

# Final Report

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## 1. Introduction

Women with inherited *BRCA* genetic change have a very high risk of developing breast cancer compared to the general population. To reduce their risks of breast cancer, women face difficult decisions on multiple complex medical options and health outcomes, and integrating these options into their life planning.

In making these complex decisions, women must consider not only the benefits and harms of the available preventive options, such as breast cancer screening, preventive medication and preventive surgery, but also their preferences and values.

Factors, such as perceived cancer risk, decisional conflict and uncertainty, psychological considerations, family context and degree of women involvement, are key aspects of this decision-making process.<sup>1</sup> This presents unique medical and psychosocial challenges to women's decision-making without the benefits of any appropriate decision support to facilitate their decision-making process.

Shared decision-making incorporating discussion of women's preferences and values is important. However, shared decision-making between clinicians and women can be impeded by many factors (for example, significant demands on clinicians' time, and incomplete, conflicting and rapidly changing scientific information and recommendations).<sup>2</sup>

One effective way to facilitate shared decision-making is by using decision aids. Decision aids provide information about breast cancer preventive options and help women think about how important the possible benefits and harms of each option are.

Research shows that women who use decision aids have increased knowledge of the options and more accurate risk perceptions, and feel better informed and clearer about what matters most to them. They probably have more accurate expectations of the benefits and harms of options and probably participate more in decision-making. Women who use decision aids may achieve decisions that are consistent with their values. Women and their clinicians also were more likely to talk about the decision when using a decision aid.

Thus, this research aims to reduce the risk of breast cancer and improve quality of life for women with a *BRCA* genetic change through a new value of shared decision-making between clinicians and women.

To achieve this objective, a BREast CAncer prevention Decision Aid (BRCADA) for women with a *BRCA* genetic change was developed, field-tested and distributed to clinicians in Malaysia. A resource website (<https://brcada.um.edu.my>) was also developed to provide information about the different breast cancer preventive options that are available, and to help women clarify their values, concerns and support system that are important to their decision-making.

## **2. Method**

The development of BRCADA was guided by Ottawa Decision Support Framework in accordance with the International Patient Decision Aids Standards (IPDAS) quality criteria. The systematic development process of BRCADA consisted of three phases (Figure 2.1), using a combination of qualitative and quantitative methods.

### **2.1 Conceptual framework**

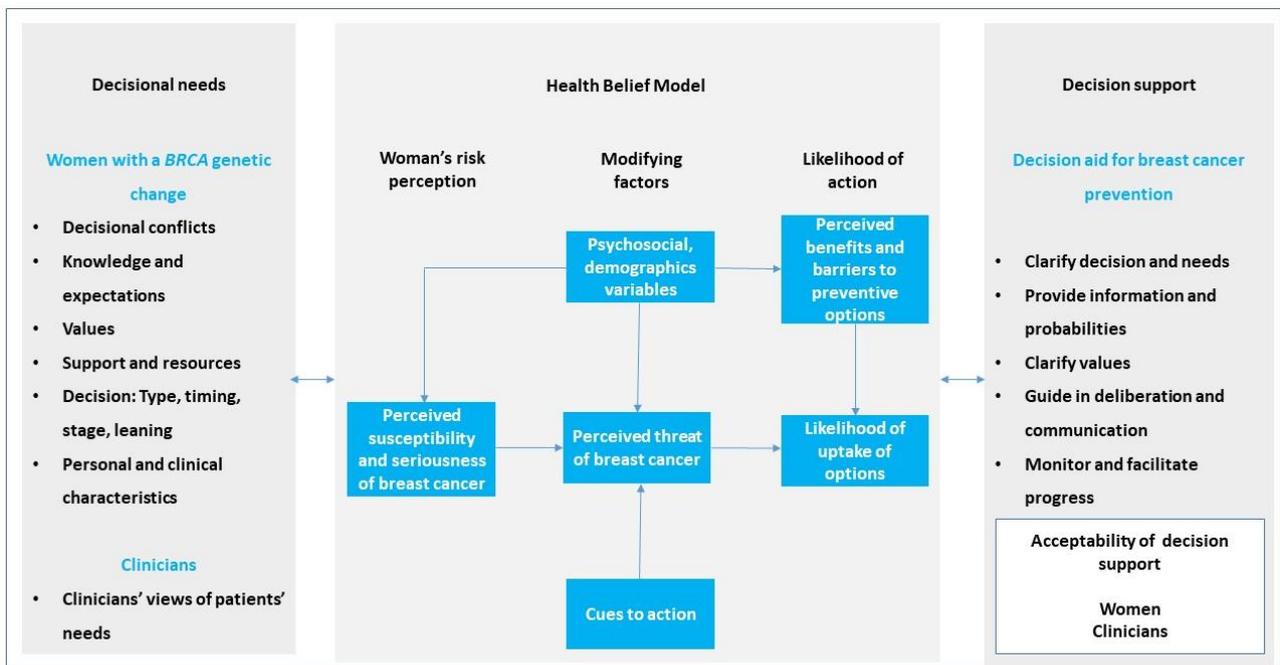
The Health Belief Model and Ottawa Decision Support Framework (ODSF) were used to guide the development and field-testing of BRCADA (Figure 2.2).<sup>3,4</sup>

### **2.2 Research ethics**

The study protocol was developed in accordance with the World Medical Association Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects. This study was approved by the Research Ethics Committee, UMMC (MECID.NO: 21161-1995), Ministry of Health Malaysia (NMRR-16-952-30969 IIR) and Ramsay Sime Darby Health Care (IRB Reference Number: 201208.1 and 201810.1). Written informed consent to participate in this study was obtained from all participants according to the approved study protocol.



**Figure 2.1:** Study Design – Exploratory Sequential Design



**Figure 2.2:** Study Conceptual Framework (Adapted from Health Belief Model and Ottawa Decision Support Framework)<sup>3,5</sup>

## 2.3 Data collection

### 2.3.1 Phase 1: Needs assessment

To guide the development of BRCADA, a qualitative study was conducted in phase 1 to understand clinicians' and women's perspectives about how *BRCA* carriers perceive their breast cancer risk and decide on preventive options available to them. Using purposive sampling technique, women with a *BRCA* genetic change were recruited from a specialized multidisciplinary risk management clinic of a large university-teaching hospital in Kuala Lumpur and an outpatient breast surgery clinic of a private hospital in Selangor, Malaysia.

Eligible clinicians comprising of breast surgeons, general surgeons, clinical geneticists and genetic counselor were purposively sampled and recruited from 19 private, Ministry of Health and university-teaching hospitals and non-profit organization in Malaysia.

In-depth interviews, using a semi-structured interview guide, were conducted with 32 clinicians and 35 women with a *BRCA* genetic change. Developed based on the standard needs assessment questions of Jacobson and O'Connor, the interview guide, which consisted of three parts, was used to explore the breast cancer risk perception, preventive decision-making and decisional needs of *BRCA* carriers from the perspectives of clinicians and women.<sup>6</sup>

The in-person interviews with women were conducted in the preferred language (5 interviews in Bahasa Malaysia, 21 in English and 9 in Mandarin/ Cantonese) of the participants. The interviews with women lasted between 39 to 101 minutes (Mean = 64 minutes). All interviews with clinicians were conducted in English, and in-person except for one phone interview. The interviews with clinicians lasted between 41 to 100 minutes (Mean = 73 minutes).

Field notes were written. Audio-recording of the interviews were transcribed verbatim, coded and analyzed using thematic analysis. Thematic analysis is a useful qualitative analysis method to examine the perspectives of different research participants, highlight similarities and differences, and generate unanticipated insights.<sup>7</sup>

Findings from the in-depth interviews with clinicians and women with a *BRCA* genetic change

were used to guide the development of BRCADA in phase 2.

### **2.3.2 Phase 2: Development of BRCADA**

In phase 2, the draft BRCADA was developed to provide decision support regarding breast cancer prevention to women with a *BRCA* genetic change and to facilitate shared decision-making during a physician consultation.

The draft BRCADA was developed using a systematic process outlined by Coulter *et al.* that involved assembling the expert steering group, conducting a review of scientific information, drafting the outline, content and graphic, and field-testing by clinicians and women with a *BRCA* genetic change.<sup>8</sup> A standardized Ottawa decision aid template that conforms to the IPDAS Collaboration was adapted for development of the draft BRCADA.<sup>9</sup>

The multidisciplinary expert steering group, consisting of 11 clinical experts and *BRCA* carrier representative was assembled and formed to oversee the development of BRCADA. The expert steering group comprised of a *BRCA* carrier, an expert in decision science and shared decision-making, a cancer epidemiologist, a medical psychologist with extensive experience in psychosocial oncology, a clinical geneticist with specialty interest in cancer genetics, a genetic counselor, a plastic surgeon, an oncoplastic breast surgeon and three breast surgeons.

Suggestions and comments received from the expert steering group members were taken into consideration for refinement and redesign of the draft BRCADA. The refined draft was then reviewed by eight women with a *BRCA* genetic change and six clinicians who are not members of the expert steering group. The refined draft was revised and returned to the expert steering group for further refinements until a satisfactory version is ready for field-testing in phase 3.

### **2.3.3 Phase 3: Field-testing of BRCADA**

In phase 3, BRCADA was field-tested to assess the acceptability and feasibility of the decision aid for women with a *BRCA* genetic change who are considering breast cancer preventive options. Fifty-

one clinicians and 20 women with a *BRCA* genetic change who are not members of the expert steering group from 22 private, Ministry of Health and university-teaching hospitals in Malaysia participated in the field-testing of BRCADA.

### ***Design***

The field-testing used a pre-test–post-test design with measures at two time-points for women with a *BRCA* genetic change (before and after using BRCADA) and one time-point for clinicians (after using BRCADA).

### ***Main outcome measures***

The main outcome measures were acceptability, preparation for decision-making, decisional conflict, values, knowledge and choice predisposition/ decision (Table 2.1).

### ***Questionnaires***

The main outcomes measures were measured using the Acceptability questionnaire, Preparation for Decision-Making Scale, Decisional Conflict Scale, Values questionnaire, Knowledge questionnaire, and Choice Predisposition/ Decision.

**Table 2.1:** Main Outcome Measures

| Outcomes                                       | Pre-test measures<br>(before using BRCADA<br>questionnaires) | Post-test measures<br>(after using BRCADA<br>questionnaires) |
|--|--|--|
| <b><i>Women with a BRCA genetic change</i></b> |  |  |
| Primary outcomes                               |  | 1. Acceptability   |
|  |  | 2. Preparation for decision-making                           |
| Secondary<br>outcomes                          | 1. Decisional conflict                                       | 1. Decisional conflict                                       |
|  | 2. Values  | 2. Values  |
|  | 3. Knowledge   | 3. Knowledge   |
|  | 3a. Risk perception of breast cancer                         | 3a. Risk perception of breast cancer                         |
|  | 3b. Breast cancer preventive options                         | 3b. Breast cancer preventive options                         |
|  | 4. Choice Predisposition                                     | 4. Decision  |
| <b><i>Clinicians</i></b>                       |  |  |
| Primary outcome                                |  | 1. Acceptability   |

### 3. Results

#### 3.1 Phase 1: Needs assessment

##### 3.1.1 Characteristics of participants

A total of 35 women with a *BRCA* genetic change and 32 clinicians from 19 study sites in Malaysia participated in the study (Table 3.1). Characteristics of women with a *BRCA* genetic change are summarized in Table 3.2 whereas characteristics of clinicians are summarized in Table 3.3.

##### 3.1.2 Needs assessment regarding contextual factors on women's decision-making

Findings from interviews with clinicians show that breast cancer risk management is not a well-known concept in Malaysia as most clinicians have limited experience managing women with a *BRCA* genetic change. Cancer risk communication, preventive recommendations and follow-up counselling varied greatly between clinicians.

**Table 3.1** Study Setting

| Study setting                    | Number of sites | Number of participants                  |            |
|----------------------------------|-----------------|---|------------|
|                                  |                 | Women with a <i>BRCA</i> genetic change | Clinicians |
| 1. University-teaching hospitals | 2               | 25                                      | 7          |
| 2. Ministry of Health hospitals  | 9               | -                                       | 17         |
| 3. Private hospitals             | 7               | 10                                      | 7          |
| 4. Non-profit organization       | 1               | -                                       | 1          |
| <b>Total</b>                     | <b>19</b>       | <b>35</b>                               | <b>32</b>  |

Most clinicians did not provide any numeric information of age-related risk estimates to women, just verbally informing them that they are at high risk for developing breast cancer while others might draw a family pedigree if there were significant family history of breast cancer.

Clinicians were aware of the various screening and breast cancer preventive options available in Malaysia. However, despite the availability of international practice guidelines, clinicians' recommendations on preventive options were influenced by their values and beliefs. Most clinicians have limited understanding of women's values and psychosocial issues influencing breast cancer preventive decision-making as these were seldom addressed during follow-up counselling.

Across all practices, clinicians highlighted that choices for breast cancer preventive surgery were the lowest among women as fear of losing their husbands, lack of spousal support, unwilling to remove something that is healthy and financial constraints were the main barriers to women's decision-making.

### 3.1.3 Needs assessment regarding influencing factors on women's decision-making

Needs assessments of clinicians and women with a *BRCA* genetic change identified four overarching themes that influence women's decision-making regarding prevention of breast cancer: risk perception of breast cancer, values and beliefs, fears and concerns, and support system (Table 3.4).

**Table 3.2** Participant Characteristics – Women with a *BRCA* genetic change (N = 35)

| <b>Characteristics</b>                      |  | <b>n</b> |
|---|--|----------|
| Age   | Range: 27 – 68 years old<br>Median: 43 years old |          |
| <i>BRCA</i> genetic change                  | <i>BRCA1</i>                                     | 18       |
|   | <i>BRCA2</i>                                     | 17       |
| History of breast/ ovarian cancer           | No cancers                                       | 6        |
|   | Cancer in one breast                             | 25       |
|   | Ovarian cancer                                   | 3        |
|   | Breast & ovarian cancers                         | 1        |
| Ethnicity                                   | Malay  | 7        |
|   | Chinese  | 18       |
|   | Indian   | 7        |
|   | Others   | 3        |
| Religion                                    | Islam  | 9        |
|   | Buddhism   | 15       |
|   | Christianity                                     | 4        |
|   | Hinduism   | 3        |
|   | Others   | 4        |
| Marital status                              | Single   | 7        |
|   | Married  | 23       |
|   | Separated/ divorced                              | 5        |
| Children                                    | Have children                                    | 24       |
| Education level                             | Secondary school (Form 1 – 6)                    | 13       |
|   | Diploma/ degree                                  | 19       |
|   | Postgraduate                                     | 3        |
| Employment status                           | Working full time                                | 23       |
|   | Part-time/ unemployed                            | 12       |
| Monthly household income                    | < USD1,190                                       | 17       |
|   | USD1,190 – 2,380                                 | 11       |
|   | > USD2,380                                       | 7        |
| Choices of breast cancer preventive options | Screening only                                   | 20       |
|   | Breast cancer preventive surgery                 | 9        |
|   | Ovarian cancer preventive surgery                | 6        |

**Table 3.3** Sample Characteristics – Clinicians (N = 32)

| Characteristics |  | n  |
|-----------------|--|----|
| Age             | Range: 34 – 60 years old<br>Median: 45.5 years old |    |
| Gender          | Male   | 12 |
|                 | Female   | 20 |
| Ethnicity       | Malay  | 19 |
|                 | Chinese  | 10 |
|                 | Indian   | 1  |
|                 | Others   | 2  |
| Specialty       | Surgeons   | 29 |
|                 | - <i>Breast surgeon</i>                            | 16 |
|                 | - <i>Breast &amp; endocrine surgeon</i>            | 10 |
|                 | - <i>Breast fellow</i>                             | 2  |
|                 | - <i>General surgeon</i>                           | 1  |
|                 | Clinical geneticist                                | 2  |
|                 | Genetic counsellor                                 | 1  |

### ***Risk perception of breast cancer***

#### *Perceived seriousness*

Most women perceived breast cancer as a “*very scary*” (P22) and life-threatening disease, one for which they are at risk due to their *BRCA1/2* carrier status or family history.

#### *Perceived risk and perceived threat*

Findings indicate that cancer risk is not a well-understood concept among *BRCA* carriers in Malaysia. This is despite that all participants in this study had received genetic counselling from the same genetic counsellor or clinical geneticist prior to the qualitative interviews.

Most women correctly perceived that they have a higher risk of developing breast cancer, while others perceived that they have the same risk as the normal population. However, majority did not know the breast cancer risk estimates of their carrier status. They either overestimated or underestimated their lifetime risk for breast cancer, which affected their decision-making on preventive measures.

Women who chose breast cancer preventive surgery perceived that they have a high or very high

**Table 3.4** Factors Influencing Women’s Decision-Making on Prevention of Breast Cancer

| Themes                           |                                  | Conceptualizations  |  |
|----------------------------------|----------------------------------|---|--|
| Overarching themes               | Sub-themes                       | “Why remove something that is healthy?”   | “Peace of mind from cancer worry is more important than breasts”                     |
| Risk perception of breast cancer | Lifetime risk                    | High or very high risk of developing breast cancer  | High or very high risk of developing breast cancer                                   |
|                                  | Comparative risk                 | Higher risk of developing breast cancer than normal population                                    | Higher risk of developing breast cancer than normal population                       |
| Values and beliefs               | Importance of breasts            | Breasts are important for women’s self-esteem and body image                                      | Life and peace of mind from cancer worry are more important than breasts             |
|                                  | Keeping the healthy breasts      | Want to keep the healthy breasts  | Not worth taking the risk of developing breast cancer by keeping the healthy breasts |
|                                  | Removing the healthy breasts     | Removing something that is healthy is not acceptable  | Removing the healthy breasts is worth it   |
|                                  | Breast cancer prevention         | Preference for other options rather than preventive surgery                                       | Prevention of breast cancer is better than cure                                      |
|                                  | Breast cancer screening          | Preference for early detection and early treatment of breast cancer                               | Screening is not enough for prevention of breast cancer                              |
|                                  | Breast cancer preventive surgery | Preventive surgery is not an acceptable option for prevention of breast cancer                    | Preventive surgery is the best choice for prevention of breast cancer                |
| Fears and concerns               | Fears                            | Fears of surgery and losing the healthy breasts   | Fears of developing breast cancer and going through treatment (again)                |
|                                  | Concerns                         | Concerns about the potential impact of preventive surgery on body image, femininity and sexuality |  |
| Support system                   | Support system                   | Lack of support system  | Have enough support and encouragement  |

risk of developing breast cancer: “*Before I removed my breasts, very high chances ... very high risk*” (P13). The perception of threat was high among these women, “*it was a matter of time before I got breast cancer*” (P13), even in those who never had breast cancer before. They perceived the threat that breast cancer is inevitable as they have a *BRCA* genetic change and strong family history: “*I will think it’s pretty high [risk] after I got to know that I’m a BRCA2 carrier.... I think that I’ll definitely get cancer*” (P23).

The threat of breast cancer motivated them to adopt this preventive measure. They also tended to overestimate their cancer risk estimates, between 80% to 90% for *BRCA1* genetic change: “*Oh my chance...90% at least*” (P13), and 40% to 80% for *BRCA2*.

In contrast, women who adopted screening, very few (four) of them perceived that they have a high or very high risk for breast cancer. Most women either did not know, “*What is the risk? Don’t know*” (P10), or were not sure of their risk, “*I think maybe 50-50. I am not sure*” (P21).

Among women who have breast cancer before, they either perceived that they are still at risk for a second breast cancer or not at risk: “*Risk? I think don’t have*” (P7, translated). The latter had no perception of threat of developing a second breast cancer. They believed that they would never develop breast cancer again: “*I know it [breast cancer] will not happen (soft chuckle)*” (P27).

### ***Values and beliefs***

Women have diverging values and beliefs that influenced their decision-making regarding breast cancer prevention. Women viewed their healthy breasts on an implicit continuum between two divergent conceptualizations, “*Why remove something that is healthy?*” and “*Life and peace of mind from cancer worry is more important than breasts*”.

### ***Importance of breasts***

#### *Breasts are important for women’s self-esteem and body image*

On one end of the spectrum, breasts are regarded as important for a woman’s self-esteem and body image: “*You know that to lift yourself up, you have to look pleasant. It’s very important in life, I think. For me, I must look perfect*” (P11).

Society's expectation of a woman's body image reinforces women's beliefs on the importance of breasts: *"The ideal image of a pretty girl...must have long hair, must have full breasts, you must be thin...you must be slim. So, all that are image that fits into a woman"* (P21). Losing the breasts is akin to losing the body image: *"I will look like a man if no more breasts (laughing)"* (P10). It also would affect women's self-esteem: *"My mood and self-esteem would be affected...feel lacking if I had to remove my breast...not a real woman anymore. That's why, I have not thought of removing my breast"* (P20, translated).

Breasts are regarded as *"a woman's assets (laughing)"* (P20) and are important for women to *"look perfect, look normal"* (P7, translated). *"Breast is asset, right? So if don't have breast, she will not be perfect"* (P7). Without breasts, women *"would feel less complete in terms of body image"* (P5) and *"would not look like a real woman"* (P24).

#### *Life and peace of mind from cancer worry are more important than breasts*

In contrast, on the other end of the spectrum, women believed that a woman *"don't need to have boobs to look beautiful. At the end of the day, what is it that you want? You want to wear curvy clothes or something like that? Which was not my priority"* (P15).

For these women, they want life and psychological peace of mind from cancer worry. They regarded life as the most important thing: *"Life is the most important"* (P17). So, they chose life over their breasts: *"I mean I spared my life la. I have a longer life to live now...and don't need to worry about cancer so much"* (P13). And, health and survival over their breasts: *"I based on my desire for survival; I want to be healthy because I hate being sick"* (P19, translated).

Breast cancer preventive surgery was conceptualized as peace of mind from cancer worry: *"The most important factor for me was I don't have to worry about recurrence because there are no breasts left"* (P2). Women felt *"安全 (ān quán; safe) and 放心 (fàngxīn; relieved)"* (P17) from the worry and fear of breast cancer. They *"feel peaceful. Because after I removed my breasts already, I no need to worry I might get breast cancer"* (P22).

## ***Keeping the healthy breasts***

### *Want to keep the healthy breasts*

About one-third of women refused preventive surgery as they want to keep their healthy breasts:

*“As long as I can save my breast, I will save”* (P20). Many factors influenced women’s choice to keep her healthy breasts. The two most significant factors are consideration for significant others, and beliefs in God and fate.

In our collectivist culture with strong family values, family is important to women in many aspects, including health preventive decision-making. In this group of *BRCA* carriers, women were aware of the benefit of preventive surgery as they had received genetic counselling: *“Risk of getting cancer...reduced; 99% reduced of getting cancer”* (P11). However, very often, women put their families first before themselves.

Their children come first: *“If I go for breast surgery, I might need to take time to rest, to recuperate. Yes, my biggest concern is because I have young children. They are dependent on me. So, I cannot see myself taking that option”* (P21).

They considered their spouse first: *“I also don’t think it should be removed if it’s healthy. I mean for happy family lifestyle. I mean your husband also will have feelings”* (P32).

They put their parents first: *“Doc, if I have to go for op, I have to be away from the stove. My mum is not young. My mum is even older now. So, I don’t want to disturb [her]”* (P11).

### *Not worth taking the risk of developing breast cancer by keeping the healthy breasts*

Conversely, women who chose preventive surgery believed that it’s not worth taking the risk of developing breast cancer by keeping the healthy breasts: *“Breast cancer is very scary...So, it’s no point to take the risk. Actually, I feel that it is not worth for me to continue to keep my breasts because the risk is so high for us to get breast cancer. That’s why I decide to remove it”* (P22).

Women carrying a *BRCA* genetic change often metaphorized breast cancer as a bomb: *“Actually, this cancer is like a bomb, which can explode anytime”* (P25). As the onset of breast cancer is thus unpredictable, this puts *BRCA* carriers in a situation of uncertainty with regard to their future

prospects. Subjected to unpredictability and anticipation, they believed that their lives would be at risk if they keep their healthy breasts: *“If I keep my breast, my life would be at risk”* (P19).

Keeping the healthy breasts is akin to inviting trouble: *“What is the point of keeping the healthy breasts? If breast cancer really happens and spreads around, that’s even more troublesome”* (25).

For women who have breast cancer before, they chose preventive surgery to remove the other breast as they do not want to be diagnosed with the disease twice: *“I made that decision because I...did not want to face this thing [breast cancer] twice”* (P19), and *“I don’t want my life to come to another stop and then I have to start all over again”* (P2). Preventive surgery of the other breast is the right decision as women have a *BRCA* genetic change: *“My decision to remove both breasts is a right decision because I have BRCA2”* (P19).

### ***Removing the healthy breasts***

#### *Removing something that is healthy is not acceptable*

Why fix something that is not broken? *“If nothing is wrong, then just leave it (laughing), don’t remove”* (P10). This is a pervasive belief among women who conceptualized preventive surgery as *“redundant and unnecessary”* (P29), a *“very drastic and illogical”* (P21) option for prevention of breast cancer.

Removal of the healthy breasts is not an acceptable option for breast cancer prevention *“because that is a drastic measure that I’m not prepared to take yet”* (P21). This was echoed by both unaffected women (never had breast cancer before): *“I won’t remove it if it’s healthy because it’s part of you”* (P32), and affected women (have had breast cancer before) alike: *“Of course, I don’t want to remove if it’s healthy”* (P24).

“Removing something that is healthy” is a very difficult concept for women and their families to understand: *“If it’s a healthy [breast], why need to remove?”* (P27). *“My husband said, why disturb something [that] is ok? A lot of my family members also said that”* (P6).

“Removing something that is healthy” is believed to be unnatural and may affect normal body functions: *“Many people told me, don’t remove. They said our bodies’ organs are healthy. If you go*

*and remove, of course, the entire person would change, not the same anymore” (P10).*

### *Removing the healthy breasts is worth it*

In contrast, on the other end of the spectrum, women believed that removing the healthy breasts is worth it for their health and survival as well as for their family and children.

Some women, including their spouses, conceptualized the healthy breast as a “bomb” (P34), while others felt that there is a “bomb” inside their bodies: *“It’s like a BOMB (laughing). I don’t know when...it will like Explode” (P1).* *“You can describe [it] as a bomb in [the] future; it will take your life away” (P34’s spouse).*

Due to the perceived risk and certainty of losing their lives to this “bomb”, they chose to remove the healthy breasts to protect their lives: *“Because it’s already a bomb, after removing the healthy breast, life is guaranteed” (P34).*

Not only they wanted to live a longer life, they also wanted their lives to be of worth: *“I feel very worth it and comforted if can live a longer life and a life of value” (P17).*

Removing the healthy breasts is *“worth the pain and you get to live longer” (P5).* It’s worth it *“because I am now very healthy; I can watch my two children grow up” (P29).*

### ***Breast cancer prevention***

#### *Preference for other options rather than preventive surgery for prevention of breast cancer*

On this end of the spectrum where preventive surgery is not an acceptable option, women conceptualized prevention of breast cancer as monitoring for breast cancer: *“Prevention means to monitor. Screening comes to my mind” (P21).*

Of all the options available to them, women chose screening because *“it is the easiest option” (P11)* compared to preventive medication and surgery. It is also *“the easiest decision to make” (P11).*

Overall, women were aware of the goal of breast cancer screening and adhered to their screening schedules. They believed that screening is enough for prevention of breast cancer as they are scheduled to have routine surveillance every six months: *“When you scan every year in six months, you’ve already find out, is there anything wrong with you” (P11).*

### Breast cancer prevention is better than cure

Conversely, on the other end of the spectrum, women believed that breast cancer “*prevention is better than cure*” (P26). Sacrificing their healthy breasts to prevent breast cancer is preferable to treatment: “*I will prefer to remove breasts rather than treatment*” (P23).

For these women, the single most significant motivation is that they never want to go through breast cancer, breast biopsy, chemotherapy or lymphedema (again): “*I don’t want to go through that cancer thingy, going through the chemo, going through the radiotherapy...I am not prepared to go through that again...That experience fueled our decision to have the risk-reducing surgery*” (P9).

Between the two, most women believed that the psychological impact of chemotherapy is worse than preventive surgery “*because the battle with chemotherapy is worse compared to the psychology of removing my breast*” (P19, translated). For others, they did not want to trouble or burden their loved ones: “*I don’t want to trouble other people (soft chuckle) with my disease. So, if possible, I really don’t want to go through chemo*” (P30, translated).

For unaffected women with cancer experience in the family, “prevention is better than cure” as they had experienced the psychological, emotional and economic impact of treatment on their families: “*Treatment, besides the cost, the impact to the family is very great because my mother also died of cancer*” (P23).

### **Breast cancer screening**

#### Preference for early detection and early treatment of breast cancer

Women preferred early detection and early treatment of breast cancer when it occurs rather than surgical removal of the healthy breasts: “*So, I would like to catch it before it turns aggressive, before it turns advanced, so I can get treatment earlier rather than to remove the healthy part of the body as a prevention*” (P21). They preferred screening “*because early detection and early treatment will ensure the best survival for a person*” (P21).

Unlike preventive surgery, screening is non-invasive, relatively inexpensive and does not have any consequent morbidity: “*It’s not harmful for anybody....You don’t need to go for an op because*

*you have to go through pain and all these” (P11).*

Women felt “very secure” (P6) with their choice of screening. They had trust and confidence in screening that it “*can catch the cancer early*” (P26). Screening provided them with psychological peace of mind “*because I wouldn’t like to worry about things that I do not know*” (P21).

#### *Screening is not enough for prevention of breast cancer*

Women who chose preventive surgery believed that screening is not enough for prevention of breast cancer “*because when you go for screening only...sometimes the screening... does not show up the breast cancer*” (P26). Women were aware of the inherent limitations of breast cancer screening: “*It is sometimes quite difficult to detect the disease at a much earlier stage because of dense breasts, and the false negative and false positive you have in the screening tools*” (P2).

Because of this, women had no confidence nor trust in screening: “*I don’t trust it... The tools are not accurate*” (P2). Women were psychologically distressed that screening might lead to false negative results, where an existing cancer is missed: “*I’m fearful about surveillance. I mean I wouldn’t know if there’s something growing inside me. Neither would the doctor know because of the tools that are not good enough*” (P2).

Due to their lack of trust in screening, women chose preventive surgery for peace of mind from cancer worry: “*...Because I don’t trust screening, forever in the back of my mind, I will not have peace. So, when the risk-reducing surgery option was there, I took it because I have nil, nil trust for screening*” (P9).

#### ***Breast cancer preventive surgery***

##### *Preventive surgery is not an acceptable option for prevention of breast cancer*

Women who refused preventive surgery perceived that the harms of removing the healthy breasts outweigh the benefits. A few women perceived that there are no benefits, only harms: “*Harms yes (laughing), benefits none*” (P7, translated).

Preventive surgery is not an acceptable option for prevention of breast cancer as it “*has a...very big impact on a woman, psychologically and mentally*” (P21). “*If I did not have breasts, I think I’ll*

*go crazy la (laughing)*” (P7).

Besides potential psychological harms, preventive surgery may cause significant physical morbidity: *“It’s not just the removing of a body part. It’s also how it affects the women physically and mentally”* (P21). Potential harms include negative impact on sexuality, femininity and body image: Sexual *“turn-off”* (P32), *“don’t feel attractive”* (P21), *“looks ugly”* and *“I would feel less feminine; I would feel less complete in terms of body image”* (P7). Also, loss of sensations in the reconstructed breasts: *“No feelings if I touch it...because it’s not original anymore”* (P7, translated).

After weighing the benefits and risks of preventive surgery, women preferred other preventive options: *“To remove, of course, you have to spend a lot of money, to get yourself healed, somebody to take care of you. Then you will be thinking, argh it’s okay la, no need to go through all that; just go for scanning”* (P11).

Moreover, the penetrance of *BRCA1/2* genetic change is not 100%. As women may never develop breast cancer in their lifetimes, why undergo preventive surgery needlessly: *“I was thinking that...if you didn’t remove and you didn’t reconstruct, and you live your life until...die of old age and it [breast cancer] did not happen, so what’s the point of removing earlier?”* (P27).

#### *Preventive surgery is the best choice for prevention of breast cancer*

Of all the options available to women, they believed that preventive surgery is the *“best option”* (P9) for prevention of breast cancer. Three significant factors influenced women’s belief that preventive surgery is the best choice for breast cancer prevention: Effectiveness of preventive surgery in reducing breast cancer risk, no recommended screening schedules after preventive surgery, and desire for breast symmetry in women who have had one breast removed.

Foremost among these is prevention of breast cancer: *“You have eradicated the disease that might happen in the future by...more than 90%”* (P2). Most women were aware that preventive surgery is the most effective option for reducing breast cancer risk in *BRCA* carriers: *“It will greatly reduce my risk of getting breast cancer”* (P4) and *“by removing the breasts, I am reducing the risk*

by 98%” (P5).

For unaffected women, they chose double preventive surgery (remove both healthy breasts) to reduce breast cancer risk: *“I am okay to remove and reconstruct as long as it can reduce my risk of getting breast cancer because seeing my mum going through the process, it was suffering. So, I hope can reduce or can avoid those suffering”* (P31).

For affected women, they chose preventive surgery of the other breast to prevent recurrence and to reduce risk of cancer in the other breast: *“That’s why I already made up my mind to remove both of the breasts. To prevent the new cancer from forming and the recurrence”* (P26). Sacrificing their healthy breasts is worth it to reduce breast cancer risk: *“Importantly, cancer does not recur. I am willing to sacrifice anything. Most crucial is reducing breast cancer risk, that’s worth it”* (P25).

Financial cost is another factor, especially for women who have to pay out-of-pocket for screening: *“Every 6 months, I have...to do a screening...doing mammogram, ultrasound...and then to see the doctor... it's very costly for me... not worth it”* (P22). Women weighed the economic impact of intensive screening versus preventive surgery: *“Doing a mastectomy is economically so much cheaper than going under surveillance”* (P2).

### ***Fears and concerns***

Women’s choices of preventive options were largely driven by their fears and concerns. These can act as barriers or motivators to women’s choice of preventive surgery.

#### ***Fears of surgery and losing the healthy breasts***

Fear of surgery and losing their healthy breasts were the biggest barriers facing both unaffected and affected women when making decision about breast cancer prevention. Surgery was perceived as a big event.

For affected women who had gone through surgery before, the thought of going through another surgery is *“really scary”* (P11) because they perceived that *“anything can happen in a surgery”* (P26). They were concerned about the risk of surgery including risk of death from surgery, post-op recovery and potential complications from surgery: *“So, the fear is*

*there...operation and then the pain...the most is my self-esteem as...a woman” (P26).*

#### Concerns about the potential impact of preventive surgery on body image, femininity and sexuality

Given the irreversible nature of preventive surgery, women were concerned about the potential impact of the procedure on their body image, femininity and sexuality.

Losing their healthy breasts would be “*terrifying*” (P6) as the impact on body image “*is going to be terrible*” (P6). For unaffected married women, they were more concerned about losing sexual arousal in the nipples and the impact on their sexuality: “*Personally, I am more worried about (chuckle) how it’s going to affect my intimate relation with my husband because they said that you are going to lose all the sensation*” (P4).

Uncertainty of husband’s future acceptance and fear of losing their husbands are another big barrier to women’s choice of preventive surgery: “*If really remove both breasts, not sure how my husband will treat me even though he said it’s alright now, but not sure if he will change in the future*” (P10).

#### Fears of developing breast cancer and going through treatment (again)

In most cases, fears of developing breast cancer, going through treatment or dying from the disease were the defining factor that drives women to choose preventive surgery after they were diagnosed with a *BRCA* genetic change.

For women who never had breast cancer before, fear of vulnerability to breast cancer was the motivator for choosing double preventive surgery: “*I knew it [breast cancer] will come...it can come anytime. The risk was high, especially because of my dad. So, in spite of the fact that I was not having any problem when I did the mastectomy, the fear was there*” (P12).

Both unaffected and affected women feared developing breast cancer. This fear affected women psychologically and acted as motivator for unaffected women to choose double preventive surgery: “*Every day, you [are] still thinking of the time bomb, when it will explode...when the breast cancer will come, it’s very scary*” (P22). Most often, women had a recent cancer scare, cancer death or traumatic cancer experience in the family or felt the urgency to make a decision in case it was too

late.

For affected women, fear of breast cancer recurrence was the biggest motivator for choosing preventive surgery of the other breast: *“Better remove fast, don’t have to be so fearful. If don’t remove, I am scared it might be too late. If the breast cancer comes back, then I have to do chemo again. It will be suffering. So, better remove fast”* (P25).

### ***Support system***

Lastly, notwithstanding women’s cancer risk perception, values and beliefs regarding breast cancer prevention, and fears and concerns, their support system (or lack of) affected and influenced women’s choice for screening or preventive surgery. Also, for married women, spousal attitudes towards preventive surgery exerted a significant influence on women’s decision-making. Thus, women’s support system and spousal attitudes towards preventive surgery can act as barriers or motivators to their decision-making.

### ***Lack of support system***

Lack of support system was a significant barrier to women’s choice for preventive surgery. In some instances, women were oriented towards preventive surgery. However, lack of support and consent from their spouses prevented them from choosing this option: *“I can’t decide on my own. If you ask me, I just want to remove [the healthy breast] and just be ok...I can’t do anything without the consent of my husband. If he gives the signal, I would like to...go into that process”* (P6).

Most women did not have the support and encouragement from their spouses to pursue this preventive measure: *“I had discussed with my husband before. He also said why remove if there’s no cancer. So, from his reply, I felt that breast is very important to my husband”* (P24).

Women were also lacking in support from family. Family exerted influence by explicitly discouraging preventive surgery, which affected women’s choice of breast cancer preventive options: *“My mum also said, why is the doctor asking you to go for op? She said, you are going to go and op, it’s going to be difficult for you. Yea, I said. I thought of it, so I just go for...ultrasound and mammogram la”* (P11). *“He [husband] told me to remove the healthy breast as well, but my*

*sisters said if there's nothing wrong then don't remove it. Keep it. If you removed already, later not sure how will your husband feel? So, I listened to my sisters...keep it, don't remove" (P10).*

#### *Have enough support and encouragement from family, husband and doctor*

Having enough support and encouragement from the people in their lives was the crucial motivator for women to choose preventive surgery. Women's sources of support and encouragement included their spouses, family, children, friends, breast cancer support groups and health professionals.

For married women, the support and encouragement from their spouses and families gave women the courage and strength to make the difficult choice for preventive surgery: *"I felt that it's very hard to lose my beautiful breasts...My husband is such a wonderful person and if he can be so supportive, why am I so weak that I can't decide? And he is the one who pushed me and gave me the courage to do what I have to do...So I have a wonderful supportive system" (P12).*

Spouses' positive attitude towards preventive surgery and explicit encouragement provided the support for women to choose this drastic preventive option: *"Life is more important than breast. If this [preventive surgery] is going to be future life-curing, I will put very serious consideration to remove the healthy breast. To keep her [wife] life is more important" (P34's spouse).*

For single women, though they feared the negative impact of preventive surgery on their body image, they were able to make the decision to remove their breasts with the support and encouragement from their families, friends and support group: *"And also family encouragement...They kept on telling me, don't wait until it's too late... Friends and family...encouraged me to have it done" (P13).*

#### **3.1.4 Needs assessment regarding a decision aid**

About half of the women wanted a decisional support that provides information on *BRCA* genetic change, breast cancer risk, benefits and harms of preventive surgery, what to expect if they choose preventive surgery, and stories about other *BRCA* carriers who had chosen different preventive options. They also wanted guidance/ coaching on decision-making.

About two-thirds of the clinicians indicated that information on different preventive options, advantages and disadvantages of each option and breast reconstruction is important for women to know before making a decision. They also felt that information on breast cancer risk is important. This information was incorporated into BRCADA.

### 3.2 Phase 2: Development of BRCADA

Based upon findings from the needs assessment study, review of scientific information and meeting with the expert steering group, the scoping, format and distribution plan of BRCADA were determined (Table 3.5).

**Table 3.5** Key Elements of BRCADA

| Element                                   | Description   |
|---|---|
| Target audience                           | Both breast cancer unaffected and affected women with a <i>BRCA</i> genetic change who are considering preventive options for reducing their risks of breast cancer   |
| Purpose                                   | To support women with a <i>BRCA</i> genetic change in making an informed decision that is right for each woman through shared decision-making with their surgeons   |
| Format                                    | Paper-based and web-based tools to facilitate efficient communication between surgeons and patients in the clinics  |
| Language                                  | English, Malay and Mandarin   |
| Timing of introduction to patient pathway | BRCADA will be introduced to women after they are diagnosed with a <i>BRCA</i> genetic change and have received genetic counselling   |
| Distribution                              | Surgeons will hand out BRCADA to their patients during consultation in the clinics  |
| Content                                   | Stories of other women, breast cancer risk, options (screening, preventive medication, preventive surgery, lifestyle changes), types of breast reconstruction, clarifying values, guidance in decision-making and resources |

Content development of BRCADA was guided by the IPDAS framework. BRCADA is divided into six sections:

*Section 1: Introduction*

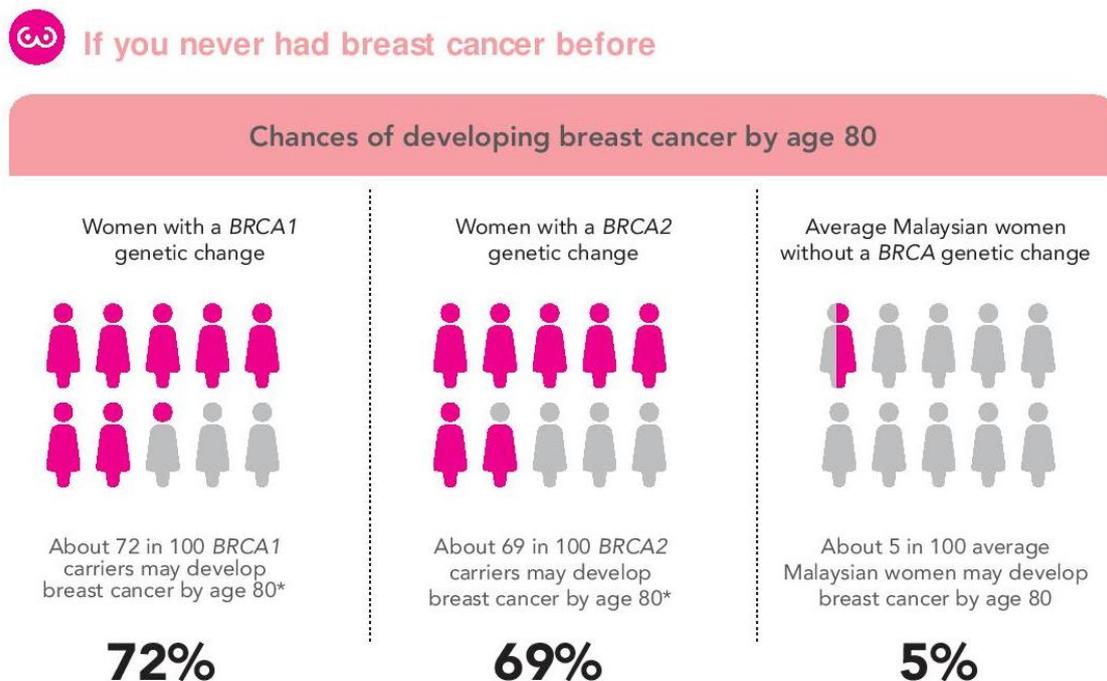
It begins with an introduction of BRCADA and how to use the decision aid.

*Section 2: Stories of Other Women*

This section illustrates the true stories of Ming Ming and Devi (not their real names), women with a *BRCA2* and *BRCA1* genetic change, respectively, who had made decisions regarding breast cancer preventive options. Ming Ming shared about her decision to choose breast screening for early detection of breast cancer, rather than removal of her healthy breast. Devi shared about her values and beliefs that led her to choose preventive surgery to remove her healthy breast for prevention of breast cancer.

*Section 3: Understanding Breast Cancer Risk*

This section contains information about cumulative risks of breast cancer and cancer in the other breast as well as the comparison of breast cancer risk between women with a *BRCA* genetic change and the average women (who do not have a *BRCA* genetic change) (Figure 3.1).



**Figure 3.1:** BRCADA – Chances of developing breast cancer by age 80

## Section 4: Your Preventive Options

This section contains information about the different breast cancer preventive options that are available in Malaysia: breast screening, preventive medication, preventive surgery and lifestyle changes (Figure 3.2). It also provides information on the different options of breast reconstruction available in Malaysia.

## Section 5: Your Decision-Making

This section provides structured guidance to decision-making in five simple steps. It contains value clarification exercise to help women clarify their values related to breast cancer prevention and their healthy breasts, ensuring that the preventive options chosen by women are in congruence with their values. It also contains worksheets to help women explore their support needs before making a decision, choices they are leaning toward and feelings about their choices.

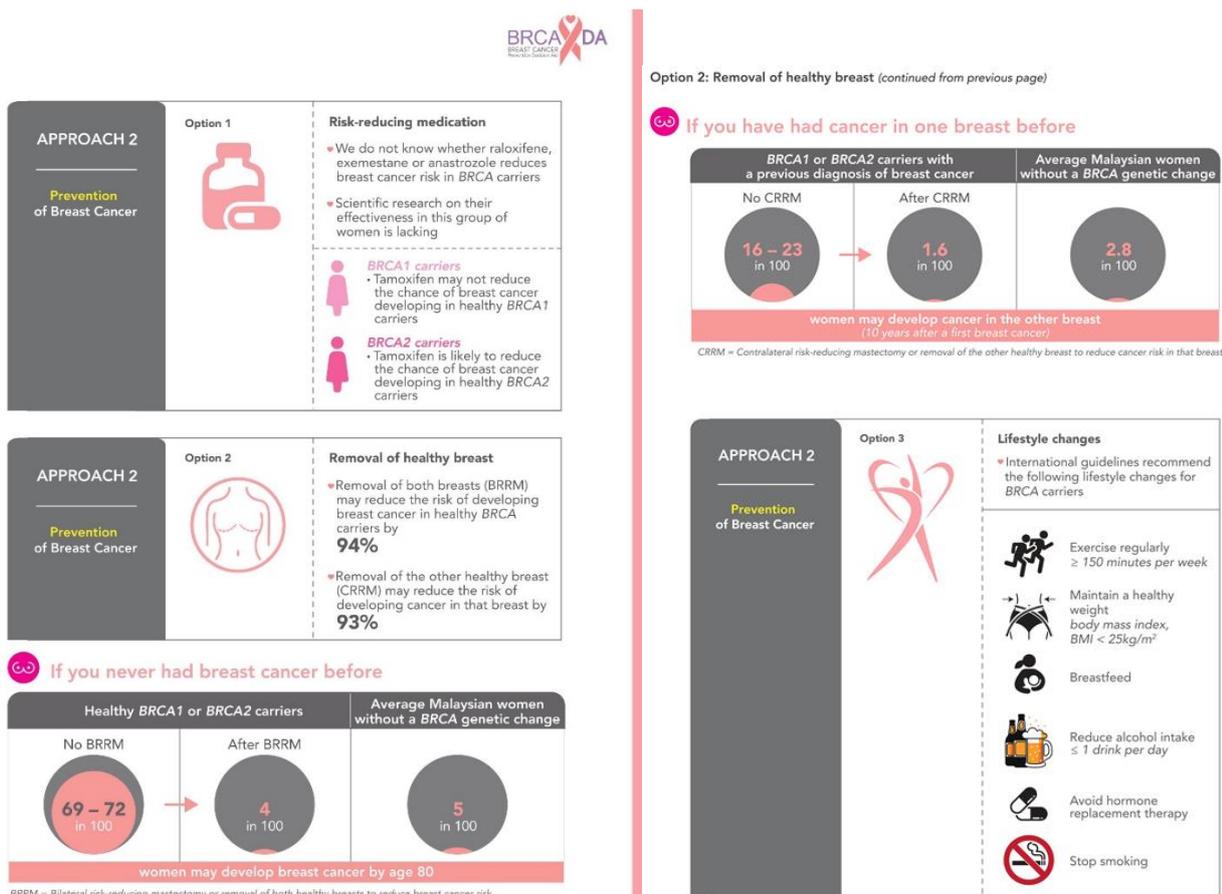


Figure 3.2: BRCADA – Breast cancer preventive options for women with a BRCA genetic change

## Section 6: Resources

The last section of BRCADA contains resources on listing of hospitals with breast surgeons, listing of breast cancer support groups, glossary and credentials of the expert steering group members, reviewers and developers.

### 3.3 Phase 3: Field-Testing of BRCADA

BRCADA was field-tested with 51 clinicians and 20 women with a *BRCA* genetic change from 22 private, Ministry of Health and university-teaching hospitals in Malaysia (Table 3.6).

**Table 3.6** Study Setting

| Study setting                   | Number of sites | Number of participants, n (%)           |            |
|---------------------------------|-----------------|---|------------|
|                                 |                 | Women with a <i>BRCA</i> genetic change | Clinicians |
| 1. University teaching hospital | 4 (18.2)        | 11 (55.0)                               | 8 (15.7)   |
| 2. Ministry of Health hospital  | 10 (45.5)       | 3 (15.0)                                | 33 (64.7)  |
| 3. Private hospital             | 8 (36.3)        | 6 (30.0)                                | 10 (19.6)  |
| <b>Total</b>                    | <b>22</b>       | <b>20</b>                               | <b>51</b>  |

All 51 (100%) clinicians and 20 (100%) women found BRCADA to be easy to understand, balanced, visually appealing with helpful graphics and just right in length. All of them would recommend BRCADA to *BRCA* carriers who are considering breast cancer preventive options.

Most clinicians agreed that the overall content of BRCADA is excellent and the amount of information is just right. All clinicians perceived that BRCADA clearly describes the preventive options for breast cancer and provides essential information for women's decision-making. Furthermore, they agreed that the description of benefits and harms of options are supported by scientific evidence and are presented in an unbiased manner.

All clinicians rated BRCADA as a reliable tool for helping women with a *BRCA* genetic change to make decisions about breast cancer prevention. All except one clinician (98%) agreed that using

BRCADA would result in their patients making more informed decisions.

Thirty-seven clinicians (73%) would be very comfortable offering BRCADA to their patients while the remaining 14 would be comfortable. Most clinicians agreed that BRCADA would be easy to use in their practice and likely to be used by most of their colleagues.

As for women, 10 (50%) of them found the overall content of BRCADA to be excellent while the remaining 10 found the content to be good. Nineteen (95%) women rated the amount of information as just right, while one woman felt the information was too much. Thirteen (65%) women found everything in BRCADA to be clear while 6 (30%) women, most things to be clear and one woman (5%), some things were clear.

All 20 women (100%) felt that BRCADA increased their knowledge about breast cancer preventive options. This finding is consistent with women’s knowledge measures of cancer risk perception and preventive options, before and after using BRCADA. Using BRCADA results in significant improvements in women’s risk perception of breast cancer ( $p = 0.001$ ) and knowledge of breast cancer preventive options ( $p < 0.001$ ) (Table 3.7).

**Table 3.7** Comparison of scores on knowledge pre- and post-decision aid (N = 16)

|                                     | Pre-decision aid |                | Post-decision aid |                | Z      | p-value <sup>a</sup> |
|-------------------------------------|------------------|----------------|-------------------|----------------|--------|----------------------|
|                                     | Mean (SD)        | Median (IQR)   | Mean (SD)         | Median (IQR)   |        |                      |
| Knowledge                           |                  |                |                   |                |        |                      |
| a. Risk perception of breast cancer | 35.42% (33.26)   | 33.33% (58.34) | 91.67% (19.25)    | 100.00% (0.00) | -3.225 | <b>0.001</b>         |
| b. Breast cancer preventive options | 50.50% (11.58)   | 48.00% (22.00) | 88.75% (9.82)     | 92.00% (15.00) | -3.525 | <b>0.000</b>         |

<sup>a</sup>*p-value is derived from the Wilcoxon Signed Rank Test.*

*SD = standard deviation, IQR = interquartile range.*

Seventeen (85%) women rated BRCADA as very helpful in making a decision about breast cancer preventive options, while two (10%) women, somewhat helpful and one (5%) woman, a little helpful. This high score obtained for the decision aid acceptability measures is consistent with

the measures of women’s perceived level of preparation for decision-making. Overall mean score for the Preparation for Decision-Making scale is 85%, which indicates a high perceived level of preparation for decision-making (Table 3.8). Women with a *BRCA* genetic change perceived that BRCADA was useful in preparing them to communicate with their surgeons at a consultation visit and to make a health decision on breast cancer prevention.

**Table 3.8** Preparation for decision-making scale (N=17)

|  | Mean (SD) | Median (IQR)    |
|--|-----------|-----------------|
| Perceived level of preparation for decision-making | 85% (13)  | 78% (100% -75%) |

*SD = standard deviation, IQR = interquartile range.*

Twelve (60%) women were very satisfied and eight (40%) were satisfied with BRCADA. From a scale of 1 (very dissatisfied) to 10 (very satisfied), all 20 (100%) women rated their satisfaction as 8 and above, with a median score of 9 (interquartile range, IQR 8 to 10).

Furthermore, using BRCADA significantly reduced decisional conflict in women with a *BRCA* genetic change. The mean total score of decisional conflict before using BRCADA was 27.57 (SD = 15.52) and reduced significantly after using BRCADA to 21.69 (SD = 12.38) ( $p = 0.001$ ). Mean scores for informed and effective decision subscales also reduced significantly after using BRCADA (Table 3.9).

Following the findings from field-testing, a final version of BRCADA was printed and distributed to clinicians in Malaysia. The printed version of BRCADA was then adapted onto a resource website (<https://brcada.um.edu.my>), providing information about the different breast cancer preventive options that are available, and to help women clarify their values, concerns and support system that are important to their decision-making (Figure 3.3). The BRCADA resource website is available in three languages – English, Mandarin and Malay.

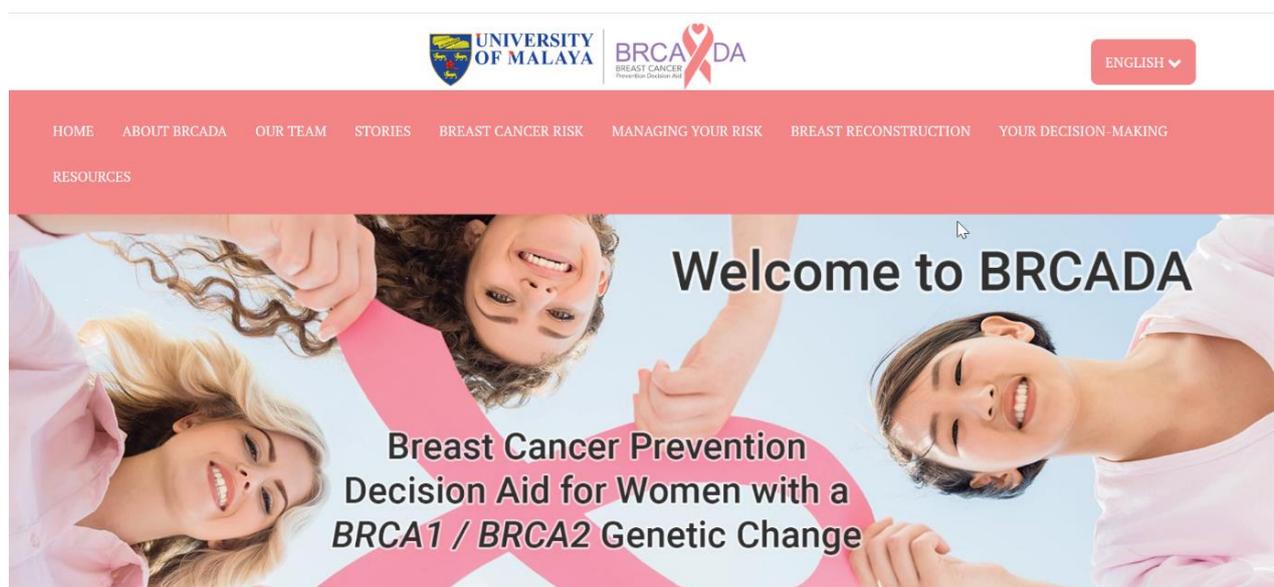
**Table 3.9** Comparison of scores on the decisional conflict scale and its subscale pre- and post-decision aid (N=17)

|                    | Pre-decision aid |                  | Post-decision aid |                  | Z      | p-value <sup>a</sup> |
|--------------------|------------------|------------------|-------------------|------------------|--------|----------------------|
|                    | Mean (SD)        | Median (IQR)     | Mean (SD)         | Median (IQR)     |        |                      |
| Total score        | 27.57<br>(15.52) | 28.13<br>(17.19) | 21.69<br>(12.38)  | 25.00<br>(15.63) | -3.192 | <b>0.001</b>         |
| Informed           | 30.88<br>(15.24) | 33.33<br>(12.50) | 20.10<br>(11.81)  | 25.00<br>(12.50) |        | <b>0.003</b>         |
| Values clarity     | 26.47<br>(18.22) | 25.00<br>(16.67) | 21.57<br>(14.15)  | 25.00<br>(12.50) |        | 0.244                |
| Support            | 24.51<br>(21.54) | 25.00<br>(20.83) | 21.57<br>(15.88)  | 25.00<br>(12.50) |        | 0.131                |
| Uncertainty        | 30.88<br>(17.62) | 25.00<br>(16.67) | 25.98<br>(17.40)  | 25.00<br>(25.00) |        | 0.098                |
| Effective decision | 25.74<br>(15.92) | 25.00<br>(21.88) | 21.32<br>(12.51)  | 25.00<br>(9.38)  |        | <b>0.031</b>         |

<sup>a</sup>p-value is derived from the Wilcoxon Signed Rank Test.

The bold values represent <0.05 significance.

SD = standard deviation, IQR = interquartile range.



**Figure 3.3:** BRCADA – Landing page of <https://brcada.um.edu.my>

#### 4. Conclusions

Overall, BRCADA was found to be feasible and acceptable to most clinicians and women in this study. Furthermore, using BRCADA significantly improved women's decisional conflict, risk perception of breast cancer and knowledge of breast cancer preventive options. The use of BRCADA helps to facilitate the new value of shared decision-making between women and clinicians towards decisions that are more aligned to women's personal values, goals and preferences. Improved decisions are expected to decrease the incidence and burden of breast cancer, and improve quality of life of women and their families. All clinicians and women in this study would recommend BRCADA to other women with a *BRCA* genetic change who are considering breast cancer preventive options. BRCADA is the first decision aid developed for women considering the very complex decision about *BRCA*-associated breast cancer prevention in Malaysia.

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