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Towards informed decisions on breast cancer screening: Development and pilot testing of a decision aid for Chinese women

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Abstract

Objective: To pilot-test a novel, self-use breast cancer (BC) screening decision aid (DA) targeting Hong Kong (HK) Chinese women at average risk of BC.

Methods: Women were recruited through a population-based telephone survey using random digit dialing between October 2013 and January 2014. Eligible participants completed our baseline survey and then received the DA by post. Participants (n=90) completed follow-up telephone interviews one month later.

Results: Most participants thought that all/most DA content was presented clearly (86.7%), and was useful in helping women make screening-related decisions (88.9%). It also achieved its expected impact of improving informed decision-making and increasing shared-participation preference without increasing participants' anxiety levels. Participants showed a modest non-statistical increase in their screening knowledge scores. Older women rated the perceived severity of a BC diagnosis as significantly lower, and more educated women reported significantly lower perceived anxiety about the disease.

Conclusion: Our DA appears acceptable and feasible for self-use by HK Chinese women who need to make an informed decision about BC screening without increasing overall anxiety levels.

Practice implications: This study supports the potential of self-use DAs for cancer screening-related decision support in a Chinese population.

INTRODUCTION

Decision aids (DAs) are systematically developed interventions that support better informed decision making by enhancing individuals' cognitive attributes and decision-making process related-outcomes, including knowledge and beliefs about a disease and its associated medical interventions, and improving their risk perception accuracy[1]. DAs play an important role in cancer screening with growing evidence indicating that they improve individual decision-making process-related outcomes[1-6] including reducing proportions of undecided patients and related decisional conflicts[5,6]. DAs are particularly useful when there are multiple possible health interventions and when each alternative has its specific benefits and harms that individuals might value differently[7].

There is a need to help women make informed choices about breast cancer (BC) screening based on appraisal of benefits and risks[8,9], in view of unresolved debates on potential benefits versus harms from mammography screening in the US and Europe[8,10-12]. Among various modalities of BC detection, only mammography has been demonstrated to be effective in reducing disease-specific mortality[11,13,14], while the effectiveness of other modalities remain unproven[15-19]. In addition to this uncertainty, false alarms, over-diagnosis and over-treatment have been cited as the major potential harms arising from BC screening[11,19]. A critical examination of the BC screening debate is particularly important in Chinese populations, especially to those living in one of the most westernized and urbanized Chinese cities, Hong Kong (HK), given the fact that its markedly lower BC prevalence might lead to more false positive cases in comparison to the Caucasian counterparts. In 2012, age-standardized incidence rates in the UK and US were 95 and 92.9 per 100,000 women respectively, while the rate in HK was 61/100,000[20]. Respecting screening uptake, by 2003-2004 approximately 14.7% of women have ever attended mammography screening in Hong Kong[21]. More

recently, haphazard opportunistic mammography ultrasonography and increasingly MRI screening of women at average risk, have proliferated in recent years.

So public information on BC screening needs appropriate balance[22]. Although HK does not provide population-based systematic BC screening, opportunistic mammography screening services are available in public and private hospital-based units and general outpatient clinics as well as in private laboratories, for a minimal user charge to potential clients. Significant promotion of mammography for HK Chinese women by these service providers, among others is seen as a means to reduce the BC-associated mortality rate[21,23]. However, difficulties in accessing scientifically validated and yet reader-friendly information on early BC detection practices, make it difficult for many Chinese women to weigh the pros and cons of BC screening before making an informed choice. Since individual judgment is a key part of any decision-making process, a tailored decision support tool or decision aid (DA) should help women formulate more realistic expectations of mammography screening and other early BC detection practices.

Most DAs for BC screening were developed and used in Western populations[7]. However, among Chinese women at an average risk of developing BC, a culturally-relevant DA that informs Chinese women of available early BC detection strategies has yet to be developed and tested. Our previous research to develop a DA that assisted women making surgical treatment choices for early BC revealed that many HK Chinese women with BC preferred a booklet over alternative formats[24]. That decisional tool was also tested in a randomized controlled trial setting indicating benefit by reducing decisional conflicts and subsequent regret and enhancing clinical services in our BC population[25]. We have therefore developed and pilot-tested a print-based DA tailored for HK Chinese women that focuses on aiding

decision-making for early BC detection strategies. We investigated the initial acceptability and utility of this DA and evaluated levels and possible changes in knowledge and perceived risk ('information'), and role in screening decision and decisional conflict ('decision-process') attributes in a sample of HK Chinese women. We also evaluated whether or not there was any systematic variation in the attributes among subgroups.

METHODS

Content development of a decision aid

The content of the DA was developed with reference to a thorough literature review using PUBMED database, the latest Cochrane BC screening leaflet[26], existing patient aids materials[27], cross-reference and expert opinion. We adapted the International Patient Decision Aid Standards (IPDAS) framework[28]. Our final DA booklet was written in the traditional Chinese characters commonly used in HK, Taiwan and Singapore and consisted of eight components (**Table 1**).

To formulate the DA content, we established a working group of neutral non-advocates to maintain objectivity, comprising a 7-member panel with backgrounds in statistics, epidemiology, public health, psycho-oncology and oncology. We reviewed common BC detection strategies: mammography, breast ultrasound, clinical breast examination, breast self-examination, and magnetic resonance imaging. These strategies are explained in the DA. A narrative review method was applied to the content development. Two panel members (IW, CNW) conducted the review using the scoping review approach[29,30], which helps to identify appropriate 'parameters' (domains or scope) relating to the potential benefits, harms and uncertainties of BC screening practices (Details in **Appendix A)**. The findings were then adapted to suit the organizational format of our DA.

During this stage, inconsistencies were resolved by iterative discussions in the working group with invited associates. Specifications regarding graphics, layout and typography design were passed on to a graphic design company which produced and printed the DA. Hand-drawn illustrations and graphical representations of proportions were used to facilitate comprehension. An illustrative example is shown in **Appendix B**.

Participants and setting

We used a prospective before-and-after survey study design to evaluate the DA effectiveness in helping women make informed decisions about early BC detection practices. Subjects were recruited by a population-based telephone survey, using random-digit dialing to obtain a sample from all fixed, land-based telephone lines, and within-household sampling of an eligible household member. If more than one female member per household met our criterion, she whose birthday was the closest to the date of the interview was selected. For non-response calls, three attempts were made before number replacement. Selected respondents were briefed about our study and invited to participate with verbal informed consent, after which the baseline telephone interview commenced. We also obtained consent to mail the DA, and followed them up through a second telephone survey conducted a month later. Those who completed both baseline and the follow-up surveys were given a HK$100 (~US$13) supermarket coupon as an incentive.

Baseline telephone interviews were administered to obtain information including the information and decision-making process attributes and socio-demographic characteristics. The follow-up survey repeated the baseline telephone survey items and included additional

questions on the acceptability and utilization of the DA, decisional conflict and perceived benefits and barriers surrounding BC screening.

The baseline survey (22nd October to 20th November 2013) yielded an overall response rate of 43.9%, while the one-month follow-up survey occurred between 22nd November 2013 and 15th January 2014. At baseline, 126 participants consented to participate and were assessed. DAs were then posted to participants, three questionnaires being returned due to addressing errors, so 123 participants received the DA; 90/123 subsequently completed the follow-up interviews, giving a post-intervention response rate of 73.2%. A sample size of 90 is sufficient to estimate population characteristics having a mean proportion of 0.5 with an error margin of 0.10 and 95% confidence interval. Ethics approval was granted by the Hospital Authority West Cluster and HKU Institutional Review Board.

Subject eligibility

Inclusion criteria were: (1) Cantonese-speaking Chinese women aged 30 or above at average risk of developing BC, (2) able to give verbal consent, (3) able to read the DA, and (4) able to answer/respond to telephone interviews. We excluded women with a personal or significant family history of breast/ovarian cancer in first or second degree blood relatives because these women are at higher risk of BC.

Outcome measures

Outcome measures were (i) acceptability of the DA, the primary outcome measure, (ii) utility of the DA and other attributes, namely (iii) knowledge regarding BC screening; (iv) perception of personal BC risk; (v) screening decisional control preferences; (vi) decisional conflict and (vii) perceived benefits of and barriers to screening. DA acceptability, and utility

and measures (vi) to (vii) were measured during follow-up assessments, while remaining outcomes were measured both at baseline and follow-up assessments.

Acceptability and utility

Seven items were adapted from Smith et al's study[31]. After receiving the DA, respondents were asked about the comprehensibility of the DA booklet relative to the amount of information presented, length, clarity, coverage of screening options and helpfulness for making BC screening decisions. We also evaluated whether the information in the booklet was new to the respondents. A utilization measure was used to evaluate whether the individuals had partially or fully read the booklet.

Knowledge of BC screening

Three simple true-false item questions focused on the potential benefits and harms for BC screening. Each correct response scored 1 point. The total knowledge score was transformed into a rounded percentile scale for analysis.

Self-perceived risk of developing BC

Perceived risk assessment comprised five domains: (i) self-rated five-year risk of developing BC; (ii) comparative risk at own age (perceived personal risk of developing BC, compared to other women at their own age); (iii) perceived severity of a BC diagnosis; (iv) perceived BC anxiety and (v) perceived worry about developing BC during their lifetime. Sub-domain scores (i) to (iv) ranged from 1 ("impossible"/"much lower"/"strongly disagree") to 5 ("certain"/"much higher"/"strongly agree"), excepting the sub-domain scores (v) for perceived worry, scored 1 (not at all) to 7 (all the time).

Preference for control in decision making process

The validated Control Preference Scale was used[32]. Respondents were asked "Who should make screening decisions?" For analyses, responses were collapsed to reflect active decision-making styles (a women should make her own screening decision without or after considering doctor's opinion), collaborative style (decision-making shared with a doctor), and passive styles (doctors decide for a women after/without considering the woman's preference).

Decisional conflict

Decisional conflict, measured by the validated Chinese version of Decisional Conflict Scale (DCS)[33], reflects the aversive subjective experience of indecisiveness[34], when choice (here choice of screening) among competing options (screening modalities) involves potential risk, regret or challenge to the life values of the individual concerned[35]. For each of 16 questions covering five domains (uncertainty, informed, value clarity, support and effective decision) five responses were possible: 'yes', 'probably yes', 'unsure', 'probably no' and 'no'. For analyses, each item response was scored 0 to 4, individuals' total scores obtained being then standardized into a scale from 0 (no decisional conflict) to 100 (extreme decisional conflict).

Perceived benefits and barriers

We surveyed and summarized important perceived factors (namely, benefits and barriers) associated with a particular health decision on BC screening practices that lead to having or not having regular screening for BC. Listed benefits included early detection at less advanced stages, understanding of health condition, and, reduced chance of dying from BC, while barriers included information of screening (where or how to go), screening costs, over-diagnosis, false alarm or psychological pressure.

Statistical analyses

Descriptive statistics were used to summarize subject characteristics, acceptability and utility of the DA. We used Wilcoxon signed rank/Kappa significance test to assess statistical significance of differences/concordance in our outcome measures (knowledge scores and decision making preference, respectively) on repeated measurements at the time of baseline and follow-up assessments. We applied multiple linear regression and logistic regression models to adjust for the potential confounding effects of age and socio-economic status (educational level and monthly household income). We used the conventional level of statistical significance of 0.05. All analyses were performed by using STATA version 13.0.

RESULTS

Subject characteristics

Table 2 summarizes the sample characteristics at baseline and follow-up assessments. Most participants were aged 50 or above and born in HK. They commonly had two or more children, had completed at least secondary education, and were not covered by private medical insurance. More than 40% of participants rated their own health status as fair or poor. There was no statistically significant socio-demographic difference (all *p-values* > 0.05) between the baseline sample and the participants who completed both rounds of survey (**Table 2**). There was also no statistically significant differences for other attributes (including level of knowledge related to breast cancer screening, perception of personal breast cancer risk, screening decisional control preferences) between drop-outs and those completing both surveys (data not shown). Thus, we restricted our analyses to respondents completing both surveys (n=90).

Acceptability and utility of the DA

We examined if the format of the piloted DA needed improvement by checking the responses to questions about preference for and satisfaction with the sections and presentation format of the booklet. Acceptability of the DA booklet was generally high **(Table 3)**. Most participants indicated that the amount of information provided was 'about right' (n = 66, 73.3%) and that the length of the DA presentation was 'about right' (n = 76, 84.4%). Most participants also felt that DA content was generally presented clearly (86.7%), and was very/somewhat helpful in their BC screening decision-making (88.9%). About half of the respondents (57.8%) felt that coverage of different screening modalities was balanced, though some women found the presentation slanted towards mammography (15.6%). Most participants (53.3%) preferred BC information in a booklet format to a web-based form (22.2%) or mobile application (22.2%).

In the DA booklet, the most commonly viewed components were the disease rates in HK and the benefits of the screening practices, with 98.9% of participants reportedly read these sections, whereas the 5-point executive summary (86.7% of participants read this) and the section on uncertainties of screening practices (87.8% of participants read this) were the least commonly viewed sections (data not shown). Respondents generally rated the quality of each section favorably: more than half of the women rated the sections as excellent/good, and only a few women (1.3%) rated one of the sections (on value clarification and guidance to reaching decisions) as being poor (data not shown). **Appendix Table C.1** lists the important perceived benefits and perceived barriers regarding regular screening. The strongest perceived benefits were: early discovery of BC at a less advanced stage (42.2%), and; knowing more about one's health condition (42.2%). Conversely, the leading barriers were: lack of adequate information on where or how to obtain screening (14.4%), and; concern about the risk of getting BC (14.4%).

Other outcome measures

Overall knowledge scores in pre- (61/100) and post- (63/100) assessments showed participants were generally knowledgeable, though significant knowledge gains over time were not observed (**Table 4)**. Using multivariable regressions, comparisons of information measures (pre- versus post-intervention) by socio-demographic subgroups showed no statistical changes in subgroup knowledge levels. Age, however, appeared to be marginally important (adjusted OR=1.03, 95% CI=(0.99, 1.09)) (**Table 5**). Furthermore, we found no statistically significant changes in women's self-rated 5-year BC risk and comparative risk at their own ages, after adjusting for the effects of age, educational level and monthly household income. However, older women perceived significantly less severity from a BC diagnosis (β=-0.03, 95% CI=(-0.06,-0.01)), and more educated women reported significantly less anxiety about developing the disease during their lifetime (β=-0.85, 95% CI=(-1.47,-0.24)) (**Table 5**).

Overall, at both baseline and follow-up (46.1% and 50.0%, respectively), many women indicated preference for an active decision-making role regarding BC screening. Notably, preferred involvement in screening decision-making changed significantly (*p-value* for *kappa* = 0.99) between pre- and post-intervention assessments. At follow-up far fewer women (30.0%) preferred a passive role compared to at baseline (48.3%) and, more women favored an active or collaborative decision-making role at follow-up (70.0%) compared to baseline (51.7%) (**Table 4**). We then investigated if any subgroup of women demonstrated significant changes from passive style to active or collaborative styles in their decision control preference after having read the DA. The results revealed that age and monthly household income were unrelated to changes in control preference, but a significant relationship

between educational level and changes in decision control preference from passive style to active/collaborative styles was observed (adjusted OR=0.36, 95% CI=(0.15, 0.84)) (**Table 5**).

Finally, we investigated decisional conflict among our participants after receiving the DA. The mean value for the total DCS scores indicated a low degree of decisional conflict among our participants. The scores for uncertainty, feeling uninformed, feeling unclear about personal values, insufficient support and ineffective decision subscales were relatively low, being below 22 (standardized to a scale of 0-100) (**Table 4**).

DISCUSSION AND CONCLUSIONS

We developed and pilot-tested a decision aid booklet that covers aspects of early BC detection strategies tailored for HK Chinese women at average risk of BC. Respondents' reports of acceptability and utility indicated that this DA was effective in helping readers understand the importance of informed decision-making, and importantly, prompted a preference for more active/collaborative participation styles in screening decision-making without elevating self-reported anxiety and worry at follow-up. This provides preliminary evidence that our DA could provide decisional support to Chinese women facing multiple screening options and help them recognize potential benefits and risks of screening choices. Such an aid is particularly relevant for the Chinese female population, as there is currently insufficiently diverse evidence available in Chinese indicating the 'best'/'optimal' screening choice.

Just over half of the women preferred the booklet format (53.3%) over website and mobile application (44.2%) formats, consistent with our recent study that developed a DA for women facing BC surgical treatment choices[25]. However, web-based or mobile-phone application

DAs may become important in the near future, as a cohort who have grown up with mobile technology enters the risk range for BC, altering preferred sources of health information. A recent systematic review concluded that internet-based DAs in general do not produce contradictory impacts to what is commonly found in conventional DAs[7]. More research is needed on preferences and utilities of DAs in innovative formats[7], especially as internet popularity grows.

About one-in-eight respondents did not read the section addressing potential uncertainties surrounding screening practices detailing the international debate about BC mortality reductions. Ambiguity of benefit will not generally clarify choice, but may ensure a default "no decision" state persists. People undecided on a topic remain equivocal when presented with mixed information, but those who have made a decision preferentially select information supporting that decision[36]. Anecdotally, local media messages emphasize 'early detection and prevention equals unequivocal good' while efforts to emphasize the limitations of screening are far fewer, potentially biasing women's values and preferences towards BC screening. These attitudinal and socio-cultural factors can hinder an individual's informed decision-making and lower her ability to make an autonomous screening choice. Some women might skip the factual material due to comprehension difficulties. Some participants suggested the inclusion of real-life stories and contact information for hospitals and clinics offering screening services would improve the content. These comments suggested that Chinese women may make informed decisions based not only on personal benefits and risks but also on actions of others who have faced similar problems. Peer conformity is an important determinant of Chinese people's vaccination and influenza-related hygiene behaviours[37]. This may also influence more general cancer-related decisions in Chinese

populations[38]. Providing contact information of health institutions, on the other hand, may help women to access screening services.

Participants showed few knowledge gains regarding BC screening. Previous HK studies on decisions for BC surgery also failed to achieve large knowledge gains[25]. Among the three knowledge questions, most women (~92%) correctly answered was 'If the cancer is detected in its early stage, the treatment that you need to undergo will be simpler'. Conversely, most women (~88%) also incorrectly and affirmatively answered the question 'Regular screening can prevent BC'. Participants may misunderstand the function of screening. Early detection does simplify treatment, but screening and early detection of pre-cancerous lesions has not been reliably confirmed to reduce the chance of developing breast cancer[10]. Our findings suggest that most participants did not understand that the purpose of BC screening is for early detection of existing disease, rather than preventing the onset of BC.

Significantly, there was a marked shift in participation preferences towards an active or collaborative role at the follow-up assessment. In other words, after having read the DA, more participants engaged and were demanding a greater role in making decisions regarding choice of BC screening. This suggests these women were empowered by the DA. Given that a very small increased level of self-estimated risk of contracting BC in the next 5 years and a lower post-intervention level of anxiety was reported, we could argue that the DA had heightened the respondents' awareness and improved their BC understanding without increasing anxiety. Moreover, since no women reported their self-rated risk of developing the disease to be 'certain' and few (n=9) rated it 'likely' at follow-up, the small increases in level of self-estimated risk appear insignificant. Incorrect perception of actual BC risk[38,39] as well as other cancers reflects optimistic bias[38]. Correcting such bias would be desirable.

Decisional conflict which might potentially interfere with women's decision-making [40] was negligible. In other words, women were unlikely to feel uncertain and uninformed about screening decision towards BC after reading our DA, although we cannot rule out the possibility that these women had low decision conflicts in general.

We have demonstrated that this piloted DA for BC screening was helpful in providing supportive information for women during their decision-making, but the effects appeared much weaker among women with lower education and literacy levels, consistent with other studies[31]. Less educated women reported higher perceived anxiety about developing the disease during their lifetime (**Table 5**). Post hoc, this subgroup was found to also have poorer self-rated health compared to the other study participants, and therefore might be more likely to report higher level of anxiety.

Several limitations need to be acknowledged. First, our analyses were based on data gathered from a longitudinal study design, using a small sample size possibly explaining why our hypothesized relationships were insignificant and could have restricted the potential to identify differences in outcome measures in subgroups. The second limitation is the potential for desirability bias in responses to the questions on knowledge of BC screening. Moreover, we could not rule out the possibility of whether the participants might already have committed to a particular BC screening practice or hold established beliefs about these. This may have affected women's willingness to accept information that possibly conflicted with their health practices or beliefs about screening. Also, we lacked data about women's screening intention at both pre- and post-intervention assessments. A randomized control trial, therefore, would provide a 'gold-standard' for evaluating the effectiveness of the DAs in changing outcomes in women's BC screening decision-making. However, as a first step, this

pilot study illustrated the feasibility and the acceptability of the DA booklet, and appears to have boosted shared participation preference among women. Third, our study tested the piloted DA as a decision-support tool for self-use in non-clinical settings. This is desirable because it does not increase clinicians' workloads. However, future research can explore applicability to consultations in primary care setting.

CONCLUSIONS

The DA's impact on fostering informed decision making for Chinese women was positive, decision-making participation preference was heightened and the booklet was well received by users. Future research on the effectiveness of the DA in prompting more informed screening behaviour should be assessed in a randomized controlled trial.

PRACTICE IMPLICATIONS

Most DAs for BC screening are developed for Western populations. This tailored DA on BC screening for Chinese women facing screening decisions improved women's desire for involvement in BC screening decision-making. In Chinese contexts there is a higher likelihood for a screening false alarm due to the relatively low disease prevalence in the population. The availability of more neutral information on the possible benefits, harms and uncertainties associated with screening options makes for more informed decisions. Whether the DA prompts changes in screening practices and improves Chinese women's ability to make autonomous choices in cancer-related decisions awaits confirmation.

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POTENTIAL CONFLICTS OF INTEREST

NIL

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Table 1 Table of contents of the booklet

Sections	Content descriptions
(1) Is breast cancer common in Hong Kong?	Provide information on incidence and mortality of breast cancer in Hong Kong.
(2) What is breast cancer screening?	Introduce and describe breast cancer screening modalities including mammography, ultrasound, clinical breast examination, breast self-examination and magnetic resonance imaging.
(3) Assess your risk and consider trade-offs	Include information on structured guidance in reaching a decision, and provide a summary table to review the potential benefits and costs of the available modalities and options for early detection of breast cancer.
(4) What are the benefits of breast cancer screening?	Discuss benefits of the screening modalities, e.g., reduction in mortality and sensitivity.
(5) What are the risks of breast cancer screening?	Discuss risks of the screening modalities, e.g., over-diagnosis, false positives, and psychological consequences such as anxiety.
(6) What are the uncertainties of breast cancer screening?	Discuss uncertainties of the screening modalities, e.g., impact on reducing mortality from breast cancer.
(7) Making informed decisions	Explain the importance of making informed decisions and considerations involved.
(8) References	Scientific studies and evidence cited.

Table 2 Demographic characteristics of study sample before (baseline / pre-intervention) or after receiving the DA booklet (evaluation / post-intervention)

Variables	All participants	Participants who have completed the evaluation survey	*p-value**
	n = 126 (%)	n = 90 (%)	
Characteristics			
Age, y			0.997
Mean (SD)	54.7 (13.17)	54.3 (12.42)	
30-39	17 (13.5)	12 (13.3)	
40-49	27 (21.4)	19 (21.1)	
50-59	39 (31.0)	29 (32.2)	
60-69	27 (21.4)	20 (22.2)	
≥70	16 (12.7)	10 (11.1)	
No. of children			
Nil	17 (13.5)	12 (13.3)	0.985
1	32 (25.4)	22 (24.4)	
2 or more	77 (61.1)	56 (62.2)	
Place of birth			0.328
Hong Kong	74 (58.7)	55 (61.1)	
Mainland China (including Macau)	46 (36.5)	34 (37.8)	
Others	6 (4.8)	1 (1.1)	
Education*			
Primary or less	26 (20.6)	16 (17.8)	0.855
Secondary	73 (57.9)	55 (61.1)	
Tertiary or more	27 (21.4)	19 (21.1)	
Family monthly income			0.953
<$10,000	26 (21.0)	21 (23.3)	
$10,000 - 19,999	33 (26.6)	24 (26.7)	
$20,000 - 29,999	17 (13.7)	13 (14.4)	
$30,000 - 39,999	23 (18.5)	13 (14.4)	
≥$40,000	24 (19.4)	18 (20.0)	
Unstable	1 (0.8)	0 (0.0)	
Missing	2	1 (1.1)	
Status of medical insurance that covers breast check-up			0.683
Insured by oneself or family	18 (14.3)	10 (11.1)	
Insured by employer or family members' employer	8 (6.3)	4 (4.4)	
Not covered by any medical insurance	106 (84.1)	78 (86.7)	
Breast cancer screening			0.862
Have heard of	25 (19.8)	17 (18.9)	
Have not heard of	101 (80.2)	73 (81.1)	

Preferred format of DA			0.717
Booklet	58 (46.0)	48 (53.3)	
Website	26 (20.6)	20 (22.2)	
Mobile application	32 (25.4)	20 (22.2)	
Don't know / Difficult to say	10 (7.9)	2 (2.2)	
Self-rated health status			0.875
Excellent / Very good	26 (20.6)	21 (23.3)	
Good	48 (38.1)	32 (35.6)	
Fair / Poor	52 (41.3)	37 (41.1)	

SD=standard deviation

* Significance tests for evaluating whether there was any socio-demographic difference between the overall baseline sample and the participants that completed both rounds of survey.
**Some percentages do not add up to 100% because of rounding error

Table 3 Acceptability of the decision aid booklet (n = 90)

Measures	Number	%
Acceptability		
Amount of information provided*		
About right	66	73.3
Too little	14	15.6
Too much	5	5.6
Don't know / Difficult to say	5	5.6
Length of DA*		
About right	76	84.4
Too short	3	3.3
Too long	9	10.0
Don't know / Difficult to say	2	2.2
Clarity		
Everything is clear	27	30.0
Most things are clear	51	56.7
Some things are clear	12	13.3
None of the information is clear	0	0
Balanced presentation*		
Balanced	52	57.8
Slanted towards mammography	14	15.6
Slanted towards breast U/S	0	0
Slanted towards CBE	7	7.8
Slanted towards BSE	6	6.7
Slanted towards MRI	7	7.8
Don't know / Difficult to say	4	4.4
Help in decision-making about breast cancer screening		
Very helpful / Somewhat helpful	80	88.9
Little helpful / Not helpful	3	3.3
Neutral	7	7.8
DA content is		
Totally new	11	12.2
Mostly new	45	50.0
Mostly already known	27	30.0
Something already known very well	6	6.7
Don't know / Difficult to say	1	1.1
'Would you recommend the decision aid booklet to others?'		
Definitely would	40	44.4
Probably would	40	44.4
Not sure	5	5.6
Probably would not	3	3.3
Definitely would not	2	1.1
Don't know	1	1.1

U/S=ultra-sound, CBE=clinical breast examination, BSE=breast self-examination, MRI= magnetic resonance imaging
*The scores do not add up to 100% because of rounding error

Table 4. Outcomes on informed decision making (IDM) of study sample before (baseline / pre-intervention) or after receiving the DA booklet (evaluation / post-intervention)

IDM outcomes	Baseline assessment, % n=90	Follow-up assessment, % n=90	*p-value* for t-test
Knowledge level*			0.34
Mean (SD)	60.7 (19.7)	61.9 (19.1)	
Preference for control in IDM			*p-value* for kappa test
Active	46.1	50.0	0.99 [a]
Collaborative	5.6	20.0	
Passive	48.3	30.0	
Self-perceived risk for breast cancer [b]	Mean (SD)	Mean (SD)	*p-value* for signed-rank test
Self-rated 5y risk	1.4 (0.9)	1.9 (1.0)	0.01
Comparative risk at own age	2.3 (0.8)	2.4 (0.7)	0.12
Perceived severity of contracting the disease	2.8 (1.3)	2.9 (1.5)	0.77
Perceived anxiety	3.7 (1.3)	3.4 (1.5)	0.17
Perceived worriness	3.0 (1.6)	2.9 (1.5)	0.87
Decision Conflict [c]		Mean (SD)	
Total score		14.8 (9.7)	
Informed subscale		21.4 (15.5)	
Support subscale		16.0 (15.8)	
Effective decision subscale		15.6 (15.2)	
Value clarity subscale		11.3 (11.6)	
Uncertainty subscale		9.4 (13.0)	

SD=standard deviation

*Knowledge score ranged from 0 to 100.

[a] Kappa test is testing the null hypothesis that there is no agreement between two assessments (i.e., pre- and post-intervention assessments in our context). Therefore, p-value>0.05 reflects that there is evidence of disagreement between two assessments.

[b] Sub-domain scores for self-perceived risk for breast cancer range from 1 (impossible/much lower/strongly disagree) to 5 (certain/much higher/strongly agree), except that the scores for perceived worriness ranges 1 (not at all) to 7 (all the time).

[c] Decision Conflict scale range from 0 to 100. The higher the score, the higher decisional conflict is. This also applies to other listed subscales. Specifically, uncertainty sub-score ranges from 0 (feels extremely certain about best choice) to 100 (feels extremely uncertain about best choice). Informed sub-score ranges from 0 (feels extremely informed) to 100 (feels extremely uninformed). Value clarity sub-score ranges from 0 (feels extremely clear about personal values for benefits and risks/side effects) to 100 (feels extremely unclear about personal values). Support sub-score ranges from 0 (feels extremely supported in decision making) to 100 (feels extremely unsupported in decision making). Effective decision sub-score ranges from 0 (good decision) to 100 (bad decision).

Table 5 Effect of the decisional aid on improved level of knowledge, changes for preference for control in IDM and increase in self-perceived risk for breast cancer

Variables	Improved score in knowledge level [a]	Changes in preference for control in IDM from passive style to active / collaborative styles	Increase in self-perceived risk for breast cancer [b]				
			Self-rated 5y risk	Comparative risk at own age	Perceived severity of contracting the disease	Perceived anxiety	Perceived worriness
	OR (95% CI)	OR (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)	β (95% CI)
Age	1.03 (0.99, 1.09)	1.03 (0.99, 1.08)	-0.01 (-0.04, 0.02)	0.00 (-0.02, 0.01)	-0.03 (-0.06, -0.01)*	-0.02 (-0.06, 0.01)	0.00 (-0.02, 0.03)
Education [c]	0.61 (0.26, 1.44)	0.36 (0.15, 0.84)*	-0.37 (-0.93, 0.18)	-0.03 (-0.31, 0.26)	-0.24 (-0.75, 0.27)	-0.85 (-1.47, -0.24)*	0.22 (-0.33, 0.77)
Monthly household income [d]	1.13 (0.77, 1.67)	1.10 (0.77, 1.57)	0.10 (-0.16, 0.37)	-0.02 (-0.15, 0.11)	-0.13 (-0.36, 0.10)	0.11 (-0.17, 0.39)	0.24 (-0.01, 0.50)
Intercept	-	-	1.26 (-1.10, 3.62)	0.39 (-0.87, 1.66)	2.66 (0.48, 4.83)	2.40 (-0.25, 5.05)	-1.51 (-3.89, 0.88)

IDM=informed decision making
SD = standard deviation
CI = confidence interval
* *p-value* < 0.05
[a] Improved knowledge scores (total) in the post-intervention assessment, compared to the pre-intervention assessment.
[b] Sub-domain scores for self-perceived risk for breast cancer range from 1 (impossible/much lower/strongly disagree) to 5 (certain/much higher/strongly agree), except that the scores for perceived worriness ranges 1 (not at all) to 7 (all the time).
[c] Education includes three levels: no education or primary; secondary; and tertiary or above
[d] Monthly household income includes five levels: less than $10,000; $10,000-$19,999; $20,000-$29,999; $30,000-$39,999; and $40,000 or above

Appendix A
Review methods

Specifically, from January to February 2013, the PUBMED database was searched for retrieving research articles in English regarding these modalities' potential benefits and risks to women. Keywords used included 'breast cancer', 'screening', and 'decision aid'. International guidelines and recommendations on breast cancer screening, in addition, were consulted to provide a more thorough explanation of the relevant benefits and harms. Initial search resulted in 2,260 records. The records were then scanned by title and abstract; irrelevant records were discarded. Related articles and reference lists from potentially relevant papers were also searched and experts consulted that no important research was missed. At the end, 38 records were reviewed, and their findings were summarized (Table below).

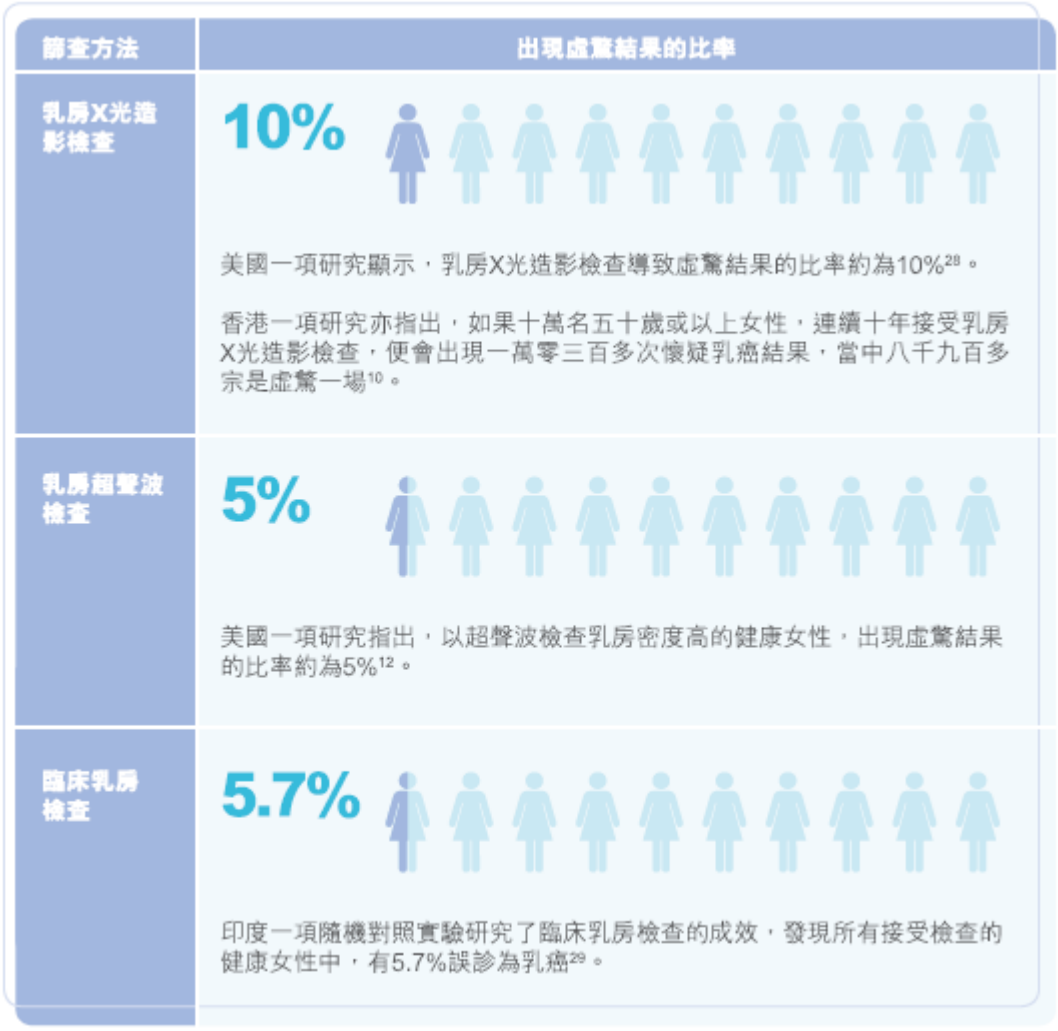
Table A.1 Summary of benefits, harms, and uncertainties of breast cancer screening

Aspects	Items	Main reference(s) (First author, year of publication, country)
Benefits	(i) Reduction in breast cancer mortality	• Public Health Agency of Canada (2010) Canada[14] • Kalager (2010) Norway[13] • Independent UK Panel on Breast Cancer Screening (2012) UK[11]
	(ii) Early detection of breast cancer	• Public Health Agency of Canada (2010) Canada[14]
	(iii) Enhancement for awareness of breast diseases	• McCready (2005) UK[41] • Dahlui (2001) Malaysia[42]
Risks	(i) Over-diagnosis or over-treatment	• Independent UK Panel on Breast Cancer Screening (2012) UK[11] • The Nordic Cochrane Centre (2012) Denmark[26]
	(ii) Wrong screening results leading to false alarm	• The Nordic Cochrane Centre (2012) Denmark[26] • Nelson (2009b) USA[19] • Chiarelli (2009) Canada[43]
	(iii) Anxiety, worry, and depression from unnecessary procedure	• Baxter (2001) Canada[18] • Nothacker (2009) Germany[44] • Kösters (2003) Denmark[45]
Uncertainties	(i) Impact on reducing breast cancer mortality	• Bancej (2003) Canada[17] • Teh (1998) UK[15]
	(ii) Differential impacts on age groups	• Nelson (2009a) USA[8] • Cancer Expert Working Group on Cancer Prevention and Screening (2010) HK [46]

Content development process

The DA was first drafted by the first author (IW). The working group then critically reviewed and revised the content and layout of several versions of the draft DA. The ‘finalized’ booklet was further reviewed by female laymen readers (n = 5) who do not possess advanced knowledge on this topic. Revision to content and layout, where appropriate, was then made. Professional production editor further reviewed the content and layout of the draft booklet. A guiding principle for the design of our DA was to produce a booklet that could accommodate the population's needs to the greatest possible extent. During the content development stage, inconsistencies were resolved by iterative discussions in the working group with invited associates.

Appendix B
Example of illustration in the booklet
The following illustration, extracted from the booklet, shows how statistics is graphically represented to facilitate understanding. The graphic and layout details were retouched by the professional graphic designers and epidemiologists.



Appendix Table C.1

Appendix Table C.1 Self-reported perceived factors (i.e., benefits and barriers) that lead to regular screening for breast cancer and to not having it

Factors	Number	Percentage
Benefits		
To discover cancer at an early stage	38	42.2
To know more about health condition	38	42.2
Psychological reassurance	31	34.4
To reduce chance of dying from breast cancer	22	24.4
Are concerned with the risk of getting breast cancer	20	22.2
Barriers		
Don't know enough about where or how to go for screening	13	14.4
Not concerned with the risk of getting breast cancer	13	14.4
Costs too much	11	12.2
Risk of over-diagnosis/over-treatment	5	5.6
Risk of false alarm	5	5.6
Psychological pressure, such as anxiety, worry and depression from follow-up procedures	5	5.6
Feel embarrassed	4	4.4