid-1800s to the 1970s [39].

Table 2. Demographics of health professionals (N=11).

Characteristics	Values
Health service type, n (%)	
Aboriginal medical service	6 (55)
NSW[a] Health service	5 (45)
Sex: female	11 (100)
Indigenous status, n (%)	
Aboriginal	4 (36)
Torres Strait Islander	0 (0)
Nonidentified	7 (64)
Role at health service, n (%)	
Registered nurse	7 (64)
Aboriginal health worker	3 (27)
Senior family health practitioner	1 (9)
Number of years at service, mean (SD; range)	12 (8.7; 3-32)

[a]NSW: New South Wales.

Design Characteristics

We identified six main design characteristics: (1) credibility, (2) Aboriginal and Torres Strait Islander designs and cultural safety, (3) family centeredness, (4) supportive, (5) simple to use, and (6) confidential.

Credibility

Mothers talked about the difficulty of finding information on the web that was evidence based. Most of the mothers said that they used Google to find real-time health information for themselves and for their children: "Literally, I Google everything." Many of the mothers said that it can be difficult to know which websites are most up to date and accurate and that it is difficult to find information: "The biggest thing I find on Google, you get everything. You don't get the ones that are reputable." Another mother said, "I'm finding you're having to like scroll, scroll, and scroll to try and find that information." Mothers said that they want current health information from reputable health professionals and organizations, including "useful websites links." Health professionals talked about the importance of credible health information to improve health literacy: "I think lack of knowledge that they are so sick. Recognizing the signs of illness that can lead to them being really, really [sick]." This highlighted why it is important that all content included in the prototype intervention be sourced from credible evidence-based health resources and broken down into palatable small chunks with links to further information.

Aboriginal and Torres Strait Islander Designs and Cultural Safety

Most of the mothers said that Aboriginal designs, language, and representation were important for engagement. A mother said, “I think if it had Aboriginal designs that would be really good because if I download an app and it doesn’t have the look, like being culturally aware [I don’t use it].” Another mother said, “Don’t make it black and white, it’s got to be like colorful.” A mother spoke about the intervention needing Aboriginal representation in images and videos: “If it’s going to be an Aboriginal app, I think you have to have Aboriginal people.” Another mother discussed using an app for quitting smoking that was not representative of Aboriginal people: “It was easy to use, but I couldn’t relate to it...didn’t seem like it was aimed at Blackfellas even though we thought it was.”

It was evident from the mothers’ experiences of racism that the intervention needed to be centered in culturally safety. Some mothers talked about feeling fearful and judged when seeking health care. A mother said, “Being an Aboriginal mum especially, I was just worried about DoCS [Department of Child Services]. Like whether they could see if I was handling having two children on top of my own family breakdown. Like my mum’s kids are in DoCS. So that’s what my biggest fear was.” Other mothers expressed feeling judged about certain health behaviors and topics, and a mother said, “The biggest thing is why people do hide it [smoking], because they don’t want to be judged. They don’t want to hear all that stuff.”

To center cultural safety in the intervention, all aspects of the intervention were codeveloped by Aboriginal people: the research was governed by an Aboriginal advisory board and coled by an Aboriginal academic (KH); 4 of the 8 members of the research team are Aboriginal; an Aboriginal graphic designer designed the module icons and logo; Aboriginal researchers were administrators of the Facebook page and shared cultural links, events, activities, affirmations, and images; an Aboriginal videographer filmed all the videos; Aboriginal health professionals presented in the videos; an acknowledgment of Country and a *welcome* message by an Aboriginal researcher was placed on the main page; and all content was cowritten by Aboriginal researchers.

Family Centeredness

It was decided unanimously that the intervention should include content for both mother and child. A mother said, “Is this just for children’s health? Because I feel like it should incorporate the mother’s health too.” The mothers asked for information on “things to do with our kids,” and “stuff for us women too. Pap smears and stuff like that.” Many of the mothers and health professionals suggested that the intervention needed to encompass the entire family, including the extended family. A health professional said, “Put the main focus on the child and then how their [family] health affects the baby’s health,” and a mother said, “I think a family app would be really good. Like, I know my husband, he’s never been around babies.” Some participants talked about how other family members help bring up children: “It’s nothing to see an aunt bringing up a child, or a grandparent or a sister” [health professional]. Family centeredness in the intervention was therefore conveyed through messaging that families are the most important role models for jarjums (an Aboriginal word meaning children) across modules and functions. Links to websites, events, and health information for partners and other family members were included.

Supportive

Most of the mothers and health professionals indicated that it was important that the intervention promoted positive self-esteem and well-being of mothers. A health professional said that the intervention should give new mothers “understanding [of] how tired you are going to be, and it’s okay, ask for help, everyone feels like that but you’re not failing or not doing something wrong.” A mother suggested that we include “some sanity sayings or something like that, or some little sage advice from mums that have been there, done that before, that’d be really helpful,” and another mother said that the intervention could be “like a reassurance type thing.” Mothers and health professionals recognized that motherhood can be “totally exhausting” [health professional] and challenging at times. A mother described the initial period after coming home from hospital: “I didn't know what to do with him. What do I do with this kid? I was lost.” To create an intervention that was supportive of motherhood and of Aboriginal and Torres Strait Islander women, positive and affirming messages were posted on Facebook, sent through SMS text messages, and included in the app. Links on where to seek help for mental health concerns were included.

Simple to Use

Mothers and health professionals recommended that the intervention be intuitive, use simple language, and have few technical barriers. Some of the mothers talked about trying to use other health apps; however, they were unable to do so because of technological challenges. For example, a mother said, “It was just too hard to log in and get started so I gave up or just called someone.” Many of the mothers and health professionals emphasized that the language used in the intervention needed to be nonjargon. A mother said, “Don’t put it in a textbook. Because I’m telling you, if my family member downloaded that and it was a textbook way, they would be like—No.” Another mother said that the content should be “just little pieces of information...then links to the bigger pieces.” We aimed for simple, intuitive app design and used other mobile functions commonly used by mothers (Facebook and SMS text messaging). To ensure that the intervention was simple and easy to use, health information was presented in short key messages with links to websites for further information. All key messages were written to be at an 8th grade reading level using the Flesch-Kincaid Grade Level Test as recommended by Abroms et al [37].

Confidential

Mothers and health professionals talked about the importance of confidentiality. Health professionals focused on confidentiality in the health care setting and the complexities for some staff regarding knowing patient health details. A health professional said, “There are big things surrounding our health services confidentiality. People don’t know or want to know what other people’s business is.” Some of the mothers spoke about confidentiality; regarding being anonymous when communicating with other mothers or health professionals in a hypothetical mHealth intervention, a mother said, “Oh God, yeah. I’d ask an anonymous person on a phone. Rather than ask the doctor face to face.” Other mothers were happy to not be anonymous: “It wouldn’t bother me having my name because it would just be, this is my experience, and it is what it is. But I would understand if some women didn’t.” To ensure that women can choose to remain anonymous and keep their information confidential, the intervention design meant that no personal data were collected in any part of the intervention, other than a mobile number for the SMS text messaging component. Joining the Facebook group is an optional part of the intervention.

Content Modules

Most of the mothers and health professionals suggested that the intervention needed to cover a wide range of health topics for both the mother and child. Health topics identified in the data included *pains after birth*, *breastfeeding*, *normal speech for toddlers*, *signs of autism*, *earaches*, *behavior*, *rashes*, *high temperatures*, and *coughs*. Similar topics were grouped by the research team and combined into 6 key content modules for women’s health and 6 key content modules for children’s health. For example, *birth*, *reproductive health*, *urinary leaking*, and *pap smears* became *Women’s business*. All health topics captured in the interviews and focus groups were included in the intervention within a module on the app, SMS text messages, or through Facebook posts. Health modules for women included Smoke-free families, Safe drinking, Feeling good, Women’s business, Eating, and Exercising. Health modules for children were Breathing well; Sleeping; Milestones; Feeding and eating; Vaccinations and medicines; and Ears, eyes, and teeth.

Features and Functions

We identified eight features and functions: (1) content feed, (2) social connection, (3) diary and storage of health information, (4) local context, (5) reminders, (6) rewards, (7) talk with health professionals, and (8) use of videos.

Content Feed

A content feed was chosen to be a feature of the intervention based on the mothers’ current mobile phone use. During the card-sorting activity, most of the mothers reported scrolling the content feed on Facebook numerous times per day. Of the 13 women who were asked how many hours per day they used Facebook, 12 (92%) reported using it >4 hours per day. When asked what kept them going back to Facebook, a mother responded, “The content keeps changing.” Mothers frequently talked about watching photo and video stories that were uplifting, funny, or motivating on Facebook. They talked about using Instagram and Snapchat, too, although less frequently. The intervention was therefore designed to include a Facebook page with daily posts covering a variety of health content.

Social Connection

Mothers talked about the social connection and learning from other women when becoming a mother, including from their “mum,” “mother-in-law,” and “girlfriends.” The importance of positive relationships when first becoming a mother was well recognized by health professionals as well as mothers. It was acknowledged by many of the mothers that some new mothers “don’t have a big support network.” A mother described mothers at playgroup being “more like a family to each other.” Some of the mothers said that connecting to other mothers would be helpful because they may be going through the same situation or challenge: “Yeah [I would like to chat with mums in the intervention] because they might have experienced something that I’m starting to experience.” Some of the mothers talked about the possibility of meeting up with mothers outside of the intervention: “It’s hard to meet people...[could there be] like a mums and bubs [babies] thing [as part of the intervention],” and another mother said, “Say, if I needed to ask them a question or something that I wouldn’t want to write on Facebook [I would like to meet up with them in person].” Another mother identified that connection is important for mental health: “When they [new mothers] don’t have anybody, depression kicks in.” The Facebook page was designed to make it easy for mothers to connect and share stories and ideas. Discussion points were created to be posted on the Facebook page to facilitate discussion; for example, “Tell us how you engage your jarjums in cooking or take a pic or video of your deadly (great or excellent) li’l chef in the kitchen.”

Diary and Storage of Health Information:

A feature that enabled users to store specific information about a child’s health received mixed responses. Some of the mothers thought that having their child’s health information on hand would be of practical benefit when attending medical appointments: “Like a diary section...I found, when [my child] was sick I started recording when I gave the medication, those sorts of things. That’d be good to have an app when you go into the hospital, you go, this is his recordings.” Another mother said, “So they [health professionals] could just add in medication, add in reports...it’d be good because like [the health service] is only open during the week. Usually, like on the weekend, I’d have to go up to the hospital...So it would be good if there was information like after the visit. Because you don’t always take everything in. It goes right over your head.” Other mothers and health professionals thought there would be confidentiality concerns. Because of the confidentiality concerns raised in the co-design process, a diary feature was not included, although it may be considered as an optional feature in future iterations.

Local Context

Many of the mothers and health professionals spoke about the uniqueness of their community and said that the intervention needed to be relevant to each community, including language and environment (eg, coastal and desert), as well as health services and other resources. A mother suggested, “You could put in your postcode, location, or area or something and then it could be localized,” and a health professional said, “The contact numbers, if they can’t get into emergency, the [local] health line numbers where they can get a bit of advice would be handy on there as well.” The intervention included phone numbers of local health services for each community in the app, and Facebook posts were designed promoting local health services, events, organizations, and languages.

Reminders

Many of the mothers talked about the usefulness of SMS text messaging reminders from their health services for appointments, and they said that reminders for other areas of health care would be useful too. A mother said, “I would probably like all of them [milestone reminders]. I’d like the whole lot, make sure I’m not missing anything.” Another mother said, “If someone notified me on this app that I’m due for a [pap smear] or something like that, I would like being reminded of things like that.” Most of the mothers said that they would prefer reminders through SMS text messages rather than a push notification from an app because they could go back to the message and reread it. For the intervention, SMS text messages were developed covering a range of reminders, including vaccinations, developmental milestones, check-ups, smoking quit date, exercise, and eating well. Reminders about local health initiatives and events were also created for posting on the Facebook page.

Rewards

The mothers talked about rewards and incentives from health programs and services increasing their motivation. They talked about material rewards such as “shirts,” “caps,” and “supermarket vouchers,” as well as social rewards, including “comments” and “likes” on social media and “clapping” and “cheers” on health apps. The mothers who were asked about receiving rewards for a variety of health behaviors were unanimous in their opinion that rewards were enjoyable and motivating. In the intervention, weekly competitions were created for posting on the Facebook page involving mothers sharing a picture of a health activity; for example, active play or exercising with their children. Prize draws were also incorporated into the intervention for those who participated in the competitions.

Talk With Health Professionals

Some of the mothers suggested that being able to communicate with health professionals using SMS text messages or a live chat function would be beneficial. Some of the mothers said that this function would be useful to confirm whether they required face-to-face health care and for reassurance. A mother said, “Sometimes you don’t know if you should go up there [health service] or not, so you could kind of message and say, ‘Hey, this is what’s happening...is it worth coming up or is it just a viral thing going around?’” Another mother said, “I know a lot of women are just like, ‘What do I do?’ So just having that reassurance I suppose online.” Another mother suggested that it would be helpful to be able to ask health questions anonymously: “The option to be anonymous or not known by people [health professionals] would be handy I guess for more embarrassing health concerns.” Mothers living in rural areas mentioned being anonymous more often in the discussions. Although it was suggested, facilitating a chat with health professionals directly was out of the scope of the current prototype because of cost and resources. Telephone numbers for national, state, and local health services were listed in the app to enable users to connect with health professionals, if needed, regarding the questions they might have.

Use of Videos

Most of the mothers reported during the card-sorting activity that they frequently watched short videos on social media and YouTube. A number of mothers and health professionals advised us that videos and images may be more accessible and preferable for some mothers. A health professional said, “Videos, everyone can watch a video and understand.” Therefore, a video for each health module was developed for the intervention. Each video was stored in the app and added to the Facebook page. Additional health videos from external sources were also able to be shared on the Facebook page.

Final Prototype

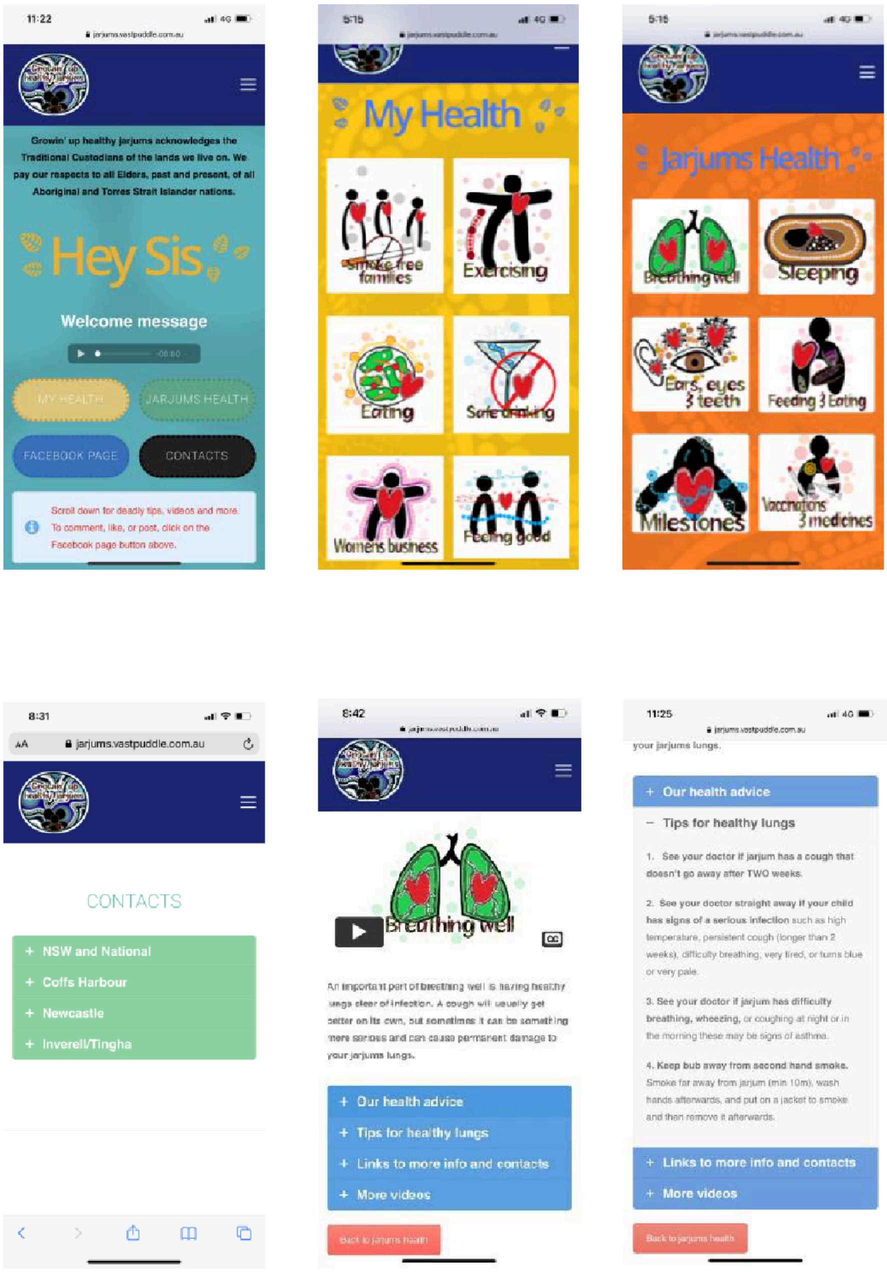
The final mHealth intervention, named Growin’ Up Healthy Jarjums, aimed to improve health knowledge and health behaviors, along with providing access to health services. The intervention comprises 3 delivery modalities: app, SMS text messaging, and Facebook page.

App

The app is a central place for users to access all content. The app is primarily for the user who wants in-depth information and has the necessary digital device, internet connection, and literacy skills to access it. It is designed to allow the user to navigate to the topic of interest; for example, *exercise,* where they will find small amounts of written information, videos, links to websites, and useful contacts. The user may choose to access any topic, in any order, and consume as much information as they like.

The app has four menu screens: (1) home screen, (2) women’s health, (3) children’s health, and (4) contacts (Figure 1). The home screen includes four buttons: (1) *My Health*, (2) *Jarjums Health*, (3) *Facebook Page*, and (4) *Contacts*. The user may click on a button to move to the next screen or scroll down to access the embedded Facebook content feed. The embedded Facebook content feed allows the user to remain in the app and read the posts, but to comment or *like* a post, the user needs to access the Growin’ Up Healthy Jarjums Facebook page. An acknowledgment of Country and a spoken welcome message are also included on the home screen. The women’s health (*My Health*) menu page includes six buttons, one for each of the women’s health modules: (1) Smoke-free families, (2) Safe drinking, (3) Feeling good, (4) Women’s business, (5) Eating, and (6) Exercising. The *Jarjum’s Health* menu page has the same layout, including six buttons for the children’s health modules: (1) Breathing well; (2) Sleeping; (3) Milestones; (4) Feeding and eating; (5) Vaccinations and medicines; and (6) Ears, eyes, and teeth. Each module, for example, *Breathing well*, includes (1) *Key messages* incorporating perceived threat of illness and benefits of changing health behavior; (2) *Tips* to address barriers to change through reassurance and credible advice; (3) cues to action; for example, “Each time jarjum sees a nurse or GP ask them to have a quick look in bub’s ears to check if there is any infection”; and (4) links to further information, including skills and activities; for example, exercises and healthy recipes to support self-efficacy. The information is presented using small chunks of written information and videos using the same layout in each module.

Figure 1. Examples of Growin' Up Healthy Jarjums app screens: (top, from left) home, women's menu, and children's menu; (above, from left) contacts, Breathing well, and Our health advice (accessed from Breathing well).



Growin' up healthy jarjums acknowledges the Traditional Custodians of the lands we live on. We pay our respects to all Elders, past and present, of all Aboriginal and Torres Strait Islander nations.

Scroll down for deadly tips, videos and more. To comment, like, or post, click on the Facebook page button above.

An important part of breathing well is having healthy lungs clear of infection. A cough will usually get better on its own, but sometimes it can be something more serious and can cause permanent damage to your jarjums lungs.

1. See your doctor if jarjum has a cough that doesn't go away after TWO weeks.

2. See your doctor straight away if your child has signs of a serious infection such as high temperature, persistent cough (longer than 2 weeks), difficulty breathing, very tired, or turns blue or very pale.

3. See your doctor if jarjum has difficulty breathing, wheezing, or coughing at night or in the morning these may be signs of asthma.

4. Keep bub away from second hand smoke. Smoke far away from jarjum (min 10m), wash hands afterwards, and put on a jacket to smoke and then remove it afterwards.

SMS Text Messaging

Alongside the app, the prototype included an SMS text messaging library comprising 112 SMS text messages (Table 3). The SMS text messaging component allows users access to health information regardless of mobile phone type, Wi-Fi access, or digital literacy. The SMS text messages covered the content topics identified by the participants. The SMS text messaging portion of the program is 1-way (unidirectional), other than 3 SMS text messages developed for users who indicate that they want to quit smoking when registering for the program. In total, 23 behavior change techniques from 15 behavior change clusters were incorporated in the SMS text messages (Multimedia Appendix 1).

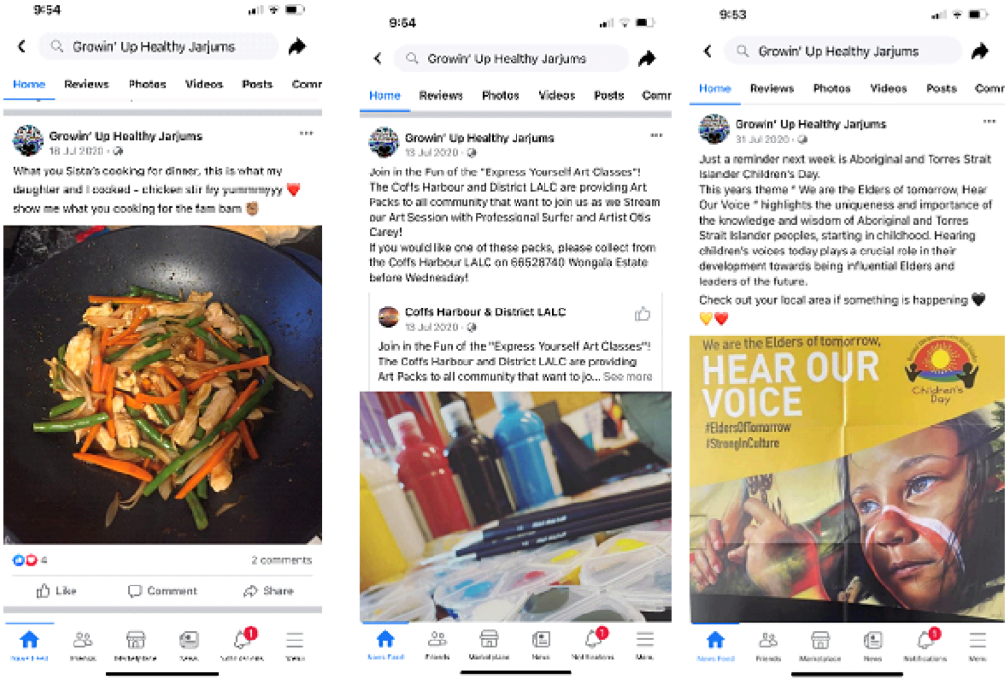
Table 3. Example SMS text messages developed for the Growin' Up Healthy Jarjums modules.

Module	Example SMS text message
Women's health	
Smoke-free families	Text4jarjum: Giving up the smokes is the best thing you can do for your health. Be a role model and be smoke free. Get support from Quitline 13 78 48 or a doctor and quit for good!
Safe drinking	Text4jarjum: While under the influence of alcohol, people can make less safe decisions about their jarjums. Check out 'Safe drinking' for tips to set limits.
Feeling good	Text4jarjum: You're probably not getting much sleep right now. Try to make time for yourself, ask for support from family & friends, and nap when bub does. If you feel that you are not coping, talk to your doctor or midwife. There is help.
Women's business	Text4jarjum: Be kind to yourself. Your body has gone through some big changes during and after birth. It will take time to bounce back. Whether you had a caesarean or vaginal birth, both may require rest & time for recovery. Here's what to expect after birth.
Eating	Text4jarjum: The Australian Breastfeeding Association has some useful tips on nutritional needs for breastfeeding mums.
Exercising	Text4jarjum: Any amount of movement is good for you. Start by doing a little, and gradually build up. You could start with a walk around the block a few times a week and then gradually increase.
Children's health	
Breathing well	Text4jarjum: A cough is often caused by a cold. Usually, a cough gets better on its own and is not serious, but if your child has a cough that doesn't go away after TWO weeks, or if you are concerned sooner – see your doctor or child health nurse.
Sleeping	Text4jarjum: A routine that includes relaxing time like bath, book, a gentle song before bed and a regular bedtime each night can help your child settle better.
Milestones	Text4jarjum: Playgroups, day care and pre-school are great places for jarjums to play and develop. Contact your AMS (Aboriginal Medical Service) or health nurse and find out what's on.
Ears, eyes, and teeth	Text4jarjum: Ear infections are really common and can cause long term hearing loss if not treated. Often there are no signs. Ask your doctor to have quick look in [insert child name] ears each visit to make sure there is no infection.
Vaccinations and medicines	Text4jarjum: Immunising [insert child name] is a safe and easy way to keep jarjums healthy and prevent disease. To check that [insert child name] is up to date with immunisations click here.
Feeding and eating	Text4jarjum: It's recommended you breastfeed exclusively until [insert child name] starts solid foods at around 6 months of age. Keep breastfeeding until at least 12 months and beyond.

Facebook Page

The final modality included in the prototype was the Facebook page. The purpose of the Facebook page was to create community and connection, allow 2-way communication, and use a platform that is highly popular among users. Daily content was designed to be added to the Facebook page, including (1) links to reliable health websites, (2) activities for families, (3) weekly competitions, (4) key messages (written and video), (5) events in the community, and (6) supportive affirmative posts. The page was administered by 2 Aboriginal team members (NS and BH), who shared posts relevant to their community and region. The Facebook page was embedded into the main screen of the app; it could also be accessed through Facebook. Examples of posts are presented in Figure 2.

Figure 2. Examples of the content feed shared on the Growin' Up Healthy Jarjums Facebook page.



Growin' Up Healthy Jarjums
18 Jul 2020

What you Sista's cooking for dinner, this is what my daughter and I cooked - chicken stir fry yummmmyyy ❤️ show me what you cooking for the fam bam

Growin' Up Healthy Jarjums
13 Jul 2020

Join in the Fun of the "Express Yourself Art Classes"!
The Coffs Harbour and District LALC are providing Art Packs to all community that want to join us as we Stream our Art Session with Professional Surfer and Artist Otis Carey!
If you would like one of these packs, please collect from the Coffs Harbour LALC on 66528740 Wongala Estate before Wednesday!

Coffs Harbour & District LALC
13 Jul 2020

Join in the Fun of the "Express Yourself Art Classes"! The Coffs Harbour and District LALC are providing Art Packs to all community that want to jo... See more

Growin' Up Healthy Jarjums
31 Jul 2020

Just a reminder next week is Aboriginal and Torres Strait Islander Children's Day.
This years theme " We are the Elders of tomorrow, Hear Our Voice " highlights the uniqueness and importance of the knowledge and wisdom of Aboriginal and Torres Strait Islander peoples, starting in childhood. Hearing children's voices today plays a crucial role in their development towards being influential Elders and leaders of the future.

Check out your local area if something is happening 🖤💛❤️

We are the Elders of tomorrow,

Discussion

Principal Findings

We codeveloped a prototype mHealth intervention focused on the knowledge of mothers of young Aboriginal and Torres Strait Islander children. The aim of the intervention was to improve health knowledge, health behaviors, and access to health services. The final prototype incorporates 3 modalities—app, SMS text messaging, and Facebook page—and includes a range of health topics. In addition, it is centered on being supportive of mothers and culturally safe.

The modality choices were based on a few factors: (1) early discussions with mothers and health services about the need for an app that is culturally relevant and safe, (2) evidence suggesting that SMS text messaging is the most effective mHealth function for health behavior change, and (3) findings from focus groups and interviews indicating that Aboriginal and Torres Strait Islander women were high users of Facebook and SMS text messaging. As suggested in a recent pilot study of a smartphone app with Aboriginal Australians, a *one app fits all* approach is unlikely to be successful [24]. Using mHealth modalities commonly used by the target group to deliver a health intervention may appeal to more families.

Strengths and Limitations

The first limitation of this research is that it was initiated by a research institution rather than by the community itself. True co-design should begin with completing a needs assessment with communities to see what the health priorities and potential solutions are for that community [38]. This is well described in a New Zealand co-design study [29,40]. To ensure that adequate time and resources are available for relationship building and needs assessment, both should be specified in protocols and funding applications so that sufficient budgets and time frames are allocated. Second, although the intervention covers a range of topics in brief, it does not cover any topic in depth. Although an mHealth intervention with wide-ranging topics seems to be preferred by participants, this may dilute the impact of the intervention on any one risk behavior. Providing links within the *Growin' Up Healthy Jarjums* intervention to specific mHealth interventions for target behaviors may overcome this limitation by providing tips for more intense behavior change for those people who are *ready* to change. Third, because the participants were from only 3 NSW communities, the intervention may have limited generalizability in other Aboriginal and Torres Strait Islander communities. Aboriginal and Torres Strait Islander communities are made up of >250 language groups in which there is great diversity. If this intervention is to expand to other communities, systematic adaptation of the intervention would need to be carried out to ensure that the intervention is suitable to the context of each community [41].

A key strength of this study is that Aboriginal researchers (BH, NS, and BL) led engagement with participants and community organizations. Understanding the importance of trusted and strong cultural relationships, we only engaged with communities that the Aboriginal researchers had a relationship with, which likely resulted in trust as well as interest in participating in this study. Another strength of this study is the thorough reporting of the co-design processes. Inadequate reporting of intervention development was identified as a weakness in a recent systematic review on mHealth development (33). An additional strength is the involvement of primary health services and professionals. A recent review on health promotion programs in Aboriginal communities highlighted that an important consideration is to partner with primary health care services because they are well placed with frequent patient contact, health expertise, and often intricate knowledge of the community [42]. A final and important strength is that we developed a flexible portal for ongoing development and enhancement. The COVID-19 experience has reinforced how important it is to have alternatives to face-to-face health care. Useful additions in future iterations of this mHealth intervention might include development of a flexible platform suitable for inclusion of initiatives inspired by the COVID-19 pandemic, such as subsidized telehealth and videoconferencing. There are also opportunities to develop content on this platform in Aboriginal and Torres Strait Islander languages to better suit users.

Comparison With Prior Work

Design characteristics identified in this study, including *social connection* and *family centeredness*, reflect Aboriginal and Torres Strait Islander perspectives of health. Connection to family, community, and culture, among other factors, are understood to be equal contributors to health [43]. Arabena et al [44] suggest that community and social connection can ultimately be the health promotion intervention for Aboriginal and Torres Strait Islander communities.

The finding that Aboriginal and Torres Strait Islander women were high users of social media, in particular Facebook, was unsurprising. Aboriginal and Torres Strait Islander health organizations have capitalized on the popularity of Facebook among Aboriginal and Torres Strait Islander people and have been early and adept users of social media for health promotion [25]. An Aboriginal-led social marketing campaign for health promotion, *Deadly Choices*, has 94,035 Facebook followers, 19,300 Instagram followers, and 9000 TikTok Followers [26,45].

As stated earlier, the methodologies used in this study were based on a co-design study for a health app with Māori and Pacific Islander people [29,40]. There were a number of similar co-design findings. In both studies, participants expressed a holistic view of health and connections to people and place as being central components of health. Participants in both studies talked about a family approach to health, rather than an individual approach, as well as accessible healthy activities in the community. Social support was found to be an important strategy in both studies.

Culture was also identified as important in both studies, although cultural representation may have been a more nuanced finding in the New Zealand study. In our Australian-based study, participants expressed the importance of Aboriginal and Torres Strait Islander representation in terms of designs, colors, images, people, organizations, and safety. Participants in the New Zealand study [29,40] expressed the need to include Māori knowledge, Whakapono (faith and spirituality), and Whakataukī (traditional proverbs), which were to be woven throughout the intervention; for example, the app depicts the completion of challenges as colored footsteps, which is analogous to the journey that the participants' tūpuna (ancestors) embarked on. There may be differences in participants' connection to culture. In Australia, up to 1 in 3 Aboriginal and Torres Strait Islander children were removed from their families during the period from the mid-1800s to the 1970s. These children are known as the Stolen Generations [39]. Of the 31 mothers in this study, 6 (19%) reported that they had family members from the Stolen Generations, whereas 13 (42%) were unsure. The effect of the Stolen Generations on the loss of culture is profound [39] and is likely reflected in the findings of this study. This intervention may, in a small way, help to promote culture through links to Aboriginal and Torres Strait Islander organizations, connection to mothers of Aboriginal and Torres Strait Islander children, and culturally safe health information.

Conclusions

An mHealth intervention that included app, SMS text messaging, and Facebook page modalities was developed based on co-design findings. The intervention incorporates health behavior change theory, evidence-based information, and the preferences of Aboriginal and Torres Strait Islander women and health professionals. The next step of this research is to assess the acceptability and feasibility of the intervention in a pilot study. The pilot study will be conducted with the Aboriginal Health Services and NSW Health sites that participated in this co-design study. Participating mothers will also be invited to participate in the pilot study. If the *Growin' Up Healthy Jarjums* intervention is shown to have adequate acceptability and feasibility, the next phase will be to measure its effectiveness in improving health knowledge and changing health behaviors. Assessing the effectiveness of this intervention will provide valuable evidence for the use of mHealth in improving the health and well-being of Aboriginal and Torres Strait Islander populations and contribute to the evidence for using co-design methodologies, both of which have been highlighted as gaps in the literature [46].

Acknowledgments

The authors would like to acknowledge and pay their respects to the Aboriginal and Torres Strait Islander women who shared their views and knowledge in the study. The authors would also like to acknowledge the Aboriginal Community Controlled Health Services that participated in the study (Armajun Aboriginal Medical Service [AMS], Galambila AMS, Awabakal AMS, Kulai Aboriginal preschool, and Muloobinba Aboriginal Corporation) as well as the New South Wales Health sites that participated (Aboriginal Maternal and Infant Health Services located in Inverell, Coffs Harbour, and Newcastle). The authors wish to thank researchers from the National Institute for Health and Innovation, Auckland University, Auckland, New Zealand, for sharing expertise on mobile health and Sam McCrabb for coding behavior change techniques.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Behavior change techniques in SMS text messages.
[DOCX File , 15 KB-Multimedia Appendix 1]

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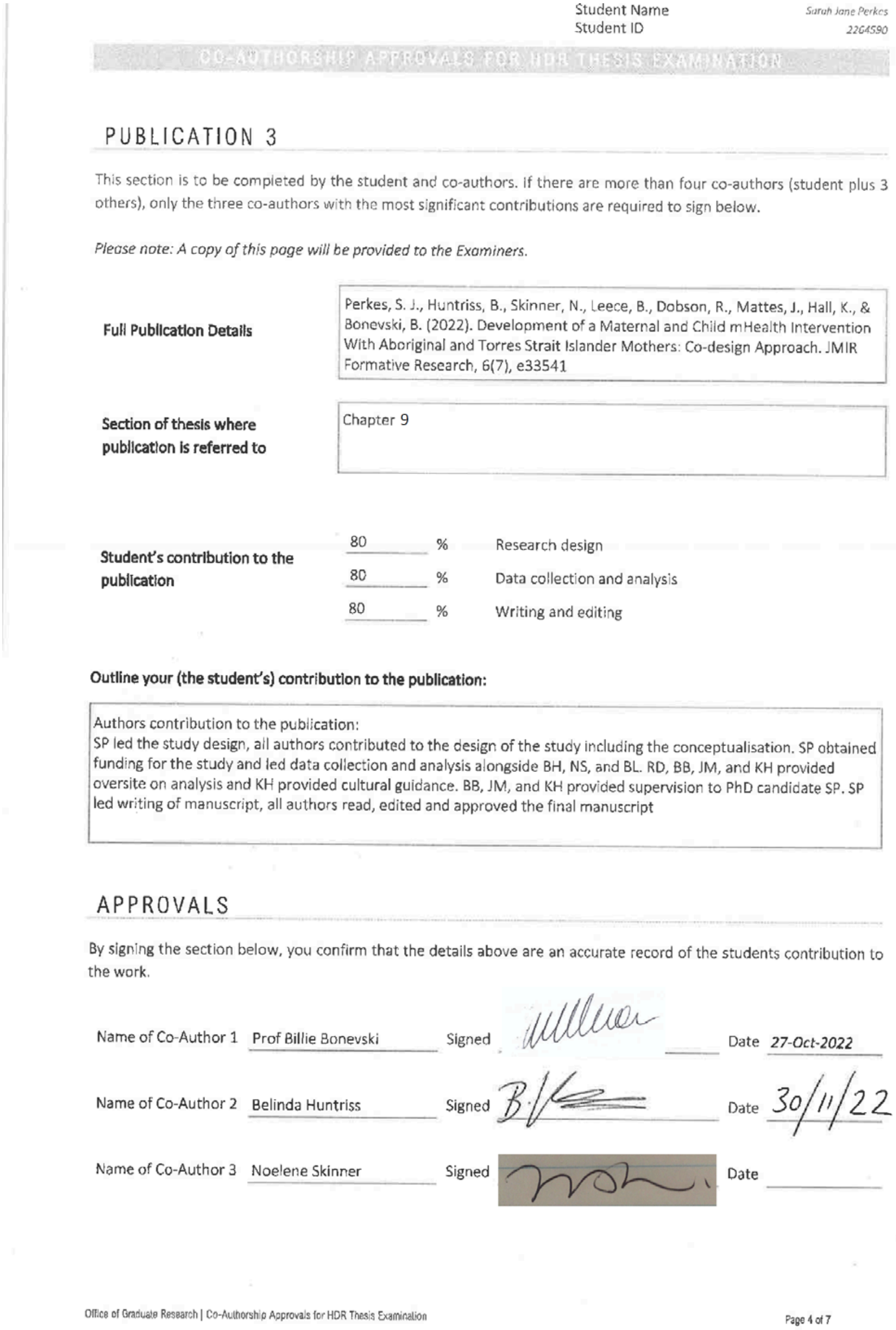
Abbreviations

AMS: Aboriginal Medical Service
mHealth: mobile health
NSW: New South Wales

Edited by A Mavragani; submitted 28.10.21; peer-reviewed by U Bork, C Baxter; comments to author 02.01.22; revised version received 16.03.22; accepted 18.03.22; published 08.07.22

Please cite as:
Perkes SJ, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B
Development of a Maternal and Child mHealth Intervention With Aboriginal and Torres Strait Islander Mothers: Co-design Approach
JMIR Form Res 2022;6(7):e33541
URL: https://formative.jmir.org/2022/7/e33541
doi: 10.2196/33541
PMID: 35802404

Appendix 15 – Co-authorship approval for Chapter 9 manuscript



Student Name Sarah Jane Perkes
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CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 3

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details: Perkes, S. J., Huntriss, B., Skinner, N., Leece, B., Dobson, R., Mattes, J., Hall, K., & Bonevski, B. (2022). Development of a Maternal and Child mHealth Intervention With Aboriginal and Torres Strait Islander Mothers: Co-design Approach. JMIR Formative Research, 6(7), e33541

Section of thesis where publication is referred to: Chapter 9

Student's contribution to the publication	80	%	Research design
	80	%	Data collection and analysis
	80	%	Writing and editing

Outline your (the student's) contribution to the publication:

Authors contribution to the publication:
SP led the study design, all authors contributed to the design of the study including the conceptualisation. SP obtained funding for the study and led data collection and analysis alongside BH, NS, and BL. RD, BB, JM, and KH provided oversite on analysis and KH provided cultural guidance. BB, JM, and KH provided supervision to PhD candidate SP. SP led writing of manuscript, all authors read, edited and approved the final manuscript

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 Prof Billie Bonevski Signed Date 27-Oct-2022

Name of Co-Author 2 Belinda Huntriss Signed Date 30/11/22

Name of Co-Author 3 Noelene Skinner Signed Date

Office of Graduate Research | Co-Authorship Approvals for HDR Thesis Examination

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Appendix 16 – Chapter 10 manuscript

Original Paper

Evaluation of an mHealth Intervention (Growin' Up Healthy Jarjums) Designed With and for Aboriginal and Torres Strait Islander Mothers: Engagement and Acceptability Study

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Abstract

Background: Aboriginal and Torres Strait Islander women have access to and interest in mobile health (mHealth), although few culturally relevant, evidence-based mHealth programs are available. We codeveloped an mHealth program in New South Wales with Aboriginal and Torres Strait Islander women, focusing on women's and children's health and well-being.

Objective: This study aims to assess the engagement with and acceptability of the Growin' Up Healthy Jarjums program among mothers caring for Aboriginal and Torres Strait Islander children aged <5 years and assess the acceptability of the program among professionals.

Methods: Women were given access to Growin' Up Healthy Jarjums—a web-based application, a Facebook (Meta Platforms, Inc) page, and SMS text messages—for 4 weeks. Short videos of health professionals presenting health information were tested within the application and on the Facebook page. Engagement with the application was examined through the number of log-ins, page views, and links used on the application. Engagement with the Facebook page was examined through likes, follows, comments, and the reach of posts. Engagement with the SMS text messages was examined through the number of mothers who opted out, and engagement with the videos was examined through the number of plays and videos watched and duration of the video watched. The acceptability of the program was examined through posttest interviews with mothers and focus groups with professionals.

Results: A total of 47 participants joined the study (n=41, 87%, mothers and n=6, 13%, health professionals). Interviews were completed by 78% (32/41) of the women and 100% (6/6) health professionals. Of the 41 mothers, 31 (76%) women accessed the application, 13 (42%) scrolled the main page only, and 18 (58%) clicked on other pages. There were 48 plays and 6 completions of the 12 videos. The Facebook page received 49 page likes and 51 followers. The post with the most reach was a supportive and affirming cultural post. No participants opted out of the SMS text messages. Almost all mothers (30/32, 94%) reported that Growin' Up Healthy Jarjums was useful, and all mothers reported that the program was culturally appropriate and easy to use. Of the 32 mothers, 6 (19%) mothers reported technical problems with accessing the application. Moreover, 44% (14/32) of mothers suggested improvements to the application. All the women reported that they would recommend the program to other families.

Conclusions: This study demonstrated that the Growin' Up Healthy Jarjums program was perceived useful and culturally appropriate. SMS text messages had the highest engagement, followed by the Facebook page and then the application. This study identified areas for technical and engagement-related improvements to the application. A trial is needed to assess the effectiveness of the Growin' Up Healthy Jarjums program at improving health outcomes.

(JMIR Pediatr Parent 2023;6:e43673) doi: 10.2196/43673

KEYWORDS

mobile health; mHealth; co-design; Aboriginal and Torres Strait Islander; mother; baby; young children; mobile phone

Introduction

Background

Aboriginal and Torres Strait Islander people are the oldest surviving culture in the world [1]. The health of Aboriginal and Torres Strait Islander people changed significantly upon colonization and has continued to be disrupted by subsequent policies [2]. Improving the health and lives of Aboriginal and Torres Strait Islander people is a national priority. Mothers and babies receiving the best possible care and support for a good start to life is 1 of the 12 health priorities of the National Aboriginal and Torres Strait Islander Health Plan 2013-2023 [3]. Providing access to culturally responsive health information and services is an important strategy for achieving this goal [3].

Improving health literacy provides a foundation for individuals and communities to take action to improve their own health [4]. There is limited evidence on effective health literacy programs for Aboriginal and Torres Strait Islander people [5]. A systematic review examining interventions for improving health literacy among Aboriginal and Torres Strait Islander people included 5 studies with the following interventions: exercise classes, nutrition and cooking workshops, discussions and role plays, presentations, other learning activities, incentives, and reduction in the cost of fresh and frozen produce and low-sugar beverages and education at the point of sale [5]. All the included studies demonstrated statistically significant improvements in at least 1 health literacy–related outcome measure, although it should be noted that study quality was compromised because of small sample sizes and poor attendance [5]. More rigorous trials are needed on health literacy programs designed and implemented by Aboriginal and Torres Strait Islander people for Aboriginal and Torres Strait Islander people.

An array of mobile technologies is available to find, share, and generate health information [6]. The major benefit of mobile health (mHealth) is its ability to reach a large number of consumers, including those who cannot attend health services. Aboriginal and Torres Strait Islander women have a high interest in using mHealth [7] but have different preferences for delivery as well as content. Evidence to date shows that Aboriginal and Torres Strait Islander people are frequent users of Facebook (Meta Platforms, Inc) [8-11] and SMS text messaging [12-14] and report high acceptability of, but low engagement with [15], apps, as is often the case universally [16]. Content that centers on culture and frames positive health messages has greater acceptability [9,10,17]. Furthermore, certain delivery mechanisms may be particularly engaging to mothers. A report on Australian women's use of digital health found that women caring for infants and young children were more likely than other women to use social media and web-based forums to share and create health information [8], whereas other studies have found SMS text messaging to have high acceptability among mothers [10,11].

Available mHealth programs for Aboriginal and Torres Strait Islander mothers or their children are limited but growing, including an app, a website, and SMS text messaging on infant feeding [18]; SMS text messaging, videos, and multimedia messaging service for otitis media in children [13]; SMS text messaging, a phone call, Facebook, or an email for postpartum blood glucose screening [12]; a prototype app for social and emotional well-being during pregnancy [19]; and a mindfulness app for women and children of all ages [20]. In the gray literature, the authors are aware of the Deadly Tots app and interactive website on child development [21] and Facebook pages such as Stay Strong and Healthy page for health during pregnancy [21] and Yarn and Heal—Our way for Aboriginal women of all ages to connect and yarn [22]. It is important that we seek to advance mHealth solutions developed by and for Aboriginal and Torres Strait Islander women to promote digital inclusion and access to health information, particularly as it is known that cultural minorities are less likely to use mainstream web-based health technologies [6].

In 2019, we co-designed a multimodality mHealth program for Aboriginal and Torres Strait Islander women's and children's health [23]. The aim of the program was to improve health literacy and health behaviors as well as increase access to health services. Formative research with 31 women and 11 health professionals took place in 3 communities in New South Wales (NSW) and included focus groups with storyboards, card sorting, and design activities [23]. On the basis of the findings from the formative research, we developed a web-based prototype application, an SMS text message library, and a Facebook page, collectively called the Growin' Up Healthy Jarjums (an Yugambeh word used on the East Coast of Australia meaning children) program.

Following a formative research phase, subsequent steps to develop and evaluate mHealth interventions include conducting a pilot study, a randomized control trial, and an evaluation of the implementation impact [24]. The purpose of the pilot study stage is to determine acceptability, improve and refine the intervention, and test the content and regimen early in the research process [24]. Refining the intervention is often an iterative process in each research phase and beyond [24]. Continual improvements to mHealth interventions are important, given the constant upgrades to technology and that long-term engagement with mHealth can be difficult to achieve [25]. We used a pilot study design to evaluate the acceptability of and engagement with the Growin' Up Healthy Jarjums prototype program.

Objectives

The aims of this study were (1) to assess the engagement with the Growin' Up Healthy Jarjums program among mothers (or other women) caring for Aboriginal and Torres Strait Islander children aged ≤5 years; (2) to assess the acceptability of the Growin' Up Healthy Jarjums program among mothers (or other women) caring for Aboriginal and Torres Strait Islander children aged ≤5 years; and (3) to assess the acceptability of the Growin' Up Healthy Jarjums program among health professionals and early educators.

Methods

Project Design

A 4-week pilot study of the Growin' Up Healthy Jarjums mHealth program was undertaken with Aboriginal and Torres Strait Islander women caring for children aged <5 years. Health professionals and early educators from the participating services provided feedback on the intervention in focus groups. Details on the development of the Growin' Up Healthy Jarjums mHealth program can be found elsewhere [23]. The Aboriginal Health and Medical Research Council (AH&MRC) Ethical Guidelines: Key Principles (2020) version 2.0 were used to guide the implementation of this pilot study [26].

Research Team

This research was governed by an Aboriginal advisory board in partnership with Aboriginal organizations (listed in the *Acknowledgments* section) and coled by a Kuku Yalanji and Lama investigator (KH), as well as 2 non-Indigenous investigators (BB and JM). In total, 3 team members were Aboriginal women from (or connected to) the communities where the research took place: a Gumbaynggirr woman (NS), Gomeroi woman in the Kamilaroi Nation (BL), and Worimi woman working in the Awabakal community (BH). The cultural identities of the remaining team members are Macedonian-Australian (BB), German-Australian (JM), Pakeha or European-New Zealand (RD), and European-Australian (SJP). The team has various professional backgrounds: 4 women with Aboriginal lived experience (KH, NS, BL, and BH), a behavioral scientist (BB), a pediatrician and academic (JM), a nurse and public health researcher (KH), an mHealth and public health researcher (RD), an early educator (BH), an Aboriginal health practitioner (NS and BL), and an occupational therapist and PhD candidate (SJP). All team members contributed to the conception of this study. Aboriginal researchers from the participating communities (NS, BH, and BL) led the implementation of the project to support cultural safety.

Participant Sampling

Women aged ≥16 years who were either mothers or primary carers of Aboriginal or Torres Strait Islander children aged birth to 5 years or were pregnant (≥30 weeks' gestation), owned or regularly used a smartphone, and had accessed a participating service (an Aboriginal health service or NSW health service) were eligible to participate. Health professionals from the participating health services and early educators from the participating preschools of all cultural identities who worked with women or children were eligible.

Procedures

This study was conducted remotely from August 2020 to March 2021 using telephone, SMS text messages, and videoconferencing owing to COVID-19 restrictions. Participants were recruited from 3 regional locations in NSW, Australia. A total of 5 Aboriginal organizations (2 Aboriginal health services, 2 Aboriginal preschools, and 1 Aboriginal family and parenting corporation) and 3 NSW health sites participated. In total, 2 Aboriginal researchers (NS and BH) completed most of the recruitment, consent procedures, interviews, and communication with the participants and services in line with the AH&MRC Ethical Guidelines to ensure culturally safe, best practice research procedures *(2.2.3, 2.3.3, 2.5.2, and 3.3.1)* [26].

Women who participated in the co-design phase [23] were contacted via phone and invited to participate in the pilot study. Convenience snowball sampling was also used [27]. The Aboriginal researchers (BH, NS, and BL) used their personal networks to recruit additional participants. The participants were also asked whether they would like to recommend a friend or family member to the study. The participating health services also reached out to potential participants. Potential participants were screened for eligibility when contacted by the researcher via phone. The researcher explained the study and obtained informed consent. The participants were sent an SMS text message with a link to a baseline survey on REDCap (Research Electronic Data Capture; Vanderbilt University) before starting the pilot study. During the 4-week study period, the participants were given access to the intervention (Textbox 1). The participants were sent a link via an SMS text message to access the application, and where possible, the research team contacted the participants to check whether they were able to access the application, explain the use of the application, check whether they were receiving SMS text messages, and explain how to like the Facebook page. The participants were asked to access the application as often as they felt compelled to, that is, there was no required amount of time that women needed to spend on the application or other parts of the program. Following the Facebook page was optional. After 4 weeks, the participants were contacted via telephone for an interview. Semistructured interviews with a mixture of open- and closed-ended questions [28] were conducted by Aboriginal researchers (NS and BH) and a non-Indigenous PhD student (SJP). The interviews were 6 to 25 minutes in length. They were recorded and transcribed, and interview notes were taken as a backup to recordings [28]. The participants were reimbursed with a shopping voucher worth Aus $20 (US $30) at baseline, a shopping voucher worth Aus $10 (US $15) per week for the 4-week pilot study Aus $40 (US $60) in total to cover data use, and a shopping voucher worth Aus $20 (US $30) for participating in the follow-up interview. The interviews were completed between August and September 2020.

Textbox 1. Components of the prototype intervention.

Application

- The application is a central place for users to access all content. The application is primarily for the user who wants in-depth information and has the necessary digital device, internet connection, and literacy skills to access it. The application has four menu screens as follows: (1) home screen, (2) women's health, (3) children's health, and (4) contacts. The Facebook (Meta Platforms, Inc) page content feed was embedded into the home screen. The women's health menu page includes six buttons, one for each of the women's health modules as follows: (1) smoke-free families, (2) safe drinking, (3) feeling good, (4) women's business, (5) eating, and (6) exercising. The Jarjum's Health modules include (1) breathing well; (2) sleeping; (3) milestones; (4) feeding and eating; (5) vaccinations and medicines; and (6) ears, eyes, and teeth. Each topic includes (1) key messages incorporating the perceived threat of illness and benefits of changing health behavior; (2) tips to address the barriers to change through reassurance and credible advice; (3) cues to action, for example, "Each time jarjum sees a nurse or GP ask them to have a quick look in bub's ears to check if there is any infection"; and (4) links to further information, including information regarding skills and activities such as exercises and healthy recipes to support self-efficacy. The information is presented using small chunks of written information and videos using the same layout in each module.

Videos

- A total of 12 videos were developed (1 per topic). The length of the videos ranged from 1 minute and 42 seconds to 5 minutes. The videos included health professionals from the participating sites or contacts of the research team presenting key messages on each health topic. The presenters were given short scripts and encouraged to use their own expertise and experience. The videos were displayed in the application under each topic as well as added to the Facebook feed at least once. The users were able to watch the videos within the application; however, on Facebook, the users were taken to an external Vimeo (Vimeo, Inc) platform to view.

Facebook page

- The purpose of the Facebook page was to create community and connection, allow 2-way communication, and use a platform that is highly popular among users. Daily content was added to the Facebook page, including (1) links to reliable health websites, (2) activities for families, (3) weekly competitions, (4) key messages on the health topics listed earlier (written and video), (5) events in the community, and (6) supportive affirmative posts. The page was administrated by 2 Aboriginal team members (NS and BH), who shared posts relevant to their community and region.

SMS text messaging

- The SMS text messaging component allowed the users access to health information regardless of their mobile phone type, Wi-Fi access, or digital literacy. The SMS text messaging portion of the program was 1 way (unidirectional). The SMS text messages included two core topics: (1) breathing well and (2) smoke-free families, and the participants chose 3 additional topics (from the topics covered in the application). The women received 1 message per day for 5 days per week for 4 weeks (20 SMS text messages in total).

The professionals who participated in the co-design phase were contacted via phone and invited to participate in the pilot study. Where these professionals were no longer working at the service, other professionals known to the Aboriginal researchers were contacted to participate. A total of 2 focus groups were conducted in February and March 2021. Focus groups [28] were conducted rather than individual interviews as per the professionals' preference. Consent was initially obtained over the phone and then again in person, videoconference, or email before starting the focus group. A brief survey was conducted at the start of the focus group. The professionals accessed the program during the focus group only (not during the 4-week pilot study). We were interested in the professional's feedback on the content only, not in how they might engage with the program over 4 weeks, as they were not the target end users. It was important, however, to obtain feedback from professionals who routinely provide health information to mothers, as they may be instrumental to the implementation of the program, if the program is effective. One focus group was conducted in person (as COVID-19 restrictions had been lifted) and another over videoconference. The focus groups were 13 and 21 minutes in length. The professionals were not reimbursed.

Measures

Demographics and Cultural Characteristics

The survey completed by mothers was a 16-item survey including demographic, cultural, and socioeconomic items. The items were selected from a previous study [29], with all items having been tested with Aboriginal and Torres Strait Islander mothers previously. The survey completed by professionals comprised 5 items related to demographic and professional practice characteristics.

Engagement

Objective measures are common for measuring the engagement of applications [30]. The user activity metrics collected included the number of log-ins, number of page views, length of page view, and number of links used on the application. We used user activity metrics in combination with interview data to identify user typologies. Data collected for the videos included the number of plays in total and per video, number of videos watched in full (completions), duration watched (in seconds; mean seconds and percentage), and number of unique videos. Data collected for the Facebook page included the number of posts by administrators, number of page likes, number of comments, number of followers, and the reach of posts and videos. Data were collected on topics that the women chose to receive SMS text messages on and the number of women who opted out of receiving SMS text messages. User engagement was evaluated only for the women participants (end users), not for the professionals.

Acceptability

An interview schedule was adapted from a previous study on the acceptability of a culturally tailored SMS text messaging program for mothers [31]. The interview schedule included the following topics: usefulness of the program, cultural appropriateness of the program, ease of understanding, appropriateness of the program, relevance of the program, perceived impacts, and suggestions for improvements. A shortened and adapted version of the interview schedule was used with professionals, which included items on usefulness and cultural appropriateness.

Data Analysis

The interview data were analyzed and summarized using descriptive quantitative analyses including means, SDs, and proportions [32]. Qualitative comments were analyzed using a simple thematic analysis with predetermined codes based on the research areas, for example, cultural appropriateness [28]. One of the researchers (SJP) cleaned and coded the responses for each predetermined code. Then, 3 researchers (SJP, BH, and NS) reflected on and discussed the participant quotes to form a summary statement for each code and select representative quotes.

Ethics Approval

Human research ethics approval was received from the AH&MRC (1485/19) and University of Newcastle (H-2019-00760).

Results

Overview

A total of 47 participants were recruited for the study: 41 (87%) women and 6 (13%) health professionals. The average age of the women was 31 (SD 7.35) years. The women were from 15 different communities; Kamilaroi (12/41, 29%) and Gumbaynggirr (10/41, 24%) were the most common. Almost half of the women (20/41, 49%) in this study had participated in the co-design phase of the project. The demographic characteristics of the participants are presented in Tables 1 and 2.

Table 1. Demographic and cultural characteristics of women (n=41).

Characteristics	Values
Age (years), mean (SD; range)	31.54 (7.35; 17-50)
Participation in the co-design phase, n (%)	
Yes	20 (49)
No	19 (46)
Not sure	2 (5)
Indigenous status, n (%)	
Aboriginal	34 (83)
Torres Strait Islander	0 (0)
Both	0 (0)
Nonidentified	6 (15)
Unknown	1 (2)
Identified with an Indigenous community, n (%)	
Yes	25 (61)
No	5 (12)
Unknown	11 (27)
Maintain cultural connections at home (yes), n (%)	28 (68)
Ways of connecting to culture, n (%)	
Music or dance	22 (82)
Storytelling	21 (78)
Art	20 (74)
Indigenous television	18 (67)
Food	12 (44)
Indigenous internet sites	12 (44)
Indigenous newspapers	7 (26)
Traditional medicine	5 (19)
Indigenous radio	4 (15)
Other	3 (11)
Family members from the Stolen Generations[a], n (%)	
Yes	14 (34)
No	13 (32)
Unknown	14 (34)
Education of the mother, n (%)	
Did not finish high school	7 (17)
High school	13 (32)
Certificate	11 (27)
Bachelor’s degree	4 (10)
Diploma	3 (7)
Postgraduate degree	2 (5)
Not applicable	1 (2)
Number of people living in household, mean (SD; range)	4.17 (1.72; 1-8)
Number of children (aged <18 years) living in household, mean (SD; range)	2.44 (1.48; 1-6)
Smoking status of the mother, n (%)	

Characteristics	Values
Nonsmoker	31 (76)
Yes, daily	10 (24)
Yes, at least once a week	0 (0)
Yes, less often than once a week	0 (0)
Number of cigarettes smoked per day (on smoking days), mean (SD; range)	10 (4.32; 2-15)
Smoking status of the partner (yes; n=25), n (%)	9 (36)
Number of smokers in household, n (%)	
0	24 (59)
1	14 (34)
>2	3 (7)
Child exposure to indoor tobacco smoke (yes), n (%)	0 (0)
Child exposure to outdoor tobacco smoke (yes), n (%)	7 (17)
Child exposure to tobacco smoke in the car (yes), n (%)	0 (0)

[a] The Stolen Generations refers to a period in Australia's history where Aboriginal children were removed from their families through government policies. This happened from the mid-1800s to the 1970s [33].

Table 2. Demographics of professionals (n=6).

Characteristic	Values
Service type, n (%)	
Aboriginal medical service	3 (50)
Aboriginal preschool	3 (50)
Sex (female), n (%)	6 (100)
Indigenous status, n (%)	
Aboriginal	2 (33)
Torres Strait Islander	0 (0)
Nonidentified	4 (67)
Role at health service, n (%)	
Registered nurse	2 (33)
Midwife	1 (17)
Codirector or early educators	3 (50)
Number of years at service, mean (SD; range)	10.5 (8.8; 1-25)

User Engagement (n=41 Women)

App

Of the 41 women, 31 (76%) participants accessed the application. Among these 31 participants, there were 154 log-ins, with an average of 5 log-ins per person. Of these 31 women, 13 (42%) users scrolled the main page only, and the remaining 18 (58%) users moved past the main page by clicking on other pages. A total of 23% (7/31) of the users clicked on 10 website links.

A total of four user typologies were identified: (1) could not use the app, (2) obligated to use the app, (3) reviewers, and (4) researchers. The "couldn't use the app" group included those who could not log into or download the application. The "obligated to use the app" group included those who used the app to provide feedback in a research context and probably would not use the application in a real-world setting. The "reviewer" group included those who logged in once or twice out of curiosity to see what the application included but did not consistently use the application. The "researcher" group included those who used the application more regularly; they were users who likely wanted more information than available in the SMS text messages or on the Facebook page. By analyzing the user activity metrics, we estimated that 20% (8/41) of the women were "researchers," indicating that they may have long-term engagement with the application in the real world.

Videos

There were 48 plays of the 12 videos (Table 3). The number of plays ranged from 0 for "Milestones" and "Exercise" videos to 11 plays for "Sleeping" video. The number of unique viewers ranged from 1 to 5 per video. The highest number of unique viewers was for the “Feeling Good” video. Among the 48 plays, there were only 6 (13%) video completions. The mean viewing time was 38 seconds. The ability to obtain feedback on the video content may have been limited by the fact that the videos were not watched by most women. One reason for this was that to watch the videos on the Facebook page, the user needed to leave the Facebook page and watch them on an external host (Vimeo [Vimeo, Inc]). Another reason may have been that the videos were not clearly displayed in the application. Finally, the duration of the videos may have been too long.

Table 3. Engagement with the application videos.

Video	Plays (n=48), n (%)	Completions (n=6), n (%)	Viewing time (seconds)[a], mean	Unique viewers, n[b]
Sleeping	11 (23)	1 (17)	22	3
Ear health	9 (19)	1 (17)	77	3
Eating well	7 (15)	1 (17)	6	3
Breastfeeding	5 (10)	1 (17)	115	4
Feeling good	5 (10)	0 (0)	63	5
Women’s business	4 (8)	1 (17)	72	1
Smoke free	4 (8)	0 (0)	11	1
Safe drinking	1 (2)	0 (0)	0	1
Vaccinations	1 (2)	0 (0)	0	1
Breathing well	1 (2)	1 (17)	89	1
Milestones	0 (0)	0 (0)	0	0
Exercise	0 (0)	0 (0)	0	0

[a] Total mean viewing time was 38 (SD 42.2) seconds.

[b] The average number of unique viewers was 2 (SD 1.62).

Facebook Page

Facebook administrators (Aboriginal researchers BH and NS) posted 101 posts over the 4-week pilot study. The page received 49 page likes and 51 followers, indicating reach beyond the study participants. The post with the highest reach was a supportive and affirming cultural post, which reached 308 people and had 17 reactions, comments, or shares. The second most popular post was a competition post, which reached 58 people and had 23 reactions, comments, or shares. The videos posted on Facebook (n=12) had an average of 20 people reach but only 1 to 2 reactions, comments or shares or clicks to watch externally.

SMS Text Messages

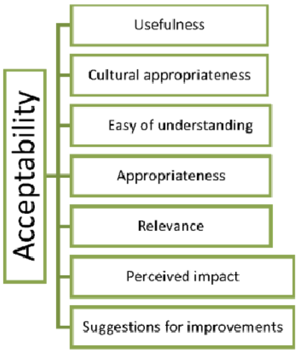
No participants opted out of the SMS text messages. The participants selected 3 topics to receive SMS text messages on. In the order of popularity, the topics chosen were ears, eyes, and teeth (23/41, 56%); sleeping (19/41, 46%); exercising (17/41, 41%); feeding and eating (13/41, 32%); eating (12/41, 30%); women’s business (12/41, 30%); milestones (10/41, 24%); feeling good (10/41, 24%); vaccinations and medicines (6/41, 14%); and safe drinking (0/41, 0%).

Acceptability

Overview

Of the 41 women, 32 (78%) were interviewed at the end of the pilot study. All the 6 professionals were interviewed. There were 7 themes identified in the analysis related to the acceptability (Figure 1).

Figure 1. Themes.



Usefulness

Almost all women (30/32, 94%) reported that the Growin' Up Healthy Jarjums program was useful. On a scale of 1 (a little useful) to 5 (extremely useful), the mean rating of usefulness was 3.9. Furthermore, 84% (27/32) of the women reported that the program was relevant to them.

All women (30/32, 94%) reported that they would recommend the program to other families; the reasons included the following: helpful to first-time mothers, younger mothers, and mothers without family and other supports; ease of having all information in 1 spot; connection with other mothers; provides a sense of community; visually appealing and representative of Aboriginal and Torres Strait Islander people; and an accessible place for women feeling too ashamed or isolated to go the hospital or physician to access reliable health information:

> *I reckon just the feeling of still being connected, and being supported. I think it's a nice way, especially for mums with little, little kids, I reckon sometimes you feel pretty isolated, especially if you're not working and stuff. I think it's a nice way to still feel like someone's looking out for you or thinking of you.* [Participant 6]

> *I think it's a good tool for our community, especially the young ones that we've got who may not have anywhere else to go to find that information or who are too ashamed to ask. I think having it in a way that they can find it themselves in an easy format is a good thing.* [Participant 27]

All professionals (6/6, 100%) reported that the Growin' Up Healthy Jarjums program was useful. On a scale of 1 (a little useful) to 5 (extremely useful), the mean rating of usefulness was 3.3. All the professionals reported that they would recommend the program.

The professionals reported that the program would be useful to families for different reasons. Some of the cited reasons are as follows: the program is relatable to mothers because of co-design methods; using Facebook will result in family and friends seeing the health information; "Storytime" would be good for families that have less access to books; Facebook page was welcoming, easy to access, and visually attractive; the app was easy to navigate and would be easy for mothers to look through while "on the go"; overall, the program has a good balance of content, including health information, affirmations, and what is on in community; the Facebook page may be a good place for women to get ideas from each other and chat about recommendations from the posts; the Facebook page would be a good place for women to connect and not feel isolated; and the content is largely positive, which is important:

> *I like, on the Facebook page, it gives you a sense of not being so isolated. The Facebook page is a really nice place for Aboriginal mums or families to not feel isolated if they're being recommended all this stuff and things to do outside of their lives, and then there's the affirmations. It's probably a really nice place for them to be especially if they're suffering any mental health or with any isolation in their own lives.* [Participant 6]

Cultural Appropriateness

All the women (32/32, 100%) reported that the program was culturally appropriate. They reported that the colors, graphics, and language used were culturally representative. Of the 32 women, 1 (3%) woman recommended using different languages depending on what community the program is intended for. Another woman who had no exposure to her culture said that it was a helpful way to learn about her culture:

> *I'm Aboriginal, but I only just learnt of my Aboriginality, so I wasn't actually brought up that way [according to her culture]. So it was helpful for me to learn new terminologies and stuff like that.* [Participant 3]

All the professionals reported that the program was culturally appropriate. A total of 33% (2/6) of the professionals commented on the cultural appropriateness of the language in a positive light. Overall, 17% (1/6) questioned whether the language would be difficult for some women to understand. She emphasized the need to ensure that representatives from each community that the program would be used in be involved in developing the content as well as to administer the Facebook page to ensure that the program continues to be relevant to women from different communities:

> *You've got different lingos, different meanings, different sayings that's going to grab attention [in different communities]. When I look through these text messages there are some words in here that I*

> *would think some of our women wouldn't really understand. You actually need the women to do it, they're very different to the workers. They're the ones that are going to give you the right language.* [Participant 1]
>
> *It's all culturally appropriate...the language is really nice. It's really easy to read and interpret. It doesn't have any of those big, yukky words that can be quite clinical.* [Professional 5]

Easy to Understand

All the women (32/32, 100%) reported that the content was easy to understand. They talked about the program being jargon free but not too simplified:

> *It was spoken to you normally, not like all the medical jargon, do you know what I mean? It was understandable and relatable. I think if it's too technical sometimes, it gets overwhelming.* [Participant 20]
>
> *It wasn't dumbed-down. Like some things that we give to Aboriginal families that we get, some of them are so simplified that makes people think that we're stupid, but this wasn't. It was easy to understand, but it didn't make me feel stupid, didn't make me feel bad.* [Participant 27]

Appropriate

Most women (28/32, 88%) reported that the activities and information were appropriate. However, of the 32 women, 1 (3%) woman suggested that the language in the SMS text messages could have been more professional rather than colloquial:

> *We followed what was on those messages each day. We made it a project with our kids because we thought we would see how it would go. My son likes looking at the pictures of it when they've had the Facebook competitions because it was all kids that he knew.* [Participant 27]

Relevance

Most women (27/32, 84%) reported that the program was relevant to them and their family. They said that it was good having other mothers to relate to and access to reliable health information to talk to family about:

> *Just sort of seeing other women with kids and stuff and sort of just having someone to relate to, somebody that's a little bit more similar to me. So you don't feel so alone in what you're kind of going through. Things that you might think are silly or you're a bit shamed to ask anyone. At least the messages address it and then you can see other women on the Facebook page.* [Participant 4]
>
> *I learnt some good stuff. I think the thing I like most about the program for us personally, it allowed me to have conversations with my partner about smoking. With the program I was able to say 'hey I got a text about smoking,' 'do you know this' it meant that it wasn't just me making points. I sort of used the app as the conversation starter.* [Participant 18]

The women who did not find the content relevant to them (2/32, 6%) said that they already knew the information or felt that the information was targeted toward women caring for younger children. Of the 32 women, 2 (6%) women also made comments about some SMS text messages not always being relevant to their family:

> *Some of them [SMS] might not be relevant to me personally, but I think as a community they are. The messaging was consistent, and I think that's really important.* [Participant 6]
>
> *My little boy is older now, he's two. So I felt like a lot of the messages and stuff like that, was more around the newborn stuff. But in saying that, if I had a newborn still, then it would have been more relevant.* [Participant 10]

Perceived Impact

Of the 31 women who commented on the overall positive impact of the program, 22 (71%) women reported that the program had an overall positive impact on themselves and their family. Table 4 presents a summary of the perceived impacts. The most common perceived impact was feeling more supported (21/29, 72%), followed by improvements in knowledge or understanding of child health (13/26, 50%), eating habits (11/29, 38%), and exercise (11/29, 38%). Many women commented on the supportive and affirming aspects that the program provided, including the validation of how hard parenting can be; information that certain health problems, such as ear infections, are common in children (validating that it was not their fault); the feeling that a service cared about their child's health; and the feeling that someone cared about them, which arose because of the reception of regular messages:

> *The favourite text of mine was the reminder that we all have rough days...And that it was okay, I thought you know what, yeah, I am going to take a breath right now, and it is all okay.* [Participant 10]
>
> *It was good to know that there was a service out there that did care I guess or had an interest in my son's health.* [Participant 14]

Other positive impacts that the women discussed included getting their child's ear health checked by a general practitioner, more play with children, spending time together as a family, taking children for hearing and vision tests, more exercise, taking care of themselves, talking to friends and family about quitting or reducing smoking, cooking with children, limiting alcohol, getting their child immunized, improved knowledge of contraception, and improved family eating:

> *Usually I'm the type where I walk to the park and then watch her play. When I read the messages, I'm like, I should actually try with her more, and be more active with her at the park.* [Participant 24]
>
> *I was drinking far too much, it was just a stress handling thing, because we did have a lot of problems, and it was difficult the first couple years. And so,*

> *getting that information, that really helped me to kind of kick that habit and to look at my own lifestyle and stuff.* [Participant 9]

Other women experienced stressful life situations at the time and had competing priorities, limiting the potential impacts of the program.

Table 4. Perceived impact (n=32).

	Participants who responded, n (%)	Participants whose response was yes, n (%)
Overall positive impact	31 (97)	22 (71)
Improvements to your smoking habits (if a smoker)	30 (94)	5 (17)
Family or friend smoking habits (if a smoker)	30 (94)	2 (7)
Child's exposure to second-hand smoke	29 (91)	8 (28)
Positive impact on family eating habits	29 (91)	11 (38)
Positive impact on physical activity	29 (91)	11 (38)
Improvements to knowledge of women's health	28 (88)	8 (29)
Improvements to knowledge of child health	26 (81)	13 (50)
Feeling more supported	29 (91)	21 (72)

Suggestions for Improvements

The most common suggestion for improving the program was to make changes to the application to overcome technical challenges. Of 32 women, at least 6 (19%) experienced technical problems. Difficulty in downloading and saving the web-based application, rather than accessing an Android or iOS (Apple Inc) app, was the main difficulty. Almost half of the women (14/32, 44%) suggested improvements to the application, including making the web-based application an Android or iOS app so that it "looks" like an app, removing the step of saving to the application to home screen, implementing single log in, making navigation simpler, making the application accessible on all phone types, localizing the application to specific communities, and making the application more interactive:

> *I had to log back in and it would take me to the web page. It kept wanting me to resave it to my home screen, but it was already saved to my home screen. I wasn't too sure what was going on there.* [Participant 30]

The next most common suggestion is related to the SMS text messages. A total of 59% (19/32) of the women reported that there was just the right number of SMS text messages, but 38% (12/32) of the women reported that the SMS text messages were too frequent. The women indicated the preferred timing of SMS text messages to be earlier in the day and a preference to have SMS text messages from the same sender phone number for ease of reviewing.

Other suggestions to improve the program overall included suggestion to ensure better tailoring to the child's age as well as suggestions for alternate topics (eg, parenting, toilet training, separation, toddler development, mental development for boys, available services, preschool readiness, allergies, and resources and services specific to Aboriginal people), suggestion to provide less content about smoking, suggestion to provide more links to further information (eg, local mothers' groups), and suggestion to provide to make the program more interactive:

> *If it is targeting under five, some of the information could be more around toilet training, difficulties with separation, entry to preschool, advice on services and stuff, like Koori stuff around.* [Participant 9]

In total, 6% (2/32) of the women talked about web-based groups: 1 woman suggested a Facebook group (rather than a Facebook page) and another suggested a chat group within the application (to discuss specific topics). Moreover, 6% (2/32) of other women talked about the importance of the continuation of the program and the longevity of Aboriginal and Torres Strait Islander health programs in general, as Aboriginal health programs often have short funding cycles and the community is left with a gap:

> *I would have benefited more with the Facebook group if it was an actual group created, because normally you get notifications and stuff when you're in the group and it tells you who's posted what. I probably would have had more interaction with that if that was a constant notification coming up.* [Participant 13]

> *Keep it going. We find sometimes that programs are really good and then they stop. When the funding runs out or it doesn't get approved or whatever it stops and then that's a gap.* [Participant 27]

The professionals suggested several ways to improve the program, including continued involvement of women in the development of the program to ensure that the language and content remain relevant and appropriate, including for families living in regional and remote areas. Another professional suggested that the content should be current and tailored to the age of the child. Another suggested a "search" feature in the application so that families could easily search for the health issue or topic that they are interested in (otherwise, mothers will likely Google health information, which can make it difficult to determine reliable sources). Another suggested more specific steps about how to manage certain illnesses and to include more common childhood illnesses. Another suggested that the application needs to be more interactive, for example, tailored specifically to the child's age, with notifications for activities for that age group or milestones. One other professional suggested forums or private group chats so that discussions are not public, whereas another suggested providing grandparents and other family members access to the program.

Discussion

Principal Findings

Overall, the Growin' Up Healthy Jarjums program was found to have high acceptability. The results indicate that women found the program to be useful, culturally appropriate, and easy to use, and most women reported positive impacts. None of the participants withdrew from the SMS text message portion of the program, which indicated the high acceptability of and engagement with this component. Engagement with the Facebook page was found to be higher than that with the application. Individual users preferred different modes (SMS text message, Facebook page, or application), indicating that a multimodal intervention increases reach. Importantly, this pilot study showed several ways to improve the program, including technical changes to the app.

Similar to other studies with Aboriginal and Torres Strait Islander people, the SMS text message component of this program appeared to have high acceptability and engagement [12-14]. This pilot study provided an additional opportunity to focus on mothers and examine the desired frequency of SMS text messages. The frequency of SMS text messages sent in mHealth trials is often 1 SMS text message per day, although it can vary from multiple SMS text messages per day to weekly SMS text messages [34]. In our study, women were sent 1 SMS text message per day for 5 days of the week over 4 weeks. Most women (19/32, 59%) reported that the frequency was just right, 38% (12/32) of the women reported that the SMS text messages were sent too often, and 3% (1/32) of the women reported that the SMS text messages sent were not enough. This finding is similar to that of another study that reported that 1 SMS text message per day was preferred by the majority (42%), whereas the remaining 58% preferred either more or less frequency [24]. Giving a choice of frequency of either 1 SMS text message per day or 3 SMS text messages per week may be more appealing to users.

The women reported that they liked having a choice of topics for SMS text messages, as this increased relevance. Some women commented on the core (requisite) topics, indicating (1) breathing well and (2) smoke-free families as being irrelevant to them and their families. SMS text messages on smoking cessation and child lung health were requisite based on the original focus of the intervention to promote child lung health, including smoking cessation. The focus on child lung health was based on the call for more culturally appropriate information on childhood coughs [35]. In addition, there is strong evidence that SMS text messages are effective for quitting smoking [36]; thus, we decided to keep the focus on child lung health, including smoking cessation, for the SMS text message portion of the pilot. Furthermore, many of the SMS text messages were targeting the first 2 years of life, as that was the age range in which we expected to recruit most children; however, many of the children were older, which meant that some of the information was not relevant, although most women commented that they could see how beneficial the information would have been when their children were young. Encouragingly, the number of women who reported the SMS text messages to be irrelevant was low (3/30, 10%), similar to another study on SMS text messages for new mothers (6/22, 21%) [31]; however, giving users the choice of all topics may be a more acceptable and useful approach allowing for better tailoring to end users' health information needs and interests.

Many participants experienced technical challenges in accessing the app, with nearly one-fourth (10/41, 24%) having been unable to access it. The prototype application used in the pilot study was a web-based application. A web-based application is accessed through an internet browser, such as Google Chrome (Google LLC) or Firefox (Mozilla Foundation), and is essentially a website designed to look like an Android or iOS app. Android or iOS apps are downloaded from an app store and saved on the phone [37]. The benefits of web-based applications are that they are fast to build, they are cost-effective, and their content can be changed easily [37]. The benefits of Android or iOS apps are that they are faster than web-based applications; they can work without internet connection; and end users are generally more familiar with them, including with downloading and saving them [37]. Using a web-based application for this trial resulted in many women having difficulty logging in and saving the application on their home screen. The women also commented that it did not "look" like an application and that it was slow. Other application trials with Aboriginal and Torres Strait Islander people have largely used Android or iOS apps [15,38-41]. Of these studies, 1 was unable to collect use data for 34% (21/61) of the participants reporting flat batteries, connectivity issues, and other problems [41]. A second study reported technical difficulties for participants with using the "challenge" function and signing in and out, although it was noted that technical challenges did not significantly impact the use for many participants [15]. In a third study, an app was used by clients with a practitioner present, and technical difficulties were reported with an Android emulator to enable compatibility with Windows [40]. The fourth study used the same app as the previous study [40] with a different population; thus, it was also used by clients with a practitioner present, but no technical difficulties were reported [39]. Although many studies evaluating mHealth apps have reported technical challenges, it seems that using a web-based application may have resulted in more users experiencing technical challenges and a more substantial challenge of not being able to log in or save the application. With a large proportion of women having had difficulty accessing the application, most of the feedback on the application was centered on the technical challenges, and there was limited feedback on the content. However, it was useful to discover during this early phase that a web-based application is not feasible. An Android or iOS app will need to be considered before further evaluation with a small group of end users to provide detailed feedback on content and navigation.

In addition to considering the technical barriers to accessing applications, careful consideration must be given to long-term engagement [16]. In a longitudinal study examining the reasons for continued use of mHealth apps, two connected factors were described: (1) users' assessment of the mHealth app (related to the technology and content) and (2) users' persistence of health goals (ie, those who have higher persistence toward reaching their goals appear to have longer engagement with health apps) [16]. The authors concluded that long-term engagement with health apps occurs when there is high user assessment and high persistence toward health goals [16]. With improvements to the technical aspects of the Growin' Up Healthy Jarjums application, we expect to see improvements in initial access and a small increase in long-term engagement, although it is evident that an application is not going to be engaging to all users. Health applications are suggested to be most engaging for users who are younger, are more educated, and have higher levels of eHealth literacy skills [42]. It is also suggested that the use of health applications can improve when support from a clinician or another medical professional is provided [43]. The findings from this pilot would also suggest that those experiencing distressing life situations may find it difficult to engage with a health application, similar to the findings that suggest mental health applications may be more suitable for those with less severe illness [43]. As health applications are likely to continue to improve as technology continually does, engagement with health applications will also improve. However, at this point in time, it seems apparent that mHealth tools should be provided in a range of delivery modes to increase reach, digital inclusivity, and equity.

One such delivery mode is social media. It has been established that Aboriginal and Torres Strait Islander people are avid users of social media, Facebook in particular [8-11], which is a key reason why a Facebook page was part of the Growin' Up Healthy Jarjums program. The qualitative findings from our pilot suggest that the Facebook page had high acceptability. The women commonly reported that they valued the connection and seeing what other families were doing. It can be difficult to track engagement with Facebook using objective data because of privacy measures and the complexity of identifying whether users accessed the page as "observers," rather than more active users, which can be done only by examining page likes, comments, shares, etc [10]. A qualitative study examining social media and health information sharing among Aboriginal and Torres Strait Islander people shed more light on how social media are used for health promotion by identifying six typologies: (1) observer, (2) post sharer, (3) positive supporter, (4) educator, (5) expert, and (6) influencer [10]. Although we do not have the data to compare all typologies with the previous study, our results indicate that mothers were more likely to be "observers," with many women reporting the value of connection and seeing what other families were doing but not often commenting, liking, or sharing posts during the study. Posts that were shared or commented on were more likely to have been posts uploaded by Aboriginal organizations, posts affirming Aboriginal culture, or posts about competitions where a prize could be won. The previous study used a methodology different from the one used in this study, wherein they had participants monitor their social media accounts for health-related content and conducted weekly interviews to explore perspectives and actions on posts. Interestingly, the authors found that users moved between typologies depending on the health topic and how information was provided [10]. In future research on the Growin' Up Healthy Jarjums Facebook page, it may be useful to use a similar methodology with a subset of participants to better understand what and how health information is shared among mothers with young children, as well as how this correlates with changes in health literacy offline; given the high acceptability of and engagement with Facebook among this group of end users, Facebook has great potential to improve health literacy.

Limitations

A limitation of this study was the need to conduct all recruitment and instruction of the program remotely using SMS text messages, links, and phone calls owing to COVID-19 restrictions. In the initial protocol, we proposed recruiting women, setting up the app, and providing instructions on how to use the application in person to reduce technical problems. Unfortunately, this was not possible, and women experienced a high number of technical problems. With a large proportion of women having had difficulty accessing the application, most of the feedback on the application was centered on the technical challenges, and there was limited feedback on the content; however, it was useful to discover during this early phase that a web-based application is not feasible. An initial in-person setup would be considered important for further use of the program.

Another limitation of this study is that generalization to other communities is limited. Aboriginal and Torres Strait Islander communities are made up of many diverse cultural and language groups [1]. Each community has a unique history, cultural practices, and health needs. The Growin' Up Healthy Jarjums program would need to be adapted, including by making changes to language, images, and health advice, to ensure cultural safety and relevance to women from other communities.

Conclusions

This study demonstrates that the Growin' Up Healthy Jarjums program was perceived as useful and culturally appropriate by users and health professionals. The SMS text messages had the highest engagement, followed by the Facebook page and then the application. This study identified suggestions for improving the application. A trial is needed to assess the effectiveness of the Growin' Up Healthy Jarjums program at improving health outcomes.

Acknowledgments

The authors would like to acknowledge and pay their respects to the Aboriginal and Torres Strait Islander women who shared their views and knowledge in the study. They would also like to acknowledge the Aboriginal Community Controlled Health Services that participated—Armajun Aboriginal Medical Service (AMS), Galambila AMS, Awabakal AMS, Kulai Aboriginal preschool, and Muloobinba Aboriginal Corporation—and the New South Wales health sites that participated—Aboriginal Maternal and Infant Health Services located in Inverell, Coffs Harbour, and Newcastle. Furthermore, the authors would like to acknowledge the incredible graphic designs completed by Krystal Randall of Culture, Art and Digital Design. Finally, the authors thank the researchers from the National Institute for Health and Innovation, Auckland University, for sharing their expertise on mobile health.

Conflicts of Interest

None declared.

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Abbreviations

AH&MRC: Aboriginal Health and Medical Research Council
mHealth: mobile health
NSW: New South Wales
REDCap: Research Electronic Data Capture

Edited by S Badawy; submitted 19.10.22; peer-reviewed by V Kerrigan, M Cozad; comments to author 20.01.23; revised version received 17.03.23; accepted 30.03.23; published 26.05.23

Please cite as:
Perkes SJ, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B
Evaluation of an mHealth Intervention (Growin' Up Healthy Jarjums) Designed With and for Aboriginal and Torres Strait Islander Mothers: Engagement and Acceptability Study
JMIR Pediatr Parent 2023;6:e43673
URL: https://pediatrics.jmir.org/2023/1/e43673
doi: 10.2196/43673
PMID:

Appendix 17 – Co-authorship approval for Chapter 10 manuscript

Student Name Sarah Jane Perkes
Student ID 2264590

CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 4

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	**Perkes SJ**, Huntriss B, Skinner N, Leece B, Dobson R, Mattes J, Hall K, Bonevski B. Evaluation of an mHealth intervention (Growin' Up Healthy Jarjums) designed with and for Aboriginal and Torres Strait Islander mothers: engagement and acceptability study. JMIR Pediatrics and Parenting. 2023;6:e43673. https://doi.org/10.2196/43673
Section of thesis where publication is referred to	Chapter 10

Student's contribution to the publication	80	%	Research design
	80	%	Data collection and analysis
	80	%	Writing and editing

Outline your (the student's) contribution to the publication:

Authors contribution to the publication:
SP led the study design, all authors contributed to the design of the study including the conceptualisation. SP obtained funding for the study and led data collection and analysis alongside BH, NS, and BL. RD, BB, JM, and KH provided oversite on analysis and KH provided cultural guidance. BB, JM, and KH provided supervision to PhD candidate SP. SP led writing of manuscript, all authors read, edited and approved the final manuscript.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1	Prof Billie Bonevski	Signed		Date	27-Oct-2022
Name of Co-Author 2	Belinda Huntriss	Signed		Date	30/11/22
Name of Co-Author 3	Noelene Skinner	Signed		Date	

Office of Graduate Research | Co-Authorship Approvals for HDR Thesis Examination

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Appendix 18 – Chapter 11 manuscript

Perkes *et al. BMC Pediatrics* (2020) 20:368
https://doi.org/10.1186/s12887-020-02255-x

BMC Pediatrics

RESEARCH ARTICLE Open Access

Respiratory, birth and health economic measures for use with Indigenous Australian infants in a research trial: a modified Delphi with an Indigenous panel

Sarah Perkes[1*], Billie Bonevski[1], Joerg Mattes[1], Kerry Hall[2] and Gillian S. Gould[1]

Abstract

Background: There is significant disparity between the respiratory health of Indigenous and non-Indigenous Australian infants. There is no culturally accepted measure to collect respiratory health outcomes in Indigenous infants. The aim of this study was to gain end user and expert consensus on the most relevant and acceptable respiratory and birth measures for Indigenous infants at birth, between birth and 6 months, and at 6 months of age follow-up for use in a research trial.

Methods: A three round modified Delphi process was conducted from February 2018 to April 2019. Eight Indigenous panel members, and 18 Indigenous women participated. Items reached consensus if 7/8 (≥80%) panel members indicated the item was 'very essential'. Qualitative responses by Indigenous women and the panel were used to modify the 6 months of age surveys.

Results: In total, 15 items for birth, 48 items from 1 to 6 months, and five potential questionnaires for use at 6 months of age were considered. Of those, 15 measures for birth were accepted, i.e., gestational age, birth weight, Neonatal Intensive Care Unit (NICU) admissions, length, head circumference, sex, Apgar score, substance use, cord blood gas values, labour, birth type, health of the mother, number people living in the home, education of mother and place of residence. Seventeen measures from 1-to 6 months of age were accepted, i.e., acute respiratory symptoms (7), general health items (2), health care utilisation (6), exposure to tobacco smoke (1), and breastfeeding status (1). Three questionnaires for use at 6 months of age were accepted, i.e., a shortened 33-item respiratory questionnaire, a clinical history survey and a developmental questionnaire.

Conclusions: In a modified Delphi process with an Indigenous panel, measures and items were proposed for use to assess respiratory, birth and health economic outcomes in Indigenous Australian infants between birth and 6 months of age. This initial step can be used to develop a set of relevant and acceptable measures to report respiratory illness and birth outcomes in community based Indigenous infants.

Keywords: Indigenous, Infant, Respiratory, Measures

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Background

Indigenous Australian children experience unacceptably high rates of respiratory disease [1–4]. Up to 1 in 3 Indigenous infants are hospitalised for acute respiratory infections in their first year of life [5]. Rates of chronic respiratory disease are also high among Indigenous children, including asthma (19.5%), bronchitis (16.8%), bronchiolitis (12.2%), pneumonia (7.2%) and bronchiectasis (1.5%) [6]. Poor respiratory health continues across the lifetime for Indigenous Australians leading to a shorter and poorer quality of life. In 2011–15 there were 1092 respiratory disease deaths among Indigenous Australians (8% of Indigenous deaths), twice the non-Indigenous rate [7].

A combination of social, historical, and cultural contexts contribute to the high, and unacceptable rates of disease [2]. Risk factors include overcrowding, malnutrition, young maternal age, low birthweight, anaemia, poverty, illiteracy, overcrowding, exposure to tobacco smoke and parental smoking [8], pollution, socioeconomic status, social behaviours, cultural exposure, family history, and a history of prior illness [2]. Addressing the social determinants of health will see the greatest reduction in respiratory disease among Indigenous children, though clinical care must be improved simultaneously [2, 9].

Despite respiratory disease being a leading contributor to the total burden of disease among Indigenous children, there is scarcity of community level data [2]. One single urban centre study with 180 Indigenous children under 5 y of age used monthly interviews over 12 months to measure acute respiratory illness [10]. One in five children experienced at least one episode of chronic cough [11]. More than half of the children identified with chronic cough were diagnosed with an underlying lung disease, mostly protracted bacterial bronchitis, asthma and bronchiectasis [11]. A second study in remote Indigenous communities with 651 children under 6 y of age using observations to measure illness reported a point prevalence for cough (acute or chronic) of 39% [3]. In national parent reported data from 2012 to 2013 asthma prevalence is 15% as compared to 9% in non-Indigenous children [12].

As well as limited data, inconsistent measures have been used to capture respiratory illness. There are no standard measures for respiratory symptoms or illness specifically developed for Indigenous children [2]. In research trials, respiratory symptoms are typically collected via parent-reported questionnaires, interviews, or symptom diary cards [13]. Parent-reported measures are valuable and clinically relevant with wide reach at relatively low cost. However parent-report is reliant on accurate recall and health literacy and response rates can be low [14]. Cough is the main outcome collected via parent-report for respiratory illness [13]. Reliability of parent reported cough for children is reported to be good for daytime cough and poor for nocturnal cough [13]. Accuracy of parent reported wheeze is reported to be low [15]. Gold standard measures for detecting respiratory illness are clinical assessment including observation and objective tests such as spirometry and/or x-ray [16], though these measures can be impractical for trials due to the ongoing and fluctuating nature of symptoms as well as being costly, time intensive and burdensome for families.

Culturally safe, effective measures for detecting respiratory illness in Indigenous infants needs further development to improve respiratory health outcomes [2]. Accurate data is vital to enable us to understand the current state of Indigenous infant health, to acknowledge progress, and to determine how to reduce inequalities between Indigenous and non-Indigenous children [17]. There is an entrenched lack of trust from Indigenous Australians in health care professionals and systems [18], medical research [19] due to historical and current policies (including the Stolen Generations) which requires intense consultation with Indigenous leaders, consumers and topic experts to ensure that cultural safety of Indigenous peoples is paramount in research [19]. The purpose of this study was to systematically consult a group of Indigenous academics, clinicians and women on the most accurate, culturally safe, and feasible respiratory health measures for use with Indigenous mothers and infants for a research trial.

Method

Study design

A modified Delphi with an Indigenous expert panel was used. The Delphi method is a culturally acceptable method of gaining consensus and has been used in other areas of Indigenous health research [20, 21]. The consensus process was completed between February 2018 and April 2019. The Delphi technique is a method used to collect opinions from a group of experts to achieve consensus on a particular research question [22]. Repeated questionnaires are used to facilitate independent, gradual and considered opinions [23]. Modified versions involving group discussion may be used where feasibility and operational aspects are solved through group problem solving [24–26]. In this study, discussion was also an opportunity for dialogue on cultural safety considerations. This study was conducted in the context of identifying Australian Indigenous culturally acceptable measures for use in a trial to assess infant respiratory symptoms and illness. The measures would be used to follow up infants born to mothers enrolled in the SISTAQUIT® (Supporting Indigenous Smokers To Assist Quitting) smoking cessation trial (Australian New

Zealand Clinical Trials Registry trials (ACTR N12618000972224).

Participants

An Indigenous expert panel participated in the three round Delphi process and Indigenous women provided feedback on the 6-month surveys. Using a snowball recruitment strategy, a list of 12 potential expert panel members known to study Investigators were invited to participate by email. The 12 potential participants were sent a summary of the study and asked to share the invitation with colleagues. Twenty Indigenous health organisations were also contacted via email and phone and invited to participate. Eight panel members agreed to participate in total. The 8 panel members were emailed the full SISTAQUIT study protocol prior to the first round. Panel members included, 1) Postdoctoral researcher in acute respiratory illness with Indigenous children, 2) Principal Research Fellow in mothers and babies health, 3) representative of HealthInfoNet, 4) Associate Professor at an Indigenous research unit 5) Representative of Indigenous Allied Health Australia (IAHA), 6) Obstetrician, 7) Paediatrician and 8) Representative of The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM). The 8 panel members participated in the each round for each measurement tool, with the exception of 1 participant who did not attend round 1.

Indigenous women (n = 18) were recruited as part of a separate study (unpublished) on resources used for Indigenous women's and child's health. Women were recruited through known networks of Indigenous research assistants in Hunter New England and the Mid North Coast of New South Wales. Women were 16 years or over and mothers of young children.

Description of the modified Delphi method used

A three round modified Delphi with teleconference and two repeat questionnaires was used. An overview of the consensus process is presented in Fig. 1. Round one involved a group discussion with the Indigenous expert panel and rounds two and three used repeat online questionnaires. Feedback from 18 Indigenous women on potential respiratory questionnaires for use at 6 months of age were gathered between rounds two and three.

Review of literature

The lead author (SP) reviewed the literature to identify outcome measures used with Indigenous Australian infants up to 6-months of age. Outcomes of interest were 1) birth outcomes related to adverse impact of exposure to tobacco in-utero (as per broader study), 2) respiratory symptoms and illness, 3) health care utilisation, and 4) developmental outcomes. Keywords were used to search electronic databases including HealthInfoNet, Google Scholar, ScienceDirect, Cochrane Library and CINAHL. Reference lists and grey literature were searched. Known experts in the field were contacted and asked of knowledge on measures used in clinical practice.

Round one: teleconference

The first teleconference was used to provide an overview of the study; and to seek preferences for the Delphi process i.e. online questionnaires or interviews. During this call, participants were also asked to share knowledge on potential measures and were given guidance on the

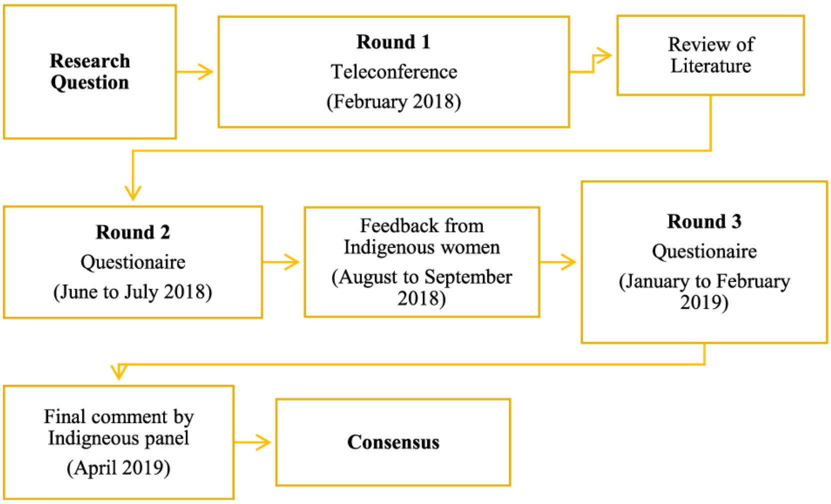

Fig. 1 Overview of consensus process

information required by the panel to support decision-making.

Questionnaire development

The questionnaire of potential outcomes included items on types of outcome measures, mode and frequency of data collection and acceptability of existing surveys for use at 6-months of age. Potential birth outcome measures were derived from a Cochrane review on smoking cessation interventions used during pregnancy [27], acute respiratory symptoms from a survey used in a longitudinal study on respiratory symptoms in Indigenous children [10] and items on health care utilisation from a systematic review and a cost-consequence analysis [28, 29]. Two additional items on breastfeeding and exposure to environmental tobacco smoke were added from the respiratory symptoms survey [10]. Potential questionnaires identified for use from a literature review at 6 months included two respiratory screening tools, 1) a 50-item respiratory questionnaire [30] and 2) an 18-item respiratory adapted into Creole [31] as well as a clinical assessment form developed for the purpose of the larger study. A development screening tool with an adapted version for remote Indigenous communities was also identified [32, 33]. A Respiratory Paediatrician (JM) and Health Research Economist (SD) provided expertise on respiratory health and health care utilisation items respectively.

Round two: questionnaire

An online questionnaire delivered on REDCap software was used. The questionnaire consisted of three sections with 58 items. Participants were also asked for feedback on four existing questionnaires for use at 6 months of age. In total, participants took approximately 30 min to complete. In section one, participants were asked to answer two multiple-choice items. The first to identify measures to be collected at birth including birth weight, gestational age, Apgar score, Neonatal Intensive Care Unit (NICU) admissions, sex, length, and head circumference. The second item to identify how to collect birth information including hospital discharge summary or data linkage. Consensus was pre-determined for multiple-choice items as 80% agreement [25, 34]. Items were included if 80% agreement was reached (7/8 participants selected a measure), items progressed to round three if agreement was between 50 and 80% (4 to 6 participants selected a measure) and omitted if below 50% (less than four participants selected a measure). Two open-ended questions were also included in section one on additional measures to collect at birth and other modes of data collection. Additional items suggested in qualitative responses were added to the round three questionnaire.

In section two, participants were asked to rate respiratory symptoms and health care utilisation items using a 4-point Likert scale (very essential, somewhat essential, non-essential and unsure) as to whether each item should be collected in the trial. As above, consensus was pre-determined as 80% agreement (using 'very essential' only). Items progressed to round three if agreement was 50 to 80% and omitted if below 50%. In the final section, participants were asked for qualitative feedback on 4 potential questionnaires for use at 6-months: two respiratory, one developmental and one clinical assessment form. Qualitative responses were synthesised and used to modify questionnaires.

Feedback from indigenous women

Two focus groups were held by Indigenous research assistants to gain feedback from 18 Indigenous women on two respiratory questionnaires. Both focus groups were conducted in regional areas of New South Wales. The focus groups were part of a separate study on resources used for Indigenous women's and child's health Women were 16 years or older, and were all mothers of young children. Questions used to gather feedback on acceptability include: 1) Are the questions easy to understand? 2) Is the language appropriate? 3) What do you think of the length of the questionnaire? 4) Would you feel comfortable answering this questionnaire? Women provided feedback verbally and in writing. Feedback was used to modify questionnaires.

Round three: questionnaire

The round three survey was sent via email to the panel and took participants approximately 45 min to complete. Additional information was provided as requested by participants in round two to aid decision making. In section one, participants were asked to indicate 'yes' or 'no' for inclusion of additional birth measures added by participants in round two (substance use in pregnancy, cord blood gas values, labour (induction, spontaneous), birth type (caesarean, vaginal), health of mother, number people living in home, education and place of residence). Items were included if 80% agreement was reached (7/8 participants selected a measure) and omitted if below 50% (less than four participants selected a measure). If consensus was not reached a fourth round would have been conducted over phone or email.

In section two, participants were asked to rate respiratory symptoms and health care utilisation items that had not reached consensus in round two using a 4-point Likert scale. A rule was enacted to combine 'very essential' and 'somewhat essential' responses. Items that reached 80% agreement when 'very essential' and somewhat essential' were combined were included. This rule was not pre-determined and enacted due to the timeline of the larger study.

In section three, participants were provided summary points of the qualitative feedback as well as the modified versions of the three questionnaires and asked to indicate 'yes' or 'no' for the acceptability of the modified versions. A space was available for qualitative feedback. The final questionnaires were presented to the panel. If consensus had not been reached a fourth round would have been conducted over phone or email.

Results

Round one: teleconference

Four of the eight panel members attended a group teleconference and three members were interviewed individually by SP. The panel agreed to participating in online questionnaires rather than interviews to increase flexibility in participation for future rounds. The panel recommended qualitative feedback be included as well as the rating of items.

Birth outcomes

Round one: teleconference

Birth outcomes discussed as important included birth weight, small for gestational age, head circumference Apgar score, delivery at less than 37 weeks gestation, stillbirth, NICU admissions and sex. Panel members considered it essential to limit women's burden to answer surveys straight after birth by using discharge summaries or data linkage.

Round two: questionnaire

Seven measures at birth (birth weight, gestational age, Apgar score, NICU admissions, sex, length, head circumference) were presented for consensus. Three items reached consensus and four progressed to round three (Table 1). The panel suggested an additional seven outcomes in qualitative responses including substance use in pregnancy, cord blood gas values, labor type (induction, spontaneous), birth type (caesarean, vaginal), health of the mother, number people living in home, educational attainments of the mother and place of residence. Seven members (> 80%) indicated the best mode of data collection to be hospital discharge summary.

Round three: questionnaire

Twelve items were presented for consensus (Table 1). All 12 items in round 3 reached consensus (Table 1). A total of 15 items were accepted as essential items to collect. (see Additional file 1 for data extraction form).

Round one: teleconference

Panels members were asked to consider the best mode of data collection from the mothers of the infants from one to 6 months of age. Options discussed included phone call, face-to-face, text message, online diary using phone application or weblink. The panel recommended phone calls or face to face (with use of text message to organise time/venue). The panel advised that women were unlikely to use a mobile phone application to report data. The panel recommended gaining feedback from Indigenous women on their preference for the

Table 1 Consensus for birth outcomes

Items	Round 2 ***n*** = 8	Round 3 ***n*** = 8	Consensus
Gestational age	7	–	✓
Birth weight	7	–	✓
NICU admissions	7	–	✓
Length	6	7	✓
Head circumference	4	8	✓
Sex	5	8	✓
Apgar score	5	8	✓
Substance use in pregnancy	–	8	✓
Cord blood gas values	–	8	✓
Labour (induction, spontaneous)	–	8	✓
Birth type (caesarean, vaginal)	–	8	✓
Health of mother	–	8	✓
Number people living in home	–	8	✓
Education	–	8	✓
Place of residence	–	8	✓
Total:	**7**	**12**	**15**

Data collection from one to 6 months of age for respiratory symptoms and health service utilisation modality of data collection i.e. phone call, face-to-face, email, mobile phone application. Options discussed for personnel to collect data included an on-site research facilitator (a volunteer for the service who would be aiding the main trial) or other female health worker with a trusted relationship with the woman. The panel members advised additional information would be required to form a decision on the inclusion of respiratory items and requested input from Respiratory Paediatrician (JM) as required to support decision making.

Round two: questionnaire

Forty-eight items were presented in total for consideration. Five items were presented on how data should be collected (frequency, number of survey questions, modality, personnel to collect data and reimbursement amount) (Table 2). Two items reached consensus, 1) frequency of data to be collect monthly rather than fortnightly and 2) modality of collection for women to choose their preference. Three items progressed to round three (number of survey questions, personnel to collect data, reimbursement amount). Forty-three items were presented on acute respiratory symptoms, health care utilisation, exposure to tobacco smoke and breastfeeding status. Of the 43 items, one item reached consensus (exposure to tobacco smoke). Twenty-eight items progressed to round three and 16 items were omitted (Table 3).

Round three: questionnaire

Thirty-one items were presented in total. Of the three items presented on how data should be collected, number of questions was 5 to 10, site to choose personnel to collect data and site to choose $15 gift card or $15 baby bundle. Of the 28 measures to be collected presented in round three, 17 were accepted (see Additional file 2 for

Table 2 Frequency, number of questions, mode, personnel to collect data and reimbursement

Items	Round 2 ***n*** = 8	Results 3 ***n*** = 8	Consensus
Frequency of data collection:			
Fortnightly	0	–	
Monthly	7	7	✓
Number of questions:			
1 to 5	0	–	
6 to 10	4	5*	✓
11 to 15	1	1	
16 to 20	2	2	
Modality			
Phone call	3	–	
Survey	2	–	
Phone app	2	–	
Email	1	–	
Women's preference	7	7	✓
Women randomised to different modality	1	–	
Who should collect data			
Research facilitator (based on site, Indigenous or non-Indigenous)	6	2	
Indigenous researcher (based at research institution)	5	3	
Non Indigenous researcher (based at research institution)	2	–	
Research facilitator, if not possible, Indigenous researcher	–	3*	
Unsure	1	–	✓
Reimbursement to mother, amount per survey:			
$15 voucher	3	1	
Baby bundle (value of $15)	3	2	
v$10 voucher	1	–	
$5 voucher	0	–	
Research site to choose either $15 or $ baby bundle	–	5*	✓

* Rule enacted, highest frequency accepted if consensus not achieved in Round 3

Table 3 Consensus for outcomes for acute respiratory symptoms, health care utilisation, and exposure to tobacco and breastfeeding status from 1 to 6 months of age

Item	Round 2 ***n*** = 8	Round 3 ***n*** = 8	Consensus
Has your baby had wheeze or whistle in the past 4 weeks?	4	7	✓
Has your baby had a moist or wet cough in the past 4 weeks?	6	7	✓
Has your baby had a dry cough in the past 4 weeks?	6	7	✓
Has your baby had shortness of breath in the past 4 weeks?	4	7*	✓
Has your baby had an earache in the past 4 weeks?	4	7*	✓
Has your baby had a runny nose in the past 4 weeks?	4	7*	✓
Does your baby have a cough today?	6	5*	✓
Have you been worried about your baby's health for any reason in the past 4 weeks?	5	7*	✓
If yes, what have you been worried about?	4	8*	✓
Has your baby been hospitalised in the past 4 weeks?	6	7*	✓
If yes, what were the reasons your baby went to hospital?	5	7*	✓
If yes, how many days was your baby hospitalised?	6	7*	✓
Has your baby been to see a doctor at any time in the past 4 weeks?	5	7*	✓
If yes, what were the reasons?	5	7	✓
Has your baby been given medications in the past 4 weeks?	6	7*	✓
Has exposure to tobacco smoke changed?	7	–	✓
Has breastfeeding changed in the past 4 weeks?	6	8*	✓
Any out of pocket expenses to care for your baby's sickness?	4	3	✗
Has your baby had any feeding difficulties in the past 4 weeks?	4	3	✗
Has your baby had a fever/temp/feel hot in the past 4 weeks?	2	–	✗
Has your baby had chills in the past 4 weeks?	1	–	✗
Has your baby vomited in the past 4 weeks?	1	–	✗
Has your baby had diarrhea in the past 4 weeks?	1	–	✗
Has your baby had irritability in the past 4 weeks?	0	–	✗
Has your baby had increased tiredness in the past 4 weeks?	0	–	✗
Has your baby had unsettled sleep in the past 4 weeks?	0	–	✗
Has your baby had fast breathing in the past 4 weeks?	4	0	✗
How many days has your baby had the cough for?	6	6	✗
Are you worried about your baby's cough becoming worse?	5	1	✗
What is your baby's cough like in daytime?	5	0	✗
What is your baby's cough like in night time?	5	0	✗
Total number of days the baby was in hospital.	3	–	✗
Anything else that affects your family getting health care for your baby?	4	3	✗
If yes, how many times has the baby been to the doctor?	3	–	✗
Total number of days baby was in hospital	3	–	✗
Amount of time spent from work/home to get health care for baby?	3	–	✗
How many hours per week have been spent getting health care for your baby?	1	–	✗
Has your baby been given antibiotics in the past 4 weeks?	6	1	✗
What is the name of the hospital?	0	–	✗
Has any person in the baby's household had a respiratory illness?	2	–	✗
Has your baby seen any other health professional?	5	4	✗
How many times has your baby been to see the health professional?	3	5	✗
Reason (s) baby seen by other health professional	3	7	✗
Total	**43**	**28**	**17**

* Rule of combining 'very essential' and 'somewhat essential' enacted

final version of monthly survey). Five items reached consensus by achieving a response frequency of ≥80% and 12 items reached consensus through enacting the rule to combine votes for 'very essential' and 'somewhat essential'. Items accepted include seven acute respiratory symptoms, two general health items, six items on health care utilisation, one item on exposure to tobacco smoke and one item on breastfeeding status. Additional recommendations from the panel were to provide families and health providers with education on detecting and managing chronic cough, and to ensure adequate follow up of infants with chronic cough.

Measures for respiratory illness and development for 6 months old infants

Round One: teleconference

Five measures were discussed, 1) 50-item parent report respiratory symptom screening questionnaire [30], 2) 18-item respiratory screening questionnaire adapted into Creole [31], 3) a clinical assessment form developed for the purpose of the larger study, 4) Ages and Stages Questionnaire (ASQ) [32] and 5) an adapted version of ASQ for remote Indigenous communities, ASQ-TRAK [33]). Participants were not aware of any other suitable measures or existing surveys.

Round two: questionnaire

Of the five assessments tools, none reached consensus for use in the existing form. Qualitative feedback from the panel recommended a shorter length questionnaire. The questionnaire adapted into Creole language from the Torres Strait was not considered suitable for most Indigenous women. Participants recommended specific language changes or inclusion of definitions for words such as 'posset', 'wheeze' and, 'rattles/ruttles'. Minor feedback was received on the clinical assessment form including a recommendation to ask more broadly about a child's respiratory health and then use prompts for specific respiratory conditions, e.g. bronchitis.

Five of eight participants indicated it was important to collect developmental outcomes at 6 m and five of eight indicated that the ASQ and ASQ TRAK were suitable tools. Key feedback on how the data should be collected included: a health professional should complete it with the woman and infant, the health professional must be familiar with working in Indigenous communities, and the questionnaire should be completed prior to a clinical assessment and the results provided to the clinical assessor.

Feedback from indigenous women Overall feedback from the Indigenous women indicated a preference for the 50-item questionnaire compared to the 18-item questionnaire adapted into Creole. There was an overwhelming consensus to shorten the length and clarify certain terms, such as 'posset' and 'rattly breathing'. Similar to the Indigenous panel, women advised that the Creole language was only suitable for Indigenous people who speak Torres Strait Creole. Women also recommended a simpler layout, particularly if surveys are to be parent completed.

Round three

Based on the feedback gathered from participants, several changes were made to the 6 months of age questionnaires presented in round three. The 50-item questionnaire was reduced to 33- items (see Additional file 3). The clinical assessment form was reduced to one page and included growth parameters, immunisations, respiratory illnesses since birth, other significant illness since birth, and current medications. The clinical assessment form (see Additional file 4) was recommended to be completed with information extracted from the clinical notes and parent report. A consensus from participants, 8/8 (100%), was achieved for use of the three assessment tools in their amended form.

Discussion

A modified Delphi process was completed with eight Indigenous experts, and focus groups were conducted with 18 Indigenous women about culturally safe measures for Infant respiratory health. To our knowledge, this is the first consensus-based study on measures for detecting respiratory illness in Indigenous Australian infants. Measures that reached consensus included 15 measures at birth, 17 measures from 1 to 6 months of age, and three questionnaires to be used at 6 months of age. The preferred mode for data collection differed for the different time points. Consensus was reached that birth measures should to be collected via a hospital discharge summary, 1 to 6 month measures via parent report with mode decided by woman i.e. phone call, mobile phone application, or online survey, and 6 months of age measures collected using parent report questionnaires completed with a trusted health professional in conjunction with clinical notes.

Birth measures had a high rate of inclusion (15/15), which might be due to the standard nature of measures and minimal burden to participating women. In contrast, respiratory symptoms collected on a regular basis were much slower to reach consensus with only five items accepted for inclusion in rounds two and three. The five items were 'wheeze/whistle', 'moist/wet/cough', 'dry cough', 'reasons for seeing a doctor' and 'change in exposure to tobacco smoke'. These are well aligned with the literature. Wheeze is the most reliable symptom to detect asthma [35] and wet cough for bronchiectasis [4, 9, 36]. Seeing a doctor may indicate severity, and exposure to environmental tobacco smoke during infancy doubles the risk of hospitalisation for respiratory illness in infancy [37], so an important variable to collect.

Two potential respiratory questionnaires for use at 6 months of age were presented to the panel It was consistent between the panel and women in the focus groups that Torres Strait Creole is not suitable for most Indigenous women, though a questionnaire with fewer items was preferred. The language of the 50 item questionnaire was largely understood and accepted by women, which is unsurprising as it stems from the ISAA C protocol which has been tested in 97 countries [38]. The 50-item questionnaire was ultimately shortened to 33 items based on feedback. A developmental screening measure, the Ages and Stages questionnaire [39] as well as the adapted version for remote Indigenous communities [33] were also presented to the panel. Interestingly all panel members indicated inclusion of a measure on child development, when not typically measured in studies on respiratory health. The strong interest to include a developmental measure raises the question of what other measures may be important, and perhaps more meaningful to Indigenous communities. Other less commonly reported measures in child respiratory studies include child parent quality of life [40, 41] and child functioning [42].

This study had several limitations. The involvement of Indigenous women was limited. Women participated in one focus group to provide feedback on one type of measure (6 months of age respiratory questionnaires); we did not obtain final feedback from women on changes made to the questionnaire recommended by the expert panel (removal of 17 items). The measures identified in this study may be more confidently used if greater end user involvement had occurred [43]. While we strongly acknowledge the importance of end-user involvement, the focus here was to gain expert consensus from Indigenous academics and clinicians on essential respiratory measures, future studies should place emphasis on pre-testing the identified measures with end-users from a range of communities. A second limitation was that findings may not be generalisable to the diversity of Indigenous peoples of Australia. While panel members were from different regional, remote and urban communities, the number of panel members was relatively small and women were from NSW communities only. The number of participants in a Delphi study is usually 11 to 25, though less than 10 is also common [44]. A third and important limitation was that the measures identified focus on a rather short period in a child's life, birth to 6 months of age. The 6 months age range was of focus as it is the follow-up period of the larger trial. As many chronic respiratory illnesses only develop later in childhood and are uncertain in infancy, e.g. asthma and bronchiectasis, accepted measures for use throughout childhood are needed. Lastly, if further rounds of consensus were completed the number of items may have been reduced, which can result in higher response rates for trials [45]. An important consideration to be examined if pre-testing of measures.

The strength of this study was the engagement of Indigenous experts from several disciplines to work together and identify a comprehensive set of respiratory measures in the context of cultural safety for Indigenous infants. Knowledge was generated with Indigenous academics, clinicians and women to optimise the cultural safety of data collection in a trial examining infant respiratory outcomes. The measures identified are for a number of time points in the first 6 months of life using a range of sources (medical records, parent report and observation). A range of sources is important given the known pitfalls of relying on any one of these sources alone [14].

A modified Delphi process may be a useful method to systematically involve Indigenous people in decisions for trials. The Delphi has been used in other areas of Indigenous health research including to develop mental health guidelines [20] and data collection strategies for maternity experiences [21]. Other high-level consultative methods to develop measures for use with Indigenous people have also been used. A recent example is the development of a survey for the Mayi Kuwayu Study, a national longitudinal study on adult Indigenous Australian well-being [46]. Consultation was completed with 165 Indigenous peoples attending 24 focus groups across Australia from 2014 to 2017. Pilot testing of the survey was completed with 160 and 209 Indigenous participants. A second example is the Healing the Past by Nurturing the Future study, a study in part to develop a measure to identify complex trauma experienced by Indigenous parents [47]. Consultation includes four large-scale co-design workshops across three States with Indigenous parents, service providers, community leaders, researchers and wider community members. Comprehensive consultation is expected from conception to conclusion in research with Indigenous peoples [48]. With varying methods and approaches for consultation, a Delphi methodology is one approach that can provide a systematic, transparent and feasible process for expert consensus in trials.

The Indigenous panel that participated in the consensus process made two important unexpected recommendations that may aid more accurate data collection and increase recruitment and retention in trials. The first was to provide education to participating families and health providers on respiratory symptoms and management pathways. This recommendation aligns with a recent qualitative study with 40 Indigenous community members reporting 70% considered chronic cough normal in children [49]. By providing culturally appropriate definitions on respiratory terms such as wheeze and wet cough, and information on the importance of seeking treatment, the accuracy of parent report may improve and lead to better disease detection and optimal treatment [50]. The second recommendation was to provide adequate follow up of participating infants. Cough guidelines recommend children aged 14 years or less with a chronic cough of 4 weeks should have a chest radiograph and spirometry test (when age appropriate) [51]. In research studies on infant respiratory health, we have opportunity and ethical responsibility [48] to ensure that children receive adequate treatment during and on study completion. Studies designed with a reciprocal approach including assured access to quality treatment may improve retention rates, as in a recent study on incidence of respiratory illness in Queensland [11].

This is a preliminary step in developing a set of standard measures to detect respiratory illness in community based Indigenous infants. Future research is needed to test the validity of the identified measures for use in trials and practice. The 6 month respiratory questionnaire has been found to have good repeatability, though the authors acknowledge that validity testing is needed [30]. We anticipate that results from the larger trial will allow for comparison of self-report to clinical notes which will give indication of validity for certain questions including questions on health service utilisation and diagnosed respiratory illness. To validate questions on acute respiratory symptoms such as runny nose, ear ache, wheeze, shortness of breath, and cough, a comparison to objective measures such as recordings of cough or wheeze, and clinical observation is needed [30]. This is a resource intensive process that may involve twice weekly home visits [52] or potentially video conferencing. While it was not feasible for the measures to be validated as part of this study, the process we undertook in it's development consulting with a range of consumers and stakeholders has contributed to strengthening the tools face validity when used with Indigenous Australians. Additional considerations for testing these measures may include information for families to combat the normalisation of respiratory illness [53], flexible mode of delivery given the many other needs and problems Indigenous families experience [19], and trusted and skilled interviewers to ensure cultural safety.

Conclusions

A modified Delphi process with Indigenous multidisciplinary experts determined culturally safe measures to identify respiratory illness in Indigenous infants from birth to 6 m of age. We set out to develop a set of measures that would meet the needs of families, clinicians and researchers that were culturally safe and feasible. In total, 15 items for birth, 17 items from 1 to 6 months and 3 surveys for use at 6 months of age were identified. Future studies are required to assess the validity and reliability of and participation in surveys using these relevant and acceptable measures.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12887-020-02255-x.

Additional file 1. Birth outcomes data extraction form.

Additional file 2. Acute respiratory symptoms, health care utilisation, and environment monthly survey.

Additional file 3. Respiratory questionnaire for infants (6 months).

Additional file 4. Six-month clinical assessment form.

Abbreviations

IAHA: Indigenous Allied Health Australia; Australian: Indigenous HealthInfoNet; CATSINaM: The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives; NICU: Neonatal Intensive Care Unit; ASQ: Ages and Stages Questionnaire

Acknowledgements

The term Indigenous is used to refer to both Aboriginal and Torres Strait Islander peoples in Australia, with recognition and respect of the autonomy of the two peoples. We acknowledge and give sincere thanks to the Indigenous women, Indigenous research assistants, Delphi panel members and Indigenous organisations that contributed to and mentored us in this process. Women who participated were from Gumbainggir country and Kamilaroi country. Delphi panel members included Dr. Kerry Hall, Dr. Marilyn Clarke, Dr. Sandra Campbell, Associate Professor Maree Gruppetta, Dr. Dennis Bonney, Ms. Kathy Ride (representing HealthInfoNet), Ms. Kylie Stothers (representing Indigenous Allied Health Australia (IAHA)), and Ms. Karel Williams (representing The Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)). This study was developed with the guidance of A/Prof Maree Gruppetta, who passed before this manuscript was developed. We acknowledge her important contribution to this work as a leading Aboriginal academic. We also thank Simon Deeming for his contributions to items on health economics.

Authors' contributions

All authors contributed to the design of the study including surveys used during the study. SP collected and analysed the results and wrote all manuscript drafts. JM provided expertise on respiratory health items. KH provided expertise on respiratory health and cultural guidance. BB, GG, JM, and KH provided supervision to PhD candidate SP throughout study. All authors read, edited and approved the final manuscript.

Funding

This research was funded as part of the NHMRC/Global Alliance for Chronic Disease grant APP1116084. GG was supported by NHMRC fellowships APP1150165, APP1092028 and a CINSW Fellowship. SP is supported by an Australian Government Research Training Program Scholarship and a Hunter Medical Research Institute Greaves Family Top Up Scholarship. Funders had no role in the design of the study, data collection, analysis, interpretation of data or in writing the manuscript.

Availability of data and materials

The datasets supporting the conclusions of this article are included within the article and its additional files. Additional files include:
Additional file 1 Birth outcomes data extraction form
Additional file 2 Acute respiratory symptoms, health care utilisation, and environment monthly survey

Additional file 3 Respiratory questionnaire for infants (6 months)
Additional file 4 Six-month clinical assessment form

Ethics approval and consent to participate

This consultation process was part of a larger study, SISTAQUIT (Supporting Indigenous Smokers To Assist Quitting): a Cluster Randomised Controlled Trial to Improve Strategies for the Management of Smoking Cessation in Pregnant Aboriginal and/or Torres Strait Islander Women. The consultation was approved by The University of Newcastle Human Research Ethics Committee (HREC Ref H-2015-0438) and several other HRECs. The HRECs approved that a committee would be convened to consult on the collection of the infant outcomes, and the recommended outcome measures were later accepted into the protocol by the ethics committees. Ethical approval for participation of Indigenous women in focus groups was obtained as part of a separate study from The University of Newcastle HREC (REF H-2017-0247) and the New South Wales Aboriginal Health and Medical Research Council (AH&MRC) (1303/17) HREC. Written consent was obtained from women.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no financial or non-financial competing interests.

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Received: 18 February 2020 Accepted: 23 July 2020

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Appendix 19 – Co-authorship approval for Chapter 11 manuscript

By signing below I confirm that Sarah Jane Perkes contributed to the design of the study including surveys used during the study, collected and analysed the results and wrote all manuscript drafts to the paper/publication entitled Perkes, S. J., Bonevski, B., Mattes, J., Hall, K., & Gould, G. (2020). Respiratory, birth and health economic measures for use with Indigenous Australian infants in a research trial: A modified Delphi with an Indigenous panel.

Co-authors:

Professor Billie Bonevski,

Date: 15 December 2020

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date 17.12.2020

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[signature of ADRT]

The purpose of this statement is to summarise and clearly identify the nature and extent of the intellectual input by the candidate and any co-authors.

Appendix 20 – Birth outcomes data extraction form

Birth outcomes data extraction form

Participant details and birth outcomes	
Health of mother	
Number or people living in home	
Education attainment of mother	
Place of residence	
Labour (induction/spontaneous)	
Birth type (caesarean, vaginal)	
Substance use in pregnancy	
Gestational age	
Weight (kg) (%)	
Length (cm) (%)	
Head circumference (cm) (%)	
Sex	
Apgar score	
Cord blood gas values	
NICU admissions	

Note: To be extracted from discharge summary and clinical notes.

Appendix 21 – Monthly respiratory survey

Acute respiratory symptoms, health care utilisation & environment infant survey (2,3,4,5,6 month)

1. Has your baby had any of these symptoms in the past 4 weeks (select any that apply)?

a.	Runny nose	☐Yes ☐No
b.	Earache/ear discharge	☐Yes ☐No
c.	Wheeze/whistle	☐Yes ☐No
d.	Shortness of breath	☐Yes ☐No
e.	Moist/wet/gurgly cough	☐Yes ☐No
f.	Dry cough	☐Yes ☐No

If yes (to cough e or f):

1a: Does your baby have the cough today? ☐Yes ☐No

(If yes to "does your baby have a cough today?"

Note to interviewer: send question weekly (day 7, 14, 21, 28) until mother responds "no")

2. Have you been worried about your baby's health for any reason in the past 4 weeks? ☐Yes ☐No

If yes:

2a. What have you been worried about? [open text]

3. Has your baby been hospitalised for any reason in the past 4 weeks? ☐Yes ☐No

3a: How many days was the baby in hospital for (including multiple admissions)? [Open text]

3b: What were the reasons the baby went to hospital (tick any that apply)?

☐ Lower respiratory tract infection (e.g. bronchiolitis, cough, breathing problems, chest infection)
☐ Upper respiratory tract infection (e.g. ear infection, sore throat, 'cold')
☐ Gastrointestinal infection (e.g. vomiting or diarrhoea)
☐ Other (open text)

4. Has your baby been to see a doctor, nurse or any other health professional in the past 4 weeks (not including hospital admissions)? ☐Yes ☐No

If yes:

4a: What were the reasons the baby saw the health professional?

☐ Vaccination/ routine baby health check
☐ Lower respiratory tract infection
☐ Upper respiratory tract infection
☐ Gastrointestinal infection
☐ Other (open text)

5. Has your baby been given any medications in the past 4 weeks? ☐Yes ☐No

6. Has the baby's exposure to tobacco smoke changed in the last month? ☐Yes ☐No

6a: If yes,

☐ No household exposure: household members stopped smoking inside
☐ Less household exposure: household members have reduced smoking inside
☐ More household exposure: (there is more smoking inside)

7. If your baby was being breastfed at the time of the last survey, has breastfeeding type changed?

☐ Yes, gone from fully breastfed to partially breastfed
☐ Yes, stopped breastfeeding completely
☐ No change
☐ Not applicable, baby not breastfed when I completed last survey
☐ Unknown

Appendix 22 – 6-month respiratory questionnaire

Respiratory Questionnaire for infants (6 months)

Questions on wheezing

By "wheezing" we mean breathing that makes a high-pitched whistling or squeaking sound from the chest, not the throat.

1. **Has your child ever had wheezing or whistling in the chest at any time in the past?**

   Yes ☐ No ☐

• If you answered "no" please skip to question 10

2. **How old was your child when he/she first began to wheeze?** Months ___________________

3. **In the last 6 months, has your child had wheezing or whistling in the chest during or soon after a cold or flu?**

   Yes ☐ No ☐

4. **In the last 6 months, has your child had wheezing or whistling in the chest even without having a cold or flu?**

   Yes ☐ No ☐

5. **How many attacks of wheezing has your child had during the last 6 months?**

   None ☐ 1 to 3 ☐ 4 to 12 ☐ More than 12 ☐

6. **Do these attacks cause him/her to be short of breath?**

   Yes, always ☐ Yes, occasionally ☐ No, never ☐

7. Which of these two descriptions fits best your child's wheeze? (tick one only)

My child has only short attacks of wheeze, for example with colds.
In between these attacks, he/she does not normally wheeze ☐

My child wheezes always or a lot of the time. With colds he/she
has attacks with more severe wheeze ☐

8. In the last 6 months, how often, on average, has your child's sleep been disturbed due to wheezing?

Never woken with wheezing ☐
Less than one night per week ☐
One or more nights per week ☐

9. In the last 6 months, how much did wheezing interfere with your child's daily activities?

Not at all ☐
A little ☐
A moderate amount ☐
A lot ☐

---

10. Looking back on the last 6 months, do you think that your child had asthma?

Yes ☐ No ☐

11. In the last 6 months, did your child suffer from rattly breathing (ruttles)?

Never ☐
Only with a cold ☐
Sometimes ☐
Even without a cold ☐
Almost always ☐

12. Does your child attend day care, nursery school or play school?

Yes ☐ No ☐

13. Was your child breastfed?

Yes ☐ No ☐

- If yes, how long:
  - Less than a month ☐
  - 1-3 months ☐
  - 4-6 months ☐
  - More than 6 months ☐

14. During the first 6 months of life, did your child vomit?

Not at all ☐ A little ☐ A lot ☐

15. Has your child ever suffered from any of the following conditions?

• Pneumonia?	Never ☐	Once ☐	More than once ☐
• Whooping cough?	Never ☐	Once ☐	More than once ☐
• Bronchiolitis?	Never ☐	Once ☐	More than once ☐
• Croup?	Never ☐	Once ☐	More than once ☐

16. Has your child had this itchy rash at any time in the last 6 months?

Yes ☐ No ☐

17. In the past 6 months, has your child had eczema?

Yes ☐ No ☐

Questions on ears, nose and throat

18. In the last 6 months, how many times has your child had a cold or flu?

Never ☐
1 - 3 times ☐
4 - 6 times ☐
7 -10 times ☐
More than 10 times ☐

19. How long does a cold usually last in your child?

Less than 1 week	☐
1 to 2 weeks	☐
2 to 4 weeks	☐
More than 4 weeks	☐

20. In the past 6 months, has your child had a problem with sneezing, or a runny, or blocked nose when he/she did NOT have a cold or the flu?

Yes ☐ No ☐

21. Over the past 6 months, has your child snored at night?

Yes ☐ No ☐

- If yes, how often:

Only with a cold	☐
Sometimes even without a cold	☐
Almost always	☐

22. In the past 6 months, has your child had ear infections?

No, never	☐
Yes, once	☐
Yes, more than once	☐

Questions on coughing

23. Does your child usually have a cough with colds?

Yes ☐ No ☐

24. Does your child have a cough even without having a cold?

No, never ☐ Yes, sometimes ☐ Yes, always ☐

25. In the last 6 months, has your child had a dry cough at night, apart from a cough associated with a cold or a chest infection?

Yes ☐ No ☐

Questions on the household and family

26. Does your child have brothers and sisters?

Yes ☐ No ☐

- How many? ____ (please fill in number)
- How many of them have:
  - Asthma or wheezing? ____ (please fill in number)
  - Hayfever? ____ (please fill in number)
  - Eczema? ____ (please fill in number)

27. Has the child's father ever suffered from any of the following conditions?

• Asthma or wheezing?	Yes	☐	No	☐	Don't know	☐
• Bronchitis?	Yes	☐	No	☐	Don't know	☐
• Hayfever?	Yes	☐	No	☐	Don't know	☐
• Eczema?	Yes	☐	No	☐	Don't know	☐

28. Has the child's mother ever suffered from any of the following conditions?

• Asthma or wheezing?	Yes	☐	No	☐	Don't know	☐
• Bronchitis?	Yes	☐	No	☐	Don't know	☐
• Hayfever?	Yes	☐	No	☐	Don't know	☐
• Eczema?	Yes	☐	No	☐	Don't know	☐

29. Which fuel is mainly used for cooking in the home?

Electricity ☐
Gas ☐
Other fuel ☐

30. How do you heat your home? (tick as many as apply)

Central heating ☐
Gas heaters in rooms ☐
Coal or wood fire ☐
Other (electricity, oil) ☐

31. Do you keep any household pets?

Yes ☐ No ☐

• If yes, do you keep any of these pets? (tick as many as apply)

Dog ☐ Cat ☐ Other furry pets ☐ Bird ☐

32. How would you describe the location of your house?

In a street with very dense traffic (main road) ☐
In a street with moderate traffic (residential road) ☐
In a quiet street with little or no traffic ☐

33. Did you have problems understanding this questionnaire?

Yes ☐ No ☐

Please write any comments you have about your child's health or about the questionnaire in the space below:

Appendix 23 – 6-month clinical assessment form

6 Month Clinical Assessment Form

Participant details			
Subject ID (child)		Date	
MAP ID (mother)		Infant's age (months)	
Growth parameters			
Weight (kg) (%)		Head circumference (cm) (%)	
Length (cm) (%)			
Immunisations			
Immunisations (2/12)	☐	Immunisations (4/12)	☐
Immunisations (6/12)	☐		
Respiratory Illnesses since birth (including pneumonia, bronchiolitis, protracted bacterial bronchitis-CSLD, upper respiratory tract conditions, otitis media/effusion)			
Other significant illnesses/surgery since birth :			
Current Medications prescribed (include dose, name of medication, number and timing of doses) (medications may include puffer, steroids, vitamins, antibiotics, traditional medicine or others):			

Note: This clinical assessment is to be completed by a health professional (e.g. nurse, GP or paediatrician) with family member and baby at 6 months (+/- 1 month).It is preferable that the developmental assessment (Ages and stages questionnaire) is completed prior to this clinical assessment and results are provided to health professional prior this assessment (if clinician is different).