BCNA Consultation Report

Meeting the needs of Australian men diagnosed with breast cancer
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About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We support, inform, represent and connect people whose lives have been affected by breast cancer. BCNA represents more than 120,000 individual members and 300 Member Groups from across Australia. BCNA works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.
Introduction

Like women, men have breast tissue. This means that men can develop breast cancer, although it is uncommon. Around 150 men are diagnosed with breast cancer in Australia every year\[1\]. The risk of a man being diagnosed with breast cancer before the age of 85 is one in 688, while in women the risk is one in eight\[1\].

Because it is rare in men, a diagnosis can bring very specific challenges. These may include difficulties finding breast cancer information tailored to men, stigma around having what is seen to be a ‘woman’s disease’, and feelings of isolation or distress. The use of the colour pink, particularly during Breast Cancer Awareness Month each October, can also be distressing for many men, who may not feel that awareness efforts represent them.

Acknowledging the challenges for men, BCNA has made strong efforts in recent years to help improve resources and support. In 2014, BCNA developed an information booklet, Men Get Breast Cancer Too, for men who are diagnosed with breast cancer. This has been an important source of information and support for men. However, feedback from our members has indicated that more can be done to help men diagnosed with breast cancer to feel supported, informed and represented.

In 2015, BCNA supported the Medical Oncology Group of Australia (MOGA) for men with breast cancer to have access to subsidised breast cancer drugs through the Pharmaceutical Benefits Scheme (PBS). At the time, eligibility criteria stated that certain drugs, including many hormone therapies, were for treatment of breast cancer in ‘women’. This meant that men had been unable to access these commonly prescribed breast cancer drugs through the PBS, and had to pay the full cost of the drugs or rely on compassionate access through the drug companies.

To better understand the needs and challenges faced by men, in 2016 BCNA has undertaken a detailed review of the literature and a consultation with Australian men diagnosed with breast cancer.

The aims of this report are to provide a summary of the findings of this project, and to identify what BCNA and the broader community can do to improve outcomes for men. The report is for use by all those with an interest in the issues and challenges facing men diagnosed with breast cancer in Australia.
The consultation

This project has been informed by a combination of evidence from existing research, and a consultation. The consultation involved telephone interviews with five men from around Australia who had been diagnosed with early or metastatic breast cancer.

BCNA recruited men to take part through the BCNA network and through links with health professionals. Through the consultation, BCNA aimed to identify unmet needs and priorities for Australian men diagnosed with breast cancer. Through the telephone interviews, men were invited to talk about their diagnosis and treatment journeys, information needs, health care experiences, and the impact of gendered understandings of breast cancer on their wellbeing and identity. The interviews also aimed to identify what BCNA, and the community more broadly, can do to improve outcomes and experiences for men. The figure below summarises the demographics of the men who took part in the consultation.
THE CONSULTATION

The men
In-depth qualitative telephone interviews with five men from around Australia who had been diagnosed with early or metastatic breast cancer.

Age
Men were aged between 59 and 74 years. The youngest age at diagnosis was 38 years, and the oldest 64 years. Year of diagnosis ranged from 1998 to 2014.

Location
The men were from around Australia: two from NSW, and one each from QLD, WA and SA. Most lived in regional areas/towns.

Diagnosis
4/5 men had early breast cancer. One man was diagnosed with metastatic breast cancer, four years after initial breast cancer diagnosis in 2010.

Employment
4/5 men were recently retired, with one self-employed. Occupations included banking/finance, writing/editing, farming, building, education and small business.

Family and relationships
All of the men were married/living with a partner of the opposite sex. All men had at least one child.
Key findings

This project has highlighted the following key challenges for men diagnosed with breast cancer.

- Men tend to be diagnosed at a later stage than women and this adversely impacts on their health outcomes.
- There are few information resources specifically for men with breast cancer. This can leave men feeling frustrated and uncertain. However, information is getting better over time.
- Men benefit from accessing peer support and counselling, but it can be difficult for men to find supports that are tailored to their needs.
- As breast cancer is often considered a ‘woman’s disease’, a diagnosis may leave some men feeling embarrassed, self-conscious and worried about their masculinity.
- There tends to be little awareness of male breast cancer in the general population. Because breast cancer is represented by the colour pink, and gendered language, men can often feel misunderstood and overlooked within breast cancer awareness efforts.

Each of these key issues are discussed in more detail below.

Health gaps and delayed diagnosis

Early breast cancer in men is very treatable, but research has shown that men with breast cancer can have poorer health outcomes than women.\[2\] This is partly because breast cancer usually affects men at an older age than women, when men may have other illnesses that impact on their health.\[3\] Breast cancer also tends to be more advanced by the time a man is diagnosed by their doctor, with research showing that men are up to two times more likely to have cancers that have spread to the lymph nodes by the time they are diagnosed.\[4\]

Many men are not aware that they can get breast cancer, and this can impact on the time taken to go to a doctor about symptoms. Research has shown men diagnosed with breast cancer can wait for an average of 21 months before first seeing a doctor about their symptoms.\[5\] Men are also not screened for breast cancer in Australia. Men may also dismiss signs and symptoms for longer before seeing a doctor. As one of the men we interviewed said:

> My experience is that men play the hero. When you get sick, people say you should go see a doctor, and you don’t. Even I didn’t go to my wife’s female doctor initially because I had hang-ups about it. – Bob

Because male breast cancer is rare, some GPs may also not immediately suspect or investigate for breast cancer in a man.\[3\]

> My GP said to me ‘you are the first male breast cancer I’d ever seen’, and he’s been in practice for 30 odd years. - Ron
All of the men in the consultation spoke about having to persist with their doctors, and get a second opinion if needed, as highlighted here:

\[
\text{You’ve got to push the boundaries. Doctors are doctors, they’re not infallible, you’ve got to really push the envelope and say ‘listen, I want a second opinion’, and go from there. – Steve}
\]

\[
\text{I’ve met 13 male breast cancer survivors [around the world], and with these 13 guys, the story is the same: they went to GPs who didn’t diagnose them initially, and fortunately they all got a second, or in my case, a third opinion, and now we’re still around to tell the story. – Bob}
\]

A lack of research into best practice treatments for male breast cancer is a further issue. Because it is rare in men, most of the evidence on treatments for male breast cancer is based on what works in women. However, new research is showing that male breast cancer is different in some ways from breast cancer in women. A lack of research into best practice treatments for male breast cancer is a further issue. Because it is rare in men, most of the evidence on treatments for male breast cancer is based on what works in women. However, new research is showing that male breast cancer is different in some ways from breast cancer in women. For example, nearly all breast cancers in men are hormone receptor positive, which is not the case for women. ‘Hormone receptor positive’ breast cancer means that the hormones oestrogen and/or progesterone help the cancer cells to grow. Nearly 91 per cent of men diagnosed with breast cancer have oestrogen receptor positive tumours, compared to 76 per cent of women.

Treatments that work for women cannot always be assumed to work in the same way for men. An example of this is the use of aromatase inhibitors (including anastrozole, letrozole, and exemestane) in treating hormone receptor positive breast cancer. These drugs are now available through the PBS for men, however there is emerging evidence that these drugs are not as effective in men as they are in women.

**Men’s information needs**

Because breast cancer in men is rare, it is harder to find information and resources that have been developed with men in mind. Much of the standard information provided after a breast cancer diagnosis is based on women’s experiences, bodies and concerns. When men are given information or resources by their doctor or nurse, or when they look up information on the internet, it can often feel like an overwhelming task to ‘sift through’ it and work out how it applies to them. This can be confusing and frustrating, as the men in the consultation highlighted:

\[
\text{Initially the information I got was all pink and about women only. No information was suitable for me. It took quite some time to find some useful and practical information and support. – Rod}
\]

\[
\text{I was quite confused why my surgeon was showing me a picture of this female breast [as an example] of a mastectomy. It didn’t make any sense to me, or what it would look like for me. I went into that operation with really no idea of what was going to happen to me, and where this was all going to lead to. – Ronald}
\]
The lack of gender-specific information can be distressing, as men may not understand very much about breast cancer, what to expect with treatments, and where they can go for help. One of the men we interviewed summarised his experience this way:

“There was just no information there. There was nobody really to talk to, and to be honest I felt like I didn’t belong anywhere. That was really hard. Getting the right information and understanding what was happening was crucial in gaining control of my life.” – Robert

More tailored information has become available to men in recent years in Australia. This includes BCNA’s Men Get Breast Cancer Too booklet, first published in 2014, and the publication of the book Male Breast Cancer: Taking Control by Professor John Boyages in 2015.[3] None of the men in the consultation had access to this information at the time of diagnosis, as these resources had not yet been published. However, the men we spoke to said these resources had since helped to fill information gaps for them, and the increasing availability had given them more control over their cancer journeys. Online resources such as the U.S. website Male Breast Cancer Coalition were also spoken about positively, as a source of information, connection and support.

From January to September 2016, a total of 154 of BCNA’s Men Get Breast Cancer Too hard copy booklets have been ordered. Health professionals across Australia ordered the majority of the booklets (103 orders). This was followed by 15 orders from diagnosed men.1 The remaining orders were from various Cancer Councils around Australia, and a handful of other BCNA members. From May until September, there were a total of 65 external downloads of the online form of the booklet. Earlier data on downloads is not available. The predominance of orders from health professionals indicates that breast cancer specialists play a crucial role in linking men with information after a diagnosis.

Meeting men’s information needs will not require radical changes. The research shows that much can be achieved simply by providing practical, up-to-date and gender appropriate information as part of existing information resources.[2] The consultation also highlights that men with breast cancer want the option of having access to standalone/separate male-specific information packs at the point of diagnosis. The consultation did show that BCNA’s information resources for men could benefit from clearer signposting, simpler presentation and one-page guides:

“There needs to be information that’s far simpler, some sort of summary perhaps which would direct me to what I need to know.” – Ronald

1 It is possible that at present, diagnosed women are not sure of what they are ordering when they tick the Men Get Breast Cancer Too order button. This may need to be looked at, with clearer signposting of who the resource is intended for.
Finding support

Men with breast cancer are at risk of having their emotional needs overlooked. First, this is because some men are less likely to seek support from health professionals or support groups. Secondly, it is more difficult to find other men who share similar experiences as them, as breast cancer in men is rare.

Support from health professionals
Health professionals play a crucial role in helping men get access to emotional and practical support. Some studies show, however, that healthcare providers can sometimes be unhelpful for men. They may do this by being less emotionally supportive in their language with men, while also less proactive in linking men with supports — often because they assume that men will feel embarrassed or uncomfortable, or because they are not aware of local supports and resources for men.\footnote{10}\footnote{11}

In the consultation, some of the men said they had negative experiences with health professionals, including a lack of support and reassurance, and poor communication and follow up:

\emph{Within hours of arriving home [after the diagnosis] I was just enveloped with a sense of doom, a sadness. That was really my first time I experienced any real negative emotional response, and I was really in a bad way. There was no one I felt I could go to just to get help, and I was in a very distressed state.} - Ronald

\emph{I had that dreaded phone call one Monday morning: ‘The oncologist wants to see you this afternoon’. They didn’t say anything like ‘by the way, get someone to come with you’. Luckily I called my wife and she came with me, because by that night I was admitted to hospital and the shock set in. There’s not a great deal of care factor there sometimes.} - Steve

This highlights the need for better screening of psychological distress in men, and more gender-specific communication training for health professionals working with men. Research and anecdotal reports suggest that breast care nurses are an important source of supportive care for men, bridging gaps in men’s access to information, emotional and practical support.\footnote{10} Given their importance, breast care nurses would further benefit from gender-specific training and resources to work with men who are diagnosed with breast cancer.

Accessing emotional support
Men’s access to emotional and social support can also be affected by men’s own help-seeking styles. Research shows that, compared to women generally, men tend not to share their emotional needs and concerns as frequently; will use health services less often; and receive less information about ways they can reduce health risks and improve their wellbeing.\footnote{11} Despite this, research out of the UK suggests that up to a third of men with breast cancer are interested in attending a support group or formal counselling, if the opportunity for an appropriate group or counselling session is made available to them.\footnote{10}
Individual and group counselling was important for some of the men in the consultation. The Cancer Council Australia telephone support and counselling service had been of particular help, as Ronald’s account shows:

> After I was diagnosed I was in a very distressed state. I found a leaflet from the Cancer Council, and I phoned their hotline. They put me through to a counsellor who was fantastic. I continued to see her for a few months, initially on an individual basis, but after a while she rang some groups, and I attended those groups and I found them to be wonderfully supportive. To me, that was the first time that I felt I was starting to get some kind of emotional grip on this rollercoaster that I'd been on. - Ronald

All of the men pointed out the benefits of talking with others who had been diagnosed with breast cancer, as it gave them a sense of emotional relief and understanding. Some of the men we spoke to found it especially valuable to connect with other men living with breast cancer:

> Being with people who’d been through the same or similar experience was very empowering for me. – Ronald

> The biggest feeling of relief I got during this whole journey has been the contact that I’ve made with [another male breast cancer survivor] and the fact that we can feel connected in some sort of way. It felt like there was a lifelong brotherhood, from when we first met. It’s really interesting, at the end of our first conversation, we pulled up our shirts and showed our scars, and that really meant a lot. - Robert

The consultation highlighted that it can be hard for men to find support groups that are tailored to their needs and that help them to feel included and comfortable. All of the men in the consultation felt having more access to peer supports would be valuable. The men also highlighted that BCNA could play a role in promoting or strengthening the availability of peer support to men who are newly diagnosed, including through our online network and referring men to other male peers who are willing to share their experiences:

> I think it might be really useful for men, when they are ready for it, to have an opportunity to talk to another man who’s been through it. That possibly could be something that BCNA can offer them, you know, men who have indicated that they are happy to speak to other men. I’ve done that a few times now and I feel that it’s really appreciated, and that it is a really good idea. – Ronald

Stigma, body image and distress

Cancer-specific distress\(^2\) is a major issue for men with breast cancer. For example, a UK study exploring psychological distress in 161 men with breast cancer found that a quarter of the men

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\(^2\) That is, stress arising as a result of a cancer diagnosis and treatment.
surveyed had experienced post-traumatic stress.\cite{12} The main risk factors for high levels of distress in men include:

- Unmet information needs, leading to feelings of anxiety and lack of control
- Poor coping strategies
- A lack of support
- Negative body image

A diagnosis of breast cancer can be stigmatising or distressing for some men, especially if it challenges their sense of masculinity.\cite{2} Breast cancer treatment can alter how men feel about their bodies, especially in the early months following treatment.\cite{13} Changes to the chest area after treatment, including scars, hair loss, the loss of a nipple, and swelling, can affect some men’s confidence, or cause anxiety and embarrassment.\cite{13} Because breast cancer is seen as a ‘woman’s disease’, it can feel ‘emasculating’ for some men.\cite{14}

In the consultation, there were mixed opinions about the impact of a breast cancer diagnosis on men’s body image. Some of the men in the consultation did not feel that the diagnosis had an impact on how they viewed themselves:

> It never bothered me at all that breast cancer was somehow not a ‘masculine’ thing, or was a female thing. I knew it was uncommon amongst males, but it never bothered me at all. – Ronald

> In this day and age that’s all a bit old fashioned - that sort of gender thing. - Rod

Other men felt that they (or other men they knew) had been negatively affected by feelings of embarrassment or shame, especially initially after a diagnosis. This was mostly due to anxiety about breast cancer being seen as a ‘woman’s disease’:

> There are a few guys that could have joined Dragons Abreast but didn’t because [they thought] ‘it’s a female thing’, that it’s a shameful thing. Maybe you’re not quite a man, because of breast cancer. There’s that attitude out there. It’s dreadful but it’s still there. - Bob

> You know, you have those types of conversations initially where you have to tell your employee or your employer, or you have to tell your family and your friends, and it’s like “Really! You’ve got breast cancer? You’ve got a woman’s disease! You must be less of a male!” – Robert
Some of the men we spoke to had learned to use the stereotypes and unhelpful reactions they encountered to help promote awareness - especially amongst other men. This was empowering for these men:

*I'm happy to show the scar around because I owe it. Having survived, and having heard what's happened to other guys, and heard what's happened to some women because they weren't diagnosed early, it's almost a mission to me to spread the message.* – Bob

It should be noted that the men in the consultation all had strong support networks, good coping skills and resources – and most of them also had contact with other male breast cancer survivors, so they may not reflect all aspects of the gendered experiences of male breast cancer in Australia. For these men, their involvement in advocacy helped them to come to terms with the negative labelling of male breast cancer, and even to bond or connect over their shared experiences.

More broadly, research shows that factors such as financial security, and good social support networks can help men to adjust to and cope with the diagnosis of breast cancer, including its gender and body image aspects.[2][15] Improved community awareness can also help to normalise breast cancer in men and reduce stigma. As one of the men in the consultation reflected:

*Men don't expect to have breasts. Once men are less embarrassed about it and understand they need to check themselves and be aware of the symptoms and get medical help, I think that will make it less of a gender thing.* - Rod

**Public awareness: the challenge of ‘pink’**

The consultation showed us that men often feel excluded from breast cancer awareness events and campaigns, either because the language used refers to women or because of the use of the colour pink, which many men feel does not represent them.

The role of BCNA in navigating a lack of representative language was discussed in many of the interviews with men. For example, one of the men noted that there have been improvements in recent years:

*As recently as 2015 one of BCNA’s newsletters gave you the impression that it was a female only issue, but the language now is gender neutral in most cases – ‘people get breast cancer’ and then they elaborate and say ‘men and women too.’* – Bob

If men are excluded from discussion and imagery surrounding breast cancer, they are less likely to feel supported and more likely to experience stigma. As some of the men highlighted, it is important to remind the public that men get breast cancer too:

*When they have this pink ribbon day, they always talk about female breast cancer. What they should also say is that men can get breast cancer too.* - Steve
One of the tragedies, for me, is the lack of awareness. I still think that there’s an ignorance out there in the general public. – Rod

Debates about this issue highlight the need for more discussion: how do we mobilise the community to address the needs of women affected by breast cancer, while at the same time ensuring we advocate for the needs of under-represented groups? The key emphasis for men in the consultation was not to ‘take away’ from the importance of breast cancer awareness for women – but rather to open new spaces for conversation and awareness-raising that better include men. This was highlighted by Rod and Rob, two of the men we spoke with in the consultation:

This is not a gender equality issue, it’s more just some recognition. It’s not about overdoing the blue, it’s really just proportional representation. Don’t make clangers – get the language right, and be aware that men, for the reasons that they present later, their prognosis is really not as good. - Rod

I think it’s about the messaging. And I think it’s about just making sure that we’re not invisible and not hidden. So, some way of sort of raising that up a level. - Rob

The consultation has highlighted that, by giving male breast cancer more visibility, we can tackle stigma and help men who are diagnosed with breast cancer to feel more supported in the community.
Conclusions

This section outlines the conclusions that can be drawn from this consultation project. The conclusions are presented as a summary of key barriers and enablers for men diagnosed with breast cancer, followed by a set of priorities for action.

Barriers

From this consultation, it is clear that the key barriers to men feeling included and supported are:

- difficulties finding breast cancer information specifically for men
- dealing with the stigma of having what is seen to be a ‘woman’s disease’
- finding it difficult to access social, psychological and peer support
- a lack of awareness and understanding of male breast cancer in the community and amongst some health professionals.

Also worrying is that men tend to be diagnosed at a later stage. This is partly because breast cancer in men is rare and awareness of it is low and, of course, because men are not included in breast screening programs.

Until recently there has not been much tailored information for men who are diagnosed with breast cancer in Australia. The lack of gender-specific information can be distressing, as men may not understand very much about breast cancer, treatments and where they can go for help.

A diagnosis of breast cancer can be stigmatising or distressing for some men. Breast cancer treatment can change how men feel about their bodies, especially in the early months following treatment. Because breast cancer is seen as a ‘woman’s disease’, it can also feel ‘emasculating’ for some men.

Men are at risk of feeling isolated and alone after a diagnosis. Sometimes this is because men may be reluctant to bring up their emotional needs with health professionals and others. Stigma and a lack of understanding from the community can also contribute to men feeling embarrassed or excluded from supports. The men we spoke to all found it valuable to connect with other men living with breast cancer, although they told us it can be hard to find support groups that are tailored to their needs and that help them to feel included and comfortable.

Finally, the consultation showed us that men often feel excluded from breast cancer awareness events and campaigns, either because the language used refers only to women or because of the use of the colour pink, which many men feel does not represent them.
Enablers

Meeting information needs
Ensuring that men have access to tailored information on male breast cancer as soon as possible after diagnosis can increase men’s knowledge and reduce distress. In recent years, BCNA’s *Men Get Breast Cancer Too* booklet and the publication of the book *Male Breast Cancer: Taking Control* by Professor John Boyages have helped to fill some of the information gaps that men in the consultation talked about. Breast cancer specialists play a crucial role in linking men with information and support. BCNA is in an ideal position to promote the male breast cancer booklet and other resources to health professionals.

The consultation has also shown that there are specific actions and changes that BCNA and others can make now and in the future to ensure that information provided to men reflects their experiences and meets their needs. Specifically, the findings of the project show that men can benefit from:

- More awareness and education for health professionals to assist in earlier diagnosis and understanding of men’s needs
- High quality, male-specific online resources and webpages that are appropriately presented e.g. with gender neutral colour themes
- Written and interactive material that focuses on male survivors’ experiences and stories
- Images of male breasts and male mastectomies within information resources, so that men can better understand what surgery and treatment will involve for them
- Practical and concise signposting of information e.g. through table of contents or tabs, and lists of practical tips and advice.

Research
More research on the effectiveness of treatments in men is needed in future, to ensure a more robust evidence base. While men are a small population for randomised controlled trials, prospective multi-country studies, case series, and male ‘arms’ of larger clinical trials are possible options for capturing more data on breast cancer in men, and the effectiveness of treatments.

Meeting emotional support needs
Formal, individual and group counselling can be a vital source of emotional support for some men, with the consultation showing that the Cancer Council Australia telephone support and counselling service has been of particular help in connecting men with counselling services. Counselling can be especially valuable in addressing distress in the early weeks and months after diagnosis.

Accessing peer support – especially being able to link with other men who have experienced breast cancer – can be a crucial source of resilience, companionship and emotional
wellbeing for men. Many men in the consultation liked being able to help other men affected by breast cancer through peer support, suggesting that these men can play an advocacy role in extending support to other men. In the consultation, online support networks, general cancer survivor groups and dragon boating groups were also effective ways for men to access support.

More needs to be done to actively link men with available peer support and counselling early after diagnosis, both by health professionals and the community services sector.

**Improving awareness**
The consultation has highlighted that, by giving male breast cancer more visibility, we can tackle stigma and make it easier emotionally for men who are diagnosed with breast cancer. The changes required to address these issues do not have to be radical or take away from existing awareness efforts focused on women. Greater awareness can be achieved by relatively straightforward and targeted strategies, including:

- Introducing more gender-inclusive language as a standard within breast cancer organisations and consumer information, where this is appropriate e.g. ‘women and men too’; ‘people affected by breast cancer’
- Including a proportionate level of visible representation of male breast cancer—e.g. through social media, awareness campaigns and fundraising events
- Acknowledgement of male breast cancer during breast cancer awareness month
- Inclusion of men within breast cancer in consumer representation groups.

**BCNA priorities for action**

This project highlights five key **priorities for BCNA** in meeting the support and inclusion needs of Australian men diagnosed with breast cancer.

1. Continue to address the **information needs** of men through high quality, gender-appropriate resources. Ensure these resources are kept up to date, and informed by the latest research and feedback from men.
2. Improve **emotional support** for men by scoping the ways in which men’s access to peer support and counselling can be improved.
3. Improve community **awareness** through public events, campaigns, resources, consumer stories, and social media.
4. Improve men’s **participation** and **inclusion** through consumer representation and advocacy, including building and maintaining links with male members who are active in promoting breast cancer awareness in their communities.
5. Consider the ways in which the **language and presentation** of our resources and publications can better include men.
Recommendations for BCNA activities

Recommendation 1
Address information gaps

- Update the men’s section of the BCNA website and change the colour scheme to reflect that it is an information portal appropriate for men.
- Establish a protocol for using gender-inclusive language throughout our public material, where appropriate.
- Consider developing a separate information kit for men, as an alternative to My Journey Kit. This pack should consist of the *Men Get Breast Cancer Too* booklet, John Boyages’ *Male Breast Cancer: Taking Control*, and Cancer Australia’s new booklet *Understanding Male Breast Cancer*.
- Review and update the *Men Get Breast Cancer Too* booklet to reflect the key findings of this consultation.

Recommendation 2
Enhance men’s access to peer support

- Encourage men to join the BCNA online network.
- Facilitate an informal peer support network, by identifying existing male members who are willing to connect with other men who are looking for support.
- Explore opportunities for men to build member groups and/or support groups within our network. Opportunities would exist for the peer support stream at the Summit in March 2017.
- Provide an up to date list of external online support groups on our website and link men with breast cancer to these resources.
- Explore a collaboration/linkage with Cancer Council’s Cancer Connect program to connect men who are looking for peer support from other men.

Recommendation 3
Develop a position statement for men affected by breast cancer

Recommendation 4
Improve public and health professional awareness of male breast cancer

- Develop social media campaigns that periodically showcase men’s experiences of breast cancer.
- Every October, promote a male breast cancer awareness day.
- Include men with breast cancer in our Community Liaison program (to share stories in local community context).
• Inform health professionals of the needs of men diagnosed with breast cancer through our forums, health professional network, and conferences.
• Invite a man to take part and share their story in BCNA’s 2017 Summit.

Recommendation 5
Strengthen our partnerships
• Continue working closely with Cancer Australia and the Cancer Council, cross-promoting any new information and resources for men with breast cancer.
• Work closely with respected clinicians in our health professional network who have an interest in male breast cancer, including John Boyages and Christobel Saunders.

Recommendations for broader policy and practice

Based on the findings of this project, BCNA recommends the following actions to help improve outcomes for men diagnosed with breast cancer. These recommendations are intended for the community sector, health organisations, policymakers, advocates and anyone interested in improving inclusion and support for men diagnosed with breast cancer:

Recommendation 1: Improve access to gender-appropriate information
• Offer tailored resources for men as soon as possible after diagnosis, as they provide men with information that is designed to meet their specific needs. BCNA’s Men Get Breast Cancer Too booklet, and Professor John Boyages’ book, Male Breast Cancer: Taking Control are two resources which men have told us are particularly helpful.
• Tailored information for men is very helpful, as it helps men to feel included and informed about their treatment and supportive care needs.
• Be mindful of the language, presentation and content of information material intended for people diagnosed with breast cancer. General information resources should ideally include information relevant to male breast cancer too. If the information is intended to focus on women’s needs and concerns, it can be helpful to include links and information on additional resources for men.

Recommendation 2: Raise public awareness of breast cancer in men
• Highlight the signs and symptoms of male breast cancer, encourage men to seek medical advice early, and promote stories and accounts from other men which help to reduce the stigma of a breast cancer diagnosis.
• When building public awareness, consider the ways in which men’s experiences might be included in mainstream events, such as the annual October breast cancer awareness month.
• Identify and connect with men who are advocates in their local communities, as these men can play an important role in awareness campaigns and providing peer support.
Recommendation 3: Improve access to psychosocial supports

- Men should be screened for psychosocial distress after diagnosis, and should be offered information and/or a referral to appropriate counselling or psychological interventions.
- Encourage men to seek out cancer support groups, and provide information on local cancer support services. This may include breast cancer support groups that are inclusive of men; general cancer supports groups, and recreational clubs such as breast cancer survivors’ dragon boating teams.
- Online support groups and forums are a good way for men to access psychosocial support if they cannot find other men to connect with locally.
- Health professionals and patient organisations can play a role by connecting newly diagnosed men with other men who have been diagnosed with breast cancer, who are willing to offer informal peer support.

Achievements and next steps

Since the beginning of this consultation project in May 2016, BCNA has achieved a number of positive outcomes for men diagnosed with breast cancer. These achievements include:

- An update of the *Men Get Breast Cancer Too* booklet, to reflect the latest evidence and the key issues raised by the consultation.
- Involvement of one of the men from our consultation in BCNA’s new promotional video.
- Involvement of one of the men in our successful October 2016 social media campaign ‘breast cancer doesn’t discriminate’, with a short video of his story of being diagnosed with metastatic breast cancer. Other men have also been prompted to share their breast cancer stories on BCNA’s Facebook page after seeing this video.
- Involvement of the Hon Nick Greiner, a prominent public figure and male breast cancer survivor, as a keynote speaker in our 2016 Sydney Pink Lady Luncheon.
- Changes to language and gender-neutrality of the online network, as informed by feedback from the consultation project.
- Re-engagement of some of the men in the online network, and new male members joining in recent months.
- Some men have expressed interest in taking part in the Review & Survey Group and Consumer Liaison roles.
- One of the men has listed his local dragon boating group on our online directory of local services.
- All of the men who took part have expressed interest or have offered to contribute to peer support, making themselves available to speak with other men who have been
diagnosed with breast cancer and/or take part in awareness raising talks and presentations.

- Involvement with the US-based Male Breast Cancer Coalition in discussion about strategies for raising awareness of male breast cancer in the Australian community.
- Involvement of two men in BCNA’s upcoming 2017 Summit event.
- A decision has been made to tailor a My Journey Kit for men. Instead of the My Journey Kit, men will receive BCNA’s *Men Get Breast Cancer Too* booklet, and a free copy of John Boyages’ book *Male Breast Cancer: Taking Control*.

BCNA will continue to raise awareness that men can get breast cancer, including through our breast cancer campaigns, events and media. In line with our strategy for supporting men and educating the public, BCNA sponsored a man with breast cancer to attend and speak at the Clinical Oncology Society of Australia (COSA) conference in November 2016 and associated public forum for consumers. This was coordinated by prominent oncologist, Professor John Boyages. The findings of our consultation were also shared with health professionals, through a poster presentation at the COSA conference.

We will be developing a position statement on breast cancer in men, and will develop a set of strategies to improve awareness and support amongst health professionals and the broader community. The findings of this project have been shared across the organisation, and the identified priorities for BCNA will be workshopped across the organisation to ensure that we implement change at a whole-of-organisation level.
References


