



Prioritising access to risk reducing surgery for people with inherited high risks of breast cancer

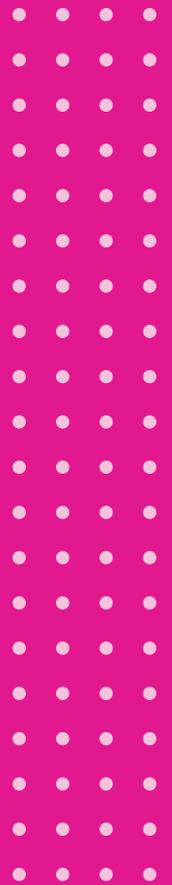
Australian Access to Breast Reconstruction Collaborative Group position statement

The Australian Access to Breast Reconstruction Collaborative Group (AABRCG) is dedicated to advocating for improved access to breast reconstruction services across Australia by bringing together primary care expertise and cancer policy and research. The group was established in 2020 as a partnership between Breast Surgeons of Australia and New Zealand (BreastSurgANZ), the Australian Society of Plastic Surgeons (ASPS), and Breast Cancer Network Australia (BCNA).

Breast cancer doesn't discriminate, but some people have at least a 70% risk of being diagnosed due to inherited genetic factors. The AABRCG advocates for all Australians at high risk of breast cancer to have timely access to life-changing risk reducing surgery (prophylactic mastectomy).

Currently, risk reducing surgeries are not consistently classified as semi-urgent elective surgeries in public health services. People with inherited risks of breast cancer often wait more than 12 months for these surgeries. They also face higher rates of emotional distress and generational trauma associated with cancer risk, and the possibility of premature death. Alternative pathways through the private health system can cost patients as much as \$50,000, making it an impossible option for many.

It is the AABRCG's position that governments reclassify prophylactic mastectomies for people with inherited high risks of breast cancer, to align with the urgency of their healthcare needs. A nationally consistent approach to the prioritisation of risk reducing surgery for this group will help reduce the risk of breast cancer diagnosis, thereby removing the need for, and cost of, breast cancer treatments including chemotherapy and radiation.



The purpose of this joint position statement is to outline:

- Current health system limitations for people with inherited high risks of breast cancer, including elective surgery urgency categorisation guidelines for prophylactic mastectomies.
- Benefits of timely access to risk reducing surgical options.
- Recommendations for urgent and future action.

The AABRCG is calling for national consistency in the categorisation of prophylactic mastectomy and reconstruction for people with inherited high risks of breast cancer.

Background

The average lifetime risk of breast cancer for the general female population in Australia is 14%. There are several genes, however, where mutations (gene abnormalities or faults) increase a person's risk of breast cancer. Approximately 5-10% of breast cancer diagnoses are a result of inherited risks.¹ The most common are in the Breast Cancer (BRCA) 1 and 2 genes.*

Women with inherited genetic risks are over four times more likely to be diagnosed with breast cancer in their lifetime. Cancer also often impacts them at a younger age. 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.²

The focus of this statement is people who have a 30% or higher risk of developing breast cancer in their lifetime, including women with a BRCA1 mutation (72%) and BRCA2 mutation (69%).³

A prophylactic bilateral mastectomy is a critical surgical procedure that removes both breasts to prevent the risk of breast cancer by at least 95%.^{4,5} However, there is no national repository for, or nationally consistent approach to, data collection for people with inherited high risks of breast cancer. This data is fragmented and held in a variety of datasets and is not consistently being reported.

This makes it difficult to understand how long people are waiting for prophylactic mastectomies for this indication, how many people are undertaking this surgery in our public health system across states and jurisdictions, and whether they were diagnosed with breast cancer whilst waiting. Commitment to addressing this need for improved data collection, and enduring health data linkages,

is needed to improve visibility of those at risk, accurately assess trends on prophylactic mastectomies and inform future health policy that improves outcomes for people with inherited high risks of cancer.

Current health system limitations for people with inherited high risks of breast cancer

While most state-based health services commit to scheduling prophylactic mastectomies within 12 months from the time of placement on the health service-based waitlist, many people with inherited high risks of breast cancer are forced to wait over 12 months due to workforce shortages and other factors. For some people, delays have exceeded five years.

The AABRCG has observed distressing cases where individuals with inherited risks develop breast cancer while waiting for risk reducing surgery, some with metastatic cancer that has already spread to other parts of the body. This has led to long term impacts on psychosocial wellbeing, including the distress and trauma that comes with having incurable breast cancer.

As a consumer-led organisation of 25 years, BCNA has consistently heard people with inherited high risks of breast cancer talk about their challenges accessing risk reducing options including surgery. For many, the decision to have a prophylactic mastectomy can be confusing and complex. It requires balancing personal motivations with clinical guidance, evaluating options like immediate, delayed or no breast reconstruction, and considering the psychosocial, physiological and functional impacts of each choice.

Consideration of cumulative wait times (not just for a planned surgical procedure but also for initial assessment by a surgeon and other pre-surgery processes) and out-of-pocket costs also affect when and how a person assesses their surgical options. The AABRCG has heard from some people that there is a lack of information and support to effectively make an informed decision about what is best for them.

A study conducted by Inherited Cancers Australia indicated that only 27% of Australians undergoing risk reducing surgery has had their healthcare needs entirely met via the public health system.⁶ Given the significant delays in availability of prophylactic mastectomies through the public health system, many people have turned to the private health system. Out-of-pocket costs for surgery, medication, allied health services, tests and other direct healthcare costs can range from \$5,000 to over \$50,000.⁷ These costs are prohibitive for many Australians, particularly those in

marginalised and vulnerable communities, creating demographic and geographic inequities. BCNA has learned that some individuals have accessed their superannuation or, in some cases, set up crowdfunding campaigns to cover the cost of their prophylactic mastectomy and reconstruction.

Benefits of timely access to risk reducing surgical options

More Australians are now proactively accessing genetic testing and counselling to understand their inherited cancer risks. Given that women with genetic mutations are more likely to have breast cancer whilst in their most productive years,⁸ being proactive about stopping the intergenerational harms of cancer is critical so they can contribute socially and economically within their families, communities and society at large.⁹ Accessing surgical options early ensures people will not be forced to wait in fear of a future diagnosis. The sector is united in advocating for improved access to risk reducing interventions, ensuring individuals at high risk of breast cancer are fully informed and supported in accessing timely and affordable risk reducing options.

For those with inherited risks of breast cancer, increased surveillance is recommended due to risk of higher rates of aggressive sub-types of breast cancer that are harder to treat and higher rates of cancer recurrence.¹⁰ But access to Medicare rebates for specialist screening such as ultrasounds and MRI scans vary significantly and can lead to out-of-pocket costs that increase exponentially over a person's lifetime.^{11, 12, 13} Prophylactic mastectomies offer economic benefits in managing an individual's lifetime breast cancer risk, regardless of whether breast reconstruction is performed.¹⁴

Breast cancer costs the Australian healthcare system \$1.056 billion (including \$269 million on screening) annually.¹⁵ Given that hereditary breast cancers account for 5-10% of all breast cancers, they are estimated to cost \$39-79 million (5-10% of the total cost of breast cancer excluding screening costs). It is therefore estimated that providing prophylactic mastectomies for people with inherited high risks of breast cancer could save the Australian healthcare system tens of millions of dollars every year by preventing cancer and reducing the need for more intensive treatments. These savings are higher when considering the indirect costs of cancer, which can include counselling and support services, lost productivity and other intangible costs.

Patients report positive outcomes following a prophylactic mastectomy beyond the health economic benefits. These include decreased

fear and anxiety about being diagnosed with breast cancer and general improvements across their health and wellbeing.¹⁶ This suggests that a prophylactic mastectomy can have immeasurable benefits for people.

Recommended next steps

1. The Federal Government, via the Department of Health and Aged Care, to endorse the position statement and partner with states and territories to lead the implementation of these recommendations.
2. The Australian Institute of Health and Welfare (AIHW) and Royal Australasian College of Surgeons (RACS) to undertake a national review and update the **National elective surgery urgency categorisation guideline**, reclassifying elective surgery for this group from a category 3 surgery to a category 2 surgery.
3. State and territory governments to endorse the position statement, support the national review and update state-based guidelines to facilitate a consistent approach to prioritising elective surgery for this group.
4. State health departments and public health services to disseminate the position statement to key staff, including surgeons and cancer care clinicians, as a necessary step to ensure the prioritisation of risk reducing surgery for people with inherited high risks of breast cancer.
5. Cancer Australia to incorporate navigation of risk reducing surgeries into the **Australian Cancer Plan** (ACP), to support people with inherited high risks of breast cancer to access a full range of options for risk reducing interventions, including navigation, specialist information, support and counselling services.
6. Cancer Australia to review and update the **Optimal care pathway for people with breast cancer** (OCP) to include best practice guidelines for timely access to risk reducing surgery.
7. National professional and peak bodies, including the Australian Healthcare and Hospitals Association (AHHA), Australian Medical Association (AMA) and RACS, to endorse the position statement and support the implementation of these recommendations.
8. The Federal Government to lead the establishment of a national, standardised system for collecting and reporting on data on prophylactic mastectomies related to inherited breast cancer risk. Enduring health data linkage is essential to inform policy reform and ensure equitable, timely access to this critical risk reducing surgery for high risk individuals across Australia.

* Other genetic mutations linked to breast cancer include mutations of the ATM, BARD1, CDH1, CHEK2, PALB2, PTEN, RAD51C, RAD51 and TP53 genes. Additionally, individuals may have an inherited high risk of breast cancer but the cause of this risk has not been detected via genetic testing.



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