Post mammographic screening behaviour: A survey investigating what women do after being told they have dense breasts

Correspondence to:

A/Prof Jennifer Stone

Genetic Epidemiology Group, School of Population and Global Health

The University of Western Australia

35 Stirling Highway, M431

Crawley, Western Australia, Australia 6009

jennifer.stone@uwa.edu.au

Telephone: +61 8 6488 1603

Authors: Ellie Darcey (ellie.darcy@uwa.edu.au)¹, Emma Jane Hunt

(10171128@student.uwa.edu.au)¹, Louise Keogh (l.keogh@unimelb.edu.au)², Kirsty McLean

(kirsty.mclean@uwa.edu.au)¹, Christobel Saunders (christobel.saunders@uwa.edu.au)³, Sandra

Thompson (sandra.thompson@uwa.edu.au)⁴, Catherine Woulfe (woulfec@hotmail.com)¹, Elizabeth

Wylie (Liz.Wylie@health.wa.gov.au)^{3,5}, Jennifer Stone (jennifer.stone@uwa.edu.au)¹

Affiliations: ¹Genetic Epidemiology Group, School of Population and Global Health, The University of Western Australia, Perth, Western Australia, Australia;

²Centre for Health Equity, The University of Melbourne, Melbourne, Victoria, Australia;

³School of Medicine, The University of Western Australia, Perth, Western Australia, Australia;

⁴Western Australian Centre for Rural Health, School of Population and Global Health, The University of Western Australia, Geraldton, Western Australia, Australia;

⁵BreastScreen Western Australia, Women and Newborn Health Service, Perth, Western Australia, Australia;

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ABSTRACT

Issue addressed: Despite widespread calls for women undergoing mammographic screening to be informed of their breast density, concerns remain as to how this is interpreted and acted upon given the absence of evidence-based supplemental screening recommendations for women with dense breasts. This study investigates the action women take in response to being notified they have dense breasts and what subsequent advice women receive from health professionals.

Methods: Via a survey of nearly 7000 women, we assessed the post-screening actions of women attending a population-based mammographic screening program (BreastScreen) in Western Australia from 21 November 2017 to 19 April 2018. Women who reported that they were notified they had dense breasts were compared to controls (where applicable). Descriptive and logistic regression analyses were used to summarize responses from 6,183 women.

Results: Half of women notified that they have dense breasts consulted or intended to consult their General Practitioner (GP), particularly those notified for the first time (55%). Of those notified women who consulted their GP, 50% were referred to have supplemental screening. Overall, 20% of women notified as having dense breasts reported that they had an ultrasound due to their breast density.

Conclusion: Self-reported health service usage after mammographic screening is higher in women who have been notified they have dense breasts.

So what? There is growing pressure for screening programs in Australia and internationally to routinely measure and report breast density to participants. Results from this study can inform screening programs of the likely impact of breast density notification on health service usage. While more information is needed to fill knowledge gaps in recommended action for women with dense breasts, the greatest risks to women arise from not being screened. Hence, health promotion practitioners and health providers should continue to encourage women to participate in BreastScreen programs.

Keywords: mammographic screening, breast density, breast cancer, risk factor

Abbreviations

ARIA	Accessibility/Remoteness Index for Areas
BIRADS	Breast Imaging Reporting And Data System
CI	Confidence Interval
GP	General Practitioner
MBS	Australian Medicare Benefits Schedule
MRI	Magnetic Resonance Imaging
OR	Odds Ratio
SD	Standard Deviation
SEIFA	Socio-Economic Indexes for Areas
WA	Western Australia

INTRODUCTION

In Australia, a population-based mammographic screening program (BreastScreen) was introduced in the early 1990s, based upon evidence of reductions in breast cancer mortality and cost benefits. (Carter et al. 1993) Mammographic breast cancer screening is free for all women aged 40+ as part of publicly funded, state-run BreastScreen programs. For every 1,000 women aged 50-74 who attend biennial mammographic screening, 8 breast cancer deaths are prevented (Australia 2019).

A mammogram is an x-ray of the breast and breast density is the white radiographic appearance of epithelial and stromal tissue on a mammogram. Breast density is one of the strongest predictors of breast cancer risk (Bond-Smith and Stone 2018) and significantly reduces the sensitivity of mammography to detect the disease (as tumours also appear white on a mammogram). (Kerlikowske et al. 2018) Women with extremely dense breasts are 2-6 times more likely to develop breast cancer compared to women of the same age with little or no breast density (McCormack and dos Santos Silva 2006) and up to 17 times more likely to develop an interval cancer (a cancer detected within 24 months after a normal screening mammogram). (Boyd et al. 2007) Legislation in the United States (US) mandating that all screened women be informed of their breast density has increased pressure for other breast cancer screening programs outside the US to routinely measure and report breast density to its participants. However, it is not clear how best to use breast density information given the lack of standardized measurements and evidence-based screening recommendations for women with dense breasts. (McLean and Stone 2018, Stone 2018) It is estimated that 43% of screen-aged women have heterogeneously or extremely dense breasts. (Sprague et al. 2014) Supplemental screening using alternative modalities (e.g. ultrasound, MRI, tomosynthesis) has been shown to find more cancers however, not all women with dense breasts will develop breast cancer and identifying those who benefit from supplemental screening is challenging. Supplemental screening for all women with dense breasts (~645,000 extra screens for the ~1.5M women who attend BreastScreen programs each year) (Australian Institute of Health and Welfare 2018), is not a cost-effective option for publicly funded screening programs, nor is it an efficient use of resources given associated high false positive rates, unnecessary biopsies, and the increased anxiety in otherwise well women (Stone 2018)

The BreastScreen Western Australia (WA) program screens around 55% of women in the targeted age range of 50-74 years (~125,000 women screened each year) and has been notifying women if they have dense breasts for over a decade. It is the only state BreastScreen program within Australia to do so, making it a unique population to study. The impact of breast density disclosure in Western Australia has not been assessed and the comparative international literature is sparse. A 2018 review reported that the introduction of breast density legislation in the US was followed by increased in supplemental screening

rates (ultrasound and MRI) and suggested a decrease in the use of mammography. (Houssami and Lee 2018) However most of these studies compared pre and post legislation outcomes, with very little information regarding the percentage uptake of ultrasound within women notified that they have dense breasts. There is also very little population-based literature examining what action women take post-notification and what advice women receive from health professionals in response to their dense breast notification. Evidence of the impact of breast density notification on the health service is critical to developing a common breast density notification protocol within public screening programs in Australia and for refining education for women and their health care providers.

We conducted a population-based survey of BreastScreen WA participants (including those women who received a dense breast notification and those who did not) to assess the impact of this breast density disclosure, particularly what action women took after they were notified they have dense breasts.

METHODS

Breast density notification

Within BreastScreen WA, the breast density measurement is dichotomous where a radiologist flags women with a Breast Imaging Reporting And Data System (BIRADS) 3 or 4 category (4th edition) as dense. If a woman is flagged to have dense breasts, the notification is included as extra information within their routine mammography report. Women are informed that mammograms are significantly less sensitive in diagnosing breast cancer in women with dense breasts and recommends women consult their General Practitioner (GP). BreastScreen WA's breast density notification protocol applies only to women who are *not* recalled for further assessment (i.e. those where no evidence of breast cancer was found). An example copy of the mammography report can be found in Supplemental Material. A copy of their mammography report is also sent to their nominated GP. Women can independently (outside the BreastScreen program and at their own cost) consult their GP regarding their breast health.

Aligned with the American College of Radiologists/Society of Breast Imaging appropriateness criteria, (American College of Radiology 2017) GPs are informed that women at intermediate risk of breast cancer due to a family history, a personal history of breast cancer, or other risk factors may benefit from regular supplemental breast ultrasound.

Survey development

A consumer consultation of seven women organized by Western Australia's Consumer Community Health Research Network was held to gain insight into key themes to be included in the survey. A comprehensive literature review generated an extensive list of validated questions to address each of the themes.

Questions were reviewed and shortlisted by the BreastScreen WA Consumer Reference Group (CRG) and the Cancer Council Epidemiology Network (CCEN)'s Consumer Advisory Council . This article presents an analysis of women's responses to the 10 survey questions designed to elicit data on women's actions post receiving dense breast notification. The software program Qualtrics was used to create an online version. BreastScreen WA generated the email invitations and the embedded survey link for women who were notified they had dense breasts was different from the link for control women (the survey questions were the same, just the links were different). This way, the researchers could track which women were notified and which women were not. After testing on a subset of BreastScreen WA women, the survey officially launched via email invitation on December 19th, 2017 with a recruitment target of 6000 completed surveys within a 6 month period and a minimum expected participation rate of 10%.

The survey also collected basic demographic information including year of birth, ethnicity and postcode. Respondents who reported being younger than the BreastScreen WA screening age (40 years) were excluded (n=4). Ethnicity was categorised into three groups; Caucasian/European, Asian and Other. Postcode was used to apply the Australian Bureau of Statistics' Accessibility/Remoteness Index for Areas (ARIA) and Socio-Economic Indexes for Areas (SEIFA). (Australian Bureau of Statistics: Themes: Socio-Economic Indices for Areas viewed 13 Feb 2019 2018) Remoteness was categorized into three groups; Major city, Inner and outer regional, Remote and very remote. We used quintiles of SEIFA's Index of Education and Occupation based on their relative socio-economic advantage and disadvantage, where the first quintile have the least advantage and most disadvantage.

Ethics and governance approval was obtained from King Edward Memorial Hospital's Human Research Ethics Committee (XXX) and The University of Western Australia (XXX).

Recruitment

All women who attended BreastScreen WA (via fixed clinics or mobile units) from November 21st 2017 to April 19th 2018 who received a negative-screen mammography report and provided an email address (~70% of women) were invited to participate. Women had the option of completing the survey either online or by telephone to avoid any potential access bias. The online survey took approximately 5-10 minutes. Breast density notification status (yes/no) was known for each participant but otherwise responses were anonymous unless women opted to provide their contact details for future contact.

Categorisation of subjects

Survey responses from all women who had participated by 18th May 2018 were exported from Qualtrics for analysis. Figure 1 shows a flow chart of all survey respondents. Respondents were categorized into three groups based on their response to “Have you ever been told by a health professional (e.g. BreastScreen WA) that your breast tissue is dense?” – controls, notified for the first time, and notified multiple times. Survey questions were the same for all three groups except controls were not asked non-applicable questions (i.e. those relating to the impact of notification).

Controls were defined as women who responded either “No” or “I don’t know” regardless of whether their mammography report included breast density notification (n=3,494). Women who were not aware that they were notified were included as controls because the survey questions relating to the impact of their notification did not apply (n=486). Sensitivity analysis revealed that these women were significantly younger than the other controls (mean=58.5, standard deviation (SD)=8.2 vs mean=61.6, SD=8.2, respectively), had a smaller proportion of Caucasian/Europeans (81.5% vs 88.4%) and a higher proportion of women in the highest education category (38.1% vs 32.7%, respectively) (all p<0.001). However, their survey responses were largely the same as the other controls (any statistically significant differences are reported in the results) and therefore included in the analysis.

The notified groups were defined as women whose mammography report included breast density notification and who responded either that they had been told by BreastScreen WA that they had dense breasts for the first time (n=1,384) or that they had been told (by BreastScreen WA) more than once (n=1,308). Henceforth “notified” women refers collectively to these groups.

To ensure that responses truly reflect the defined groups, women who did not fall into these three groups were excluded (n=935). For example, women who claim to have been told that they have dense breasts from a source other than BreastScreen WA may have received different recommendations and therefore acted differently.

Statistical Analysis

All data management and analyses were undertaken using Stata v14. Descriptive statistics were used to describe the characteristics of the three groups (controls, notified for first time, notified multiple times). To assess the sensitivity of the inclusion of controls who were notified but were not aware of their breast density notification (n=486), the descriptive statistics were repeated separately by knowledge of notification (i.e. controls who confirmed that they were not notified versus controls who did not know they

were notified). Chi-square statistics were used to test for differences in frequency of responses between the two groups of controls. For notified women, logistic regression was used to estimate predictors of having an ultrasound because of their density (compared to those who didn't have an ultrasound or who had breast ultrasound for another reason). Covariates included age, ethnicity, remoteness of residence, education and occupation, and number of times notified. Covariates significant at the 90% level in univariate analysis were added to a multivariable model.

Qualitative Analysis

Notified women who indicated that they talked to their GP (n=85) were provided an opportunity to provide open ended comments on how helpful was the information they received. The 85 responses to this question were analysed thematically through an inductive approach (Nowell et al. 2017). All responses were read by several authors and a coding framework was devised to capture the full range of responses. Given the quantitative nature of the survey and the large number of responses, once each response was coded, a count was conducted for each code.

RESULTS

Participant response and demographic information

Of the 29,416 who received email invitations, 6,922 responded to the survey resulting in a 23.5% response rate (Figure 1). The response rate was higher in the 3,444 women in the notified group compared to the 3,634 controls (28.1% vs 19.8%, respectively). Less than 1% of women opted to complete the survey by telephone. Nearly 20% of women in the notified group indicated that they had not been told they had dense breasts (14%) or that they were told, but not by BreastScreen Western Australia (6%). Similarly for controls, nearly 15% of women reported to having been told they had dense breasts either by BreastScreen Western Australia or from other sources. Women whose responses were excluded were more likely to be Caucasian/European and have a slightly higher socio-economic status (data not shown).

Characteristics of respondents by group are shown in Table 1. Mean age of participants was 60.2 years. Those notified for the first time were younger than the controls and those notified multiple times. The majority of respondents were Caucasian/European, resided in major cities and were generally in higher quintiles of the socio-economic indices.

Women's screening history

Responses to questions on women's previous screening history are presented in Table 2. Of those surveyed, 83% reported having had a clinical breast exam. Almost 38% of women reported having an

ultrasound to screen for breast cancer. Women notified multiple times were more likely to report having had an ultrasound (57%) compared to the controls (31%) and first-time notified women (35%). The most commonly reported reasons women were referred for supplementary screening via ultrasound were abnormalities in the breast (66%), dense breasts (24%), and family history of breast cancer (18%). Of all notified women (n=2,688), 20% reported that they had an ultrasound due to their breast density (n=550). Sensitivity analysis comparing responses of controls by knowledge of notification showed little evidence of differences in responses with one exception; a higher proportion of controls who were unaware that they were notified reported having a clinical breast exam within the last 12 months (compared to controls who were not notified, $p_{\text{trend}}=0.001$).

Only 3% of all women surveyed reported having an MRI to screen for breast cancer with abnormalities in the breast (67%) the most common reason for being referred, followed by a strong family history of breast cancer (15%) and having dense breasts (11%). Overall, less than 1% of all notified women reported having a breast MRI due to their density.

Predictors of breast ultrasound uptake

Table 3 shows the predictors of having an ultrasound due to their breast density. Women who had been notified multiple times had nearly a 4-fold increase in odds of having an ultrasound (odds ratio (OR)=3.74, 95%CI=3.01, 4.63) compared to those who had been notified for the first time. Remoteness of residence was also found to be associated with having an ultrasound due to breast density where those living in remote or very remote areas were 60% less likely to have an ultrasound than those living in major cities (OR= 0.418, 95%CI=0.238, 0.735).

Action(s) post breast density notification

Table 4 shows the responses related to the actions taken after notification of dense breasts. Of those notified as having dense breasts, the most common actions taken were consulting a doctor or other health professional (50%), performing a breast self-examination (38%) and looking for information about breast density (22%). Nearly 18% of respondents took no action after breast density notification, with women notified multiple times more likely not to take action (26%) than women notified for the first time (10%). A higher proportion of first-time notified women (31%) looked for additional information about breast density (e.g. on the internet) compared to those notified multiple times.

For those who responded that they talked to a General Practitioner (GP) or other health professional, two-thirds reported the health professional performed a clinical breast examination and half reported being

referred for supplemental screening (See Table 4). Receiving further information was reported by 39% of respondents, the majority reporting the information being helpful (mean 8) on a scale of 1-10 from not helpful (0) to very helpful (10).

Women's comments on how helpful the information provided by their doctor was

The 85 women who indicated that they talked to their doctor were asked to comment on how helpful the information they received was. Of the 46 responses which were related to the question, 57% of comments focused on knowledge or information, saying that they had a better understanding of breast density and/or received all of the information they needed. For example, one woman wrote "I feel I have had access to the information which is currently available - eg evidence basis for further testing and taking steps to reduce breast density". Another 17% focused more on the fact that talking to their GP helped them feel reassured about what it means to have dense breasts (e.g. "Allayed my fears, provided me with alternative examination pathways and created an opportunity for an ongoing conversation to be opened up with my GP about breast density."). Similarly, 23% of women talked about being proactive about their breast health (e.g. "Quite helpful, it makes you more aware to look for changes and discuss breast density issues with GP").

DISCUSSION

Health promotion is the process of enabling people to increase control over, and to improve, their health. Notifying women that they have dense breasts allows them to take action, but there has been a lack of information to date on how that information is received and what actions occur after notification. Both efforts to improve public policy and to ensure that health services provide the information needed by women necessitate an improved understanding and knowledge related to breast density notification towards healthier responses and actions. This study helps fill some of the existing gap in knowledge. It found that around half of women who have been notified they have dense breasts consult or intend to consult their doctor, particularly those notified for the first time. Almost half of notified women reported to having had an ultrasound to screen for breast cancer (compared to nearly a third of controls) however only 20% of notified women reported having the breast ultrasound due to their density. Remoteness of living reduced the likelihood of having an ultrasound whilst receiving multiple dense breast notifications over time increased the likelihood of having an ultrasound (due to breast density).

Within the BreastScreen programs in Australia, women who are recalled for further assessment receive diagnostic screening within the BreastScreen program (free of charge). These women who were recalled

for further assessment were excluded from this survey. In Australia, women can independently (outside the BreastScreen program and at their own cost) consult their GP regarding their breast health. The survey questions relating to ultrasound and MRI therefore refer to supplemental screening post a normal screening mammography report. Results indicate that doctors (GPs) appear to refer for supplemental screening for women with dense breasts around 50% of the time, although this estimate is based on a small subset of women (n=219). The large proportion of women who reported that they had supplemental screening due to abnormalities in the breast may be due to GP uncertainty about Australian Medicare Benefits Schedule (MBS) eligibility for supplemental screening; GPs may indicate that an abnormality (or family history) as the primary reason for the referral to ensure MBS criteria is met. Further investigation of supplemental screening referrals is warranted.

Results also indicated that women living in remote areas are less likely to have an ultrasound due to their breast density which is possibly due to reduced availability of ultrasound services. Also, after stratification of the actions taken after dense breast notification by ARIA we observed that the proportion of women who talked (or intended to talk) to their GP was lower for women living in very remote and remote areas (data not shown). Surprisingly, women in the lowest education and occupation quintile were more likely to have had an ultrasound due to their breast density but the overall trend was not significant ($p=0.094$).

To the authors' knowledge, this is currently the largest study of its kind and enabled comparisons between women who have been notified they have dense breasts compared to those who had not. Having a control population provided useful estimates of supplemental ultrasound and MRI uptake in a population-based screening program. The large sample size enabled us to stratify women who have been notified for the first time versus multiple times, highlighting the higher rate of post-screening action among first timers.

There are several known issues with breast density notification. (McLean and Stone 2018, Stone 2018) Whilst some argue that the notifications are beneficial as they increase patient awareness, others argue that it inflates risk perception without improving patient health, can increase the woman's anxiety, and leads to widespread overutilization of ultrasound and MRI screening. (Cappello 2013, Yeh et al. 2015) Questions relating to anxiety and perceptions of risk were included in the survey but will be analysed and reported separately. One of the biggest issues is the high prevalence of dense breast tissue in the general population, with an estimated 43% of all women aged 40-74 years having heterogeneously or extremely dense breasts. (Sprague et al. 2014) If all women with "dense breasts" received supplemental breast screening (ultrasound or MRI) then this would translate to around 27 million extra screens each year in the United States (Sprague et al. 2014) and around 645,000 extra screens for women who attend BreastScreen

Australia programs (which screens approximately 1.5 million women a year). (2017) This is not a cost-effective option for publicly funded breast cancer screening programs like BreastScreen, nor is it an efficient use of resources given associated high false positive rates, unnecessary biopsies, additional exposure to contrast agents, and the increased anxiety in otherwise well women. (Stone 2018) We have shown that only 20% of women who received breast density notification reported to ever having supplemental screening due to their density. However, further research to understand the decisions taken by GPs about when and who to refer to supplemental screening is required. Financial and equity issues also arise as supplemental screening is not free for most Australian women. While both ultrasound and MRI are rebated through the publically-funded MBS (MRI is rebated only for high risk women), gap payments and out of pocket costs mean that only those that can afford supplemental screening undertake this.

Currently, there is no established best-practice post breast density notification. It is the position of BreastScreen Australia and the Royal Australian and New Zealand College of Radiologists to not notify women if they have dense breasts. However, consumer advocacy organisations are lobbying for policy change. Whether or not to notify women of their breast density is a complex issue. A recent perspective of both the public health and clinical ethical issues discusses some of the issues relating to equitable care, patient autonomy in decision-making, trust in health professionals, duty of care by the physician, and uncertainties around evidence relating to measurement and clinical management pathways for women with dense breasts. (Ingman et al. 2020) There are multiple perspectives and values at stake and a clear and consistent policy framework is needed.

The strengths of this study are its size and its representativeness of a public breast cancer screening population, although a limitation is that women without email addresses and non-English speaking women were not invited to participate. It was not possible to compare demographics between those who responded and those who didn't. Responses from 935 women were excluded from the analysis to ensure that responses truly reflect the defined groups. This subset of data will be analysed separately in future to elucidate the actions of women who claim to have been notified they have dense breasts when they hadn't or notified from sources other than BreastScreen Western Australia. Also, whilst more than 400 participants indicated an ethnicity other than European/Caucasian, the number of responses for many questions were too small to stratify by ethnicity. For example, less than 2% of all women screened by BreastScreen WA identify as Aboriginal (almost 4% of the WA population are Aboriginal) and unfortunately, only 20 Aboriginal and Torres Strait Islander women participated in the survey - less than hoped. Aboriginal and Torres Strait Islander women participate less in screening and have significantly higher mortality due to breast cancer compared to non-Aboriginal women. (Roder et al. 2012) Previous work has

shown that Western Australian Aboriginal women have significantly lower breast density (McLean et al. 2019) and that the association between breast density and breast cancer risk is even stronger for Aboriginal women (compared to non-Aboriginal women). (Darcey et al. 2019) Further investigation of the impact of breast density notification on women from under-studied ethnicities, particularly those where English is not the first language, is needed. Overall, this study was a population-based survey nested within a publicly-funded breast cancer screening program in Australia so its generalisability is dependent on screening programs and healthcare system of other populations.

CONCLUSIONS

In summary, there is growing pressure for screening programs around the world to routinely measure and report breast density to its participants. This is the first population-based survey nested within a publicly-funded breast cancer screening program population that notifies women if they have dense breasts. We assessed the impact of breast density notification, particularly what action women took after they were notified they have dense breasts and what information they received. We found that around half of women who have been notified they have dense breasts, particularly those notified for the first time, consult their doctor who appear to refer supplemental screening around 50% of the time. However, only 20% of women who have been notified that they have dense breasts reported having a breast ultrasound due to their density. This study fills significant gaps in the literature regarding what action women take post-notification and what advice women receive from health professionals in response to their dense breast notification. While more information is needed to fill the existing knowledge gaps in recommended action for women with dense breasts, the greatest risks to women arise from not being screened. Hence, health promotion practitioners and health providers should continue to encourage women to participate in free mammographic screening via BreastScreen and seek medical assessment of any identified breast lumps or abnormalities.

DECLARATIONS

Ethics approval and consent to participate: Ethical approval was obtained from the King Edward Memorial Hospital's Human Research Ethics Committee (XXX) and The University of Western Australia (XXX).

Conflict of interest: The authors declare no potential conflicts of interest.

Consent for participation/publication: All women who participated in the survey provided their consent.

Availability of data and materials: The datasets generated and analysed during the current study are not publically available but can be made available upon request (and pending approval) from BreastScreen Western Australia.

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Table 1: Characteristics of respondents who were told they had dense breasts for first time (n=1,381), multiple times (n=1,308) and controls who have not been told/can't recall being told (n=3,494).

Characteristics	Total (6,183)	Controls (n=3,494)	Notified for first time (n=1,381)	Notified multiple times (n=1,308)
Mean age at survey (sd)	60.2 (8.6)	61.2 (8.3)	57.9 (9.2)	60.2 (8.1)
Age at survey (%)				
40-49 years	650 (10.5)	268 (7.7)	262 (19.0)	120 (9.2)
50-74 years	5,296 (85.7)	3,079 (88.1)	1,070 (77.5)	1,147 (87.7)
75+ years	237 (3.8)	147 (4.2)	49 (3.6)	41 (3.1)
Ethnicity (%)				
Caucasian/European	5,418 (92.7)	3,054 (87.4)	1,196 (86.6)	1,168 (89.3)
Asian	217 (3.7)	105 (3.0)	68 (4.9)	44 (3.4)
Aboriginal or Torres Strait Islander	20 (0.3)	14 (0.4)	2 (0.1)	4 (0.3)
Other	190 (3.3)	103 (3.0)	51 (3.7)	36 (2.8)
Missing	338 (5.5)	218 (6.2)	64 (4.6)	56 (4.3)
ARIA ^a (%)				
Major city	5,028 (81.3)	2,817 (80.6)	1,149 (83.2)	1,062 (81.2)
Inner regional	462 (7.5)	273 (7.8)	91 (6.6)	98 (7.5)
Outer regional	266 (4.3)	161 (4.6)	48 (3.5)	57 (4.4)
Remote	306 (5.0)	170 (4.9)	65 (4.7)	71 (5.4)
Very remote	62 (1.0)	35 (1.0)	14 (1.0)	13 (1.0)
Missing	59 (1.0)	38 (1.1)	14 (1.0)	7 (0.5)
Education and occupation index ^b (%)				
1 (lowest)	687 (11.1)	405 (11.6)	137 (9.9)	145 (11.1)
2	1,100 (17.8)	641 (18.4)	223 (16.2)	236 (18.0)
3	903 (14.6)	539 (15.4)	193 (14.0)	171 (13.1)
4	1,241 (20.1)	702 (20.1)	288 (20.9)	251 (19.2)
5 (highest)	2,193 (35.5)	1,169 (33.5)	526 (38.1)	498 (38.1)
Missing	59 (1.0)	38 (1.1)	14 (1.0)	7 (0.5)

^aAccessibility/Remoteness Index of Australia (ARIA) scores; ^bIndex of Education and Occupation is on a scale from 1 to 5, where 1 indicates the lowest 20% of the population in Western Australia (least education/occupation opportunities) and 5 indicates the highest 20% of the population in Western Australia (most education/occupation opportunities); Abbreviations: sd, standard deviation

Table 2. Screening history of survey respondents by their density notification.

Survey questions	Total (6,183)	Controls (n=3,494)	Notified for first time (n=1,381)	Notified multiple times (n=1,308)
Have you ever had a clinical breast exam?				
Yes	5,118 (82.8)	2,772 (79.3)	1,161 (84.1)	1,185 (90.6)
No	780 (12.6)	537 (15.4)	160 (11.6)	83 (6.3)
I'm not sure	75 (1.2)	46 (1.3)	21 (1.5)	8 (0.6)
Missing	210 (3.4)	139 (4.0)	39 (2.8)	32 (2.4)
How long has it been since your last clinical breast exam?				
Less than 12 months ago	5,118	2,772	1,161	1,185
At least 1 year ago, but less than 2 years ago	1,759 (34.4)	780 (28.1)	513 (44.2)	466 (39.4)
At least 2 years ago, but less than 5 years ago	931 (18.2)	462 (16.7)	185 (15.9)	284 (24.0)
At least 5 years ago, but less than 10 years ago	1,063 (20.8)	606 (21.9)	218 (18.8)	239 (20.2)
At least 10 years ago, but less than 15 years ago	668 (13.1)	415 (15.0)	130 (11.2)	123 (10.4)
More than 15 years ago	603 (11.8)	444 (16.0)	96 (8.3)	63 (5.3)
I don't know	90 (1.8)	62 (2.2)	18 (1.6)	10 (0.8)
Missing	4 (0.1)	3 (0.1)	1 (0.1)	0 (0.0)
Have you ever had an ultrasound of the breast to screen for breast cancer?				
Yes	2,328 (37.7)	1,091 (31.2)	489 (35.4)	748 (57.2)
No	3,486 (56.4)	2,181 (62.4)	814 (58.9)	491 (37.5)
I'm not sure	158 (2.6)	79 (2.3)	39 (2.8)	40 (3.1)
Missing	211 (3.4)	143 (4.1)	39 (2.8)	29 (2.2)
Do you recall the reason why you were referred to have an ultrasound of the breast? ^a				
There was an abnormality in my breast (e.g. lump)	2,328	1,091	489	748
I have dense breasts	1,547 (66.5)	790 (72.4)	324 (66.3)	433 (57.9)
I have a strong family history of breast cancer	571 (24.5)	21 (1.9)	151 (30.9)	399 (53.3)
I have a strong family history of breast cancer	417 (17.9)	198 (18.5)	70 (14.3)	149 (19.9)
Further investigation required (e.g. dark patch) ^b	75 (3.2)	44 (4.0)	20 (4.1)	11 (1.5)
Has history of abnormalities ^b	64 (2.8)	31 (2.8)	9 (1.8)	24 (3.2)
Has another risk factor (eg age, menopausal) ^b	25 (1.1)	23 (2.1)	1 (0.2)	1 (0.1)
As part of regular screening/check-ups ^b	12 (0.5)	9 (0.8)	2 (0.4)	1 (0.1)
Find mammograms very uncomfortable or painful ^b	8 (0.3)	4 (0.4)	2 (0.4)	2 (0.3)
I am a known breast cancer gene mutation carrier	6 (0.3)	4 (0.4)	1 (0.2)	1 (0.1)
Other	49 (2.1)	31 (2.8)	8 (1.6)	10 (1.3)
Have you ever had an MRI (magnetic resonance imaging) of the breast to screen for breast cancer?				

Yes	212 (3.4)	137 (3.9)	26 (1.9)	49 (3.7)
No	5,504 (89.0)	3,075 (88.0)	1,255 (90.9)	1,174 (89.8)
I'm not sure	246 (4.0)	129 (3.7)	60 (4.3)	57 (4.4)
Missing	221 (3.6)	153 (4.4)	40 (2.9)	28 (2.1)
Do you recall the reason why you were referred to have an MRI of the breast? ^a				
There was an abnormality in my breast (e.g. lump)	142 (67.0)	92 (67.2)	18 (69.2)	32 (65.3)
I have a strong family history of breast cancer	32 (15.1)	15 (11.0)	4 (15.4)	13 (26.5)
I have dense breasts	24 (11.3)	5 (3.7)	1 (3.9)	18 (36.7)
Has history of abnormalities ^b	11 (5.2)	9 (6.6)	2 (7.7)	0 (0.0)
Further investigation required (e.g. dark patch) ^b	6 (2.8)	5 (3.7)	1 (3.9)	0 (0.0)
I am a known breast cancer gene mutation carrier	3 (1.4)	3 (2.2)	0 (0.0)	0 (0.0)
Other	19 (9.0)	16 (11.7)	3 (11.5)	0 (0.0)

^aRespondents were able to select more than one option; ^bResponse option derived from common free-text from 'Other'

Table 3. Logistic regression comparing characteristics of those who got an ultrasound due to their density versus those who did not get an ultrasound and those who got an ultrasound for another reason.

Characteristics	Ultrasound for	Other ultrasound	Univariate		Multivariable ^a	
	density	or no ultrasound				
	n (%)	n (%)	OR (95% CI)	P-value ^b	OR (95% CI)	P-value ^b
	Yes (N=550)	No (N=1,992)				
Age at survey				0.080		0.279
40-49 years	66 (12.0)	303 (15.2)	1.00 (reference)		1.00 (reference)	
50-74 years	460 (83.6)	1,630 (81.8)	1.31 (0.976, 1.75)		0.964 (0.709, 1.31)	
75+ years	24 (4.4)	59 (3.0)	1.78 (1.01, 3.16)		1.51 (0.829, 2.76)	
Ethnicity				0.441		
Caucasian/European	496 (90.2)	1,799 (90.3)	1.00 (reference)			
Asian	19 (3.5)	90 (4.5)	0.780 (0.471, 1.29)			
Other	22 (4.0)	66 (3.3)	1.21 (0.744, 1.99)			
Missing	13 (2.4)	37 (1.9)				
ARIA ^c				0.003		0.005
Major city	460 (83.6)	1,621 (81.4)	1.00 (reference)		1.00 (reference)	
Inner and outer regional	65 (11.8)	218 (10.9)	1.09 (0.811, 1.47)		0.965 (0.685, 1.36)	
Remote and very remote	18 (3.3)	140 (7.0)	0.448 (0.268, 0.750)		0.418 (0.238, 0.735)	
Missing	7 (1.3)	13 (0.7)				
Education and occupation index ^d (%)				0.039		0.094
5 (highest)	203 (36.9)	755 (37.9)	1.00 (reference)		1.00 (reference)	
4	106 (19.3)	408 (20.5)	0.963 (0.737, 1.26)		1.01 (0.767, 1.34)	
3	77 (14.0)	259 (13.0)	1.16 (0.858, 1.56)		1.28 (0.928, 1.76)	
2	83 (15.1)	360 (18.1)	0.829 (0.619, 1.11)		0.972 (0.689, 1.37)	

1 (Lowest)	74 (13.5)	197 (9.9)	1.44 (1.06, 1.97)	1.48 (1.06 2.08)
Missing	7 (1.3)	13 (0.7)		
Notification number			<0.001	<0.001
Firsttime	151 (27.5)	1,152 (57.8)	1.00 (reference)	1.00 (reference)
Multiple times	399 (72.6)	840 (42.2)	3.66 (2.96, 4.52)	3.74 (3.01, 4.63)

^aLogistic regression only contains individuals with complete data (Ultrasound for density=530/ Other ultrasound or no ultrasound=1942) ^bP value for likelihood ratio test for trend; ^cAccessibility/Remoteness Index of Australia (ARIA); ^dIndex of Education and Occupation is on a scale from 1 to 5, where 1 indicates the lowest 20% of the population in Western Australia (least education/occupation opportunities) and 5 indicates the highest 20% of the population in Western Australia (most education/occupation opportunities). Abbreviations: OR, Odds Ratio; CI, Confidence Interval

Table 4. Actions taken after notification of dense breasts by whether they have been told for first time (n=1,381) or many times (n=1,308) by BreastScreen Western Australia.

Survey questions	Total (2,689)	Notified for first time (n=1,381)	Notified multiple times (n=1,308)
Action taken after dense breast notification ^a (%)			
Talked or intend to talk to GP or other health professional	1,339 (50.0)	765 (55.4)	574 (43.9)
Perform a breast self-examination	1,032 (38.5)	621 (45.0)	411 (31.4)
Look for any information about breast density (e.g. on the internet)	587 (21.9)	428 (31.0)	159 (12.2)
No action taken	478 (17.8)	136 (9.9)	342 (26.2)
Talked to a friend or family member	88 (3.3)	54 (3.9)	34 (2.6)
Talked to someone from BreastScreen Western Australia	69 (2.6)	44 (3.2)	25 (1.9)
Other ^d	35 (2.7)	n/a	35 (2.7)
Those who took no action	472	136	336 ^b
Reasons for not taking action ^a (%)			
Happy to know I didn't have breast cancer	172 (36.4)	40 (29.4)	132 (39.2)
Not concerned about breast cancer risk	72 (15.3)	28 (20.6)	45 (13.4)
Already discussed this with other health provider	71 (15.0)	17 (12.5)	54 (16.0)
Didn't get around to it	69 (14.6)	27 (19.9)	42 (12.5)
Did not understand the information provided	44 (9.3)	10 (7.4)	34 (10.1)
Didn't receive any information ^c	32 (6.8)	10 (7.4)	22 (6.5)
Information didn't say follow-up was required ^c	18 (3.8)	4 (2.9)	14 (4.2)
Have regular checks with medical professional ^c	16 (3.4)	6 (4.4)	10 (3.0)
It seemed too difficult	9 (1.9)	3 (2.2)	6 (1.8)
Was too worried	4 (0.9)	0 (0.0)	4 (1.2)
Other	22 (4.7)	6 (4.4)	16 (4.8)
Those who have talked to a GP or other health professional ^d	n/a	n/a	219
What did they do? ^a (%)			
Performed a clinical breast examination	n/a	n/a	147 (67.1)
Referred me for supplemental screening (e.g. ultrasound or MRI)	n/a	n/a	110 (50.2)
Provided me with additional information/answered any questions	n/a	n/a	85 (38.8)
Referred me to a specialist	n/a	n/a	11 (5.0)
Did nothing	n/a	n/a	3 (1.4)
Other	n/a	n/a	3 (1.4)
Those who answered "Provided me with additional information/answered any questions" above	n/a	n/a	85
How helpful was the information provided?			

Helpful	n/a	n/a	59 (69.4)
Neither helpful or not helpful	n/a	n/a	23 (27.1)
Not helpful	n/a	n/a	1 (1.2)
Missing	n/a	n/a	2 (2.4)
Mean score (10 very helpful, 1 not helpful) (sd)	n/a	n/a	8 (1.5)

^aRespondents were able to select more than one option in answer to question; ^bn=6 respondents were not asked follow-up questions as they did not select the 'no action' option but their free text comment resulted in them being coded as no action; ^cResponse option derived from common free-text actions from 'other' option; ^dQuestion not asked of those who had been notified for the first time as assumed they didn't have time to visit a health professional in time between notification and survey. Also a large proportion of women notified multiple times were not asked this question because they indicated that they spoke/intended to speak to their GP via free text (instead of selecting the provided option); Abbreviations: GP, General Practitioner; sd, standard deviation

Figure 1: Flow chart of breast density survey respondents

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Author/s:

Darcey, E;Hunt, EJ;Keogh, L;McLean, K;Saunders, C;Thompson, S;Woulfe, C;Wylie, E;Stone, J

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