

## Appendix 3

# **PARTICIPANT INFORMATION SHEET (For Yarning circles)** *THIS IS FOR YOU TO KEEP*

## **SISTASCREEN - First Nations strength-based approaches to increasing cervical cancer screening in pregnancy and postpartum**

Researchers: Associate Professor Marilyn Clarke and Professor Gillian Gould, Faculty of Health, Southern Cross University

### **Eligibility to participate in the research**

You can take part if:

- You are 18 years old and over

AND

- You are an Aboriginal woman, a Torres Strait Islander woman OR a woman who has/having an Aboriginal/Torres Strait Islander baby.

OR

- You are an Elder

OR

- You work closely in a field related to birthing/pregnancy in Aboriginal and/or Torres Strait Islander Peoples (i.e., you are a stakeholder)

### **The aim of the research project**

- To know what you think about the cancer screening services you have used or are involved in both, good and bad, and how we can improve them for women in your community.
- The yarns will provide information on how to support First Nation's women to increase cancer screening interventions.

### **What does participation involve?**

- Participation in this study is voluntary.
- The researchers will explain the study to you.
- If you would like to participate, you will be asked to sign a consent form.
- You will be asked permission for the yarn to be audio-recorded.
- You will also be asked to complete a photo consent form, which is optional. You can choose whether or not to allow photographs of you to be taken and used for research purposes (e.g., presentations, reports, publications, community feedback materials). Your decision will not affect your participation in the study.
- Once you have signed a consent form, you will be asked/supported to fill in a Participant Questionnaire. The questionnaire will not record your name. The information from the questionnaire will help us to know some background information. *[For community participants]* This may include your age, previous pregnancies, number of children, and past cervical cancer screening history.

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*[For health providers]* This may include Aboriginal status, specialty, and years of professional experience. You can answer as many questions as you feel comfortable to answer.

- Participants will be audio-recorded as part of a larger group in a Yarning Circle.
- If you prefer to have an individual yarn, please let the researcher know, and this can be organised.
- You will be asked questions about cancer screening experiences, and services that you used and cultural practices that may be relevant to the study.
- The yarning session will go for about 1 hour, but depending on the group, it may extend beyond that, but no longer than 1.5 hours. Timing will be discussed with the group at the start of the session. You are free to leave at any time during the session.
- Yarning circle community participants will receive a \$50 credit card/voucher per hour to reimburse them for their time.
- You do not have to participate in the study, and if you decline, no further invitations will be made, and you will not be disadvantaged in any way by choosing not to participate.
- You can withdraw from the study at any time and you will not be disadvantaged in any way.
- If you wish to withdraw at any time, you can do so, and take all of your personal information (informed consent, survey form) that has been collected, including a copy of any individual yarns recordings and transcripts.
- You will be asked to provide your consent for the research team to share or use the information collected from you in future research that will be an extension of, or closely related to, the original project; or is in the same general area of research.
- For yarning circle recordings and transcripts, individuals will not be identifiable. Therefore, it will not be possible to return this data to you if you withdraw from the study after completion of the yarning circles.

#### **Confidentiality and Anonymity- How we will keep your information safe**

- You will be asked on your consent form, to agree to keep the identity of all yarning session individuals, the conversation and content of the yarning sessions private and confidential.
- Your personal identity, on recordings in yarning sessions, your survey questionnaire, and your consent form, will be de-identified so that your contributions are anonymous.
- If you have an individual yarn, your recordings and transcript will also be deidentified so that your contributions are anonymous.
- All de-identified data is stored securely in a locked cabinet or on a password-protected hard drive and kept in a secure location at Southern Cross University.
- Only the project researchers can access this information and do so only to analyse the data. Data is kept for just five years and then destroyed.
- Publication and reports from this project will be reviewed by Cancer Australia. Please contact the Project Manager Ms Rebecca Hyland for any further information or to request a withdrawal from the research or for your personal data: 0466 583 559 [Rebecca.Hyland@scu.edu.au](mailto:Rebecca.Hyland@scu.edu.au)

#### **Benefits**

- While there are no Individual benefits to the participants, you will be providing important information for the development of future services to improve the participation of First Nations women in cervical cancer screening. If you wish to receive the results of the

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study, you will have the option to provide us with your email address when you sign the consent forms.

- You will get a \$50 credit card/voucher (First Nations women and Elders) to reimburse you for your time.

**Risks**

Some of the information shared may be sensitive. You are not required to answer any question that makes you uncomfortable, and you may pause or withdraw from the discussion at any time without consequence. If you become upset or distressed because of your participation in the research project and require support, the researchers will facilitate access to appropriate support services. You may also contact the following services at any time:

- Lifeline: 13 11 14 (24-hour telephone support) or text: 0 477 13 11 14
- Health Direct: 1800 022 222
- 13YARN: 13 92 76 (24-hour support for Aboriginal and Torres Strait Islander peoples)
- Beyond Blue: 1300 22 4636
- Connect to Wellbeing (NSW): 1300 160 339
- *[Local health support line (if applicable)]*

<b>Research Project Enquiries</b>	<b>Research project Complaints</b>
<p>A/Prof Marilyn Clarke (Chief Investigator)  <a href="mailto:Marilyn.clarke@scu.edu.au">Marilyn.clarke@scu.edu.au</a></p> <p>Rebecca Hyland (Project Manager)  <a href="mailto:Rebecca.Hyland@scu.edu.au">Rebecca.Hyland@scu.edu.au</a></p>	<p>If you have any concerns or complaints regarding the ethical conduct of the study, you are invited to contact Ethics Administration, Human Research Ethics Committee of AHMRC by email <a href="mailto:ethics@ahmrc.org.au">ethics@ahmrc.org.au</a></p>