

# Addressing the unmet needs of Australian men diagnosed with breast cancer

## Authors

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## About BCNA

Breast Cancer Network 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

Around 150 men are diagnosed with breast cancer in Australia every year. While men make up less than one per cent of all Australians with breast cancer\*, a diagnosis can bring very specific challenges for men. It can be more difficult for men to access appropriate information, as well as emotional and social support.

In 2014 BCNA developed a booklet, *Men get breast cancer too*, for men diagnosed with breast cancer. This year, BCNA has undertaken more work to better understand the challenges men face, based on feedback from members suggesting that more can be done to improve outcomes for men.

## >> Aims

This project aimed to identify unmet needs and challenges for Australian men diagnosed with breast cancer, and to identify what BCNA and the broader community can do to help men feel more included and supported. The project was not a representative, quantitative research project. Rather, it was a consumer consultation undertaken to inform program development and policy.

## >> Methods

This consultation project involved in-depth telephone interviews with five men from around Australia who had been diagnosed with early or metastatic breast cancer, and a detailed literature review which focused on identifying broader issues and challenges for men diagnosed with breast cancer.

BCNA recruited men to take part in the interviews through our network of members, and through links with health professionals. Through the interviews, men were invited to talk about their diagnosis and treatment journeys, information needs, health care experiences, and gender, sexuality and identity issues that shaped their breast cancer experiences. The interviews also aimed to identify what BCNA, and the community more broadly, can do to improve outcomes and experiences for men.

## >> Findings

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 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.

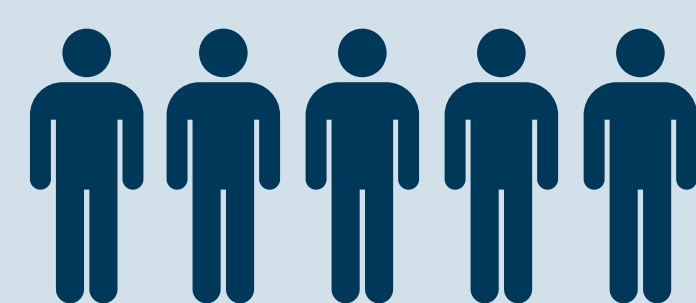


>> Rod wearing a blue shirt in a sea of pink at a breast cancer event in Cooroy, Queensland.



FIGURE ONE

## 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.

59 - 74

### 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.



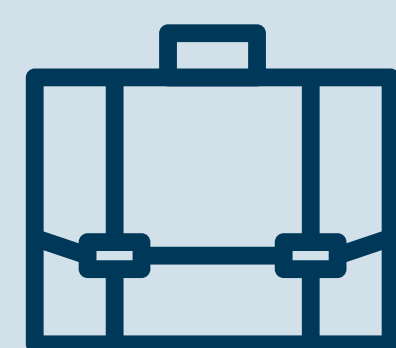
### Location

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.

FIGURE TWO

## KEY ISSUES



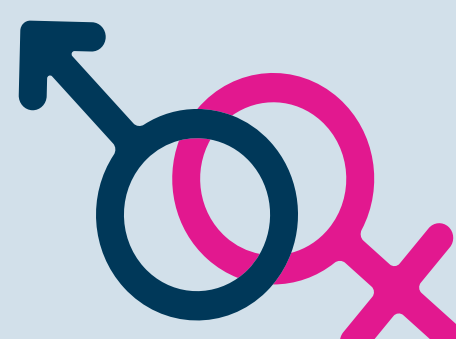
### Delayed diagnosis

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.

## >> Conclusions/recommendations

This project highlights a set of factors which can enable improved inclusion and support for men diagnosed with breast cancer. Based on the findings of this project, BCNA recommends the following actions.

FIGURE THREE

## RECOMMENDATIONS



### 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.



### 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.

## >> Further information

See BCNA's *Men with breast cancer* web page at [bcna.org.au](http://bcna.org.au).

The Executive Summary Report of this project can be found on the BCNA website, [bcna.org.au](http://bcna.org.au).

You can order a copy, or download, BCNA's booklet *Men get breast cancer too* at [bcna.org.au](http://bcna.org.au).

Professor John Boyages' book *Male Breast Cancer: Taking Control* can be ordered from [breastcancertakingcontrol.com.au](http://breastcancertakingcontrol.com.au).

## >> Acknowledgements

BCNA is grateful to the men who participated in the consultations for their assistance.

\*Reference: Australian Institute of Health and Welfare 2016. Australian Cancer Incidence and Mortality (ACIM) books: breast cancer. Canberra: AIHW.