Bringing together clinical and consumer expertise to influence policy: Improving access to prophylactic mastectomy for people with high genetic risk of breast cancer

Breast Cancer Network Australia

Background/Introduction

Women with inherited high risks of breast cancer face up to a 70% lifetime risk* of developing the disease, compared to 14% for the general female population in Australia. The most common breast cancer gene mutations (gene abnormalities or faults) are the Breast Cancer (BRCA) 1 and 2 genes. Approximately 5-10% of breast cancer diagnoses are a result of inherited risks,^ and these cases typically occur at a younger age compared to people with no inherited risks.

In Australia, national guidelines determine how quickly people can access elective surgeries in the public health system. Non-urgent surgeries (category 3) are recommended within 12 months, compared with semi-urgent (category 2, 90 days) and urgent (category 1, 30 days). For people with inherited high risks of breast cancer seeking to have a prophylactic mastectomy, these guidelines tend to classify the surgery as non-urgent (category 3). However, people with inherited risks of breast cancer often wait more than 12 months for surgery; some wait longer than 5 years. There are anecdotal reports of women developing breast cancer while on the waitlist. Women also report higher rates of emotional distress and generational trauma associated with living with high cancer risk and the possibility of premature death. Having surgery through the private health system can reduce these wait times, but the out-of-pocket costs are prohibitive for most people, ranging from $5,000 to $50,000.

The absence of nationally consistent data and reporting about people with inherited high risks of breast cancer presents additional challenges in understanding their needs and developing effective health policies.

Methodology

In response to reports of ongoing delays and inconsistencies in accessing prophylactic mastectomy as a preventative intervention, Breast Cancer Network Australia (BCNA) engaged with various stakeholder groups to better understand the barriers experienced by people with inherited high risk of breast cancer. The Australian Access to Breast Reconstruction Collaborative Group (AABRCG) partnership, formed in 2020 between BCNA, BreastSurgANZ, and the Australian Society of Plastic Surgeons, created a national platform for clinical experts and consumers to advocate to policy makers and health services to address these issues.

In November 2024, the AABRCG issued a **joint position statement** recommending amendment of national guidelines to reprioritise prophylactic mastectomies as Category 2 surgeries (indicated within 90 days) for people with 30% or higher risk of developing breast cancer, including those with BRCA1 and 2 mutations. The position statement also included recommendations for Australian states and territories and the healthcare sector to adopt this reprioritisation. A separate publication of lived experience case studies complemented the position statement to illustrate the challenges for people navigating the healthcare system and the significant psychological distress associated with surgical delays.

Notes

* The average age at which women are diagnosed with breast cancer is 39.9 years old for those with a BRCA1 mutation, and 50 years old for those with a BRCA2 mutation.

^ Other genetic mutations linked to breast cancer include mutations of the ATM, BARD1, CDH1, CHEK2, PALB2, PTEN, RAD51C, RAD51 and TP53.

> ***I found out I had a BRCA1 mutation in 2019. For me, cancer wasn't a matter of if, but when. I was told I would need to wait 2-4 years for a prophylactic mastectomy because I didn't have cancer yet, so I wasn't a priority. After waiting a few years with no progress, I accessed my superannuation to pay $40,000 for surgery in the private system. Even then, my fund denied my request twice, not seeing it as 'essential'. Even though I paid so much, I have no regrets – being proactive about my breast cancer risk was the best decision I've ever made.***
>
> – Bec, BRCA1 gene carrier

- Up to **70% lifetime** risk of developing breast cancer (BRCA 1 and 2) vs 14% general female population
- Current wait times in public system: **12 months to 5 years**
- Prophylactic mastectomies reduce breast cancer risk by at **least 95%**
- Out-of-pocket costs for private surgery: **up to $50,000**

> ***The guidelines have not kept pace with the rapid evolution of prevention strategies in the surgical space, resulting in patients waiting as long as five years.***
>
> – Dr. Melanie Walker, Chair of the AASBRCG and President of BreastSurgANZ

Left to right: At the launch of the joint position statement on 21 November 2024 are: BCNA member Linda, lived experience representative with BRCA 1 gene mutation; Vicki Durston, BCNA Director Policy, Advocacy & Support Services; The Hon Ged Kearney MP, Assistant Minister for Social Services and Prevention of Family Violence (former Assistant Minister for Health and Aged Care); Kirsten Pilatti, BCNA CEO; The Hon Mark Butler MP, Federal Minister for Health and Ageing, Disability and the NDIS

Results/Conclusion

By bringing together clinical expertise, lived experience, and evidence-based advocacy, the AABRCG was successful in achieving bipartisan support for the position statement, including acknowledgment of the need for all levels of government and the healthcare sector to work together on the issue.

BCNA will continue to work with the Australian Government, state and territory governments, and health sector peak bodies such as the Australian Healthcare and Hospitals Association, to progress recommendations in the position statement, including the establishment of a national, standardised system for collecting and reporting on prophylactic mastectomy data related to inherited breast cancer risk.

> ***This is the gold standard... BCNA is consistently and relentlessly seeking to push the envelope about ways in which we can improve the cancer journey for women experiencing breast cancer.***
>
> – The Hon. Mark Butler, Minister for Health and Ageing, Disability and the National Disability and Insurance Scheme.

Impact

Reclassifying prophylactic mastectomies as Category 2 semi-urgent surgery will help shorten wait times for the surgeries in the public health system and address geographic and socioeconomic factors that currently affect a person's ability to make preventative health decisions. Improved access can help people with inherited risks decrease their chances of future breast cancer diagnoses.

This policy shift will have significant financial, psychological, and health implications for high-risk individuals. On a system level, this change may reduce health system costs related to chemotherapy and radiation treatments for those who might have otherwise developed breast cancer. Preventative surgery could eliminate the need for cancer treatment and its associated long-term psychosocial effects.

Australia's Minister for Health acknowledged BCNA's 'gold standard' approach to consumer-led advocacy as a key driver to improve cancer experiences and positively influence health policy change.

References

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Authors

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