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Breast screening attendance of Aboriginal and Torres Strait Islander women in the Northern Territory of Australia

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The national population-based breast screening program, BreastScreen Australia, was implemented in 1991 with the objective of reducing breast cancer mortality through early detection of asymptomatic breast cancers using mammography. The target participation rate for biennial screening is 70% of all women aged 50–74 years, with the program having extended the upper target age range from 69 to 74 years from 2013. However, this objective has not been met with rates remaining around 18% to 15% lower than the target since 1996 when uptake data began to be calculated.^{1–3} In addition, inequities between subgroups of women exist with Aboriginal and Torres Strait Islander women, referred to hereafter as Indigenous women, and women living remotely having the lowest rates of attendance at screening and relatively poorer breast cancer outcomes.⁴ The efficacy of breast screening in reducing mortality depends upon adequate population coverage,⁵ therefore improving participation across all groups of women is crucial to effective national cancer control.

The BreastScreen program was implemented in the Northern Territory (NT) in 1994. The NT has the smallest population in Australia dispersed across a geographical area that makes up 17.5% of the country's total land mass.⁶ It has the lowest population density in Australia with the capital city, Darwin, classified as 'outer regional' based on the Australian Statistical Geographical

Abstract

Objective: To compare breast screening attendances of Indigenous and non-Indigenous women.

Methods: A total of 4,093 BreastScreen cases were used including 857 self-identified Indigenous women. Chi-squared analysis compared data between Indigenous and non-Indigenous women. Logistic regression was used for groupings based on visits-to-screening frequency. Odds ratios and 95% confidence intervals were calculated for associations with low attendance.

Results: Indigenous women were younger and had fewer visits to screening compared with non-Indigenous women. Non-English speaking was mainly associated with fewer visits for Indigenous women only (OR 1.9, 95%CI 1.3-2.9). Living remotely was associated with fewer visits for non-Indigenous women only (OR 1.3, 95%CI 1.1-1.5). Shared predictors were younger age (OR 12.3, 95%CI 8.1-18.8; and OR 11.5, 95%CI 9.6-13.7, respectively) and having no family history of breast cancer (OR 2.1, 95%CI 1.3-3.3; and OR 1.8, 95%CI 1.5-2.1, respectively).

Conclusions: Factors associated with fewer visits to screening were similar for both groups of women, except for language which was significant only for Indigenous women, and remoteness which was significant only for non-Indigenous women.

Implications for public health: Health communication in Indigenous languages may be key in encouraging participation and retaining Indigenous women in BreastScreen; improving access for remote-living non-Indigenous women should also be addressed.

Key words: breast cancer, screening, participation, Aboriginal and Torres Strait Islander

Standards Remoteness Areas classification (ASGSRA).⁷ Furthermore, the NT has the highest proportion of Indigenous residents compared to other Australian states or territories, with up to 30% of the population identifying as Aboriginal and/or Torres Strait Islander. Regarding breast screening, the NT consistently has the lowest participation rates in the nation. NT Indigenous attendance is less than half of the national rate (24% vs. 55%, respectively) and the overall NT

attendance (41%) is lower than all states and territories combined.^{2,8} Breast cancer is the most common non-melanoma cancer in Australian women and the number one cancer in NT women.⁸ Therefore, with evidence that screening prevents 43 deaths in 10,000 women screened,⁹ concerted efforts to improve screening attendance are needed. A lower uptake of mammographic screening is not uncommon among Indigenous peoples around the world and the reasons

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for this are multifaceted. While some reasons for non-participation by Indigenous and non-Indigenous women may be similar, cultural beliefs around breast cancer and fatalistic views on health are reported as having significant influence on Indigenous screening behaviours.¹⁰ In addition, systematic barriers to screening are also evident for Indigenous Australians, including geographic isolation, lack of means of transportation to attend services, and a shortage of culturally competent facilitators to screening.^{11,12} Evidence in the US, Canada, Alaska, Pacific Islands, and New Zealand show that Indigenous women are more likely to be underrepresented in breast screening¹³⁻¹⁵ and have higher breast cancer mortality rates compared with non-Indigenous women.¹⁴⁻¹⁶ A similar scenario is reported for Indigenous Australian women who, despite lower breast cancer incidence, have poorer health outcomes and higher rates of death from breast cancer when compared with other Australian women.¹⁷ Australian Indigenous women are also younger and more likely to have advanced tumours at the time of diagnosis compared with non-Indigenous women,¹⁸⁻²⁰ making treatment options limited and the tumours potentially more aggressive. National and local strategies to improve accessibility have been implemented with some success, such as the mobile screening vans that travel to remote communities,²¹ the process of block bookings of appointments for Indigenous women,¹¹ evidence-based and culturally sensitive materials developed by Indigenous health experts,²² and involvement of Indigenous health care workers.²³ Despite these efforts, Indigenous Australians' attendance at screening remains around 16% lower compared with non-Indigenous women (37% vs. 53%, respectively, in 2015).

There is currently limited information on the screening characteristics of women in the NT as they relate to indigeneity and attendance. The aim of the current work is to investigate variables associated with attendance at BreastScreen for women in the NT. With significant differences shown previously between NT women in the screening population,²⁴ a further aim is to measure the variations between Indigenous and non-Indigenous women's screening attendances.

Methods

Data collection

Ethical approval was obtained from the Human Research Ethics Committee (HREC)

of the NT Department of Health and Menzies School of Health Research (HREC 2016-2627). Written consent to use personal information for evaluation and research was collected from women prior to having a screening mammogram and only consenting women's data was made available to researchers. This consent request is written in the client information form routinely collected by BreastScreen NT, a population screening program.

The study was performed retrospectively using a client data sample retrieved from BreastScreen NT. The sample consisted of 4,093 women (857 self-identified as Indigenous and 3,236 reported being non-Indigenous) aged between 40 and 85 years who were screened between 30 March and 24 November 2015. BreastScreen NT sends postal invitations to women aged 50 to 74 years old to attend screening every two years; however, screening is free for women from 40 years of age. Mammograms were performed at permanent screening facilities in the NT in Darwin, Palmerston, and Alice Springs; women located in remote to very remote communities in the NT were screened via the BreastScreen NT mobile bus unit. Digital image files were sent electronically to Sydney Breast Clinic (SBC) in NSW for radiologist interpretation.

Women's radiologist-reported findings and self-reported personal details such as Indigenous status, date of birth, residential address, main language spoken, family history of breast cancer, previous breast cancer, current breast lump, and use of hormone replacement therapy (HRT) in the past six months were stored on the NT Department of Health computerised database. NT Department of Health personnel extracted the data and provided de-identified information to researchers. The number of screening rounds that a woman has attended was generated by the NT database system based on number of entries. Women's residential postcodes were categorised by the researchers based on the ASGSRA classification. In the NT, only three categories are available: outer regional, remote and very remote.

Data analysis

In the first stage of analysis, base-line differences between Indigenous and non-Indigenous women's characteristics and screening attendances were explored. Next, Receiver Operating Characteristics (ROC) curve analyses were employed for number of

visits to screening and ages to determine cut-off points for these variables for Indigenous and non-Indigenous women. Using these cut-off points, chi-squared tests were used to derive odds ratios (OR) and 95% confidence intervals (CI). A *p*-value <0.05 was considered significant.

In the second stage of analysis, we investigated Indigenous and non-Indigenous women separately and focused on potential associations with numbers of visits to screening above and below the cut-off point. Categorical variables such as age group, previous breast cancer diagnosis, family history of breast cancer, main language, geographic remoteness, current breast lump, and case outcome were analysed using chi-squared tests. Logistic regression was used to derive odd ratios (OR) and 95% and confidence intervals (CI). Next, multivariate stepwise logistic regression was performed on variables with univariate significance to determine predictive factors for low screening attendance. Factors with *p* values <0.02 were retained in the model.

BM SPSS® version 24 statistical software was used for the analyses.

Results

Women in this study had visited screening between one and 21 times in their lifetime. That is, for some women, this was their first time attending screening, for those on the highest end of the range it was their twenty-first visit, and other women ranged somewhere in between. Figure 1 displays the proportions of Indigenous and non-Indigenous women according to the number of times they have attended screening.

Table 1 shows that Indigenous women had fewer visits to screening compared with non-Indigenous women with medians of two visits (IQR 1-3) and three visits (IQR 2-7), respectively. Indigenous women were younger than non-Indigenous women with median ages of 54 years (IQR 48-60 years) and 57 years (IQR 52-63 years), respectively.

There was a higher proportion of Indigenous women residing in remote areas (67.7%) compared with outer regional areas (13.3%), and 71.3% of Indigenous women mainly spoke another language at home. In contrast, non-Indigenous women had more than half of the population (56.9%) living in outer regional areas than in remote locations (36.2%), and 84.2% mainly spoke English at home. Both groups of women reported similar experiences with HRT use

and personal and family histories of breast cancer with greater proportions answering negatively. Further similarities were shown in that larger proportions of Indigenous and non-Indigenous women reported no breast lump at screening, and majorities in both groups had normal mammograms at this round of screening.

ROC curve analyses determined that 55 years and 3 visits were the cut off-points for age and frequency of attendance at screening, respectively, as shown in Table 2. Indigenous women were 1.8 times as likely to be under 55 years of age (OR 1.8, 95%CI 1.5–2.0; $p < 0.001$) and more than 3 times as likely to have fewer than 3 visits to screening (OR 3.3, 95%CI 2.8–3.9; $p < 0.001$) than non-Indigenous women.

Table 3 shows the unadjusted results of the two-tailed tests based on screening visits above and below the cut-off point. The following describes the variables associated with low screening attendance (<3 visits). Women were likely to have attended screening less than 3 times if: they were younger than 55 years compared with older women (Indigenous: OR 10.8, 95%CI 7.4–15.7; $p < 0.001$; and non-Indigenous: OR 10.7, 95%CI 9–12.6; $p < 0.001$), had not had a previous breast cancer diagnosis compared with women who had a been diagnosed with breast cancer in the past (Indigenous: OR 7.5, 95%CI 2.0–28.0; $p < 0.001$; and non-Indigenous: OR 2.0, 95%CI 1.2–3.4; $p < 0.05$); live in remote locations compared with non-remote women (Indigenous: OR 1.5, 95%CI 1.1–2.4; $p < 0.05$; and non-Indigenous: OR 1.5, 95%CI 1.3–1.7; $p < 0.001$), and if they do not have a family history of breast cancer compared with women who do (Indigenous: OR 2.3, 95%CI 1.6–3.3; $p < 0.001$; and non-Indigenous: OR 1.3, 95%CI 1.1–1.5; $p < 0.001$).

Speaking a main language other than English was associated with low attendance for Indigenous women (OR 2.3, 95%CI 1.7–3.2; $p < 0.001$) but not for non-Indigenous women, while presenting with a current breast lump was significant for non-Indigenous women (OR 1.8, 95%CI 1.3–2.7; $p < 0.05$) but not for Indigenous women.

Both Indigenous and non-Indigenous women whose cases were recalled to assessment at the time of data collection were likely to have had fewer visits to screening than cases that were reported as normal (Indigenous: OR 5.4, 95%CI 2.1–13.6; $p < 0.001$; non-Indigenous: OR 1.9, 95%CI 1.4–2.6; $p < 0.001$).

Multiple logistic regression analysis reported that significant predictors for low screening

Figure 1: Distribution of Indigenous (n=857) and non-Indigenous women (n=3236) per number of visits to BreastScreen NT in 2015.

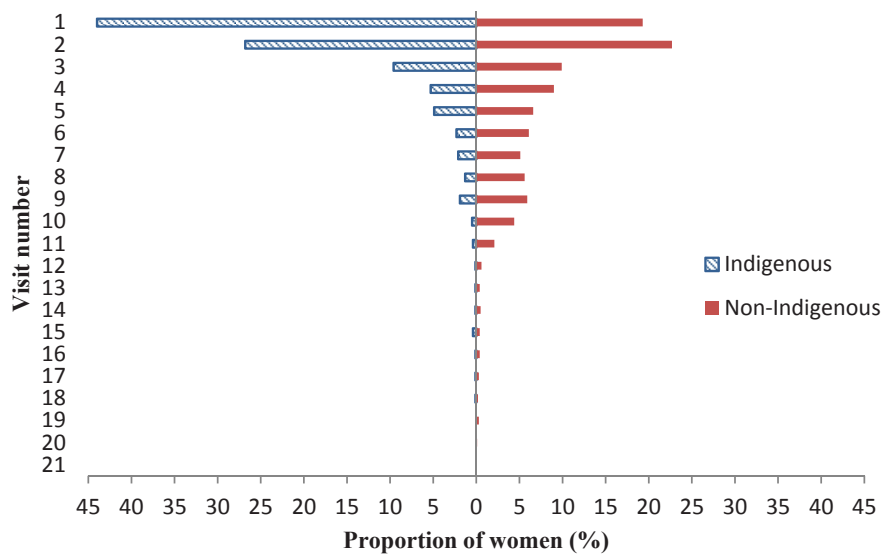


Table 1: Characteristics of Indigenous and non-Indigenous women screened in the NT in 2015.

Variables	Indigenous N=857	Non-Indigenous N=3,236
Median age (y) at screening (Q1, Q3)	54 (48,60)	57 (52,63)
min, max age (y) at screening	40,79	40,85
Median number of screening visits (Q1, Q3)	2 (1,3)	3 (2,7)
min, max number of screening visits	1,19	1,21
Place of residence^a (%)		
Outer regional	118 (13.3)	1,823 (56.9)
Remote	579 (67.7)	1,172 (36.2)
Very remote	159 (18.6)	209 (6.5)
Main language^b (%)		
English	245 (28.7)	2,721 (84.2)
Other-language	610 (71.3)	511 (15.8)
HRT use within 6 months^c (%)		
No	840 (98)	2,950 (91.4)
Yes	17 (2)	278 (8.6)
Family history of breast cancer^d (%)		
No	613 (80.7)	1,961 (66.1)
Yes	147 (19.3)	1,007 (33.9)
Previous breast cancer (%)		
No	485 (98.6)	3,161 (97.7)
Yes	12 (1.4)	75 (2.3)
Current breast lump (%)		
No	828 (96.6)	3,121 (96.4)
Yes	29 (3.4)	115 (3.6)
Case decision (%)		
Normal	729 (92.4)	3,039 (93.9)
Recalled	65 (7.6)	197 (6.1)

Notes:

a: Visitors (n=33) were excluded

b: Not known (n=6) was excluded

c: Not known (n=1) was excluded

d: Not known (n=365) were excluded

attendance for Indigenous women were younger age (OR 12.3, 95%CI 8.1–18.8; $p < 0.001$), being recalled to assessment during this screening round (OR 5.4, 95%CI 1.8–13; $p < 0.001$), no family history of breast cancer (OR 2.1, 95%CI 1.3–3.3; $p < 0.02$), and mainly speaking a language other than English (OR 1.9, 95%CI 1.3–2.9; $p < 0.02$). Remoteness and having no past breast cancer diagnosis, which had univariate significance, were non-significant and removed from the model. For non-Indigenous women, predictors for low screening attendance were younger age (OR 11.5, 95%CI 9.6–13.7; $p < 0.001$), being recalled to assessment during this screening round (OR 1.8, 95%CI 1.3–2.6), no family history of breast cancer (OR 1.8, 95%CI 1.5–2.1; $p < 0.001$), and living remotely (OR 1.3, 95%CI 1.1–1.5; $p < 0.02$). Presenting with a current

breast lump and no previous breast cancer diagnosis, which had univariate significance, were non-significant and removed from the model. These results are shown in Figure 2.

Discussion

It is widely reported that Indigenous Australian women have a lower survival rate and a younger age profile when diagnosed with breast cancer in comparison with their non-Indigenous counterparts.⁴ It is also well documented that Indigenous women have consistently lower attendance at screening for breast and cervical cancers than the rest of the population.^{1,17} However, in recent years, a 5% increase in national breast screening participation has been reported for Indigenous women aged 50–69 years,

whereas the overall rate for the entire target population has remained steady.² Also, more of the screening rounds for Indigenous women were initial screens than for other women,²⁵ a report in line with the findings of this study. The increased national Indigenous participation rate, although still about 19% lower compared with the general population, is a positive step towards better Indigenous population coverage. The improvement may be attributed to the BreastScreen National Accreditation Standards (NAS) which recommend BreastScreen services to implement strategies that increase access and participation for underserved populations. Some of the ways in which BreastScreen is trying to reduce systematic barriers to screening are, improved record-keeping of Indigenous data, targeted and culturally appropriate health promotion, growing the Indigenous health workforce, and more access points for consumers to screening sites.^{1,26,27} However, closing the gap on breast screening participation is a complex challenge that requires deep understanding of the logistical, cultural and health communication needs of Indigenous Australians.¹¹

Table 2: OR and 95% CI of Indigenous and non-Indigenous women's cut-off ages and number of visits to screening.

Variables	Indigenous N=857	non-Indigenous N=3,236	P value	OR (95% CI)
<55 years	458 (53.4%)	1,269 (39.2%)	< 0.0001	1.8 (1.5-2.0)
≥55 years	399 (46.6%)	1,967 (60.8%)		
<3 visits	607 (70.8%)	1,360 (42%)	< 0.0001	3.3 (2.8-3.9)
≥3 visits	250 (29.2%)	1,876 (58%)		

Notes:
P values obtained from Chi-squared test

Table 3: Association of factors with screening attendance for Indigenous (n=857) and non-Indigenous (n=3,236) women in BreastScreen NT.

Variable	Indigenous				Non-Indigenous			
	Less than 3 visits N (%)	3 or more visits N (%)	P value	OR (95% CI) reference is 1	Less than 3 visits N (%)	3 or more visits N (%)	P value	OR (95% CI) reference is 1
Age								
<55 years	416 (90.8)	42 (9.2)	< 0.001	10.8 (7.4-15.7)	942 (74.2)	327 (25.8)	< 0.001	10.7 (9-12.6)
≥55 years	191 (47.9)	208 (52.1)			418 (21.3)	1,549 (78.7)		
Previous breast cancer								
No	604 (71.5)	241 (28.5)	< 0.001	7.5 (2.0-28.0)	1,340 (42.4)	1,821 (57.6)	< 0.05	2.0 (1.2-3.4)
Yes	3 (25)	9 (75)			20 (26.7)	55 (73.3)		
Case decision								
Recalled	60 (92.3)	5 (7.7)	< 0.001	5.4 (2.1-13.6)	113 (57.4)	84 (42.6)	< 0.001	1.9 (1.4-2.6)
Normal	547 (69.1)	245 (30.9)			1,247 (41)	1,792 (59)		
Family history of breast cancer								
No	461 (75.2)	152 (24.8)	< 0.001	2.3 (1.6-3.3)	856 (43.7)	1,105 (56.3)	< 0.05	1.3 (1.1-1.5)
Yes	84 (57.1)	63 (42.9)			374 (37.1)	633 (62.9)		
Main language								
Other language	464 (76.1)	146 (23.9)	< 0.001	2.3 (1.7-3.2)	199 (38.9)	312 (61.1)	0.129	0.8 (0.7-1.0)
English	141 (57.6%)	104 (42.4)			1,158 (42.6)	1,563 (57.4)		
Place of residence								
Remote	533 (72.2)	205 (27.8)	< 0.05	1.5 (1.1-2.4)	647 (46.8)	735 (53.2)	< 0.001	1.5 (1.3-1.7)
Non-remote	74 (62.2)	45 (37.8)			694 (37.9)	1,139 (62.1)		
Current breast lump								
Yes	22 (75.9)	7 (24.1)	0.544	1.3 (0.6-3.1)	65 (56.5)	50 (43.5)	< 0.05	1.8 (1.3-2.7)
No	585 (70.7)	243 (29.3)			1,295 (41.5)	1,826 (58.5)		
HRT within 6 months								
No	598 (71.2)	242 (28.8)	0.101	2.2 (0.8-5.8)	1,245 (42.1)	1,712 (57.9)	0.723	1.0 (0.8-1.3)
Yes	9 (52.9)	8 (47.1)			114 (41.1)	164 (59)		

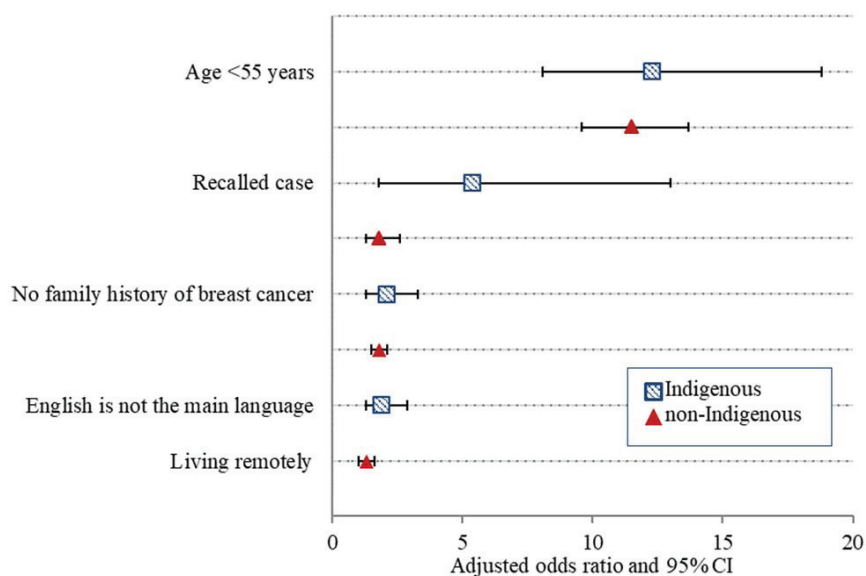
Note:
P values derived from Chi-squared test

Our results show that younger Indigenous women were more likely to have attended BreastScreen for the first and second time in 2015 than older Indigenous women and non-Indigenous women. This suggests that young Indigenous women, arguably a critical target group given the age profile of breast cancer in Indigenous Australians,⁴ are demonstrating initial engagement with the screening program. What our data do not show, however, is whether these Indigenous women are likely to have continuous and regular attendance at screening beyond their second visit. While limited with the absence of women's data over time, our findings could imply that although young Indigenous women are engaging with initial screening, significant attrition may be occurring after the second visit. With BreastScreen Australia's aim of reducing breast cancer mortality through early detection, women's ongoing participation in the program is critical.

Association between low attendance and living remotely are shown for both Indigenous and non-Indigenous women; however, it only remains significant in the multivariate model for Indigenous women. Geographic remoteness is widely reported to present barriers to screening in Australia^{1,17} and is of particular importance in the NT, with approximately two-thirds of the overall population living in remote to very remote locations.²⁸ There have been national efforts to improve access to screening via the mobile screening van that travels to remote areas and indeed may account for the increase in participation of NT women in recent years.⁸ However, overall participation rates are still lower compared with other states and territories of Australia, and evidence of poorer overall health continues to be reported with increasing geographic remoteness.²⁹⁻³²

The characteristic that was significant for Indigenous women but not for others in our dataset was language, in that Indigenous women who mainly spoke a language other than English were likely to have fewer than three attendances compared with English-speaking Indigenous women and compared with other women. This result, coupled with the earlier finding that Indigenous compared with non-Indigenous women were more likely to attend BreastScreen for the first and second time in 2015, suggests that Indigenous women are engaging with initial screening in the NT, where culturally and linguistically appropriate strategies have been implemented to meet the needs of Indigenous peoples.⁸ However, our results

Figure 2: Factors associated with less than 3 screening visits for Indigenous (n=857) and non-Indigenous women (n=3,236) in the NT.



also imply that continued attendance beyond three visits may wane with those for whom English is not the main spoken language, a finding supported by other researchers who have shown that language can be a significant barrier to health for many Indigenous cultures around the world.^{10,13,33,34} For example, it is reported that there is no word for cancer in many Indigenous languages, including Australian languages, which immediately presents difficulties when promoting screening.³⁵ While it is well established that women of diverse cultural backgrounds have historically lower uptake to screening in Australia,^{1,27} tracking whether these women remain in the program beyond their initial attendance as a true measure of appropriate engagement in NT should be the focus of further work.

Non-Indigenous women presenting with a current breast lump were associated with having fewer than three visits to screening in the unadjusted results. While BreastScreen Australia (BSA) targets asymptomatic women, there is a small group of women who present to screening with symptoms, particularly in the early screening rounds. The reported rate of symptomatic screening according to BreastScreen screening data from 1996 to 2005 is slightly higher for Indigenous women than non-Indigenous women.²⁵ Our study, however, found the opposite – that the association with a current breast lump only had univariate significance for non-Indigenous women. A study in Finland which included self-reported or radiographer-

reported breast lumps in 1.3% of women screened in a population-based program found that the risk of breast cancer was sevenfold for women with lumps reported at screening compared to women with other symptoms (including nipple retractions and secretions).³⁶ Given that the risk is high for women with breast lumps reported at screening, and with screening attendance for all women being lower than the national average in the NT, improving participation in BreastScreen NT is critically important.

A factor previously associated with low screening re-attendance in Australia and elsewhere is when a woman was previously recalled to assessment with a false-positive result.^{2,37,38} In the first round of screening, with high recall rates (up to 10.8% reported in 2012),²⁹ and low positive predictive values (1.1% of women attending a first screen in 2015 had an invasive breast cancer or DCIS detected),² low return attendance of recalled women in subsequent rounds is unsurprising. Maintaining high sensitivity and specificity in the BreastScreen program is one of the overarching goals of the NAS and therefore this must be evident, even with the first screening round.²⁷ Our results show that women who had attended fewer screenings happened to have been recalled to assessment in this round; however, limitations in the data mean we can only estimate how a false positive would affect these women's decisions about subsequent screening rounds. The current work reaffirms the importance of diagnostic efficacy to

long-term BreastScreen engagement and provides new evidence that this finding is not unique to any single grouping of women.

To improve access and program retention for diverse groups within the screening population, the NAS recommend Screening and Assessment Services (SAS) to provide equitable service to women who are culturally and linguistically diverse, are Indigenous, live in rural and remote areas and are from lower socioeconomic backgrounds.²⁶ Although an evaluation of the program in 2014 found that BreastScreen Australia SAS uniformly performed well across the high-priority standards and performance indicators (for benign biopsy rates, cancer detection rates and interval cancer rates), researchers reported that SAS with high numbers of diverse participants failed to meet the standard for time between screening and assessment.²⁷ That is, attendance at assessment within the recommended 28 days after being recalled was lower for services with high cultural diversity. The reasons are unclear and warrant further investigation; however, the concern is that longer times to assessment may affect health outcomes for these women. While strategies have been implemented at state levels to try to increase screening participation, attendance at post-screening assessment should be carefully considered at the SAS level, particularly for Indigenous women who are reportedly less likely to attend post-screening assessment within the recommended 28 days.²⁵

There were a few limitations in this study. Longitudinal data would have allowed us to provide a broader scope of women's attendance at BreastScreen in the NT. As data were only collected from an eight-month period in a program of biennial screening, the information about women's screening behaviours over time could not be surmised. A further limitation of this study is the lack of historical clinical information on women, such as the result of prior screening rounds, as a previous false positive finding is shown to affect future screening attendance.

Conclusion

The current work corroborates previously reported variations between Indigenous and non-Indigenous women's screening characteristics and provides evidence of factors strongly associated with low program attendance. Given the disparity in participation rates and known variations

in breast cancer incidence, mortality and survival for Indigenous and non-Indigenous women, strategies to optimise engagement with the screening program should be targeted to meet the logistical, cultural and health communication needs of Australian women.

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