

Participant Information Sheet (PIS)

Aboriginal Women participating in a focus groups or interview

We are inviting you to consider taking part in an important research study into understanding experiences and perceptions of Aboriginal women in relation to breast screening in NSW. The study is being conducted by Inside Policy on behalf of the Cancer Institute NSW and BreastScreen NSW.

What is the purpose of this study?

This research will help us learn what is important to our clients so we can improve the quality of our care. The research will also help us understand why some women may not screen regularly and identify what we can do differently to encourage breast screening and make it a positive screening experience.

Why have I been invited to participate in this study?

You have been invited to participate because you have recently had a mammogram through BreastScreen NSW, or you have expressed interest to participate in the study. Your contact details were obtained from you when you contacted Inside Policy and/or engaged with BreastScreen NSW staff members. You indicated that you are of Aboriginal or Torres Strait Islander background (if this is not correct, please contact the research team to have this updated) and you meet the eligibility requirements of this study.

What does participation in this study involve?

The study involves participating in an interview or a focus group (in-person or virtually). Interviews will run for up to 1 hour and focus groups will run for up to 1.5 hours, with the group session involving other Aboriginal women. You may choose to participate in an interview or focus group, unless the research team advises otherwise i.e., there are not enough participants to facilitate a focus group.

The interviewer will ask questions about your general attitudes to health and wellbeing, including your experiences and attitudes towards breast cancer screening and other health services. The research team will take deidentified notes during the session, it may also be recorded (this will be discussed and agreed with you at the commencement of the consultation).

It is just your opinions we are after, there are no right or wrong answers. If you choose to take part, Inside Policy will call you on the telephone number you provided to discuss your involvement further

The study will run from 9 October – 15 December 2023, and you may be contacted during this time. You will be paid for your time and contribution to the research. Focus group participants will receive an \$80 voucher and interview participants will receive a \$50 voucher.

Is participation in this study voluntary?

Yes, participation in this study is completely voluntary. It is entirely up to you whether you decide to take part. Your decision will not affect the treatment or care that you receive at BreastScreen NSW either now or in the future.

If you would like to participate, please complete the online screening survey, or email or call Inside Policy (see contact details below) to register your interest and obtain a copy of the Consent Form. Once registered, a researcher from Inside Policy will be in contact with you to schedule an interview or focus group.

If you are participating in an in-person interview or focus group, please bring your signed consent form with you on the day. Do not worry if you forget to bring your consent form on the day, Inside Policy will have additional copies available for you to complete ahead of participation.

Please note in-person consultations will only be available at select locations. Inside Policy will confirm these details with you when you register your interest.

If you have any questions before you decide whether you want to take part, please contact the Inside Policy team via email at renee@insidepolicy.com.au or tala@insidepolicy.com.au or by phoning 0438 236 417.

Confidentiality

Your responses in an interview or focus group will remain confidential and private. While interviews and focus groups may be recorded to support the collection and write up of information, Inside Policy abides by the Privacy Act and is required by law to remove all identifying information from the data before providing it to the Cancer Institute NSW. Therefore, your name will not be linked to anything you say in the interview or focus group. Information collected from women during this study will only be used for the purpose of this research project to inform quality improvement within the BreastScreen NSW service.

What will the research agency know about me?

If you choose to participate, Inside Policy will be provided with your name, postcode and a telephone number so they can contact you. Inside Policy will also capture information on your breast screening status i.e., have previously had a breast screen, never had a breast screen. You may also choose to share your email address if you would like to receive a copy of the community report to be published by Inside Policy. This information will only be known once you provide relevant information in the survey and/or if you disclose to Inside Policy.

Are there risks to me in taking part in this study?

A key risk associated with participating in an interview or focus group, is that some people may become concerned given the nature of the topic. If you become upset or distressed as a result of your participation in the research project, please contact one of the following support lines:

Organisation	Phone	Details
Beyondblue	1300 22 4636	Call for telephone support, information and resources for people dealing with depression or anxiety or visit their website
Lifeline	13 11 14	Call for this free, 24-hour Australia-wide crisis support and suicide prevention service.
Cancer Council Helpline	13 11 20	Open from 9am-5pm, call for telephone support, information and resources for people dealing with cancer or those who have a loved one affected by cancer.
Breast Cancer Network Australia	1800 500 258	Open 9-5pm, call for telephone support, information and resources for people dealing with breast cancer.

Will I benefit from the study?

While you may not experience any individual benefits from participating in this research, this is an important opportunity for you to have your say about a vital health service in our community. By providing your feedback you will help us learn what is important to our clients so we can improve the screening process for other Aboriginal women using the BreastScreen NSW service in the future.

A summary report of the results will be made available for you to access on the BreastScreen NSW website six months after the research has been completed. Additionally, all Aboriginal women will have the option to receive a copy of the community report (a summarised version of the evaluation report) via email.

What if I want to withdraw from the study?

You can withdraw from the study at any point without reason. If you wish to withdraw from the study once it has started, you can do so by contacting Koorinya Moreton at Inside Policy via email (koorinya@insidepolicy.com.au).

Please note that once the data analysis has commenced you will not be able to remove your data from the research as it will have been combined with the findings from other participants. If you withdraw, it will not affect the treatment or care that you receive at BreastScreen NSW in the future.

Who should I contact for further information?

If you would like any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact Koorinya Moreton (Project Lead, Inside Policy) on 0448 005 685 or via email at koorinya@insidepolicy.com.au or Yan Cheng (Senior Research and Evaluation Officer, the Cancer Institute NSW) on (02) 8374 5682.

Who should I contact if I have concerns or complaints about the study?

This study has been approved by the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee. Any person with concerns or complaints about the conduct of the study should contact the AH&MRC Ethics Committee Chairperson who is the person nominated to receive complaints from research participants.

You can contact them via email ethics@ahmrc.org.au or mail (The Chairperson, AH&MRC Ethics Committee, 35 Harvey Street, Little Bay, NSW 2036) and quote 1906/22.

This study has been approved by the NSW Population & Health Services Research Ethics Committee. Any person with concerns or complaints about the conduct of the study should contact the Ethics Coordinator on 02 8374 5600 and quote 2021/ETH11045.