

Experiences of Australians with inherited breast, ovarian and prostate cancer risk

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Aim

To understand the support needs and health experiences of Australians with an increased risk of hereditary cancer, with a focus on breast, ovarian and prostate cancer.

Methods

Qualitative and quantitative data collected from respondents through an online survey, via convenience sampling. Data from 884 responses has been analysed using descriptive analysis. Recruitment occurred through the **Inherited Cancers Australia** online community, via national media coverage and our network of clinicians and organisations that support hereditary cancer families.

Participants

Age

34 & under: n, 125 (14.2%)
35 – 44: n, 250 (28.3%)
45 – 54: n, 233 (26.4%)
55 – 64: n, 170 (19.2%)
65+: n, 102 (11.5%)
Not stated: n, 4 (0.5%)

Jurisdiction

ACT/NSW: n, 305 (35%)
VIC/TAS: n, 286 (32%)
QLD: n, 136 (15%)
SA/NT: n, 65 (7%)
WA: n, 85 (9%)
Not stated: n, 10 (1%)

Cancer profile

Had cancer: n, 321 (36.3%)
No cancer: n, 560 (63.4%)
Not stated: n, 2 (0.2%)

Undertaken risk-reducing surgery

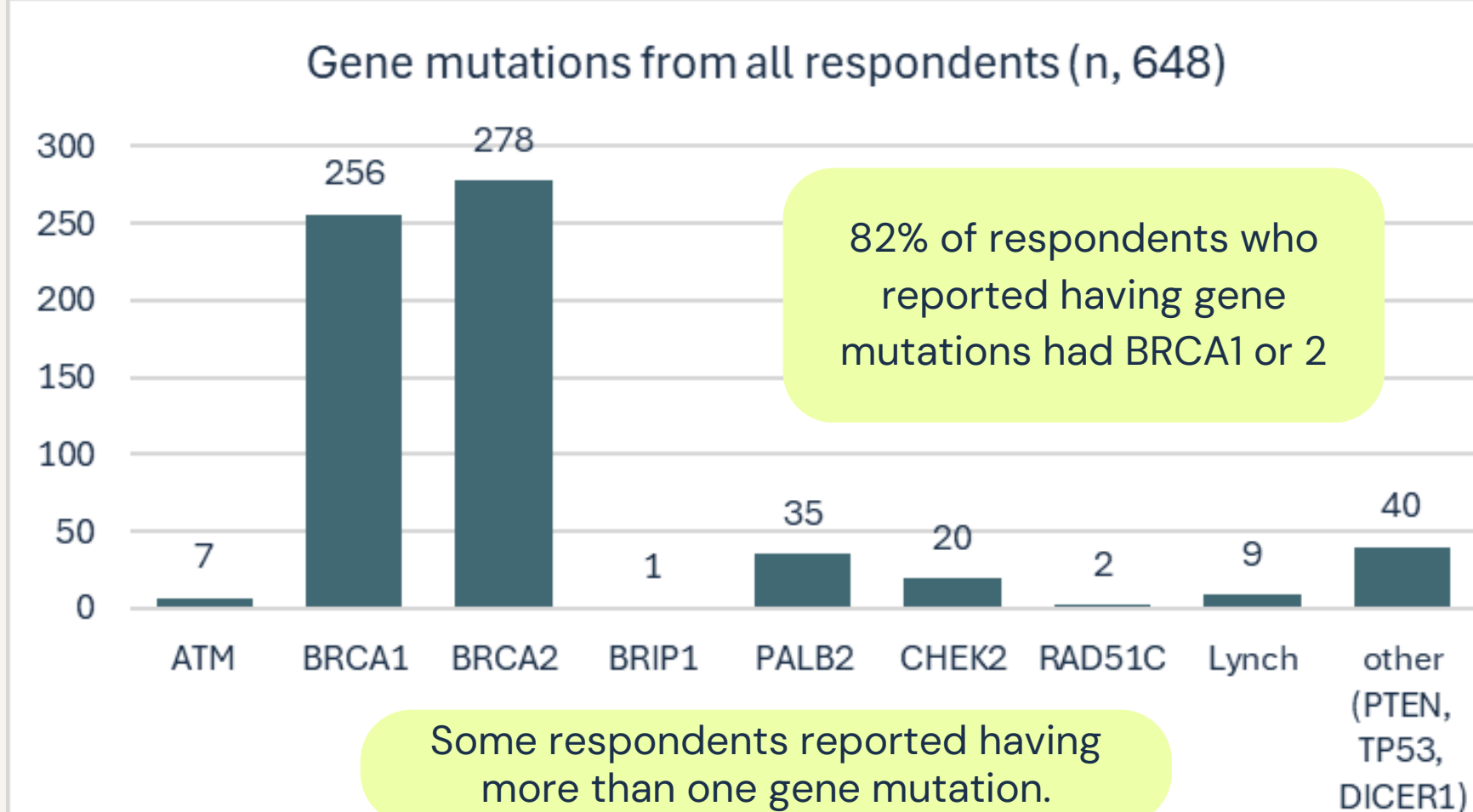
Yes: n, 486 (55%)
No: n, 398 (45%)

Regionality

Major city: n, 583 (66%)
Regional centre: n, 177 (20%)
Rural town: n, 112 (12.7%)
Remote or very remote: n, 8 (0.9%)
Not stated: n, 4 (0.5%)

Identifying as

Aboriginal & Torres Strait Islander: n, 16 (1.8%)
Ashkenazi Jewish: n, 40 (4.5%)
LGBTQIA+: n, 32 (3.6%)
Neither: n, 797 (90.2%)



Results

Key themes

- Financial burden on young women and families
- Barriers to access for risk reducing surgery (cost and extended public wait times)
- Generations impacted in the same family

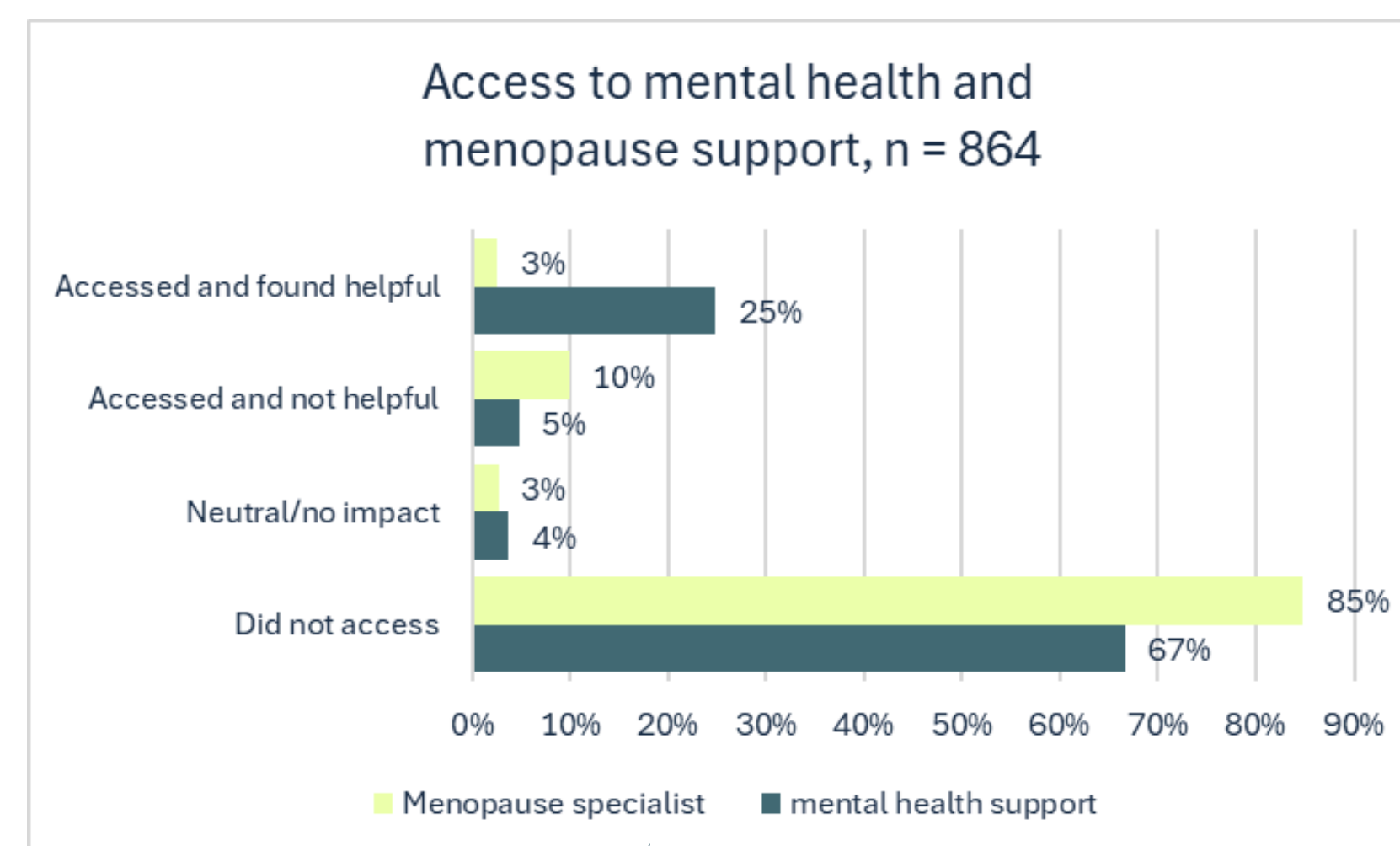
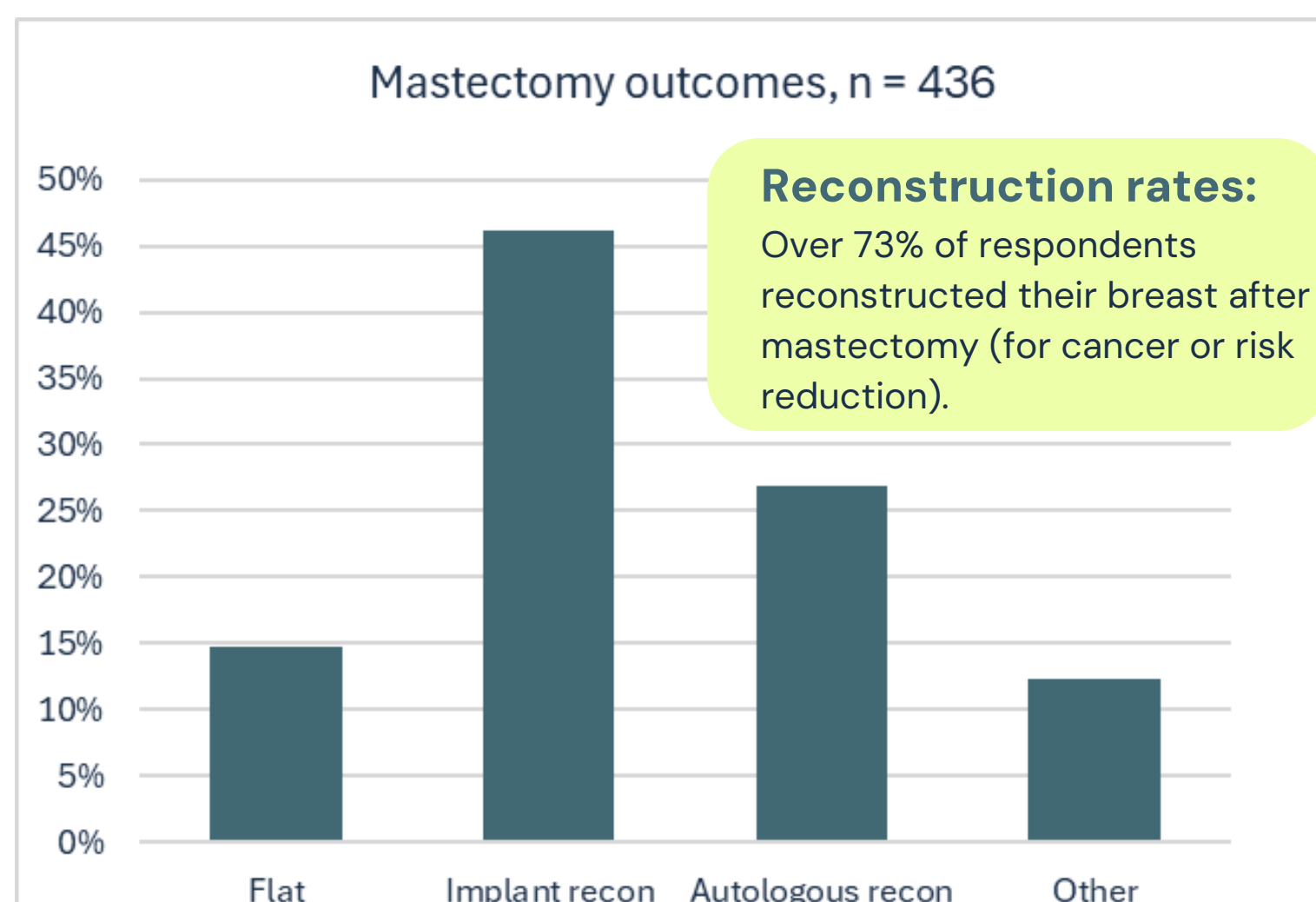
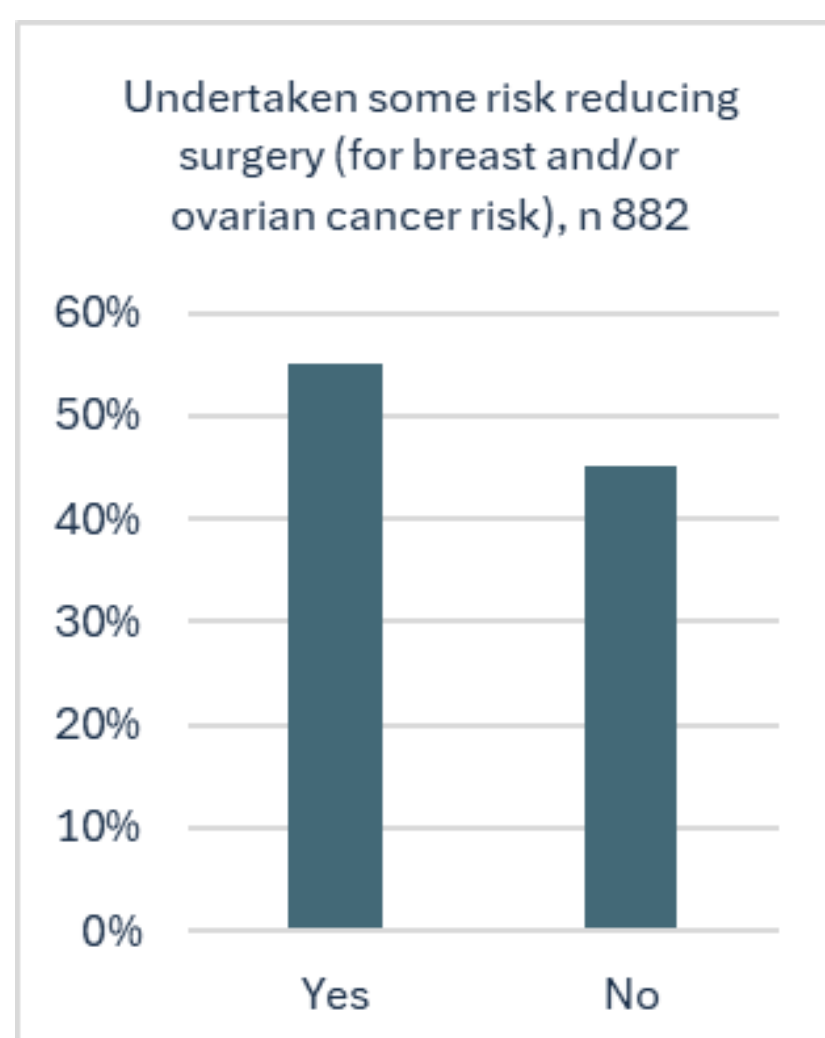
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All respondents (n, 882)

Information & Support:

Of the people who sought information, 77.5% sought information and support from ICA to investigate options to reduce their cancer risk. More than 70% of people found the online information and resources from ICA helpful in supporting their risk reduction decision.



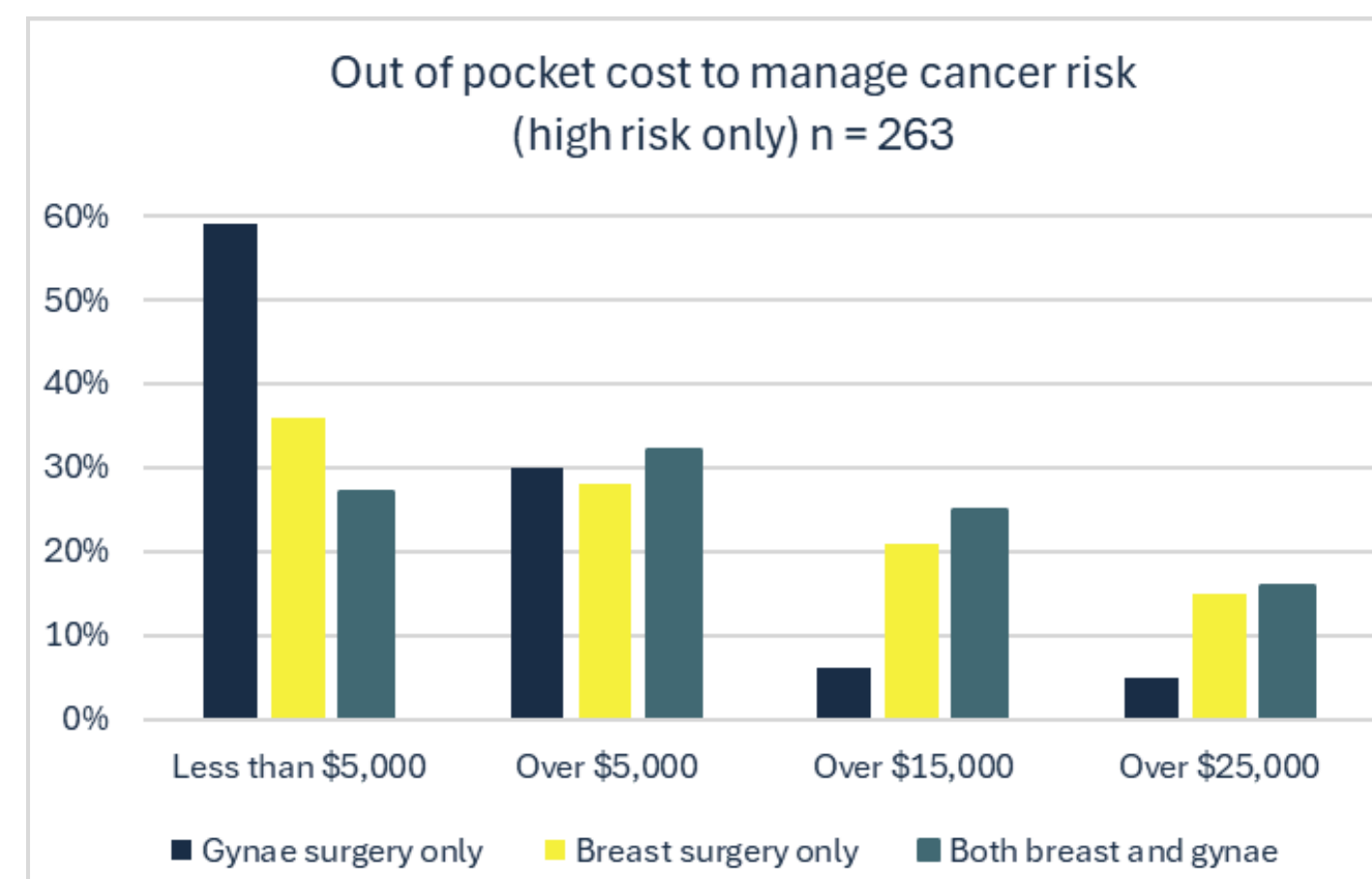
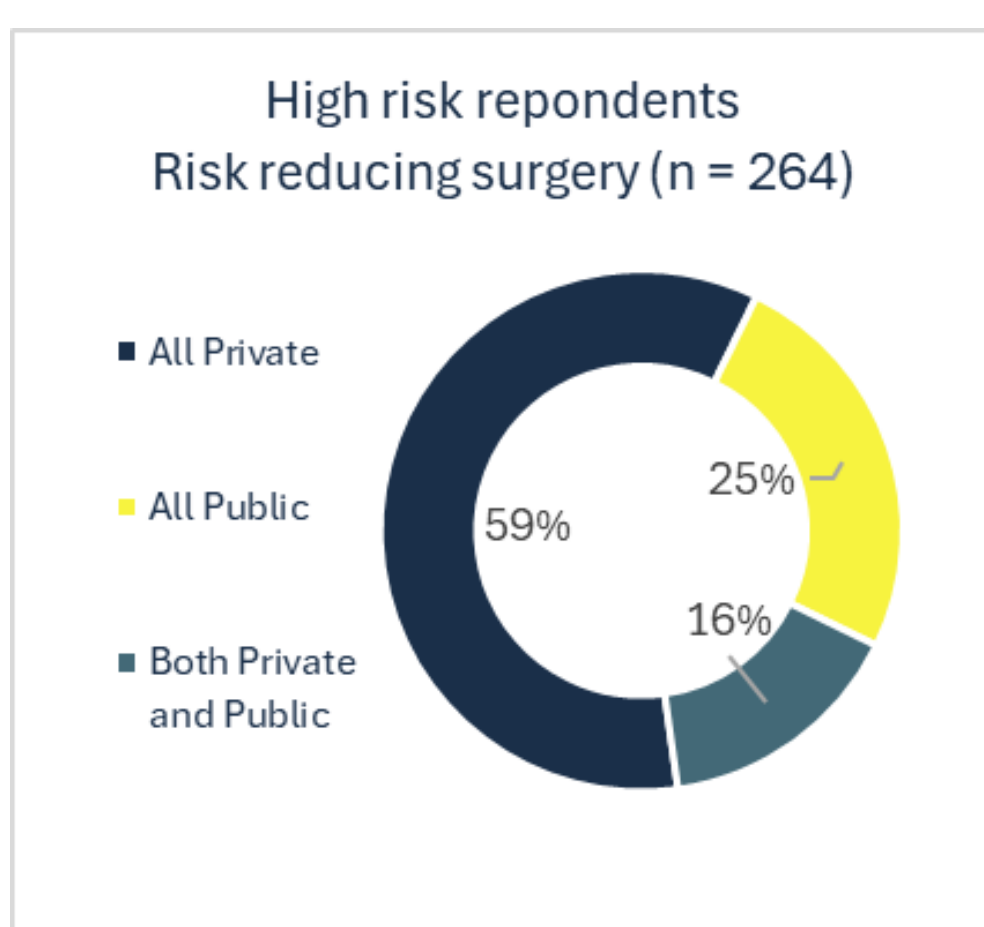
"I was on the list for ovaries to be removed but cancelled as I was worried about surgically induced menopause."

"I was also never offered any mental health support throughout my diagnosis or treatment which really shocked me."

High risk respondents (no cancer) (n, 563)

For high-risk people without a cancer diagnosis (n= 563):

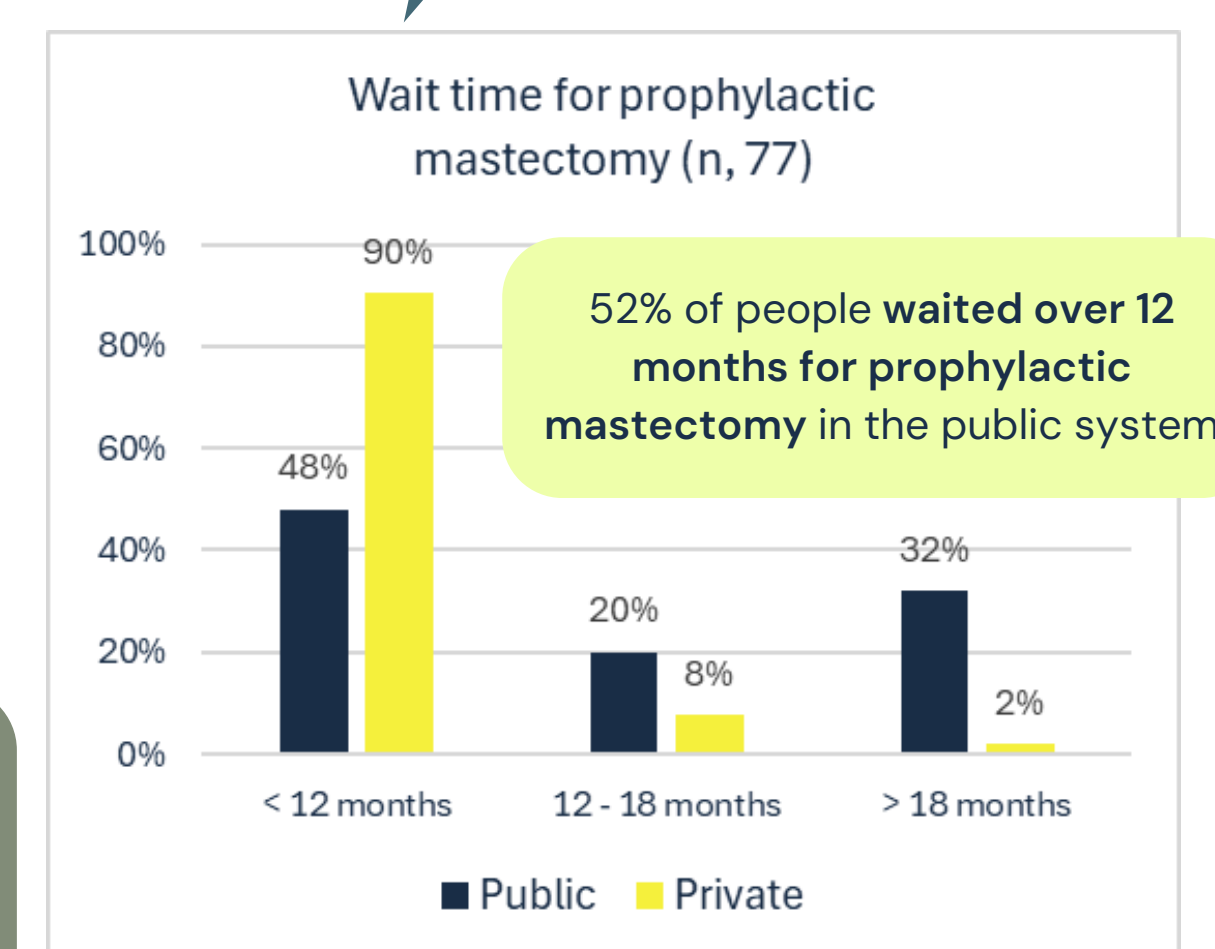
- 27% (n = 153) had 2 or more 1st degree family members with a cancer diagnosis
- 60% (n = 338) had 2 or more 2nd degree family members with a cancer diagnosis



"To afford the surgery, a go fund me campaign has helped taper about 1/3 of the costs."

"I accessed my super to cover a portion of my fees for mastectomy and reconstruction –\$13,400. The ATO then taxed me an additional \$3,400 out of my super for accessing my super early. The rest I paid for up front with what savings I had."

"Wait time blew out to 2-3 years and I couldn't bear the thought of getting cancer while on a wait list."

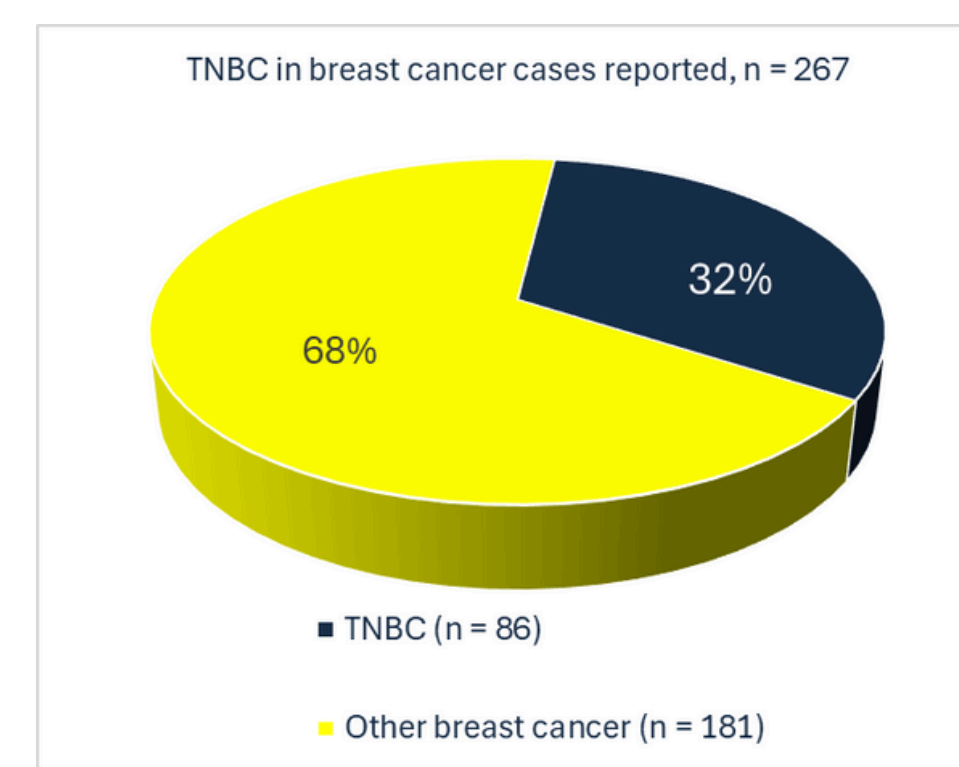
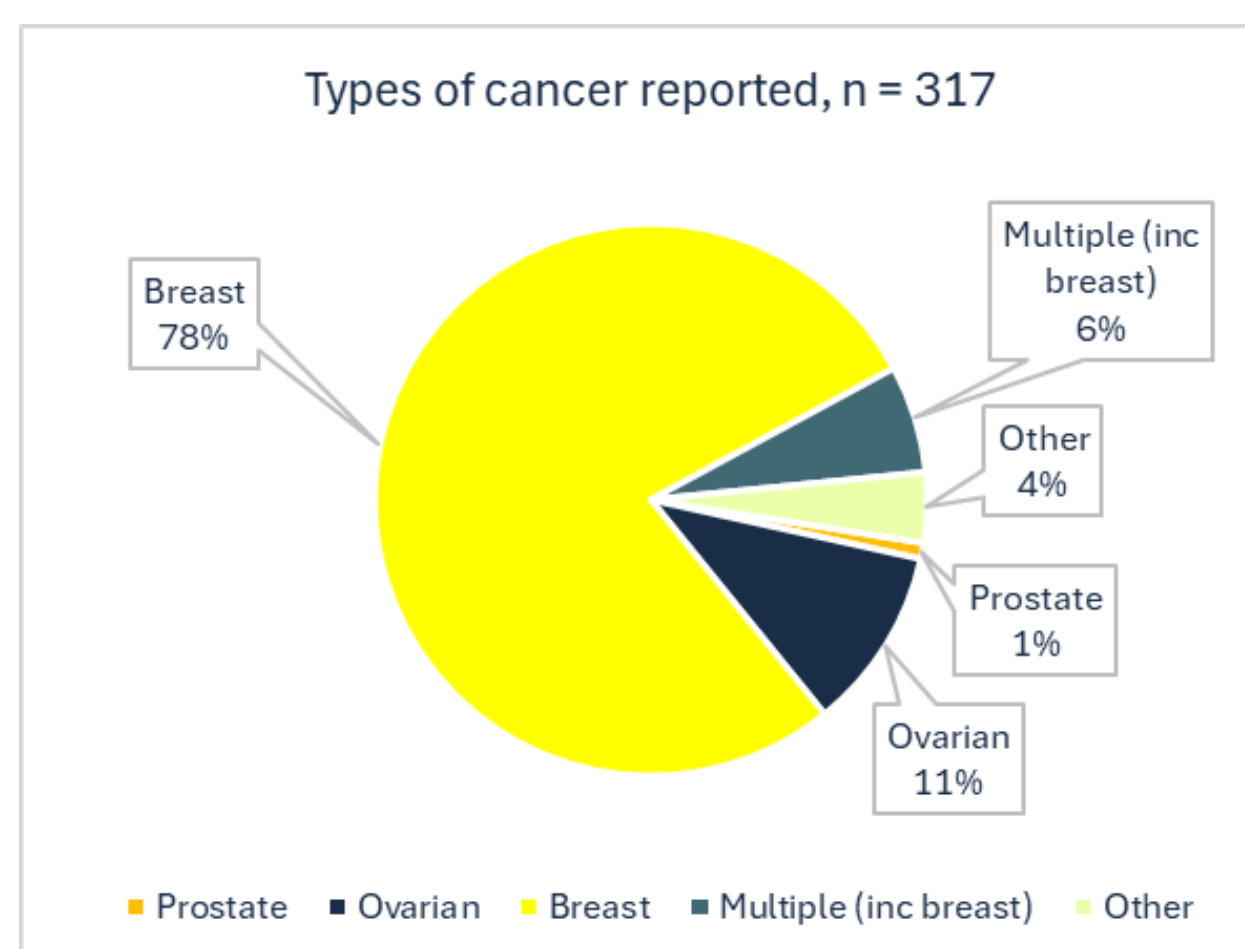


Conclusion

- Patient support groups play a key role in providing support and information.
- People in this community experience breast and ovarian cancer at a younger age than the general population.
- The breast reconstruction rate (73%) in this population is much higher than reported in research¹.
- High-risk for cancer people have large financial burden at a young age.
- Many people with inherited cancer risk aren't seeking mental health and/or menopause support.
- Men, Aboriginal and/or Torres Strait Islander people and Culturally and Linguistically diverse people were not well represented in the study group.
- Many people are not using the public health system for risk-reducing surgery.

1. <https://pubmed.ncbi.nlm.nih.gov/36651629/>

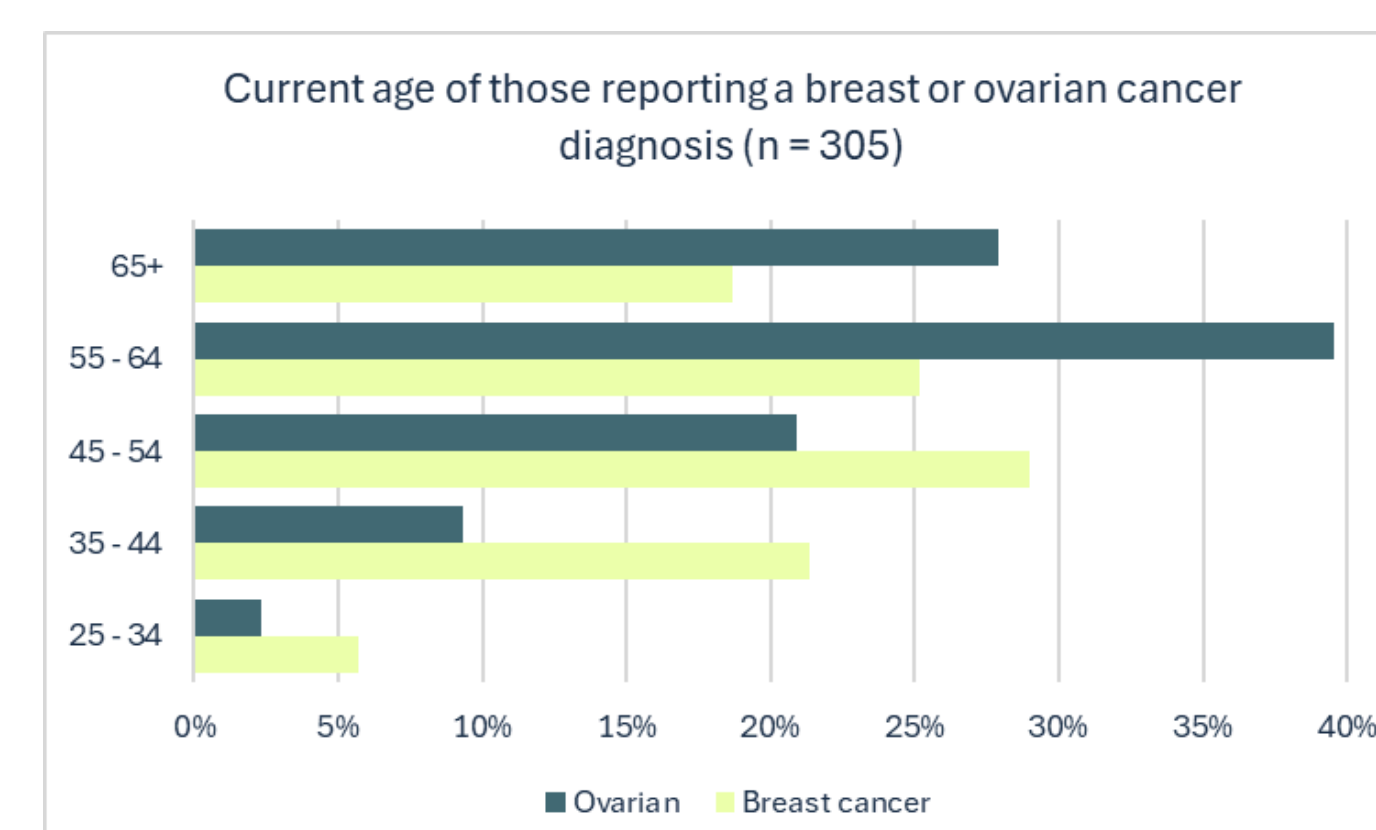
Respondents with a cancer diagnosis (n, 321)



"I was on [a wait list for] risk reducing surgery however didn't make it to it in time before my diagnosis."

Breast cancers reported:

84% of cancers reported were breast cancer (some people received multiple diagnoses). 56% of people had experienced a breast cancer diagnosis and their current age is under 54.



Acknowledgements

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Contact us

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