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Impact of personalised risk predictions on breast cancer risk perceptions: insights from the BREATHE study

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Abstract

Objective Biennial mammography screening is well-established for women aged 50 and above, but guidelines for younger women are less clear. Risk-based screening may provide women with key information to make informed decisions about their breast cancer risk and screening. This study examines how predicted breast cancer (BC) risk shapes women's perception and confidence in risk prediction.

Methods Women aged 35 to 59 years were recruited for a prospective multi-centre cohort and stratified into above-average, average, or below-average BC risk categories based on genetic and non-genetic risk factors. Perceived risk was assessed at enrolment and after participants were informed of their predicted risk. We used ordinal models to identify predictors of perceived risk and logistic regression to examine the relationship between changes in perceived risk and confidence in the risk prediction.

Results At enrolment, 43% and 47% of 4112 participants perceived their BC risk pre-result as low or average, respectively. Thirty-five percent adjusted their perceived risk to align more closely with their predicted risk. Predictors of perceived risk post-result: perceived risk pre-result, predicted risk, ethnicity and having regular menstruation. Participants who underestimated their BC risk were nearly eight times more likely to have low confidence in the accuracy of their predicted risk (OR for underestimation vs. accurate perception: 7.94 [95% CI 5.60–11.28]). Predictors of perceived risk post-result: perceived risk pre-result, predicted risk, ethnicity and having regular menstruation. Confidence in risk prediction was lowest when women's perceived risk pre-result was lower than their predicted risk ($OR_{-2\ vs\ 0}$ [95%CI] 5.06 [3.67 to 6.97]).

Conclusion Many women underestimated their BC risk, and their initial perceptions were influenced by the knowledge of their predicted risk. Women who underestimated their risk had less confidence in their predicted risk scores.

Keywords Risk-based screening, Breast cancer, Risk perception, Risk prediction

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Background

Globally, 13 to 21% of years of life lost from preventable cancer mortality is due to breast cancer [1]. A 10-percentage-point increase in uptake of mammography according to current screening guidelines averts 84 breast cancer deaths per 100,000 screened [2]. Mammography screening has the potential to reduce 33% mortality in women who participated [3], provided that the screening uptake rate reaches a minimum of 70%. However, screening also carries risks, such as false-positive results and the overdiagnosis of less aggressive lesions [4–7]. The evidence of benefits and risks of mammography screening vary with age and ethnicity, leading to differing recommendations across major guidelines regarding the optimal age to begin or cease mammography screening and screening interval for average-risk women [8]. For example, the American College of Obstetricians and Gynecologists (ACOG) recommends that women at average risk of breast cancer begin mammography screening at age 40 or by age 50 if not started earlier, with screening every 1 or 2 years based on a shared decision-making process between doctor and patient, evaluating the benefits and harms of screening [9]. Singapore's Ministry of Health (MOH) guidelines recommend starting at age 50 and offer specific recommendations for different age groups (MOH Clinical Practice Guidelines 1/2010 [10]).

Many women under 50 years, who may be at higher risk based on individual factors, are not included in routine screening recommendations in Singapore. This age group often lacks tailored advice about their personal breast cancer risk, which can influence their decision-making and screening behaviour. Moreover, the variability in risk perception among different populations, such as by ethnicity and socio-economic status, suggests that a one-size-fits-all approach to screening may not be optimal. Risk-based screening, which considers individual risk profiles, could offer a more personalized and potentially more effective approach, especially for women at elevated risk who might otherwise not participate in regular screening. By addressing both the benefits and risks more precisely, risk-based screening could bridge the gap between current guidelines and the actual needs of diverse populations.

Perceived risk or susceptibility is considered an important determinant of precautionary health behaviours and is thus central to several theoretical models of health behaviour, such as the Health Belief Model and the Precaution Adoption Process Model [11]. Perceived risk refers to an individual's subjective perception about their likelihood of experiencing personal harm [12]. Perceived risk plays a role in motivating health behaviours, with individuals who perceive their risk as low being less likely to engage in cancer screening [13]. External factors, such as a diagnosis in friends or family, can influence risk perception [14]. Additionally, women who are aware of risk factors associated with a higher likelihood of cancer or have higher perceived risk are more inclined to attend mammography screenings [15, 16]. Inaccurate risk perceptions often lead to inappropriate health behaviours, making it essential to understand these underlying mechanisms to develop effective interventions. In a meta-analysis of 42 studies by Katapodi et al., examining the role of perceived risk in predicting the adoption of health-protective behaviours, specifically breast cancer screening, it was found that women often have inaccurate perceptions of their breast cancer risk, showing an optimistic bias about their personal risk [17]. The study identifies several factors influencing perceived risk, such as family history, race/culture, and worry, with weaker influences from age and education. The analysis found a weak but significant association between perceived risk and mammography screening adherence. Given this context, it is important to investigate whether interventions such as objective risk assessments can correct misguided perceptions of breast cancer risk [18].

Changes in risk perception after an objective risk assessment can provide valuable insights into how effectively risk-based interventions in promoting beneficial health behaviours. The aim of this study is to assess the impact on perceived breast cancer risk when women are informed of their predicted risk and confidence levels related to breast cancer risk prediction.

Methods

Study population

The BREAst screening Tailored for HEr study (BREATHE) is a risk-based mammography screening where women aged 35 to 59 were recruited [19]. Eligible women must not have a histologically confirmed diagnosis of any cancer, no cognitive impairment, and were not pregnant during recruitment. Eligibility criteria was self-reported at recruitment and subsequently verified from medical records. Informed consent was obtained by trained study coordinators in either English, Chinese or Malay. The BREATHE protocol for recruitment and follow-ups is published [19]. Recruitment for the study began in October 2021 and continued until December 2023. Participants were recruited from three hospitals, two polyclinics, and one medical centre in Singapore. Of the 4,592 enrolled individuals, 74 individuals withdrew consent and 17 individuals were diagnosed with breast cancer within six months of enrolment (Supplementary Fig. 1). With an 8.6% (n =389) loss-to-follow-up, the remaining 4112 individuals completed the first follow-up between February 2022 and June 2024. Individuals lost-to-follow-up were not different from those who completed follow-up in their perceived importance of breast cancer screening, perceived risk at enrolment or their predicted risk (Supplementary Table 1).

Perceived breast cancer risk

Participants' perceived breast cancer risk was assessed at two separate occasions with a seven-point Likert scale question "What do you think is your chance of getting breast cancer?" (a score of 1 being the lowest and 7 being the highest). A seven-point Likert scale was chosen over a five-point scale was to reduce the potential that responders would choose the midpoint and increase dispersion that may result from Asian responders being less likely to respond with the extreme ends [20]. The first assessment was at enrolment before a breast cancer education questionnaire. The second assessment was at the first follow-up after the participants were informed of their predicted risk (above-average, average, below-average), derived using genetic and non-genetic information. Participants were only told their risk classification (above-average, average, or below-average). They were not made aware of the criteria that resulted in their risk classification. Details of the education questionnaire and risk prediction and classification can be found in the BREATHE protocol [19]. To begin, all participants were assigned as average risk. Those who met any of the following criteria were reassigned as above-average risk: (1) five-year absolute risk prediction by polygenic risk score (PRS) >3%; (2) five-year absolute risk prediction by the Gail model (GAIL) >1.3%; (3) high mammographic density (BIRAD 4); or (4) recall for additional mammography tests [19]. Participants aged 35 to 49 were classified as below-average risk if they did not meet the above-average risk criteria and had both PRS and GAIL to be <1.3%.

Confidence in predicted breast cancer risk and acceptability of risk classification

We were also interested in the participants' confidence in the risk prediction result as it can potentially influence the adoption of breast cancer screening recommendations and behaviour changes. Confidence was measured by "I am confident that my breast cancer risk classification in my report is reliable" (strongly agree, agree, neither agree nor disagree, disagree or strongly disagree).

To assess the acceptability of disease risk classification, we analysed responses to four questions using a scale from 1 (strongly agree) to 5 (strongly disagree). The questions were as follows: (1) "Learning about my breast cancer risk classification has affected my ability to go on with my day-to-day task"; (2) "Knowing my risk classification including my genetic risk for developing cancer is important"; (3) "Knowing my risk classification including my genetic risk for cancer will motivate me to attend cancer screening according to my risk level"; and (4) "I would like to know my genetic risk classification for other health conditions, if available."

Demographic information and breast cancer screening behaviour

Socioeconomic status and family history of breast cancer may be associated with mammographic screening [21]. Self-reported demographic information was obtained from the baseline questionnaire at enrolment: attained age at enrolment (years), ethnicity (Chinese, Malay, Indian, other), marital status (married, widowed/separated/divorced, never married), employment status (currently, previously, never employed), highest academic attained (primary and below, secondary, post-secondary, and university and above), housing type (public housing by Singapore's housing development board (HDB) 1–3 room, HDB 4-room, HDB 5-room, HDB executive, and private/other), and annual income (SGD, <30,000, 30,001 to 72,000, 72,001 to 120,000, 120,001 to 175,000, >175,000). Participants were asked if they have ever attended breast cancer screening (yes, no), and if they believe in the importance of breast cancer screening (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree).

Breast cancer risk factors

Other variables were obtained from the structured questionnaire at enrolment, including those used in the Gail model such as age at menarche (categorised as <12, 12 to 14, or ≥14 years), age at first live birth (classified as <20, 20 to 24, 25 to 29, ≥30 years, or nulliparous), number of previous benign breast biopsies, presence of atypical hyperplasia on biopsy (yes or no), and the number of first-degree relatives with breast cancer (mother, sisters, or daughters). Five-year absolute risk based on the Gail model was computed using the methodology described in BREATHE protocol [19]. Additional breast cancer risk factors and lifestyle variables, which may influence their general health seeking behaviour, assessed included menstruation status (regular or not), number of children (1, 2, 3+, or none), body mass index (BMI, kg/m2), physical activity based on the International Physical Activity Questionnaire (low, moderate/high), ever smoked regularly (ever/current, never), and ever drunk alcohol (yes at least more than once a month, no).

Statistical analysis

Differences in demographic variables, breast cancer risk factors, and perceived and predicted breast cancer risk between participants who completed follow-up and those loss-to-follow-up were assessed with univariate analysis (Chi-squared test for categorical variables and

Kruskal Wallis test for continuous variables). The associations with age at enrolment of demographic variables, breast cancer risk factors, and perceived and predicted breast cancer risk were assessed with univariate analysis. Missing values were coded as a separate category during analysis, this category was not included in the univariate analysis. For breast cancer risk factors used in the Gail model, missing values were treated the same as the reference category as indicated by the manual.

We applied the ordinal model, using polr from the MASS library, to predict the participants' perceived risk after receiving their risk prediction results. Demographic information, risk factor information known to the participants, and predicted risk (i.e. their risk classification) were tested univariately. Stepwise selection, using stepAIC, from the full model with all variables was used to select the best model. The full model includes all variables statistically significantly associated in univariate analysis. To obtain the most parsimonious model, the model with the lowest Bayesian information criterion (BIC) was selected.

Logistic regression was used to study the association between participant's confidence with our predicted risk and participant's characteristics. Stepwise selection was used to identify the combination of factors associated with participants' lack of confidence (i.e. those that (strongly) disagree or were neutral).

All analysis was done using R version 4.2.2.

Results

A total of 4112 participants completed the follow-up, of which 78% were of Chinese ethnicity, 10% Malay, 7% Indian, and 5% others (Table 1). Most of our population (44%) were between 40 and 49 years old, where, under the 2024 national guidelines, mammogram screening depended on a doctor's recommendation. This was followed by the 50 to 59 age group (41%), with 15% aged between 35 and 39 (Table 1). Ninety-five per cent of our participants attained above a primary level of education (around age 12 years). Ninety-six per cent of our participants believe breast cancer screening is important. Half of our participants aged 40 to 49 years had a mammogram in the past year and 78% of participants aged 50 to 59 years self-reported as routine screeners.

Perceived risk before receiving risk prediction results

At enrolment, before the education survey, 17% (n = 697) of our participants rated their risk to be 1 (lowest risk on the Likert scale) and 1% (n = 21) rated their risk to be 7 (highest risk) (Supplementary Table 2). Forty-four per cent perceived their risk to be below average (Likert scale 1 to 3) and 47% perceived themselves at average risk (Likert scale of 4).

Supplementary Table 3 presents the lifestyle and breast cancer risk factors by perceived risk at enrolment. Perceived risk pre-result at enrolment was predicted by age and ethnicity (Supplementary Table 4). Younger age and being of Chinese ethnicity were associated with higher perceived risk.

Perceived risk after receiving risk prediction results

Based on the BREATHE's criteria, 40% (n = 1650) of the participants were predicted to be at below-average risk, 29% (n = 1184) at average risk and 31% (n = 1276) at above-average risk (Table 1). Ninety-six per cent of the participants in the 35 to 39 age group and 59% in the 40 to 49 age group were classified as below-average risk.

After receiving their predicted risk results, 73% of participants who received a below-average risk prediction perceived themselves to be at below-average risk (Supplementary Table 2); 58% of whom received an average risk prediction perceived themselves to be at average risk; 29% of whom received an above-average risk prediction perceived themselves to be at above-average risk. Participants adjusted their perceived risk in the direction of their predicted risk (below average, average, above average) (Supplementary Fig. 2). Twenty-eight per cent were accurate in their risk perception pre- and post-result. Thirty-five per cent of participants adjusted their risk perception to align more closely with their predicted risk, while 28% continued to either overestimate or underestimate their risk. Eight per cent became more extreme in their perceived risk and < 1% overcompensated in their change in perceived risk. Notably, among the participants who received an above-average risk prediction, 20% adjusted their perceived risk to be above-average (Fig. 1).

Post-result's perceived risk can be estimated by predicted risk, perceived risk at enrolment, ethnicity and menstruation status (Supplementary Table 5). The strongest predictors were predicted risk (odds ratio [$OR_{\text{average vs below average}} = 6.00$; $OR_{\text{above-average vs below average}} = 23.60$) and perceived risk pre-result ($OR_{\text{average vs low}} = 3.29$; $OR_{\text{high vs low}} = 8.57$) (Supplementary Table 5). Figure 2 presents the prediction of hypothetical scenariosof a pre-menopausal Chinese woman, who perceived herself to be of average risk at enrolment and a predicted above-average risk. She is most likely to perceive herself to be at average risk (Probability = 0.59), quite likely to increase her perceived risk to high (Probability = 0.34), and unlikely to perceive her risk to be low (Probability = 0.07).

Receiving an above-average predicted risk or having a higher perceived risk at enrolment increases the likelihood that the woman will view herself to be at a higher risk level (average or high) post-result. A significant interaction was observed between predicted risk and

Table 1 Demographics and perceived and predicted breast cancer risk of BREATHE's participants by their perceived risk at enrolment (low, normal, high)

	All n = 4112	Perceived risk at enrolment			p
		Low n = 1797	Normal n = 1932	High n = 383	
Median age at enrolment, years (IQR)	48 (42 to 53)	49 (43 to 53)	47 (42 to 53)	46 (40 to 51)	< 0.001
Age category, years					
30 to 35	611 (15)	230 (13)	304 (16)	77 (20)	< 0.001
40 to 49	1810 (44)	753 (42)	869 (45)	188 (49)	
50 to 59	1691 (41)	814 (45)	759 (39)	118 (31)	
Ethnicity					
Chinese	3203 (78)	1303 (73)	1587 (82)	313 (82)	< 0.001
Malay	430 (10)	225 (13)	170 (9)	35 (9)	
Indian	268 (7)	159 (9)	95 (5)	14 (4)	
Other	211 (5)	110 (6)	80 (4)	21 (5)	
Employment status					
Currently employed	3301 (80)	1429 (80)	1562 (81)	310 (81)	0.007
Previously employed	761 (19)	334 (19)	354 (18)	73 (19)	
Never employed	50 (1)	34 (2)	16 (1)	0 (0)	
Highest academic attained					
Primary and below	203 (5)	93 (5)	96 (5)	14 (4)	< 0.001
Secondary	746 (18)	367 (20)	343 (18)	36 (9)	
Post-secondary	1183 (29)	519 (29)	559 (29)	105 (27)	
University and above	1980 (48)	818 (46)	934 (48)	228 (60)	
Breast cancer screening					
Once a year	911 (22)	346 (19)	442 (23)	123 (32)	< 0.001
Once every two years	1605 (39)	768 (43)	719 (37)	118 (31)	
Ever attended (not intend to continue)	92 (2)	43 (2)	41 (2)	8 (2)	
Other	190 (5)	88 (5)	83 (4)	19 (5)	
Non-regular screeners age < 50 years	657 (16)	278 (15)	328 (17)	51 (13)	
Unknown	657 (16)	274 (15)	319 (17)	64 (17)	
I believe in the importance of breast cancer screening					
Strongly agree	2419 (59)	1057 (59)	1116 (58)	246 (64)	0.061
Agree	1541 (37)	669 (37)	744 (39)	128 (33)	
Neither agree nor disagree	140 (3)	63 (4)	69 (4)	8 (2)	
Disagree	6 (0)	6 (0)	0 (0)	0 (0)	
Strongly disagree	6 (0)	2 (0)	3 (0)	1 (0)	
(At enrolment) What do you think is your chance of getting breast cancer?					
1 (Lowest)	697 (17)	697 (39)	0 (0)	0 (0)	–
2	589 (14)	589 (33)	0 (0)	0 (0)	
3	511 (12)	511 (28)	0 (0)	0 (0)	
4 (Average)	1932 (47)	0 (0)	1932 (100)	0 (0)	
5	288 (7)	0 (0)	0 (0)	288 (75)	
6	74 (2)	0 (0)	0 (0)	74 (19)	
7 (Highest)	21 (1)	0 (0)	0 (0)	21 (5)	
(At follow-up) What do you think is your chance of getting breast cancer?					
1 (Lowest)	627 (15)	465 (26)	144 (7)	18 (5)	< 0.001
2	679 (17)	379 (21)	266 (14)	34 (9)	
3	580 (14)	264 (15)	272 (14)	44 (11)	
4 (Average)	1805 (44)	588 (33)	1062 (55)	155 (40)	
5	350 (9)	86 (5)	164 (8)	100 (26)	

Table 1 (continued)

	All n = 4112	Perceived risk at enrolment			p
		Low n = 1797	Normal n = 1932	High n = 383	
6	55 (1)	12 (1)	18 (1)	25 (7)	
7 (Highest)	16 (0)	3 (0)	6 (0)	7 (2)	
Predicted risk					
Below-average	1650 (40)	714 (40)	790 (41)	146 (38)	< 0.001
Average	1185 (29)	599 (33)	534 (28)	52 (14)	
Above average	1277 (31)	484 (27)	608 (31)	185 (48)	
I am confident that my breast cancer risk classification in my report is reliable					
Strongly agree	885 (22)	445 (25)	368 (19)	72 (19)	< 0.001
Agree	2493 (61)	1074 (60)	1189 (62)	230 (60)	
Neither agree nor disagree	674 (16)	250 (14)	349 (18)	75 (20)	
Disagree	29 (1)	12 (1)	13 (1)	4 (1)	
Strongly disagree	31 (1)	16 (1)	13 (1)	2 (1)	

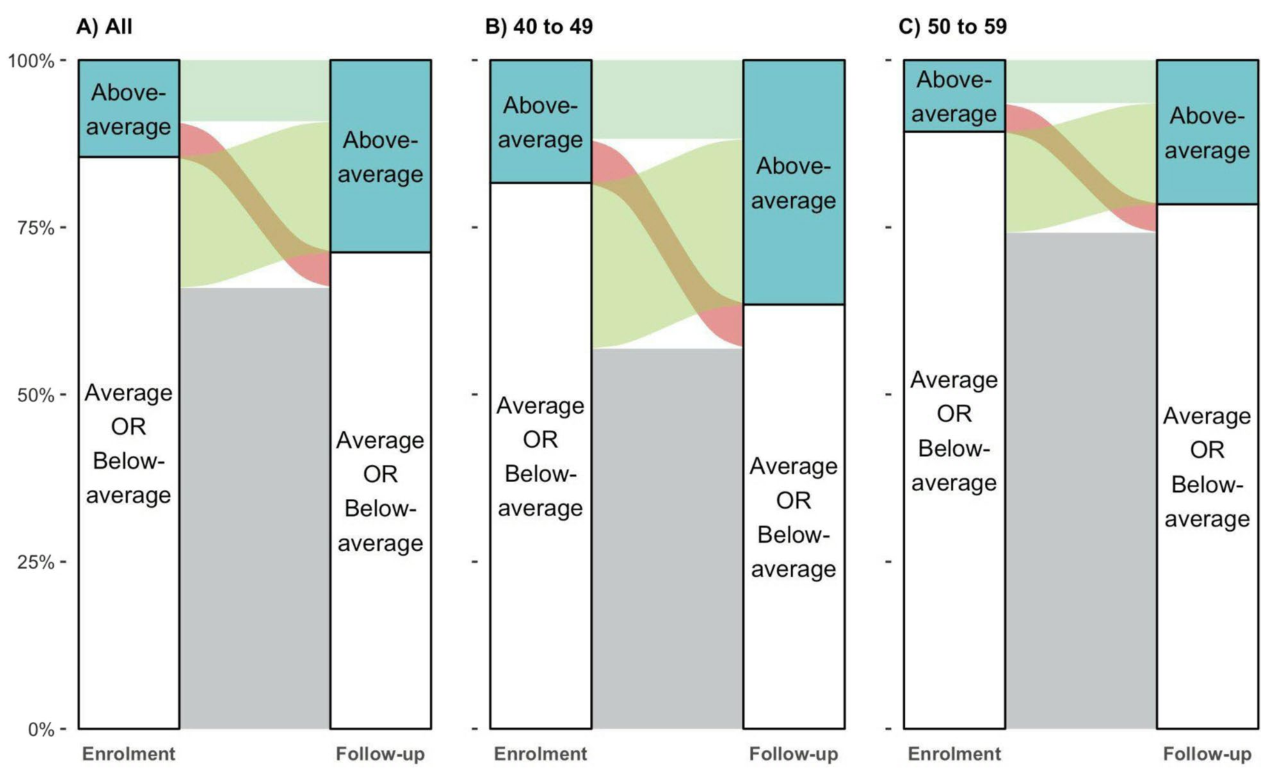

Fig. 1 Changes in perceived risk (enrolment and during follow-up) in women who were identified as above-average risk (facet label: below average, average, above average). Perceived risk was categorised as above-average (Likert scale 5 to 7) in blue and (below) average (Likert scale 1 to 4) in white

perceived risk at enrolment (Supplementary Table 5), indicating that participants' perception of high-risk post-results tends to be reinforced by an above-average risk prediction or diminished by an average or below-average risk prediction.

The current age-based screening may have influenced women's perception of risk within their age groups.

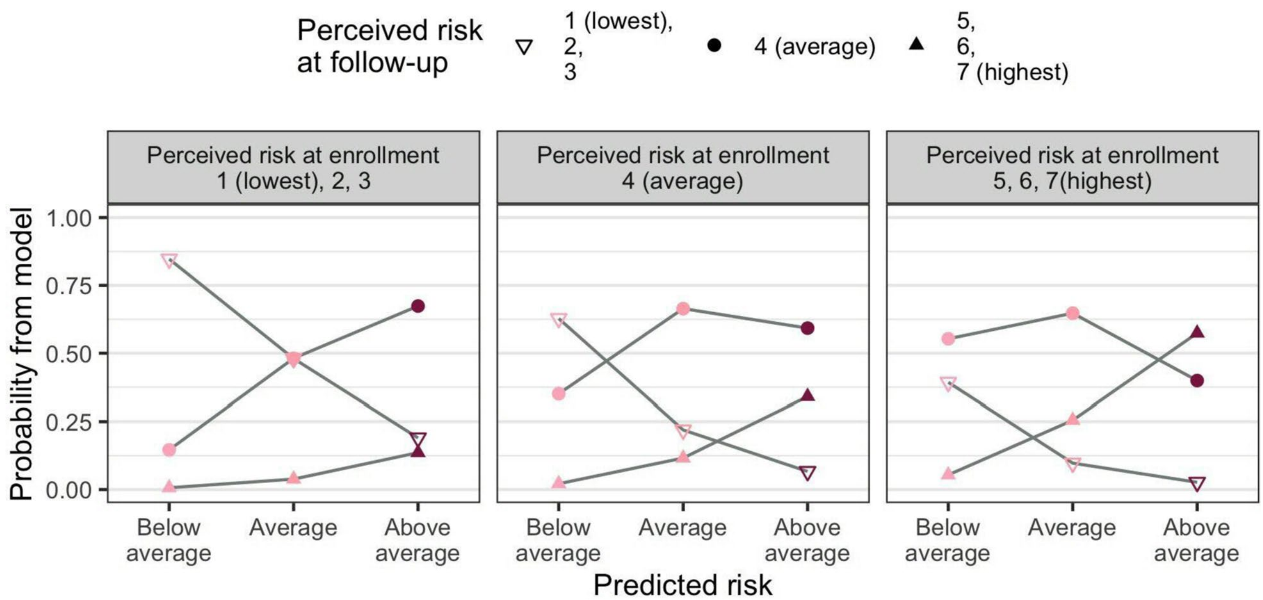

Fig. 2 Hypothetical scenarios of a Chinese pre-menopausal woman. The ordinal model to predict the woman's perceived risk after risk assessment (y-axis) included perceived risk at enrolment (panel) predicted risk (x-axis), ethnicity, and menopausal status

We repeated the analysis within the age categories and observed similar associations of pre-results perceived risk and predicted risk with post-results perceived risk within each age category (Supplementary Table 6). However, ethnicity was not associated with post-results perceived risk among the younger participants aged 35 to 39 (Supplementary Table 6). In addition, the most parsimonious model did not include ethnicity for participants aged 40 to 49.

Confidence in predicted risk result

Above 94% of our participants reported that they understood their risk classification (94%, "Q3. I have a clear understanding of my breast cancer risk classification from my report.") and study's recommendation (95%, "Q4. I have a clear understanding of BREATHE study recommendations from my report.") (Supplementary Table 7). The majority (82%) of our participants (strongly) agree with the statement "Q5. I am confident that my breast cancer risk classification in my report is reliable" (Supplementary Table 7). Proportion of participants who were neutral or (strongly) disagreed with the statement (Q5) was highest in oldest age group (21%) and lowest in youngest (12%); highest in Chinese (20%) and lowest in Malay (7%); and highest in those who were predicted "above-average" risk (30%) and lowest in "below-average" (12%); chi-square test $p < 0.001$. Similar trends were observed for the earlier two statements (Q3 and Q4).

Participants whose predicted risk closely matched their initial perceived risk were more likely to feel confident about risk prediction results (Fig. 3A). In contrast, participants who initially perceived themselves as low-risk but received an above-average risk prediction were the most likely to lack confidence in the risk prediction ($OR_{-2vs\ 0}$ (95% confidence interval [CI]): 5.06 [3.67 to 6.97] adjusted for perceived risk at enrolment, perceived risk at first follow-up, and ethnicity (Supplementary Table 8). A larger effect of the difference in perceived risk and predicted risk ($OR_{-2vs\ 0}$ [95%CI] 7.94 [5.60 to 11.28] and $OR_{-1vs\ 0}$ [95%CI]: 1.87 [1.52 to 2.30]) on confidence was observed when perceived risk post-result was used (Supplementary Table 9, Fig. 3B).

Overall, participants' prior knowledge of breast cancer, as assessed by seven questions from the education survey (Q7 to 13), was not associated with their confidence in the reliability of the risk prediction result (Supplementary Table 10). The exception was among participants, aged 40 to 59, who agreed that a lack of family history does not eliminate the possibility of developing breast cancer, whereby they were more likely to be neutral or disagree with the reliability of the risk prediction.

Discussion

Clinical guidelines advocate for a tailored approach to mammography screening for specific age groups and recommend using decision aids to enhance discussions between patients and healthcare providers [22]. In line with this, we investigated how personalised breast cancer risk prediction results affect women's perceptions of their breast cancer risk. Before receiving their predicted

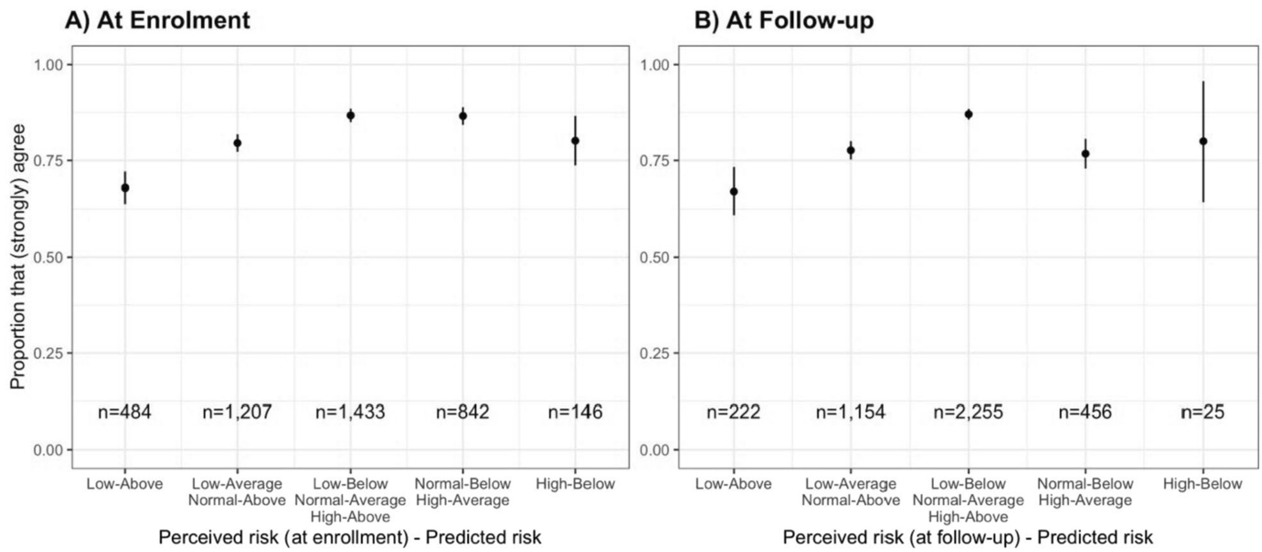

Fig. 3 Association of the difference in perceived and predicted risk with participant's confidence in their risk classification

risk results, 43% of participants perceived their breast cancer risk as below average, with 47% considering themselves to be at average risk. However, many participants tended to underestimate their risk when compared to their predicted risk category. Overall, 28% maintained an over- or underestimation of their risk post-results, and 8% became more extreme in their perceptions.

Perceiving breast cancer risk has been positively associated with adherence to screening in Western countries [23]. Our study demonstrated that the strongest predictors of post-result perceived risk were the predicted risk and the initial perceived risk, therefore highlighting the possibility of encouraging mammogram screening uptake by informing one their predicted risk. It is however uncertain if changes in risk perception will be sufficient to translate into actual alterations in screening behaviour in Asian countries, whereby mammogram screening is often viewed more negatively in terms of efficacy and cost than in Western countries [24–26]. There is thus a need for more in-depth exploration of women's perception towards mammogram to enable more alignment of health communication on mammogram towards their values.

Our study also found confidence in the risk prediction to be generally high. Participants whose predicted risk closely matched their initial perceptions were more likely to trust the results. Participants who were most sceptical of the risk prediction results were less likely to adjust their initial perceived risk to their predicted risk. The implication of inaccurate risk perception on subsequent health behaviour is unclear [27–29], although Katapodi et al. concluded with a cross-sectional study that underestimation of breast cancer risk did not predict optimum breast cancer screening practice [28]. Other studies suggest that individuals may react to risk information in ways that do not align with rational decision-making [30]. Some high-risk individuals may experience anxiety or fear that discourages them from engaging in screening, while others may adopt a fatalistic attitude. Further research is needed to explore the relationship between confidence in risk predictions, changes in perceived risk and subsequent health behaviour. Notably prior knowledge of breast cancer risk factors had little impact on participants' confidence in the risk prediction, except among between 40 and 59 years who agreed that a lack of family history did not rule out the possibility of breast cancer. This warrants further research into factors influencing confidence on risk prediction for risk prediction to be used in health behaviour change.

The complexity of risk communication, which has an aspect of uncertainty that is hard to grasp, also poses a barrier. Decision aids, which are designed to enhance understanding and confidence in decision-making, have shown mixed outcomes in practice. Eden et al. found that while decision aids helped reduce uncertainty and increase confidence in decision-making, they did not significantly alter screening intentions [31]. Additionally, a randomised clinical trial of 204 women aged 39 to 48 showed that decision aids improved knowledge but did not significantly affect risk-based screening uptake or decrease decisional conflict [32]. These findings reflect the ongoing challenges in effectively integrating individual risk assessments into practical screening decisions. Even when risk is communicated effectively, trust in healthcare systems, physicians, and genetic testing itself plays a role in determining whether individuals follow screening recommendations. Cultural beliefs, previous healthcare experiences, and perceived accessibility of screening services will affect uptake rates.

Individual breast cancer risk assessment has the potential to direct women to screening decisions that are tailored to their specific risk profile [33]. This approach is particularly beneficial for those in age groups where shared decision-making with healthcare providers is recommended or as an alternative to the traditional age-based screening guidelines [34]. This is particularly relevant in Singapore, where a substantial proportion of breast cancers occur in women under 50 years who do not have clear recommendations to attend routine screening[35, 36], and thus may not perceive themselves as being at significant risk to participate in screening. We found that most participants were open to breast cancer risk classification beyond age-based guidelines and showed interest in learning about their personalised risk for other diseases. When participants received their predicted risk, they generally adjusted their initial perceived risk to align with it. To make breast cancer screening available to young women at elevated risk, and not overburden the healthcare system, a single time point assessment of breast cancer risk, with or without mammography, may be suitable for women to determine their optimal starting age for mammography screening [37, 38]. The discriminatory ability of breast cancer risk stratification is validated by multiple observational studies [39, 40]. Large, randomised control trials are ongoing to improve the performance of population-based screening [41]. Nonetheless, we found that women who received a predicted risk higher than their initial perception tended to be less confident in the risk assessment. It should be noted that there are concerns that risk stratification might result in many breast cancers being 'missed' if women deemed to be at low risk are not screened [42, 43]. As such, healthcare providers need to develop and be trained on effective risk communication strategies to ensure women understand their risk and are confident in the recommended actions. Policymakers also need to consider other health financing model to ensure equitable access to screening despite one's personal risk. Exploring key areas for future research, such as the long-term effects of risk prediction on screening behaviours, would broaden the study's contributions to the field and help inform policies that optimize screening strategies.

The limitations of this study include several key factors. Self-reported data on lifestyle and personal risk perceptions may introduce bias and affect the accuracy of the results. In particular, social desirability bias or recall bias may have influenced the responses provided by participants, leading to an overestimation or underestimation of certain behaviours or risk factors. The study population may not fully represent the general population. BREATHE participants were generally well-informed about breast cancer and recognized the importance of screening, which made them more proactive about attending screenings compared to the general population, as reported in a national survey [36]. This higher awareness is likely attributed to the recruitment settings at established mammography providers and wellness centres, where participants were generally from less-deprived backgrounds [44]. This specific recruitment approach may affect the generalizability of the study's findings to the broader population, as the study cohort may not fully represent individuals from different socio-economic backgrounds. While the Gail model and PRS are commonly used for predicting breast cancer risk, they do not capture all possible risk factors. Other factors not included in these models may contribute to breast cancer risk, potentially influencing the accuracy of predicted risk assessments. Perceived risk was measured on a 1 to 7 Likert scale, which differs from the three-category classification of predicted risk (above-average, average, below-average). The mapping of Likert scale scores to risk categories may not align perfectly with participants'understanding of risk, potentially affecting their perception and confidence. The study also did not evaluate whether participants' lay understanding of risk matched the numerical estimates used by experts, which could have led to mismatches between perceived and predicted risk and affected overall confidence in the risk assessment. Finally, the study did not account for external factors such as physician guidance or social influences on participants' risk perceptions and confidence. These factors, such as personalized advice or societal norms, could have contributed to discrepancies between perceived and predicted risk, impacting decision-making and confidence levels.

Future research should focus on improving how we communicate breast cancer risk to women, making sure they fully understand their personal risk and feel confident in taking action. It would be helpful to explore how personalized tools, like interactive or visual aids, can help boost women's confidence in their risk assessments. Research should also look into ways to encourage women at higher risk, particularly those with a family history, to participate in screening. Long-term studies would give us a better idea of how a woman's risk perception changes over time and how this affects her decision to get screened. It is also important to consider the impact of cultural, social, and economic factors on screening, as this will help to create more accessible and effective programs for all women.

Conclusions

Participants tend to underestimate their breast cancer risk both before knowing their predicted risk result and after. The study revealed that participants' risk perceptions often aligned more closely with their predicted risk after receiving their results, indicating a tendency to adjust their perceived risk based on the predictions provided. Although most participants expressed confidence in the accuracy of their risk assessments, there was notable variability based on initial perceptions and the match between perceived risk post-result and predicted risk.

Abbreviations

BREATHE	BREAst screening Tailored for HEr study
CI	Confidence interval
OR	Odds ratio

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12967-025-06515-1.

Additional file 1. **Supplementary Figure 1**. Flowchart of individuals enrolled in BREATHE. **Figure 2**. Changes in perceived riskby predicted riskand age group.

Additional file 2. **Supplementary Table 1**. Comparing participants lost-to-follow-up with participants who completed follow-up. **Table 2**. Proportion of participants at each level of perceived risk (Likert scale 1 to 7) at enrolment and during follow-up) by predicted risk (below average, average, above average) and age group. **Table 3**. Lifestyle and breast cancer risk factors of BREATHE's participants by their perceived risk at enrolment. **Table 4**. Predicting women's perceived breast cancer risk at enrolment, using ordinal models. Variables were selected based on the lowest Bayesian information criterion. **Table 5**. Predicting women's perceived breast cancer risk after receiving risk reports, using ordinal models. Variables were selected based on the lowest Bayesian information criterion (BIC). **Table 6**. Predicting women's perceived breast cancer risk after receiving risk reports by age categories, using ordinal models. Variables were selected based on the lowest Bayesian information criterion. **Table 7**. Perceived and predicted risk variables associated with 1) understanding of the risk classification, 2) understanding of the risk recommendation, and 3) Confidence in the risk classification. **Table 8**. Association of confidence in risk classification with the difference in perceived risk at enrolment and predicted risk, using logistic models. Variables were selected based on the lowest Bayesian information criterion. **Table 9**. Association of confidence in risk classification with the difference in perceived risk at follow-up and predicted risk, using logistic models. Variables were selected based on the lowest Bayesian information criterion. **Table 10**. Association of participants prior knowledge with their perception of the reliability of their predicted risk, by age.

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Author contributions

Authors Mikael Hartman, Philip Tsau Choong Iau, Jingmei Li, and Peh Joo Ho contributed to the study conception and design. Material preparation and data collection were performed by Mikael Hartman, Philip Tsau Choong Iau, Jenny Liu, Nur Khaliesah Mohamed Riza, Ying Jia Chew, Su-Ann Goh, Han Boon Oh, Christopher Hang Liang Keh, Chi Hui Chin, Sing Cheer Kwek, Zhi Peng Zhang, Desmond Luan Seng Ong, Swee Tian Quek, and Sujith Wijerathne. Analysis was done by Peh Joo Ho. The first draft of the manuscript was written by Peh Joo Ho, Serene Si Ning Goh and Jingmei; all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability

The data generated by this study is owned by the providing institutions (NTFGH, NUH, AH, NUP and JMC). Data may be obtained with a reasonable request to the main Principal Investigator Mikael Hartman (mikael_hartman@nuhs.edu.sg). The data is not publicly available due to privacy and/or ethical restrictions. Legal agreements will need to be drawn up between data requesters and providers for access to the de-identified data. The proposed studies need to comply with Singapore's laws and regulations regarding human biomedical research and clinical investigation including The Declaration of Helsinki, International Good Clinical Practice Guidelines, Good Clinical Practice guidelines by Singapore's Health Science Authority and the Ministry of Health.

Declarations

Ethics approval and consent to participate

The BREATHE protocol for recruitment and follow-ups is published. Informed consent was obtained by trained study coordinators in the participant's preferred language (English, Chinese or Malay). Ethics approval was obtained from the National Healthcare Group Domain-Specific Review Board (ref no. 2020/01327, on 7 June 2021). Individuals who withdrew consent before 1 August 2024 ($n = 74$) were excluded from all analyses presented in this study.

Informed consent

Informed consent was obtained from all individual participants included in the study.

Competing interests

The authors have declared that no competing interests exist.

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