Executive Summary
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.
Executive Summary

“It’s about making sure that men with breast cancer are not invisible and not hidden. It’s a way of raising it up a level, to have our identity be part of the broader discussion.” - Robert

Around 150 men are diagnosed with breast cancer in Australia every year.[1] While this is a small proportion of the total number of people diagnosed – less than one per cent – a diagnosis can bring some very specific challenges for men.

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 for men. BCNA has also successfully advocated to government, along with the Medical Oncology Group of Australia, for men to have access to subsidised breast cancer drugs through the Pharmaceutical Benefits Scheme (PBS). Male breast cancer has also been regularly acknowledged through our public awareness events, such as the inclusion of blue male silhouettes in our *field of women* installations. However, feedback from our members tells us that more needs to be done to help men diagnosed with breast cancer to feel supported, informed and included.

The consultation project

To better understand the needs and challenges faced by men, BCNA has undertaken a detailed review of the literature and a consultation with a small number of 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 health professionals, policy decision makers, community sector organisations, and all those with an interest in the issues and challenges facing men diagnosed with breast cancer in Australia.

Key findings of the project

From the interviews, men diagnosed with breast cancer told us their main challenges were:

- finding breast cancer information specifically for men
- delays in seeing their GP and delays in being diagnosed
- dealing with the stigma of having what is seen to be a ‘woman’s disease’
- feeling isolated and alone due to a lack of support.

These findings are summarised in the table below.
**KEY ISSUES**

**Delayed diagnosis**
Men tend to be diagnosed at a later stage than women. This is partly because awareness of breast cancer symptoms in men is low, men may delay seeing a doctor, and men are not included in breast screening programs.

**Unmet information needs**
Men need more gender-appropriate information at the time of diagnosis. A lack of information can leave men feeling anxious and isolated.

**Gender and stigma**
Breast cancer is often seen as a ‘woman’s disease’. This can have an impact on how men view themselves and can lead to experiences of stigma or distress.

**Colour representation**
The use of the colour pink to represent breast cancer awareness can cause unhappiness for some men, who do not feel that the colour resonates with them.

**Lack of support**
Men with breast cancer are more likely to feel isolated and are more reluctant to seek help. More options for peer support and counselling services are needed.

**Lack of awareness**
Public awareness of male breast cancer is low. Awareness campaigns generally focus on women. This can contribute to delayed diagnosis, stigma and isolation for men.
Discussion

In consulting with men, we found that there has not been much tailored information for men until recently. 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. More information is now available, with the publication of BCNA’s *Men Get Breast Cancer Too* booklet and the book *Male Breast Cancer: Taking Control* by Professor John Boyages. The men we spoke to said these resources help to fill the information gaps they had experienced, and has 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.

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 embarrassing and stigmatising for some men. This can isolate men further.

The men we spoke to all found it valuable to connect with other men living with breast cancer, although they told us it is hard to find support groups that are tailored to their needs and that help them to feel included and comfortable. Other helpful supports included seeing a counsellor, connecting with other men around the world through online support groups, and joining recreational groups, such as dragon boating teams.

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 do not feel represents them. Because of the above issues, men are at risk of experiencing high levels of distress after a breast cancer diagnosis. Improvements in these areas could help to improve men’s diagnosis and treatment journeys.

Implications for policy and practice

The project has highlighted a number of factors that might help improve outcomes for men diagnosed with breast cancer. Ensuring that men have access to tailored information on male breast cancer, as soon as possible after diagnosis, can increase men’s health literacy and reduce distress. 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. Lastly, 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.
Recommendations for BCNA
This project highlights five key priorities for BCNA, in meeting the 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 identifying opportunities to improve men’s access to peer support and counselling.
3. Improve community awareness through public events, campaigns, resources, personal accounts from men, and social media coverage.
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 resources and publications can better include men.

Recommendations for broader policy and practice

Recommendation 1: Improve access to gender-appropriate information
- Offer tailored resources and information for men as soon as possible after diagnosis. 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.

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 support 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.

Outcomes and next steps

BCNA will continue to raise awareness that men can get breast cancer, including through our breast cancer campaigns, events and media. For October breast cancer awareness month 2016, BCNA has featured coverage of male breast cancer through our social media campaign ‘Breast Cancer Doesn’t Discriminate’. In line with our strategy for supporting men, BCNA also sponsored a man with breast cancer to attend and speak at the Clinical Oncology Society of Australia (COSA) conference in November 2016. This was coordinated by prominent oncologist, Professor John Boyages. The findings of our consultation are also being shared with health professionals, including through a poster presentation at the 2016 COSA conference. We will develop 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.
Bibliography