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# Consumer and clinician perspectives on personalising breast cancer prevention information

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## ABSTRACT

*Background:* Personalised prevention of breast cancer has focused on women at very high risk, yet most breast cancers occur in women at average, or moderately increased risk (≤moderate risk).

*Objectives:* To determine; 1) interest of women at ≤ moderate risk (consumers) in personalised information about breast cancer risk; 2) familial cancer clinicians' (FCCs) perspective on managing women at ≤ moderate risk, and; 3) both consumers' and FCCs reactions to iPrevent, a personalised breast cancer risk assessment and risk management decision support tool.

*Methods:* Seven focus groups on breast cancer risk were conducted with 49 participants; 27 consumers and 22 FCCs. Data were analysed thematically.

*Results:* Consumers reported some misconceptions, low trust in primary care practitioners for breast cancer prevention advice and frustration that they often lacked tailored advice about breast cancer risk. They expressed interest in receiving personalised risk information using iPrevent. FCCs reported an inadequate workforce to advise women at ≤ moderate risk and reacted positively to the potential of iPrevent to assist.

*Conclusions:* While highlighting a potential role for iPrevent, several outstanding issues remain. For personalised prevention of breast cancer to extend beyond women at high risk, we must harness women's interest in receiving tailored information about breast cancer prevention and identify a workforce willing to advise women.

## 1. Background

Despite the optimism around the possibilities of personalised prevention of cancer [1,2], and of breast cancer (BC) prevention in particular [3–5], so far, in Australia, the opportunities for personalised prevention are almost exclusively for women at high risk of cancer due to family history or a genetic predisposition [6]. Cancer Australia defines three risk categories, based on family history, for Australian women: 1) at or slightly above average risk (chance is 1 in 11 to 1 in 8); 2) moderately increased risk (chance is between 1 in 8 and 1 in 4) and; 3) potentially high risk (chance is between 1 in 4 and 1 in 2). Cancer Australia state that more than 99% of women are either at or slightly above average risk, or have a moderately increased risk of breast cancer (≤moderate risk) [7], and most breast cancers occur in this group of women. Therefore, the greatest cancer-control gains can be made with appropriately targeted

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prevention strategies, including use of risk-reducing medication such as tamoxifen and aromatase inhibitors (which reduce breast cancer risk by about a third to a half and are considered for women at moderate or high risk) [8–10] and attention to lifestyle risk factors (recommended for all women).

In Australia the national breast cancer screening program (BreastScreen) invites women aged 50–74 for a free mammogram every two years, and familial cancer clinics offer risk assessment and genetic testing to women at high familial risk. In both the United Kingdom and the United States, trials on risk-stratified breast cancer screening are underway [11,12].

In order to improve the management of the 99% of women at $\leq$ moderate risk, it is essential that health care providers can assess a woman's risk. Our research with Primary Care Practitioners (PCPs) and breast surgeons in Australia on this topic found that PCPs in particular experienced difficulty collecting and interpreting family history information and identified a lack of available tools to help them do so [13,14]. Research with PCPs in other settings has reported concerns about increasing women's anxiety [15], discomfort with risk assessment [15,16], inconsistency in risk communication [15,17] and concerns about the ethical, legal and social implications of genetic testing [18]. PCPs in Melbourne, Australia reported that a breast cancer risk assessment and decision support tool would help them discuss appropriate BC risk reduction measures with women and that such a tool would need to be evidence-based, easily accessible (e.g. web-based), and display absolute risk in multiple formats (e.g. numerical data, pictograms and graphs) [13,14].

iPrevent, which was under development at the time of this study, is a personalised, web-based, risk assessment and risk management decision support tool to help clinicians to assess and manage the spectrum of breast cancer risk (www.petermac.org/iprevent). Following the initial needs assessment with PCPs and breast surgeons, the iPrevent prototype was developed [19]. It contained; (1) data input (risk factor details); (2) risk estimation using either the IBIS [20] or BOADICEA [21] algorithms, and; (3) results output (personalised absolute risk estimation with tailored risk management options, including estimated absolute risk reduction for each option) [19].

Little research has been conducted on the need for personalised risk and risk management advice for women at $\leq$ moderate risk. There is emerging evidence that women in population screening programs are interested in finding out their individual risk for breast cancer [12,22] and that informing women about their personalised risk of breast cancer has the potential to increase appropriate preventative behavior [23], although the evidence for such risk assessments provoking lifestyle changes is weak [24]. Further research is required to understand the relationship between risk assessment and behavior change. Overall, however, there is some confidence that breast cancer risk assessment can lead to reduced worry and distress in those with a family history [25].

While risk assessment is considered standard practice for women at high familial risk, the greatest gains for population health can be made by reducing cancer incidence in the much larger group of women at $\leq$ moderate risk, yet challenges in achieving this remain. We have previously conducted focus groups with PCPs, practice nurses and breast surgeons [13,14], but there is little research on the needs, expectations and concerns of women and familial cancer clinicians regarding individualized risk assessment for this group. Genetic counsellors are experts in risk assessment for breast cancer, and with geneticists and oncologists, play an important role in the management of women at moderately increased and high risk. Therefore the views of FCC clinicians are critical to any future implementation of the personalised prevention of breast cancer. The objectives of this focus group study were to determine; 1) interest of women at $\leq$ moderate risk in personalised breast cancer risk assessment and management; 2) familial cancer clinicians' perspectives on managing women at $\leq$ moderate risk, and; 3) women's and clinicians' reactions to the iPrevent prototype, in order to inform its continuing development.

## 2. Methods

A focus group design was chosen in order to collect data on shared social meanings of breast cancer risk and risk management, and collective responses to the iPrevent prototype. Given our previous work with PCPs and breast surgeons, the groups studied were familial cancer clinicians and consumers who were unaffected by cancer and unselected for family history.

### 2.1. Clinician recruitment

FCC clinicians were recruited via two sources: 1) an annual national conference, attended by FCC staff from Australia and New Zealand, and; 2) a large FCC in Melbourne, Australia. Inclusion criteria were: employed as a genetic counsellor, clinician or nurse within an FCC and involved in providing breast cancer risk advice to women. This recruitment strategy allowed us to recruit a range of clinicians from FCCs across Australia and New Zealand. Email invitations with an attached Plain Language Statement (PLS) were sent to registered conference attendees, who were asked to respond to the study's Project Coordinator (P.W.) if they were interested in attending a focus group discussion. The Melbourne FCC was selected because clinicians from the clinic had expressed interest in participation, but were unable to attend the focus group at the familial cancer conference.

### 2.2. Consumer recruitment

Consumers were recruited through the Register4 Network, an initiative of the National Breast Cancer Foundation in Australia. Register4 is a web-based voluntary register of Australians aged 18+, both with and without cancer, who are willing to receive requests to participate in cancer research. Inclusion criteria for consumers were; female; age 20–70 years (ages eligible to use iPrevent); and no personal history of breast or ovarian cancer. To recruit a diverse range of women, email invitations were sent from a Register4 representative to eligible members in central, northern, eastern and western locations across suburban Melbourne, Australia (identified by the member's postcode). Four separate mail-outs occurred, each targeting a different group of similar postcodes. Members interested in participating then consented to the release of their contact details to the study's Research Assistant (E.S.). Interested members were emailed the PLS and then contacted by phone to determine which focus group would be most convenient for them. Focus groups were held in public libraries in four different locations in metropolitan Melbourne.

### 2.3. Data collection

Ethics approval was obtained from The University of Melbourne. The focus groups were guided by a list of themes, and run in two parts over 90 min. Authors LK and ES or ES and PW conducted consumer focus groups, and authors LK and KP conducted clinician focus groups. The first part of the clinician focus groups explored current practice in breast cancer risk assessment, including current practice, perceived problems and management options offered to women. The first part of the consumer focus groups explored what participants knew about breast cancer risk, risk factors, screening and risk management options, and how they sourced information on breast cancer. Both clinician and consumer groups were then presented with a live demonstration of the iPrevent prototype, including the data input process and example output pages for a specific hypothetical woman at 'somewhat increased' (moderate) risk. The demonstration showed how information was entered and how the risk information and advice would be provided to a hypothetical woman at moderately increased risk. Fig. 1 provides an example of the images used in iPrevent to illustrate the risk output for the hypothetical woman at moderately increased risk. Fig. 2 provides the risk reduction this particular woman would achieve by taking risk reducing medication. The second part of both focus groups elicited participant responses to iPrevent, including: questions and clarifications; responses to input and output pages; acceptability; how it might be received, and; perceived barriers or enablers to the use of iPrevent in practice.

### 2.4. Data analysis

The focus groups were audio recorded and transcribed verbatim by a professional transcriber and transcripts were checked against the audio recordings for accuracy. A coding framework was developed in collaboration by reading and re-reading both FCC and consumer transcripts and identifying key themes. Saturation was assessed by developing a list of preliminary themes based on the transcripts from the first few focus groups and determining whether new data collected at subsequent focus groups contributed any new data to the main themes. In the case of consumers, saturation was reached, with no new themes emerging in the final two groups. It was more difficult to assess saturation with clinician focus groups, as there was some variation between the two groups. However, given the wide representation of staff from 12 clinics across Australia and New Zealand in the two groups, there were few options for new recruitment. Using QSR NVivo 10 qualitative data management software, all data was coded according to the coding framework, and using the method of constant comparison, the full range of variation in each code, across both groups was summarized.

## 3. Results

A total of 49 participants took part in seven focus groups. Two clinician focus groups were conducted, including 15 clinicians from the national familial cancer conference, and seven from the Melbourne FCC. Clinicians worked in New Zealand and five states of Australia, and on average had been working in an FCC for 9.5 years (Table 1).

Fifty-five Register4 members agreed to further contact, and of these, 27 attended one of five focus groups held across metropolitan Melbourne (two inner, one northern, one eastern and one western). The average age of participating consumers was 49.5 years (Table 2). Just over half of the consumers had some family history of BC, although half of those with a family history reported only one second degree relative with BC. Based on the family history reported by women, none were likely to be classified as potentially high risk of BC. None had a *BRCA1* or *BRCA2* gene mutation identified in their families. Only two had attended a FCC, three had visited a breast surgeon, and half had spoken to their PCP about breast cancer risk. All women over 50 years of age had at least one mammogram.

### 3.1. Clinicians – problems with risk assessment and management for women at ≤ moderate risk

FCC clinicians identified two main issues with breast cancer risk assessment and management for women at ≤ moderate risk; the increased demand from these women for advice and management and; the lack of an identified clinician group willing and able to provide this care. Many commented on the overwhelming number of women interested in genetic testing and risk assessment following Angelina Jolie's 2013 disclosure of her *BRCA* mutation status and subsequent risk-reducing bilateral mastectomy and bilateral salpingo-oophorectomy, as has been reported elsewhere [26]. Saying, for example, '*They wanted something. Their anxiety levels were very high.*' In response, a number of FCCs had implemented additional personal risk assessment clinics for these women. Some ran these clinics over the phone, while others offered face-to-face appointments. They used a range of different tools to estimate a women's risk: IBIS model [20]; BRCAPRO [27]; BOADICEA [21]; or Cancer Australia guidelines [28] (see quotes 1–3, Table 3). While clinicians saw this work as a shift from their usual focus on genetic testing and as an increased workload, these clinics were reportedly valued by women, and thought to reduce anxiety. However, clinicians described that some women at ≤ moderate risk had sought inappropriate risk management strategies, such as risk-reducing bilateral mastectomy, and some struggled to accept that they were not at high risk (Table 3, Quote 4). Some felt this increased demand was likely to be an ongoing issue, with general public interest in genetic testing for BC remaining high, saying, '*What it really taught me was that this isn't gonna go away.*'

The increased number of referrals was thought to be due, in part, to PCPs not feeling confident to manage these women in their own practice. Clinicians described PCPs as lacking the knowledge and expertise to assess BC risk, and as unfamiliar with online tools. They also speculated that some PCPs make referrals at the patient's request, (not because the PCP thinks it warranted), further emphasizing some women's determination to get information (see Table 3, quote 5). Clinicians also perceived that many PCPs were unfamiliar with the prescription of risk reducing medications, such as tamoxifen. As a consequence, many moderate risk women were in *"limbo"*, with breast surgeons and FCCs at full capacity managing high risk women, and PCPs lacking the tools to manage them (Table 3, Quote 6).

### 3.2. Consumers - do women want to know their personal risk of BC?

While consumers were not offered information about their personal risk of BC as part of this study, they were asked whether they would be interested in knowing this information, should it be available. Some expressed that, personally, BC risk was not on their *"radar"*, and not something they had ever considered, either because they hadn't been "*touched*" by it (no BC among friends or family), or because other issues took priority (see Table 4, quote 1). Some women would only be interested in their personal BC risk if it was reassuring, and expressed concern about being at high risk (see Table 4, quote 2). Others expressed that risk itself is not compelling, but if, on the basis of risk, they could reduce their chance of developing BC, it would be worthwhile knowing (see Table 4, quote 3). Finally, some said that, *"information is power"*. These consumers regarded all information about their health as valuable. They assumed that knowledge of personal BC risk would be useful, and could put women in charge of their health (see Table 4, quote 4).

### 3.3. Consumers – misunderstandings about BC risk management

Consumers were all aware of BreastScreen (the Australian population screening program), and those aged over 50 years had all attended BreastScreen at least once. Yet we identified misunderstandings related to breast self-examination, lifestyle risk factors and eligibility for risk reduction strategies. Almost all

Your risk in the next 10 years

**Your risk of developing breast cancer over the next ten years is 2.3%.** This means that 23 out of 1000 women your age, with the same risk of breast cancer as you, will develop breast cancer in the next ten years.

The risk for an average woman of your age is 1.1%. This means that 11 out of 1000 women your age, at average risk in the general population, will develop breast cancer in the next ten years.

**Expand below for a picture of your risk in the next 10 years.**

Your Risk Over the Rest of Your Life

**Your risk of developing breast cancer over the rest of your life is 17.4%.** This means 174 out of 1000 women your age, with the same risk of breast cancer as you, will develop breast cancer at some time in their life.

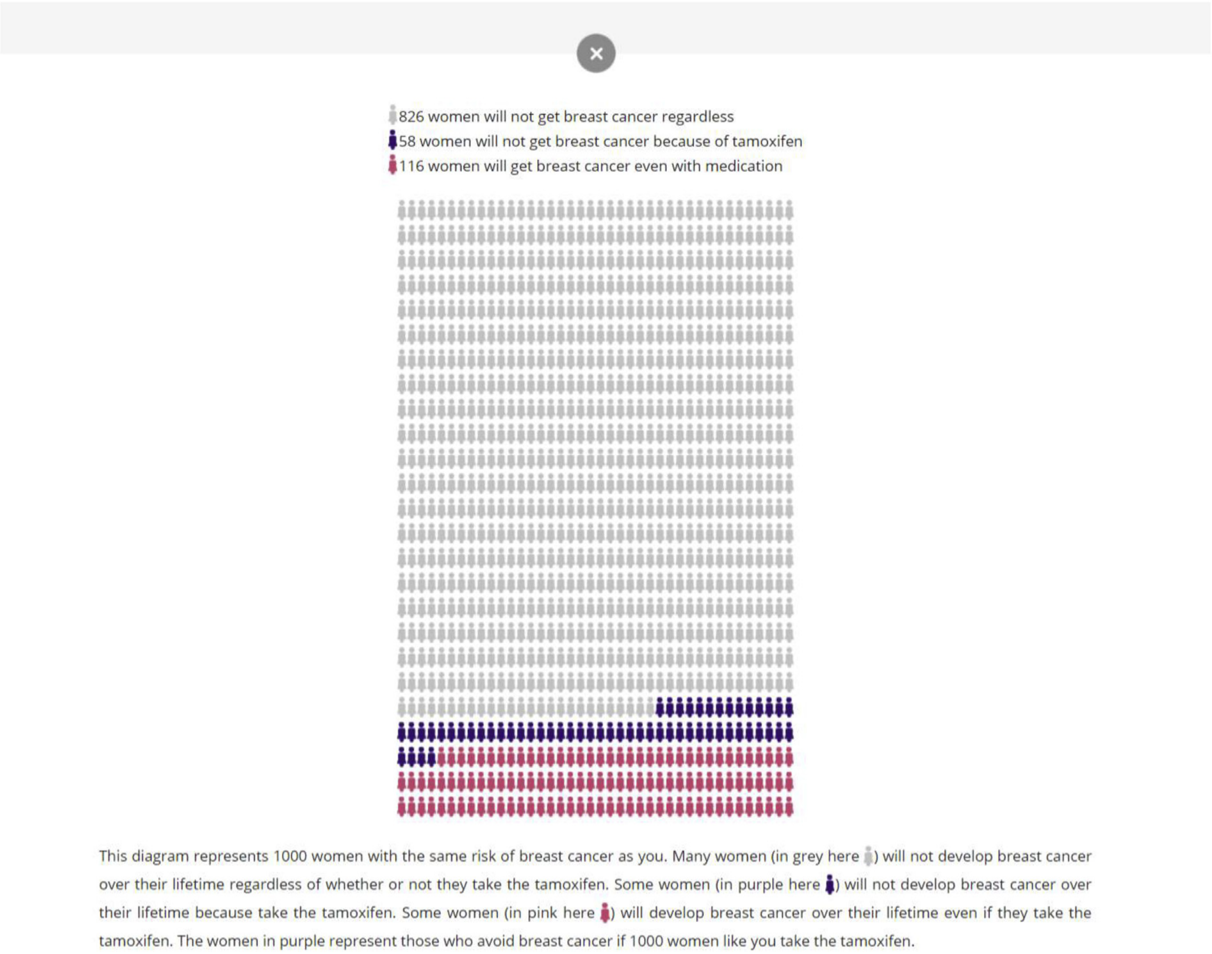
The risk for an average woman of your age is 10.3%. This means 103 out of 1000 women of your age, at average risk in the general population, will develop breast cancer at some time in their life.

**Expand below for a picture of your risk over the rest of your life.**

The diagram on the left represents 1000 women your age with the same risk of breast cancer as you. You can compare that with the diagram on the right which represents 1000 women your age with an average breast cancer risk.

Out of 1000 women of your age, 174 will develop breast cancer at some time in their lives, compared with 103 women who are of average risk.

**Fig. 1.** Images from the current version of iPrevent showing risk information for a hypothetical woman at moderately increased risk.



826 women will not get breast cancer regardless
58 women will not get breast cancer because of tamoxifen
116 women will get breast cancer even with medication

This diagram represents 1000 women with the same risk of breast cancer as you. Many women (in grey here) will not develop breast cancer over their lifetime regardless of whether or not they take the tamoxifen. Some women (in purple here) will not develop breast cancer over their lifetime because take the tamoxifen. Some women (in pink here) will develop breast cancer over their lifetime even if they take the tamoxifen. The women in purple represent those who avoid breast cancer if 1000 women like you take the tamoxifen.

**Fig. 2.** Image from the current version of iPrevent, showing the risk reduction associated with the use of risk reducing medication for a hypothetical woman at moderately increased risk.

participants reported that women should perform a Breast Self-Examination (BSE) once a month. Many recounted health promotion messages about BSE from the media. Some believed they should be carrying out BSEs, but lacked confidence in doing so and therefore disengaged, while others described themselves as ‘religious’ about performing BSE once a month (see Table 4, Quote 5&6). Other than BSE, the most commonly mentioned strategies for managing BC risk were mammography and lifestyle factors. However, many reported skepticism or confusion about lifestyle factors and how they relate to cancer, due to inconsistent and mixed messages. As a result, the majority reported disengaging with lifestyle recommendations (see Table 4, Quote 7&8). All were aware of bilateral mastectomy as a risk management option for women at high risk, and a few had heard of premenopausal bilateral salpingo-oophorectomy, however, there was a common perception that there is nothing a woman can do about her BC risk unless she has a genetic mutation. None had heard of risk reducing medications (see Table 4, Quote 9).

### *3.4. Consumers – perceived problems with access to information and advice*

Consumers identified two main problems in relation to the information available to them about BC risk management options; overload of information, and; lack of confidence in PCP's. Consumers described a wealth of information on BC, yet found it could be intimidating, leaving them with little sense of which preventative measures they should be engaging with (see Table 4, quote 10). Many consumers described problems with BC prevention in primary care, including: PCPs perceived as being more interested in other diseases than in BC; PCPs seen as not being informed about BC risk and risk management options and therefore not discussing with women; some felt that PCPs could be dismissive of breast symptoms and women's concerns; many commented that attending a PCP is time consuming and expensive (see Table 4, quote 11&12).

### *3.5. iPrevent*

#### *3.5.1. Benefits of using a tool like iPrevent*

Both clinicians and consumers responded positively to the demonstration of the iPrevent prototype, and saw advantages to its use. For clinicians, the main perceived benefit was iPrevent's provision of accurate and reliable risk estimates for both ten year and lifetime risk, and standardized risk management advice for women (see Table 5, quote 1&2). Clinicians felt that iPrevent would increase the likelihood of consistent practice across clinics, and reduce the chance of inaccurate advice being offered to women. In particular, clinicians felt that iPrevent would increase the likelihood of clinicians discussing risk reducing medication with women at moderate risk (see Table 5, quote 3&4). Clinicians also felt that iPrevent would provide support for PCPs to advise women about BC risk (see

**Table 1**
Clinician demographics (n = 22).

| Characteristic | n (%) |
|---|---|
| Gender | |
| Female | 21 (95) |
| Male | 1 (5) |
| Age | |
| 25–35 years | 10 (45) |
| 36–45 years | 5 (23) |
| 46–60 years | 7 (32) |
| Role | |
| Genetic counsellor | 17 (77) |
| Clinical geneticist | 2 (9) |
| Medical oncologist | 3 (14) |
| Country of graduation | |
| Australia | 20 (91) |
| Other | 2 (9) |
| Location of work | |
| New South Wales | 10 (45) |
| Victoria | 8 (36) |
| South Australia | 1 (5) |
| Queensland | 1 (5) |
| Australian Capital Territory | 1 (5) |
| New Zealand | 1 (5) |
| Years working in an FCC | |
| <5 | 6 (27) |
| 5-15 | 11 (50) |
| >15 | 5 (23) |
| Have you ever prescribed medication to reduce breast cancer risk e.g. Tamoxifen[a]? | |
| Yes | 1 (20) |
| No | 4 (80) |

[a] Only included those able to prescribe medication (clinical geneticists & medical oncologists).

Table 5, quote 5).

Consumers most often described the benefits of iPrevent in terms of its ability to empower women; putting the information in their hands, allowing them to make decisions based on the best available data; allowing them to have more meaningful and informed conversations with their PCP; giving them more confidence that there are things they can do to prevent BC (see Table 5, quote 6&7).

### 3.5.2. *Concerns about using a tool like iPrevent*

Clinicians' suggested changes to the iPrevent prototype such as improving: the scale of graphs; readability for lower literacy levels; the option of a printable page of output for consumers and clinicians; as well as debating the best order for presenting the options to women. However, their main concern was the need to enter the same data twice; once to draw up the pedigree using practice software; and once to generate a risk assessment from iPrevent (Table 5, Quote 9). Consumers were concerned about women's interpretation of the risk estimate in two ways; firstly, that some women may disengage from BC prevention measures if they feel reassured by a low risk estimate; and secondly, that any level of risk has the potential to provoke unnecessary fear (Table 5, Quotes 10&11).

### 3.5.3. *Implementation - how should women access their personalised risk estimate?*

While it was agreed across all of the focus groups that most women would be able to input the data at home, consumers took a strong stance on how women should receive their risk assessment and advice. Our previous research had indicated that clinicians favoured risk assessment being delivered in a medical setting, yet the majority of consumers said that women should have the option to receive their result at home. Many consumers felt the involvement of their PCP would be a barrier to them using iPrevent (Table 5, Quotes 12&13). Barriers were caused either by time and cost associated with visiting a PCP or fear that a PCP's recommendation may conflict with the advice provided by the tool (Table 5, Quotes 14).

**Table 2**
Consumer demographics (n = 27).

| Characteristic | n (%) |
|---|---|
| Age | |
| 20–35 years | 5 (18) |
| 36–50 years | 8 (30) |
| 51–70 years | 14 (52) |
| Highest Level of Education | |
| High school or leaving certificate | 6 (22) |
| Certificate or diploma | 4 (15) |
| University degree or higher | 17 (63) |
| 1st or 2nd degree relatives diagnosed with breast cancer | |
| Yes | 14 (52) |
| One 2nd degree relative only | 7 (26) |
| One 1st degree relative only | 3 (11) |
| One 1st degree relative and one 2nd degree relative | 4 (15) |
| No | 13 (48) |
| Ever spoken to a PCP about breast cancer risk | |
| Yes | 14 (52) |
| No | 12 (44) |
| Don't know | 1 (4) |
| Ever spoken to your PCP about the following[b]; | |
| Screening e.g. mammograms | 17 (63) |
| Medication to reduce breast cancer risk e.g. | 0 (0) |
| Surgery | 0 (0) |
| Ever been to an FCC to discuss breast cancer risk | |
| Yes | 2 (7) |
| No | 25 (93) |
| Ever been to a breast surgeon to discuss breast cancer risk | |
| Yes | 3 (11) |
| No | 24 (89) |
| Any blood relatives been told they have a cancer gene mutation? | |
| Yes[a] | 1 (4) |
| No | 26 (96) |
| Source of information accessed about breast cancer, if any[b] | |
| Internet | 24 (89) |
| PCP | 13 (48) |
| Friend | 5 (19) |
| News | 3 (11) |
| Specialist | 2 (7) |
| Family | 1 (4) |

[a] Family member with Lynch Syndrome.
[b] More than one option could be selected.

## 4. Discussion

The data presented here highlight the challenges and opportunities in implementing personalised prevention of breast cancer for the majority of women in the current Australian health care system. We conducted focus groups with 27 women unaffected by cancer and not selected on family history and 22 familial cancer clinicians. Both groups reported concern about which health providers can manage women at ≤ moderate risk. FCC clinicians noted a steady and persistent increase in interest from this group - dubbed the ‘Angelina Jolie effect,’ [26] and felt these women at ≤ moderate risk were often ‘in limbo’ between primary care and specialist services, not able to access advice through either pathway. Few consumers had heard of or attended familial cancer services, and few felt confident to ask their PCP for personalised risk advice. This reflects international research indicating that improvements could be made to how PCPs present breast cancer risk and risk factors to patients [17,18]. Similarly, PCPs have expressed a preference for managing breast cancer survivors in collaboration with specialists and patients also prefer to receive follow up care from a cancer

**Table 3**
Example quotes to support analysis of part 1 of clinician focus groups.

| Code | N° | Example quotes |
|---|---|---|
| Clinicians – Problems with risk assessment and management for women at ≤ moderate risk | | |
| Increased demand from women at ≤ moderate risk | 1 | *I started mainly a telephone clinic where I kept just a minimal file, did a Tyrer Cuzick over the phone, sent that on to the [PCP] with the standard detail.* |
| | 2 | *We actually do almost the same thing, except we've been seeing the patients in clinic and again, it was more emphasized after the Angelina thing when people had a higher degree of anxiety and wanted answers.* |
| | 3 | *We are using the Cancer Australia guidelines to determine risk classification.* |
| | 4 | *With those women who already decided on having the breast surgery, and they've had that decision for ages. You might say that they're average risk or moderate risk. They still can't be swayed on it* |
| Lack of an identified clinician group able to care for women at ≤ moderate risk | 5 | *There was little point in saying, "Go back to your [PCP]," because it was the [PCP]s that had said, "I don't know what to tell you, I'm referring you on." I had one [PCP] try to use FRABOC* [Cancer Australia's tool 'Familial Risk Assessment – Breast and Ovarian Cancer'] *and got completely confused … They didn't know what to tell these women. These women wanted something, they were a very vocal group.* |
| | 6 | *At the moment, those moderate risks, they're going back to their [PCPs], and their [PCP] says, "well, I don't know anything about that." Then they get sent to the breast surgeon. Breast surgeon says, "you're not high risk, my rooms are full, I can't see you." We're back at that limbo.* |

**Table 4**
Example quotes to support analysis of part 1 of consumer focus groups.

| Code | N° | Example quotes |
|---|---|---|
| **Consumers - Do women want to know their personal risk of BC**? | | |
| Preferring ignorance | 1 | *Unless you've been touched by it, it's a bit head in the sand for a lot of people. Blissful ignorance* |
| Only if low risk | 2 | *If I knew I was from a high risk category, and I'm pretty sure I'm not, I reckon I would find that so stressful. I would just worry every time there was a pimple.* |
| Only if I can do something | 3 | *I think people are more interested in their treatment options and prevention options than their actual risk* |
| All knowledge is empowering | 4 | *Until recently I didn't think that breast cancer was a preventable disease. The current thinking is that with lifestyle choices then perhaps to a certain extent it is, and that can be empowering* |
| **Consumers – misunderstandings about BC risk management** | | |
| Misunderstanding about breast self-examination | 5 | *There was a campaign on the radio a few years ago. I think that the first of every month they actually used to put a reminder ad on the radio to check your breast. It did last for a while and I think that got me started checking regularly.* |
| | 6 | *There was a big push for self-examination, which I, and I suspect most women, are absolutely appalling at … I go press, press, press, and I can't tell the difference between the bones underneath and whatever, and so I feel I've failed, so I push it away* |
| Skepticism about lifestyle factors | 7 | *We have a lot of information, much of it, sort of, questionable. We can't sort out what is the real information and what is questionable statistical correlation … Mainstream media in fact probably creates the problem* |
| | 8 | *I think a lot of the risk factors are things that are politically incorrect to say to women. So I think a lot of women don't know because no one's telling us, because they don't like to say. Like have your babies early, don't drink too much, lose weight, and sit at home and breastfeed for a long time.* |
| Only mutation carriers can take up risk-reducing strategies | 9 | *I think if you've got that gene that [Angelina Jolie] had, I think something like that you can do something about. You can make a decision to do something about it.* |
| **Consumers – perceived problems with access to information and advice** | | |
| Information hard to decipher and not well targeted or tailored | 10 | *I think we've gone from maybe not knowing, to thinking we all need to remove them (breasts) and it's really, there's a lot in between and I think maybe Angelina Jolie's been fantastic but maybe it scares people even more, not knowing what all of those options in the middle are.* |
| PCPs not always suitable for discussing BC | 11 | *I think there's so much publicity about breast cancer and raising money for breast cancer, all that sort of stuff, but in terms of you personally – it's not something my [PCP's] ever talked about … So I think it's interesting – it's sort of this huge hot air balloon, we've got all this information and fund raising and stuff like that, but the actual practical stuff [is lacking].* |
| | 12 | *Facilitator: Would you go to the internet before going to a [PCP]?*<br>*Consumer: Yes, I would. Because you get big amounts of information and you have it now. You don't have it in five days when you can get an appointment and for $35 out of pocket plus your Medicare rebate. And you can sit there and read for two hours if you want to, whereas you've got fifteen minutes with the PCP.* |

specialist [29], indicating support for the notion that PCPs do not currently see breast cancer as the domain of primary care. It is timely to reconsider this issue and reflect on who should be responsible for the domain of cancer prevention, especially given the international interest in stratified or risk based screening and the increasing availability of information about individual risk [30].

Women reported a large amount of 'hype' about breast cancer in the media, (including a great deal of fundraising) and despite the availability of ample generic information about BC, few had a clear idea of their own risk, or the specific recommendations tailored to their risk. Women felt that despite all the publicity and promotion, there was little concrete support available for prevention (in the absence of a *BRCA1* or *BRCA2* gene mutation). All women reported they should conduct regular BSE, despite the change in recommendation from monthly BSE to 'breast awareness' occurring around 2009, due to a lack of evidence of benefit. This highlights the need for attention not only on the implementation of new prevention options, but also on the de-implementation of recommendations found to be unsuccessful [31]. All were aware of the recommendation to undertake two yearly mammograms through BreastScreen from age 50, yet none had heard of risk-reducing medication for women at moderately increased risk of breast cancer, indicating the need for better dissemination of new recommendations beyond prevention guidelines. These misunderstandings and misgivings suggest that 'one size fits all' approach to health promotion about breast cancer may not be serving women well, and that recognition of the range of risk levels that exist in any population, and a capacity to address changes in recommendations as a component of health promotion is warranted. Future research must address the actual uptake of risk assessment by women, and the role that women's psychological characteristics and social environment play in uptake and response

**Table 5**
Example quotes to support analysis of consumers and clinician discussions during Part 2 of the focus groups – responses to iPrevent®.

| Code | N° | Example quotes |
|---|---|---|
| ***Benefits of using a tool like iPrevent®*** | | |
| Clinicians | 1 | *The precision and the options would make it a lot more sophisticated* |
| | 2 | *The ten year risk compared to the lifetime risk I think is really good. Particularly for women of certain ages. For a 25-year old woman, what's her risk at 35, compared with what's her lifetime risk?.. I sometimes feel that women don't comprehend a lot when all we give them is a lifetime risk.* |
| | 3 | *Clinician: Do we currently speak to moderate risk about drugs?*<br>*Clinician: No, we don't.*<br>*Clinician: No, we haven't tended to. We should be, according to guidelines.*<br>*Clinician: Yes* |
| | 4 | *I suppose it's formalizing and making sure you're less likely to miss something for a particular patient, if you were—I suppose we don't normally talk about medical prevention with like moderate risk, so I'm just saying we formalize. You're less likely to miss a step if …* |
| | 5 | *Certainly, if breast cancer risk assessment moves more away from an FCC and more into the [PCP] realm, then you need a way to make it as consistent as possible. So that high-risk women are getting called high-risk, and moderate, moderate, et cetera.* |
| Consumers | 6 | *I think the benefit is you're empowering yourself with information, you're possibly changing what you can change* |
| | 7 | *Consumer: But it helps them [PCPs] focus too I think rather than faffing around like you said.*<br>*Consumer: And they would know which bits to focus on too. They don't necessarily know which bit to focus on, why you're there.*<br>*Consumer: They can't faff if you walk in with this.*<br>*Consumer: This gives them the focus* |
| ***Concerns about using a tool like iPrevent®*** | | |
| Clinicians | 9 | *I think if we've had our data management staff go through and spend the time to … draw up a pedigree in Progeny [clinic software] from the information the woman's provided, and then we have to put the information into a different program as well. That's quite time consuming to do* |
| Consumers | 10 | *I think you could scare people when they don't need to be scared, and I think you could also make people feel overconfident that it's not going to happen* |
| | 11 | *I can see some people getting tipped over the edge if they're already an incredibly high risk and have a high anxiety state, have other medical issues, but I think you look at the greater population and you say well, do you avoid giving all these women access to this tool because of a small number of people who may have a problem?* |
| ***Implementation - how should women access their personalised risk estimate?*** | | |
| Consumers | 12 | *If I had to be sitting there going through it with my [PCP], I wouldn't do it.* |
| | 13 | *I lost interest the minute it told me to go to my doctor to get the results. It's difficult to get to the doctor. I have to do it between 9 and 5, Monday to Friday. My doctor, it costs me $40 to go. I'd have to book a double appointment for this. And the language is plain spoken … It's not like you're using any medical terms at all. I can read through all of that information myself.* |
| | 14 | *For me, I don't know if I am just being, but some of those things sound quite extreme measures … Tamoxifen, surgery, whatever. Not saying that they're bad or that I wouldn't do them, but they wouldn't be things you take lightly, but if you sort of sit with a PCP, you get all that stuff, and you go, wooah, that's something I should maybe do, but then the doctor may not think that you should do it, and that creates a lot of confusion and conflict and you go, well why can't I have it? And it creates a lot of stress.* |

to risk information.

These data were collected in the setting of urban Melbourne, Victoria, with familial cancer clinicians and women who had registered an interest in cancer research, so our findings may not be applicable to women living in rural and regional settings, women less interested in cancer, or other states of Australia. The small number of familial cancer clinicians working in Melbourne limited our ability to reach saturation on the themes discussed, yet we believe these insights provide useful data to guide efforts to increase access to personalised prevention of breast cancer. In addition, given participants were aware that the researchers were involved in the development of iPrevent they may have felt it socially unacceptable to criticise the tool. The opportunity to have end-users and developers together discussing the tool was a strength with regard to the ongoing development of iPrevent, and to mitigate the risk that participants felt constrained by the presence of the developers, we asked for honest feedback and indicated our genuine interest in developing and improving the tool.

Given our finding that a workforce willing and able to assist women access personalised risk information about breast cancer is not available, iPrevent has the potential to help fill this gap. Overall, the women we spoke to were positive about the possibility of using iPrevent, as they saw it as an opportunity to access the tailored, personalised information that they lacked. Suggested changes have been incorporated into iPrevent, and it has the potential to allow assessment and management of average and moderate risk women to occur in primary care [13,14], and includes features such as printable output and prescribing tips for clinicians. In this way the resources of the FCC and breast surgeons can be focused on high risk women, who need more intensive management. However, some consumers felt that having to access their risk assessment and advice through a PCP would limit its usefulness. Since completing this research, iPrevent has been pilot tested, and there was no evidence of an adverse impact on anxiety [32] and it is now freely available for women to use online (www.petermac.org/iprevent).

## Ethics

Ethics approval was obtained from The University of Melbourne.

## Conflicts of interest

There are no conflicts of interest to declare.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.breast.2018.11.002.

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