Women's Participant Information and Consent Form

This information sheet is for you to keep

Introduction

Thank you for your interest in our study! You are invited to take part in this research project because:

- You, or your partner, have identified as Aboriginal and/or Torres Strait Islander
- You are booked to have your baby at Shoalhaven District Memorial Hospital.

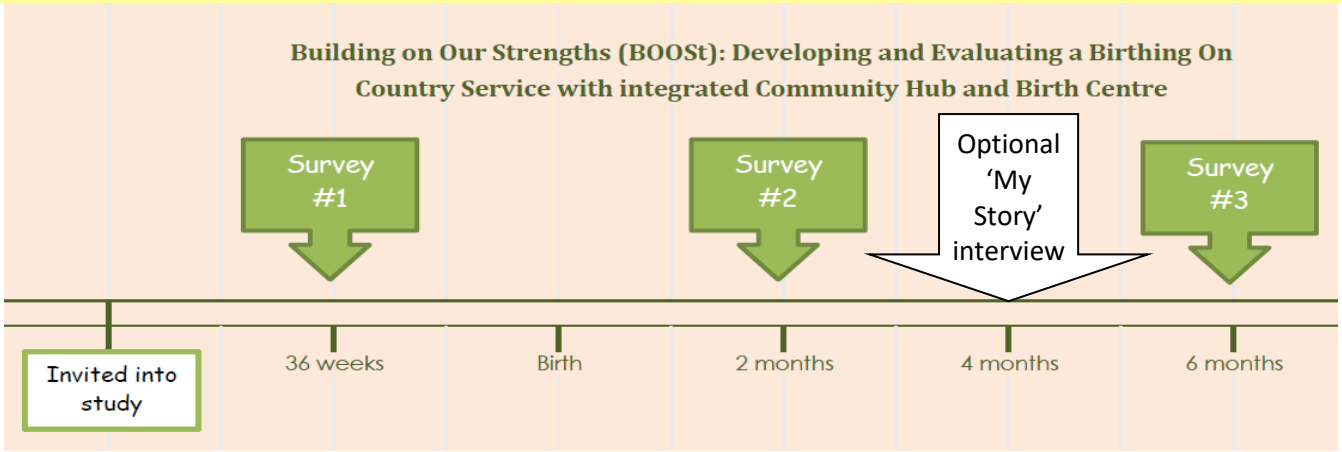
Every woman and pregnancy is different. This is a chance for you to tell your story about your pregnancy journey and help us improve health services for Aboriginal and Torres Strait Islander families.

Your story is important

Your story and experiences are really important to help us to better understand the experiences of Koori women in the Shoalhaven Region. Also, by listening to your experiences, we hope that will help us work with service providers to design and provide maternity care that is better suited to the needs of your community.

To conduct this research we are working in a partnership that is led by key Aboriginal Community Controlled Health Organisations who want to improve maternity services. This is important so that the conduct of the project and the end results of the research reflect the needs and core values of the Community. It also means that the Community owns and controls it.

Your questions are important. Don't be shame to ask any questions.
Please ask any question at any time. Before you decide if you want to be a part of this research, feel free to yarn with a relative, Elder or local health worker. If you do decide to take part, you will be asked to sign a consent form.
Participation in this research is voluntary. If you don't want to take part, you don't have to.
All information you provide is confidential. Your name will be removed from your story. From our records only CDU researchers will know that you participated.



What would being part of this study involve for me?

- **Completing surveys**

You will be asked to complete surveys **3 times** during the study: at about 36 weeks' pregnant, and then again 2 & 6 months following bub's birth.

We will ask you about (for example):

- Pregnancy and maternity care experiences
- Health and wellbeing
- Demographic questions like family background, education, housing
- Life events and worries

Each survey will take approximately **30 minutes** to complete. They can be done face-to-face with an Aboriginal Research Assistant, or you can do it by yourself online on a computer, iPad/tablet, smartphone or on a printed hardcopy. You will receive a **gift card** after completing each survey as a thank you for your time. Also a small gift after completing the 2 month questionnaire.

- **Birth & baby health records**

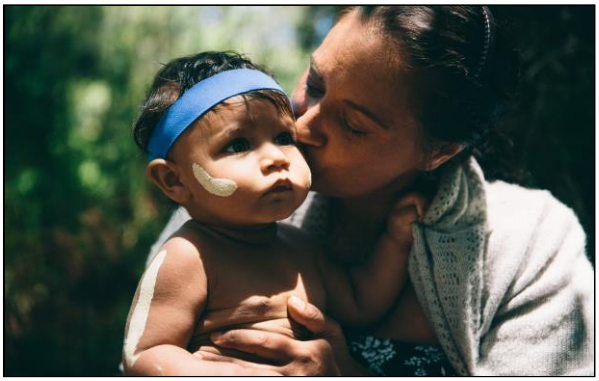
Additional to obtaining your consent for use of your survey data, this consent form includes permission for access to your pregnancy, birth and postpartum records, and baby's medical records (via medical record numbers) (up to 6 weeks postpartum). Both datasets will be joined together then have your name removed, and will only be accessed by research staff.

Who can I contact for further information or to make a complaint?

I understand that if I have any complaints or questions concerning this research project I can contact the principal researcher: Professor Sue Kildea
T: (07) 3169 4262
E: sue.kildea@cdu.edu.au

Or, the CEO of Waminda: Mrs Faye Worner
T: (02) 4421 7400
E: faye@waminda.org.au

Or, the Chairperson of the AH&MRC Ethics Committee; P.O. Box 1565 Strawberry Hills, NSW 2012 T: (02) 9212 4777
This study has been reviewed and approved by the Joint UOW & ISLHD Human Research Ethics Committee. Should you wish to discuss the study in relation to your rights as a participant, or to make an independent complaint, you may contact: UOW Ethics Officer, (02) 4221 3386 or email rso-ethics@uow.edu.au



What happens when this project ends?

This study will end in 2022. We can keep you informed about the study findings by sending you newsletters and/or a summary when we've finished. We will also share our study learnings with health professionals and Indigenous organisations so that they can also work with Aboriginal and Torres Strait Islander (and other Indigenous) families to ensure better care. We do this by presenting findings at conferences, writing papers for academic journals, newspapers/magazines, and posting summary messages on websites and social media channels.

What are the advantages of taking part in this study?

We cannot promise that you will receive any direct benefits from this study. You and everyone who does participate, however, will be helping us learn how to improve maternity care for Aboriginal and/or Torres Strait Islander families in the future. You will receive a **gift card** after completing each survey, and your bubba will receive a small gift to thank you for your time. Interestingly, we know that just the fact that you are taking part in the study can be beneficial because of the positive effects that come from helping out in this way. There may also be some benefit for you in reflecting on your birth experiences.

Are there any disadvantages if I join in this study?

Being in the study will take a bit of time to fill in the 3 questionnaires. We do not think that there are any particular risks to you or your bub if you join in this study, although some of the questions in the surveys might cause you to feel irritated or stressed.

You can skip questions you don't want to answer, and you can also tell us that you would prefer not to answer certain questions.

What will researchers do with the information they collect about me and bubba?

We will store all the information we collect about participants in this study securely at our CDU office in Nowra and it will be treated as confidential. If the information is on forms you or we have filled out, it will be kept in a locked filing cabinet. If the information is in computer files, these will be password protected. Only approved researchers will be allowed to access your information. We will also remove your name and any other identifying details (such as addresses, dates of birth) from the information and replace it with a unique study code so your information will not be identifiable by others. Data will be reviewed every 5 years and any information not needed will be destroyed. The anonymous data from the study may be kept in a data archive for other researchers to use in the future.

Do I have to take part in this research project?

Participation in any research is voluntary.

- If you do not wish to take part, you don't have to
- If you start and then later you change your mind, that's ok. You can withdraw at any time
- Your decision to take part or not will not affect your care, or your relationship with staff
- If you decide to leave the study, we will not collect any further information from you. We will keep any information already collected, which it's not possible to determine has come from you, so that we can report the results of the study.

What else do I need to know?

Who pays for this research? The National Health and Medical Research Council (NH&MRC) – the main funder of health/health services research in Australia.

Who has checked this research study? The aims, plans and approaches of this study have been reviewed and approved by:

- Charles Darwin University Human Research Ethics Committee (HREC) (No. H19054)
- Mater Misericordiae Ltd HREC (EC00332)
- The University of Queensland HREC
- The University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical HREC
- Waminda South Coast Women's Health and Welfare Aboriginal Corporation HREC
- Aboriginal Health and Medical Research Council (HREC)

This project will be carried out according to the *NHMRC Road Map 3: A Strategic Framework for Improving Aboriginal and Torres Strait Islander health through Research (2018)*. The document has been developed to protect the interests of people who agree to participate in human research studies.

Consent Form (Women)

This is yours to keep

I …… (Participant's name) understand the purposes, procedures and risks of this research project and I have:

- read or have had this document read to me in a language that I understand;
- had any questions or queries answered to my satisfaction;
- understood the purposes and procedures of the research project;
- been informed of the possible risks and benefits to participation;
- understood that participation will not affect other care options available to me;
- been informed that the confidentiality of all the information provided and collected will be maintained and safeguarded;
- been assured that I am free to withdraw at any time without comment or penalty;
- agreed to participate in the research project;
- given my permission for the research team to access my pregnancy, birth and postpartum records and my baby's medical records (via medical record numbers) (up to 6 weeks postpartum).

Signatures

Participant: …… Date……

Please also complete the duplicate consent.

Declaration by researcher or representative: I have given a verbal explanation of the research project, its procedures and risks, answered any questions, and I believe that the participant has understood that explanation.

Researcher's name (printed) ……

Signature…… Date……

Withdrawal of Consent Form (BOOSt Women)

If, at any time, you don't want to be part of this study any more, you can tell us. You can talk to us or you can return this form.

I wish to withdraw from participation in the above research project. I understand that this will not affect my care, or my relationships with staff.

Participant Name:_____

Signature:_____Date: _____

In the event that the participant's decision to withdraw is communicated verbally, the researcher should provide a description of the circumstances here:

_____

_____

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher: _____

Signature:_____Date: _____

Please return this form to:

Professor Sue Kildea
E: sue.kildea@cdu.edu.au
Level 11, East Building
410 Anne Street
Brisbane, QLD 4000

or, the CEO of Waminda:
Ms Faye Worner
E: faye@waminda.org.au
122 Kinghorne Street,
NOWRA, NSW 2541

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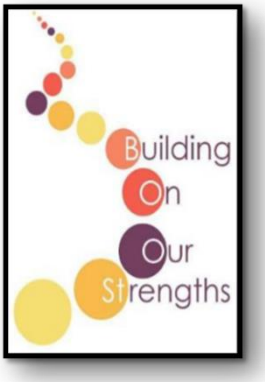
Consent Form (Women)

Please return this copy to the researcher



I …… (Participant's name) understand the purposes, procedures and risks of this research project and I have:

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- understood the purposes and procedures of the research project;
- been informed of the possible risks and benefits to participation;
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Signatures

Participant: …… Date……

Please also complete the duplicate consent.

Declaration by researcher or representative: I have given a verbal explanation of the research project, its procedures and risks, answered any questions, and I believe that the participant has understood that explanation.

Researcher's name (printed) ……

Signature…… Date……

For office use only

Study ID	
Date of birth	
URN	
Recruitment	WAM/SDMH/BB/AMIHS/GP/Other

Please let us know if you would like to receive a summary of the research results, BOOSt e-newsletters, or you would like to be contacted about future research:

I would like to receive a summary of the results of this study after it is finished (>2022)	Yes / No
I would like to receive newsletters about this study (~2/year)	Yes / No
I would like to find out about future studies related to this study	Yes / No

Contact details for receiving surveys, e-newsletters, and/or summary of research results:

Email:	1.
	2.
Current address:	
Suburb & postcode:	
Phone:	1.
	2.

In case you change address, please also provide contact details for your partner, mother, or another relative/close friend

Contact person 1:

Name:	
Relationship to you:	
Current address:	
Suburb & postcode:	
Phone:	1.
	2.
Email:	1.
	2.

Contact person 2:

Name:	
Relationship to you:	
Current address:	
Suburb & postcode:	
Phone:	1.
	2.
Email:	1.
	2.