Original article

Assessing and managing breast cancer risk: Clinicians' current practice and future needs

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ABSTRACT

Decision support tools for the assessment and management of breast cancer risk may improve uptake of prevention strategies. End-user input in the design of such tools is critical to increase clinical use. Before developing such a computerized tool, we examined clinicians' practice and future needs. Twelve breast surgeons, 12 primary care physicians and 5 practice nurses participated in 4 focus groups. These were recorded, coded, and analyzed to identify key themes. Participants identified difficulties assessing risk, including a lack of available tools to standardize practice. Most expressed confidence identifying women at potentially high risk, but not moderate risk. Participants felt a tool could especially reassure young women at average risk. Desirable features included: evidence-based, accessible (e.g. web-based), and displaying absolute (not relative) risks in multiple formats. The potential to create anxiety was a concern. Development of future tools should address these issues to optimize translation of knowledge into clinical practice.

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Introduction

As we move towards more personalized medicine [1], it is possible to estimate a woman's risk of breast cancer (BC), and discuss appropriate prevention and screening options. It is important to identify and appropriately manage women at increased risk, but also to reassure the majority at population risk and thus avoid unnecessary interventions.

While many factors influence BC risk, the most important include family history, a personal history of proliferative breast disease, and mammographic density [2]. Mathematical models already exist to identify those at higher risk of BC [3], but most are designed for use by highly specialized physicians or researchers. None of these is a patient centered decision support tool with integrated educational content.

Patient decision support tools are evidence-based tools designed to help people participate in decision-making about health care options. They provide information on available options and allow patients to make informed, values-based decisions with their clinician. They do not advise people to choose one option over another, nor do they replace medical consultations; they merely assist the decision-making process [4].

Once women at increased risk for BC are identified, there are proven interventions that decrease BC incidence [5], including;

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surgery with risk-reducing bilateral mastectomy, premenopausal bilateral salpingo-oophorectomy and medication to prevent BC with tamoxifen, raloxifene or exemestane [6] and more recently anastrazole [7]. Lifestyle modifications, including weight loss and reducing alcohol intake have a smaller benefit. While screening does not reduce breast cancer risk, and remains unproven in high-risk populations, it may aid in early diagnosis and is recommended [8]. Appropriate uptake of these measures, especially medical prevention, remains low [9,10].

A tailored decision aid may help clinicians educate women about their personal risk and the options available to manage that risk. There is evidence that with informed decisions, realistic expectations, and active involvement in the BC risk decision process, women are more likely to persist with decisions and experience less distress with the consequences [11].

To enhance the likelihood that women receive BC risk management advice consistent with their estimated risk, we are developing a personalized, web-based, risk assessment decision support tool. This tool aims to assist health care professionals to easily and accurately assess a woman's absolute BC risk, and effectively convey tailored information about the risks and benefits of relevant risk management options for that individual.

One of the challenges in developing decision support tools is their integration with clinical practice, and many approaches have been suggested. Normalization Process Theory (NPT), for example, suggests addressing three core processes to achieve a lasting change in practice; implementation of the practice, embedding in routine use and integration of the practice in a sustained way [12]. In order to develop a tool that can be effectively implemented and embedded, we conducted qualitative research to understand the current practice of BC risk assessment and management, to inform the design of this decision support tool.

We identified that the clinicians most likely to use this tool in clinical practice were Primary care physicians (PCPs) (with support of practice nurses (PNs)) and breast surgeons (BSs). PCPs are often a point of first contact for women concerned about breast cancer risk, and breast surgeons would see women concerned about risk, including those diagnosed with benign breast disease, and those seeking prophylactic mastectomy.

Methods

Recruitment

Clinicians were identified and recruited through professional networks in Melbourne, Australia, including the Victorian Primary Care Practice-Based Research Network (VicReN) [13] and the Melbourne Breast Surgeons Group— a network for all breast surgeons working in Melbourne. Invitation emails were sent through these networks, those interested replied were then contacted by phone to confirm attendance. While participants were not reimbursed for participation, they were provided with a meal and refreshments during the focus group. The study was approved by the Human Research and Ethics Committee (HREC) of the University of Melbourne, and all participants provided written consent.

Data collection

Participants completed a short demographic questionnaire. Focus group discussions were guided by the use of a theme list and prompts, and other themes raised by participants were followed up and explored. The discussion was conducted in two parts within a single session, the first part explored the theme; current practice of risk assessment and risk management for BC, including knowledge, attitudes and experience. Information was then distributed to the participants, which described and illustrated examples of a proposed BC risk assessment and risk management tool. During the second part of the focus group, further themes were explored; participants were asked to describe their reaction to the idea of the tool, specify particular desirable or undesirable features, and identify perceived barriers and enablers to its use in practice.

Data analysis

Focus group discussions were audio recorded and transcribed verbatim, de-identified and analyzed thematically by authors ES and LK. Based on several readings of all transcripts, a coding framework was developed, consisting of three main themes and a number of sub-themes. All data were coded to the level of sub-themes. Each sub-theme was analyzed in order to describe the variations and patterns present. QSR NVivo qualitative data analysis software [14] was used to manage the organization and analysis of the data.

Results

Twenty-nine clinicians participated in four focus group discussions (four to eleven participants in each). Table 1 summarizes participant characteristics. Unfortunately we were not able to identify the denominator for our sample and therefore cannot report a response rate. Two of these groups included only BSs, one group included only PCPs, and one group included PCPs and PNs. After coding, 3 main themes (Table 2) were analyzed; risk assessment in current practice; risk management in current practice; views on the proposed tool.

Participants identified difficulties assessing and managing BC risk and lack of available tools to standardize their currently inconsistent approach to risk assessment and management. Most felt confident identifying high risk women, but found differentiating women at population risk from those at moderately increased risk more difficult. They felt a tool would help them reassure anxious low to moderate risk women and better identify and refer or manage high risk women. They identified several key elements they would like to see in a tool. Each theme is illustrated with quotations, identifying participants by profession and number (Table 3).

Breast cancer risk assessment — current practice

On whom is risk assessed?

While most BSs indicated that all women attending their practice will undergo some BC risk assessment, PCPs reported BC risk

Table 1
Demographic characteristics of participants.

Characteristics		Number (%) $n = 29$
Gender	Male	13 (45)
	Female	16 (55)
Age (years)	25—35	8 (28)
	36—45	3 (10)
	46—55	13 (45)
	56—70	5 (17)
Type of clinicians	Breast surgeon	12 (41)
	Primary care physician	12 (41)
	Practice nurse	5 (18)
No. of years as a clinician	1—15	16 (55)
	16—25	12 (42)
	>25	1 (3)
Average no. of clinical sessions per week	1—5	8 (28)
	6—10	18 (62)
	11—15	3 (10)
Education about familial cancer in the past year	Yes	14 (48)
	No	15(52)

Table 2
Coding framework.

Theme	Subtheme
Breast cancer risk **assessment** – current practice	On whom is risk assessed?
	Why do clinicians perform risk assessment?
	How is risk assessed?
	Risk factors assessed.
	Risk assessment tools used in practice.
	Problems with risk assessment.
Breast cancer risk **management** – current practice	Knowledge/perceptions of the options
	Risk reducing medication
	Factors influencing decisions in risk management
The proposed breast cancer risk assessment and risk management tool.	Would a tool be useful in their practice?
	If so, how would they use it?
	Problems or concerns about the tool in practice
	Practical comments about inputs
	Practical comments about outputs

assessment happening on an ad-hoc basis. When risk assessment was discussed in detail, one key theme emerged. All participants made a distinction between assessing BC risk in symptomatic and asymptomatic women, though slightly different language was used by different professional groups. BSs talked about 'symptomatic' patients, where risk assessment is constrained by patient's anxiety about their symptom, and 'surveillance' patients who attend to discuss their risk and get a full assessment (quote 1). PCPs described patients with a sign or symptom and 'check-up' patients. They described instances where the 'check-up' was aroused, not by a family history of cancer, but by a cancer diagnosis in a colleague or friend.

Why do clinicians perform risk assessment?

Participants identified several reasons for performing risk assessment; to aid surveillance decisions, to inform the patient's understanding of their risk -either reassuring her that she is at population risk (quote 2), or explaining increased risk - and to determine who needs specialist referral (quote 3).

How is risk assessed?

Participants described conducting risk assessment differently depending on the reason for the consultation. It was generally agreed that for all women, history of cancer in first and second degree relatives is recorded, as well as past medical history, but further details would be gathered only in certain situations (e.g. 'surveillance' or 'check-up' patients).

Risk factors assessed

There were differences in risk factors identified by participants as relevant. BSs identified a range of risk factors, including; Jewish heritage, exposure to radiation, age of cancer diagnosis of relatives, previous proliferative breast disease, breast density, hormone replacement therapy (HRT) use and reproductive factors. There was not always agreement about the relative importance of these factors. In primary care, risk assessment is reportedly done by PCPs alone or in combination with a PN (quote 4). PCPs limited the factors they consider to family and personal history. Most BSs talked about three risk groups (quote 5), population risk, moderately increased, and significantly increased risk. Other participants did not use such stratifications.

Risk assessment tools used in practice

Some BSs talked about using specific tools [15,16] to assess risk (quote 6) while others identified risk based on family history using their own expertise (quote 7). PCPs were less likely to use risk

assessment tools but identified close or first degree relatives, as well as past history of breast disease, as risk factors (quote 8). Some used the Cancer Australia guidelines [17], others had difficulty accessing them (quote 9), and others were unaware guidelines existed.

Problems with risk assessment

There was agreement among BSs that the 'moderately increased' risk group were the most difficult to assess and manage (quote 10). BSs struggled with presenting lifetime BC risk to patients in a meaningful way (quote 11). PCPs talked about being challenged when a patient is not satisfied with a BC risk discussion, and insists on inappropriate investigations (quote 12). BSs will also refer to a Familial Cancer Centre (FCC) if they think a patient is eligible for genetic testing. PCPs were concerned about informing women of their BC risk if there is little she can do to change it. They highlighted the importance of finding the right time for the discussion.

Breast cancer risk management – current practice

BSs talked about 'giving women the options' and then 'giving them time' to make a decision. PCPs would manage investigation of a symptom, but refer asymptomatic women they assessed at higher risk to a specialist.

Knowledge and perceptions of the options

Following risk assessment, some PCPs discussed radiological screening, referral to Familial Cancer Centers (FCC) or other specialists. BSs will discuss risk management options with women at high risk. Both PCPs and BSs said they would discuss diet and other lifestyle changes with their patients, often as part of an overall health discussion (quote 13).

Risk reducing medication

Neither PCPs nor BSs felt comfortable prescribing tamoxifen to reduce BC risk. Some BSs reported that talking about tamoxifen was confronting (quote 14). There were a number of reasons for this discomfort, including a perceived lack of survival benefit, lack of prescribing guidelines, a concern oncologists may not feel this role was appropriate for them, and concern for patient's safety. PCPs felt they would prescribe tamoxifen if supported with clear guidelines and education (quote 15). Some BSs felt 'outside of their comfort zone' managing the side effects of tamoxifen (quote 16).

Factors influencing decisions in risk management

Both PCPs and BSs described a desire to focus on the BC risk management options with which they felt they had adequate expertise. This was one of the strongest factors impacting on their decision about which strategies to offer women. Some BSs talked about adjusting screening intervals depending on breast density (quote 17), though this is not evidence based. The age of the woman, her ability to pay out-of-pocket costs, her anxiety and personality were all factors clinicians took into account in deciding which management strategies to discuss (quote 18).

The proposed breast cancer risk assessment and risk management tool

Would a tool be useful in their practice? If so, how would they use it?

All clinicians reported that the proposed tool is worth developing, and that it would be useful to standardize their practice, fill in the gaps in their knowledge and increase their confidence discussing BC risk with women. There were differences between the

Table 3
Quotations from focus group participants.

Quote no.	Participant	Quote
Breast cancer risk assessment − current practice		
1.	BS3	*… The symptomatic patients are often almost semi-resentful, 'I don't wanna talk about that, I wanna talk about my symptom,' so it is a different process … And the ones who've come for the specific purpose of risk assessment, you give them the bells and whistles*
2.	BS1	*Interviewer: so what's the purpose of the risk assessment for you guys?*
		BS1: making sure that they're actually well informed about what their risk is, cause we do see a proportion of people who have got a great-aunt who had breast cancer at sixty-five and perceive this as a genetic risk to them.
3.	PCP3	*Interviewer: Yep. So how do you decide who gets that referral?*
		PCP3: my alarm bells are starting to ring, you know there maybe two, possibly a third person in the family … I'll often suggest that they go and see these guys [Familial Cancer Centre (FCC)]
4.	PN4	*We use a combination of both [PCP and PN]. Ideally I try and grab the new patients while I'm there for a detailed family history, I'm part time, so days when I'm not there the [PCP] will take new patients … so it's a collaborative effort.*
5.	BS1	*And I guess what you're kind of roughly doing is saying 'is this person at population risk? Or are they in the risk group that's say more than a twenty percent lifetime risk and they should be having increasing surveillance and potentially looking at preventative strategies?' Or are they in a really high risk group where you should be pushing those preventative strategies potentially harder? (like the BRCA patients)'*
6.	BS4	*Interviewer: So you use IBIS [a Risk Evaluation Tool] sometimes but not all the time?*
		If someone came to me for a family history assessment I would, I would use it - just cause I think it's important to give them something … .or if someone comes who's very anxious about a risk of breast cancer and has, you know, nothing more than normal population I will sometimes use it. It's rare that I will do that but I will sometimes use it just to try and reassure them that they're within the normal population risk
7.	BS5	*Interviewer: Do you use any guidelines or –*
		BS 5: No I don't use Gail models and things like that … I just look at the pedigree
8.	PCP5	*The first degree relatives [if] there's more than two, [I] get very worried … If it's one and at early age, I'm worried as well … also with past history[of breast disease], some of them had examinations done … so past history I also include in that data collection to assess the risk*
9.	PCP2	*Most people have these [Cancer Australia Guidelines]; This … laminated card I used to use a bit … but now it's all morphed into the Cancer Australia website … I looked at that website and I couldn't find it … The website was really hard to find the equivalent*
10.	BS7/ BS9/ BS6	*BS 7: To me there are three outputs, it's either FCC, more than BreastScreen or BreastScreen [Australian national breast screening program]. And so the question actually is who needs a yearly mammogram? And does anyone need more than that?*
		BS 9: Yeah and who's, and so it's that middle group. Cause this group's easy, that groups easy, and, and how do you filter people
		BS 7: Or who do you filter to start mammograms before fifty or forty-five or whatever
		BS6: And in a way I think … that's the most difficult woman in a way
11.	BS1	*Lifetime risks still I struggle with. Well I think patients struggle with it you know in that sort of sense of you know you've got a patient who's thirty-five who's got a lifetime risk of getting breast cancer that's fifty odd percent. What do they do? Like the decisions they're making are often not decisions for when they're eighty. They're actually making decisions for when they're fifty, for when the kids leave school, and so I think in fact we need to give people smaller windows to look at.*
12.	PCP2	*So one of the difficulties I have is the expectation that the concern has to be followed up with doing something more technical than talking*
Breast cancer risk management − current practice		
13.	BS7/ BS9	*BS7: They're the things that they can modify though, the lifestyle factors … and then we, we actively talk diet*
		Interviewer: What sort of things do you tell them to do?
		BS7: Oh diet is, is the human has evolved on a diet of unprocessed food with particularly vegetables (yep). I go no further than that.
		BS9: All things in moderation
14.	BS7	*I feel a cooling in the atmosphere as soon as I start mentioning tamoxifen, it's kind of not because patients aren't interested in it but I don't know that they necessarily see it as our role … they're exactly the same side effects that we talk about for our breast cancer patients, … but it is quite confronting I think for a surgeon to be talking about chemoprevention even with you know good evidence that is helpful*
15.	PCP7	*but look if it's something that should be done by us then you know fine, I think most [PCPs] are happy enough to do what is expected and if this is something that we could do, the last thing I want to do is fill up a hospital waiting list and give huge anxiety to patient … by them waiting for a couple of months for something I can do*
16.	BS2/ BS3/ BS4	*Interviewer: But you will prescribe [tamoxifen] if they want it?*
		BS2: I would but … our uptake's been really poor (yeah) but certainly discuss –
		BS3: I mean I do it, but very reluctantly - only if I can find no one else
		BS2: But there's even immediate effects like menopausal symptoms and so forth
		BS4: Yeah and I mean do I start them on Effexor? How much effexor? Do I double it? You know, I don't understand all that …
		BS3: I mean before you know it we're getting right out of our comfort zone
17.	BS1/ BS4/	*Interviewer: And so what would the moderate risk woman end up with? At a similar age [forties]?*
		BS1: Depending a bit on the breast density, I'm pretty, pretty influenced by breast density I would say
		BS4: Has to be tailored, how useful their mammo is going to be
18.	BS2/ BS9	*BS2: It's not sort of bog standard sort of this is what we do for our moderates, it's tailored to that individual*
		BS9: That's how you can't put that into a risk calculator, of what the patients like, highly anxious, highly educated, highly motivated, here's an MRI, four hundred bucks is nothing to them
The proposed breast cancer risk assessment and risk management tool.		
19.	BS3/ BS9	*BS3: I suppose, when you look at it, ninety-five percent of patients are at average risk, and what you want is a tool to prove that to them*
		BS9: It will help put those people in the right context when they walk in the room, and the consultation becomes twenty times more valuable to them and to us for that reason, and I think that's fantastic
20.	BS3	*I think this will be very useful for [PCPs] because I think there are a number of patients who kind of agitate through their [PCP] for a referral for a risk assessment who feel that their regular [PCP] has not paid due attention or has falsely reassured them when in actual fact they haven't falsely reassured them, they reassured them appropriately*
21.	PCP3	*The beauty like about this is that if you have properly risked someone, you know, if you've got the support documentation, then you know exactly what you're supposed to be doing with that person, whereas at the moment I still feel a bit wishy washy and I tend to refer off a lot of my patients*
22.	BS8	*And to me, the beauty of the tool, if it gives us an answer in a format like in the next five years or the next one year or the next ten years, to me that's where it's really helpful. So you don't want the whole lifetime risk, like the eighty percent, that's very terrifying*
23.	BS3	*Now it's [DCIS decision aid] gone into routine practice and you hand them the brochure, I don't know how, whether they read it but they come back and they say what do you think I should do?*
24.	PCP3	*I would say that if you're doing your family history and you've picked a woman who's got two close relatives with breast cancer, you know it's gonna be on their mind so you are gonna approach the subject and if they disengage, absolutely, you know been there, done that, not interested, fine. But, if they do engage, well now you'll have a tool that you can actually really take them through in a lot more detail*

Table 3 (continued)

Quote no.	Participant	Quote
25.	PCP8	*I think initially when I start to use this tool; I will just use it in three [types of] sessions. One is that a patient's request … Secondly I identify according to my medical knowledge or experience this is high risk. Thirdly I would take a piggy back off a similar program because Australia has pap smear program running very well and they come in two yearly and I just take that opportunity to ask a couple of questions*
26.	PCP12	*How reliable is this data going to be? It might change in another three or four years … the data will be changing, if it changes even if the mathematical model is there, the ongoing studies and … about lifestyle and breast cancer, if these variables change how often are you going to update this tool?*
27.	PN2	*… the patient doing the tool online without a health professional being with them. I, to me it's a bit concerning that there could create some hysteria*
28.	PN5	*It strikes me as an ideal tool if we, if you don't have time in the consult to say could you make an appointment with the practice nurse. It just makes me think it would be an ideal thing to do with a nurse or a doctor*
29.	BS5	*Well I guess what I'm saying is simplicity and I'm happy to look at different options but it's gotta be simple. If it's too complex people won't use it, and it won't be useful to anyone*
30.	PN5	*Not everybody's computer savvy as well – understands percentages. I think the pictograms are good in terms of health literacy and low levels of literacy … Personally I like the pictograms … I just think it's more personalized, easier to identify with as a person*
31.	BS2	*I think that's a nice end point actually, just to have something really simple at the end of it which summarizes everything cause they've probably been through quite a bit of data and if it does actually just summarize … And recommendations, that would be quite a nice page for that*

Identified by professions and participants number; Breast surgeons (BS), Practice nurses (PN) and Primary Care Physicians (PCP).

groups in their motivations to use the tool, but all agreed they would be unlikely to use it with every woman.

As BSs felt confident in their ability to identify women at increased risk of BC, so they would be more likely to use the tool on women who they thought were moderate or population risk, as a reassurance strategy (quote 19). The tool was considered a communication aid for discussions around BC risk and risk management. BSs felt the tool might be useful for alerting PCPs as to who needs increased surveillance or FCC referral, as well as reassuring the PCP and their patient that her risk assessment is accurate, and her management plan appropriate (quote 20). This was echoed by the PCPs, who viewed the tool as giving more certainty and control, and standardizing the process (quote 21). The BSs suggested the tool could provide women with accurate information on their risk over time (quote 22), and illustrate the absolute benefit of interventions.

Problems or concerns about the tool in practice

Some BSs described their experience with a paper decision aid regarding options for ductal carcinoma in situ, which was piloted with good results. In practice, however, patients still asked their surgeon what to do (quote 23). Participants indicated there will always be some women less interested in playing an active role in medical decisions. There was concern that the new tool would be insufficiently complex to capture all the relevant risk reducing strategies, and that a lengthy conversation would be required for each strategy.

There was concern amongst the PCPs that patients need to be ready to receive information about their BC risk, and they would take cues from women as to whether or not they would like the information (quote 24). One PCP suggested a specific strategy for raising the topic involving 'piggy backing' onto an existing cervical cancer screening program (quote 25).

Participants expressed a need for confidence in the tool and its evidence base, and that it be up to date (quote 26). Ideally the tool would also be endorsed by professional bodies. While PCPs felt that reimbursement for consultation time using the tool was important, BSs felt this was not a barrier to use. Participants reported no concerns regarding data persistence (storing data) or data security.

Practical comments about inputs

All participants made similar comments about the process of inputting a woman's risk factor information into the tool. There was some concern about women inputting their own data and agreement that women should not be presented with their BC risk while alone (quote 27). Participants felt that the tool should be used with a health professional to avoid anxiety, and the possibility of disengagement. Despite concerns regarding time constraints, PCPs thought that if the tool was easy and worthwhile to use, they would use it at the time, rather than plan a future consultation. It was also suggested that a PN could input the patient's information and discuss screening options, with a plan for further consultation with the PCP (quote 28); many felt this joint approach could aid data accuracy too. An easily accessible tool with a visual, simple input process was requested by all clinicians (quote 29); ideally data could be updated at future times.

Practical comments about outputs

While some participants felt that numerical data displays would be preferable, others felt pictograms and graphs more useful (quote 30). All accepted the need to present data in different formats. Overall, more rather than less information was favored. The summary messages presented should be simple and easily understandable, allowing for lower literacy levels (quote 31). A future goal should be integration with patient electronic health records.

Overall, participants felt that the proposed tool could become part of routine clinical practice, as tools in other health domains, including cardiovascular disease, have done.

Discussion

Breast cancer risk assessment and management is currently not standardized among Australian clinicians. Risk assessment for BC is ad-hoc, with clinicians relying on a range of inadequate approaches, with the process often initiated by women themselves. Risk assessment is similarly variable in the presentation of the options to women depending on factors other than their BC risk. Participants in this qualitative study identified the features they would require in a computerized, personalized breast cancer risk assessment and risk management tool, to allow its integration in to clinical practice. This integration may be reason other, well developed tools [18], have not been widely adopted in clinical use.

PCPs have an important role in initial assessment of a woman's BC risk and identifying those at increased risk. The first step of risk assessment is to take a detailed history of cancers in the family and other personal risk factors. Pedigree assessment in primary care is feasible, but occurs consistently only when a strong maternal family history is present [19]. Several studies have revealed insufficient data is recorded in primary care records to make an appropriate risk estimation [20]. Of 734 patient records in one family

medicine center in the US, the presence or absence of a cancer family history was documented in 97.8% of records, although in 69.5% of records there was insufficient information to assess risk [21]. The amount of time required for accurate risk assessment, poor reimbursement, and a lack of confidence in their knowledge of risk can be barriers to accurate risk assessment [20]. When PCPs were provided with a computer decision support system in the UK, referral rates increased and were more appropriate, family pedigrees were more accurate, and management decisions were significantly more suitable [22,23]. Ninety-two per cent (246/268) of PCPs stated they would be extremely likely or fairly likely to use that system in the future [24]. BSs felt more confident in their ability to accurately assess a woman's BC risk.

Effective implementation of risk management is dependent on the clinician's knowledge of the appropriate options and their confidence in presenting these options to women. Many of the participants of our focus groups were unsure about whether or not they should prescribe tamoxifen for example, and the majority currently feel uneducated and under-resourced to do so. We have recently shown that the uptake of medication to prevent BC is very low [10]. Medical prevention with selective estrogen receptor modulators (SERMS) such as tamoxifen can reduce the risk of BC in those at high risk of disease by 38%. Data in the primary prevention setting for *BRCA1* and *BRCA2* mutation carriers specifically is inadequate, however observational data suggesting that tamoxifen treatment for first breast cancer in carriers approximately halves the risk of contralateral cancer [25]. Awareness and understanding of the benefits and risks associated with SERMs is crucial in ensuring uptake in appropriate women. We have shown that a major barrier to the prescribing of SERMs for breast cancer prevention is the perception that side effects outweigh benefits [26]. In fact, data from randomized prevention trials show that the absolute risk of serious side-effects is low, particularly for pre-menopausal women [27] and that global health status is similar in women on tamoxifen or placebo [28,29]. Presenting the magnitude of the benefits and risks of management options may help educate and reassure women and their clinicians.

All of the participants in this study thought the proposed tool worth pursuing, and that it would be useful in their practice. BSs envisage using the tool as a communication aid in their discussions with women around BC risk and risk management. BSs are more likely than PCPs to talk to women about their treatment options as surgery is a proven intervention to reduce breast cancer incidence. Surgeons have reported that decision aids are feasible to use in practice, and that in 91% (159/175) of the consultations in which the decision aid was incorporated, they were satisfied with the decision making process [30]. Decision aids may improve a patient's ability to make an informed choice about surgery by increasing her knowledge of treatment options, thereby potentially improving the quality of their care [31].

This study has revealed a number of important factors that must be incorporated into the design of a clinical decision support tool for breast cancer risk; attention to the realities of clinical practice (e.g. time limitations); simplicity of use; a strong evidence base with endorsement by professional bodies; consideration of the needs and capacities of women to process information; capacity of the tool to reassure anxious women; and the capacity of tool to convey absolute risk information in a number of different ways for different levels of literacy. Our findings suggest that the recommendation of some of the risks management options suitable for women, including medications, still present significant challenges in both primary and specialist care. This study is the first step in designing and informing how best to implement this tool in clinical practice [32]. Next steps include qualitative research with both consumers and familial cancer clinicians to determine what they want and need from such a tool, incorporating these findings into the next iteration of the tool, and then piloting the tool with a range of clinicians and settings.

Among the limitations of this study are the sample size. While the authors felt participants represented the variety of clinicians who may use the proposed tool, it is possible that different views to the ones expressed here are present in the wider community of PCPs and breast surgeons. All data were collecting in urban Melbourne, therefore the views of those working in regional and rural area, and smaller cities have not been represented.

This qualitative study provided end user input essential to the development of breast cancer risk assessment and risk management tools. These findings may aid the development and implementation processes for any such tool, prior to research demonstrating its potential to improve clinical practice. Incorporating these needs and addressing barriers to implementation may maximize the uptake of such tools in clinical practice. Thus growing knowledge regarding BC risk can be effectively translated in to better understanding by women of their risk and their options to manage that risk.

Conflict of interest statement

The authors declare they have no conflict of interest.

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