

Experiences and information needs of Australians who experience Medically Induced Menopause

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Background

Medically Induced Menopause (MIM) is a significant yet often overlooked consequence of cancer treatment or preventative surgery, involving the abrupt onset of menopause. Little is known about the psychosocial impact and information needs of those experiencing MIM.

Methods

Inherited Cancers Australia conducted an online survey to explore the lived experiences of individuals with MIM. Using convenience sampling, the survey was shared via networks and social media, incorporating both closed and open-ended questions. De-identified data was analysed from **764 people**, using descriptive statistics and thematic analysis.

Participants

Age

18 – 24: n = 5 (1%)
25 – 34: n = 31 (4%)
35 – 44: n = 262 (36%)
45 – 54: n = 295 (40%)
55 – 64: n = 107 (15%)
65+: n = 31 (4%)
Average age: 42.2yrs

Jurisdiction

ACT/NSW: n = 229 (31%)
VIC/TAS: n = 244 (34%)
QLD: n = 128 (18%)
SA/NT: n = 65 (9%)
WA: n = 56 (8%)

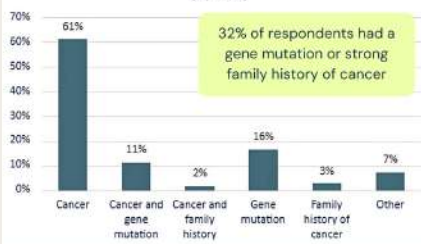
Regionality

Capital city: n = 472 (65%)
Rural area: n = 236 (33%)
Remote area: n = 18 (2%)
Identifying as
Aboriginal & Torres Strait Islander: n = 15 (1.9%)
Ashkenazi Jewish: n = 19 (2.5%)
LGBTQIA+: n = 20 (2.6%)

In menopause because of

Treatment: n = 440 (58%)
Removed ovaries: n = 324 (42%)

Why did you have surgery or treatment? (n, 712)



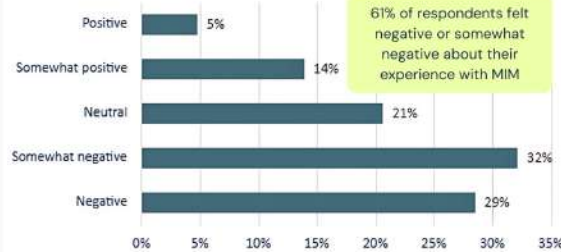
Results

Key themes

- Negative experiences related to MIM
- Reliance on self-research and personal advocacy
- Confusion arising from conflicting information within a fragmented system
- Frustration due to the inadequate information and support related to MIM

Experience with MIM

How do you feel about your experience of medically induced menopause? (n, 712)



"I felt very unprepared for medically induced menopause. I felt particularly ill-prepared for the effects on my sexuality." – Age 31

"I am worried about the health impacts of being in menopause for 10+ years, yet I had to do this to reduce my risk of ovarian cancer." – Age 43

Additional insights from open-ended responses

- Inadequate support and information
- Severe and debilitating symptoms
- Mixed feelings about the trade-off between treatment/surgery and managing MIM
- Impact on relationships
- Impact on quality of life and long-term health concerns
- Some reported minimal side effects

Resources for Patients



Biggest Concerns

Respondents were presented with a list of health topics and challenges and asked to select those they were most concerned about in relation to MIM. They could select multiple options. This graph displays the eight most frequently reported concerns.

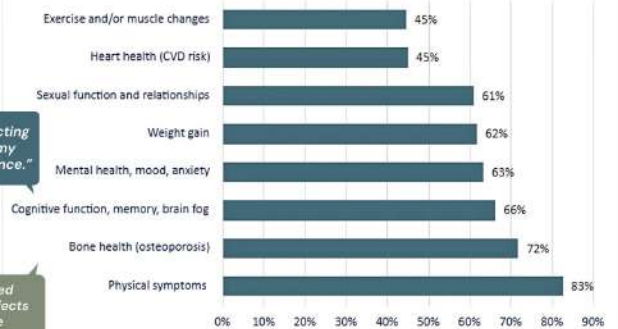
Physical and mental health impacts were reported as the most concerning part of MIM, while decision making, conflicting information, access to specialists and medications were of less concern.

"I wasn't expecting a change in my work performance."

"My concerns have been somewhat dismissed due to my cancer." – Age 40

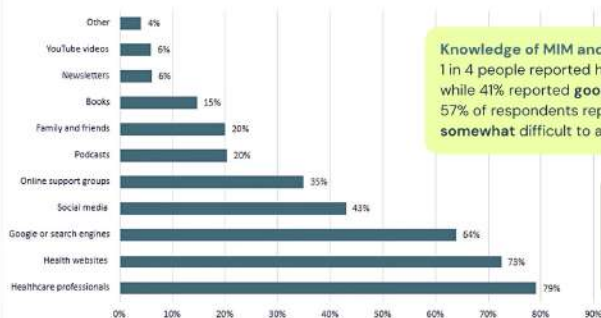
"Medically induced menopause side effects have been more devastating than cancer treatments." – Age 50

What are your biggest concerns about medically induced menopause? (n, 764)



Information Needs and Access

Where have you sought information about MIM (n, 597)



Knowledge of MIM and accessing information: 1 in 4 people reported having **poor knowledge** of MIM, while 41% reported **good or excellent knowledge**. 57% of respondents reported it was **difficult or somewhat difficult** to access information about MIM.

"There was little support or information about managing symptoms and impact of medically induced menopause and conflicting information about treatment options." – Age 43

Conclusion

- People entering MIM are younger than the general patient population and tend to remain in MIM for longer
- Many participants felt **underserved** and **inadequately informed** about MIM
- Access to clear, evidence-based information could significantly improve the patient experience of managing MIM.
- Early referral to a specialist presents an opportunity to improve patient outcomes.

Acknowledgements

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- The Inherited Cancers Australia team

Contact us

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