Gynecologic Oncology Reports 54 (2024) 101427

Contents lists available at ScienceDirect

Gynecologic Oncology Reports

journal homepage: www.elsevier.com/locate/gynor

Self-reported awareness of genetic testing, the impact of family history, and access to clinical trials for people diagnosed with ovarian cancer in Australia

Deborah Roczo [a], Vanessa Alford [b,*], Alison Trainer [c], Anna DeFazio [d], Amy Pearn [e], Caitlin Delaney [f], Megan Cotter [g], Sue Hegarty [h]

[a] Healthcare Management Advisors
[b] Ovarian Cancer Australia
[c] University of Melbourne
[d] University of Sydney
[e] The Gene Council
[f] CareFully MD
[g] Alfred Health
[h] Ovarian Cancer Australia

ARTICLE INFO

Keywords:
ovarian cancer
genetic testing
patient perspectives

ABSTRACT

Objectives: To assess the understanding of people diagnosed with ovarian cancer regarding genetic testing; to understand knowledge gaps among people diagnosed with ovarian cancer that may impact best practice care; and to monitor overall changes in understanding from 2015 to 2022.
Design: Longitudinal 'opt-in' study using an online survey tool at three timepoints: 2015, 2018 and 2022.
Participants: People in Australia (or their families / caregivers) diagnosed with ovarian cancer between 2010 and 2022).
Main outcome measures: Self-reported awareness of heritable risk factors for ovarian cancer, genetic testing approaches and participation in clinical trials.
Results: The study indicated that there have been improvements in the understanding and awareness of people diagnosed with ovarian cancer regarding familial risk (an increase from 43.6% (45 of 149) in 2015 to 62.9% (166 of 264) in 2022); but people were less likely to be aware of the difference between somatic (tumour) and germline testing (120 of 266, 45.1%). However, there were self-reported improvements to clinical trial access in non-metropolitan areas (12 of 64, 18.8% in 2022 compared to 22 of 145, 15.2% in 2018), bringing it on par with metropolitan areas (32 of 169, 18.9% in 2022).
Conclusions: Despite improved awareness about genetic testing among people diagnosed with ovarian cancer, there remain knowledge gaps in understanding of genetic testing types (germline and somatic) and gene variant targeted therapies; and further work to improve clinical trial awareness and access is required.

The known: Approximately one in four to six cases of all ovarian cancers are associated with inheritable genetic variants. Promoting genetic testing is important as it impacts clinical decision making.

The new: Understanding and awareness of Australians diagnosed with ovarian cancer regarding familial risk and clinical trials has improved since 2015, as has clinical trial access in non-metropolitan areas. However, knowledge gaps exist in the awareness of gene targeted therapies and understanding the distinction between somatic and germline genetic testing.

The implications: Further work is required to improve clinical trial awareness for the estimated 30% of Australians who are unaware.

1. Introduction

An estimated 1,815 new cases of ovarian cancer (OC) were diagnosed in Australia in 2022, the majority of which were of epithelial cell origin

* Corresponding author at: Queen Victoria Women's Centre, Level 1, 210 Lonsdale St, MELBOURNE 3000.
E-mail address: vanessa.alford@ovariancancer.net.au (V. Alford).

https://doi.org/10.1016/j.gore.2024.101427
Received 18 March 2024; Received in revised form 22 May 2024; Accepted 27 May 2024
Available online 7 June 2024

(Australian Institute of Health and Welfare, Cancer Data in Australia [Web report]. Cancer summary data visualisation, new cancer cases diagnosed, 2022). Approximately one in four to six cases of all epithelial ovarian cancers are associated with hereditary (germline) genetic variants. Having a first degree relative with OC increases lifetime risk from an average of 1.4% to 5% (Weissman et al., 2012 Jul-Aug), while identifying a *BRCA1* pathogenic variant confers an average 45% risk (Kuchenbaecker et al., 2017).

In Australia, all individuals diagnosed with epithelial ovarian cancer (including invasive, non-mucinous ovarian, fallopian tube and primary peritoneal cancer) are eligible for germline genetic testing (MBS, 2024). This allows medical professionals to assess 1) tailored treatment options for the individual, 2) risk of other cancers to the individual, and 3) the hereditary OC risk for family members. Although it is considered best practice for people with OC to have genetic testing and counselling, access to these services are not always equitable. Over the last decade, efforts to address barriers to access and the costs of genetic testing for OC have been implemented in Australia, such as changes to *BRCA1/BRCA2* testing guidelines and inclusion of rebatable items on the Medicare Benefit Schedule (MBS) and Pharmaceutical Benefit Schedule (PBS), as follows:

- In 2013, the eviQ guidelines for *BRCA1 / BRCA2* testing were updated to extend the target population from people with high grade invasive non-mucinous ovarian, fallopian tube or primary peritoneal cancer less than 60 years of age to less than 70 years of age, or any age if there is a family history of breast cancer or OC (CIN, 2023).
- In 2017 germline testing for variants in *BRCA1* and *BRCA2* and a small number of other genes was added to the MBS – item number 73296 (AGDH, 2023a) and poly(ADP-ribose) polymerase inhibitors (PARPi) *olaparib* was listed on the PBS for treatment of recurrent OC for eligible patients (OCA, 2023)
- In 2020 the guidelines for *BRCA1 / BRCA2* testing were updated, separating the target population into two subsections for clarity – 'germline *BRCA1* and *BRCA2* testing' and 'pathogenic variant specific *BRCA1* and *BRCA2* testing' (CIN, 2023).
- In 2020 tumour testing for *BRCA1* and *BRCA2* variants was added to the MBS to determine eligibility for access to PARPi – item number 73301 (AGDH, 2023b) and PARPi was added to the PBS as first-line treatment for eligible patients (OCA, 2023).

It is important to identify other barriers that prevent OC patients and their families from receiving optimal care.

Promoting germline genetic testing among people with OC is important for identifying other family members at risk for cancers, enabling risk-reduction, or early detection strategies to be used. For those patients with OC who are found to carry a *BRCA1* or *BRCA2* pathogenic variant, there are also OC treatment impacts (Esplin et al., 2022). *BRCA* mutations are associated with better response to platinum-based chemotherapy and response to PARPi (DiSilvestro et al., 2022) (Alsop et al., 2012). Studies have shown that if germline *BRCA* testing is restricted to people with a significant family history of ovarian (or breast) cancer, approximately 44% of carriers are missed (Alsop et al., 2012). These findings led to changes in the Australian guidelines for germline genetic testing for *BRCA* variants, which now recommend testing for almost all people with high-grade epithelial ovarian cancer (CIN, 2023).

Although pathogenic variants associated with increased ovarian cancer risk are most commonly found in *BRCA1* and *BRCA2*, research has identified other genes that contribute to OC risk including: *TP53, BARD1, BRIP1, RAD51C, RAD51D, MLH1, MSH2, MSH6, PALB2* and potentially *ATM* (Norquist et al., 2016) (Liu et al., 2021). One study predicted that more than half of inherited ovarian cancers are due to yet to be identified gene mutations (Jones et al., 2017). Unlike *BRCA1/BRCA2* gene variants, potential treatment implications for other variants that contribute to OC risk are not yet known.

Our study sought to assess the understanding of genetic testing of people diagnosed with OC to identify knowledge gaps that may impact on best practice care and monitor overall changes in understanding from 2015 to 2022.

2. Methods

2.1. Participants

Ovarian Cancer Australia (OCA) is a non-profit organisation that raises awareness of and facilitates OC research. OCA has an interest in all forms of OC and has built a database of people diagnosed with or affected by OC (and/or their families or caregivers).

The study targeted people diagnosed with OC (or their families/caregivers) in Australia. The target audience was reached by emailing contacts in the OCA membership database, and via the OCA website and social media. The method of survey distribution did not allow for exclusion of out-of-scope responses. The OCA membership includes people affected by all types of OC, including types that may not benefit from genetic testing.

2.2. Measures

An online survey was distributed (via email (through the OCA database), website and social media) at three time points: 2015, 2018 and 2022. Each round the survey questions were reviewed for accuracy and appropriateness by the OCA Research and Advisory Group. Each round survey questions were updated for currency, while maintaining consistency of questions where possible to enable longitudinal comparison of the results. Survey responses were collected anonymously; therefore it was not possible to track people over the course of the three surveys.

Within this study the term OC refers to ovarian, fallopian tube and peritoneal cancers.

The surveys were open for three to four weeks. Reminder emails and new social media posts occurred after two weeks.

Survey data were cleaned to remove incomplete and duplicate responses and people who did not indicate consent to participate. BOX 1 shows the volume of survey responses from each round in total and by jurisdiction. A response rate could not be calculated because of the method of survey advertising (promotion via website and social media). However, survey response numbers for each cohort are presented as a proportion of OC incidence (new cases of OC as reported by the Australian Institute of Health and Welfare) as an indication of the representativeness of survey responses.

Data was analysed using descriptive statistics, including frequency of response types and percentage of total responses. within each survey cohort, comparison of response percentages were made by age range and location. Changes in response percentages between survey cohorts were also analysed.

The study was approved by Bellberry Human Research Ethics Committee (reference 2022-02-168).

3. Results

3.1. Self-reported awareness of the link between family history of breast or ovarian cancer and the risk of developing OC

When asked '*Before your diagnosis, did you know there could be a link between having a family history of breast and/or ovarian cancer and the risk of developing breast or ovarian cancer?*' over half of the 2022 respondents indicated an awareness before they were diagnosed (166 of 264, 62.9%). This was an increase compared to the proportion of 2018 respondents (185 of 368, 50.3%) and substantially higher than the proportion of 2015 respondents (45 of 149, 43.6%). BOX 2.

Younger respondents were more likely to be aware of family history

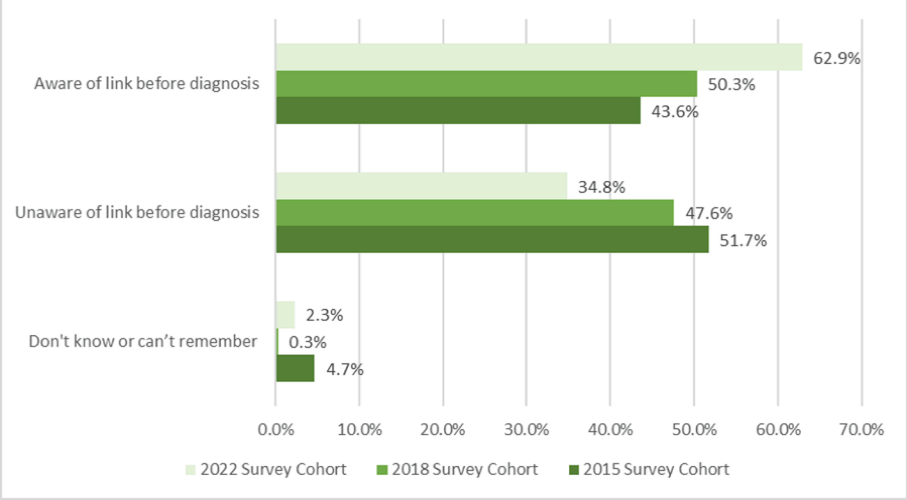
BOX 1
Survey response numbers by jurisdiction and as a proportion of ovarian cancer (OC) incidence.

Jurisdiction	2015 Survey cohort		2018 Survey cohort		2022 Survey cohort	
	Response number	2015 survey response number as a proportion of OC incidence in 2015	Response number	2018 survey response number as a proportion of OC incidence in 2018	Response number	2022 survey response number as a proportion of OC incidence in 2018
NSW	47	8.4%	122	19.4%	83	13.2%
Vic	39	8.9%	97	21.5%	71	15.7%
Qld	31	9.0%	71	19.7%	75	20.8%
WA	13	7.8%	33	19.0%	35	20.1%
SA	6	4.2%	20	14.2%	12	8.5%
Tas	4	11.1%	11	28.2%	0	0.0%
ACT	0	0.0%	12	52.2%	5	21.7%
NT	0	0.0%	3	50.0%	1	16.7%
Total	**154**	**9.0%**	**371**	**20.3%**	**284**	**15.5%**

OC incidence data from the Australian Institute of Health and Welfare estimates for females with ovarian and serous carcinomas of the fallopian tube, and peritoneal cancer in 2018 or 2015 (Australian Institute of Health and Welfare, Cancer Data in Australia [Web report]. Cancer by state and territory data visualisation, age-standardised incidence rates for ovarian cancer and serious carcinomas of the fallopian tube (females), 2018).

2022 incidence data was not available at the time of preparation.

BOX 2
Awareness of link between family history and risk for OC; comparison of survey response proportions from 2015, 2018 and 2022 responses.



BOX 3
Number and percentage of survey respondents aware of the link between family history and risk for OC by age group.

Age group	2015 Survey Cohort		2018 Survey Cohort		2022 Survey Cohort	
	n	%	n	%	n	%
40–49 years	15	48.4%	29	59.7%	24	72.7%
50–59 years	16	40.0%	61	44.5%	53	67.9%
60–69 years	23	52.3%	62	49.6%	63	61.8%
70+ years	5	31.3%	24	51.1%	24	52.2%
Total	**77**	**43.6%**	**368**	**50.3%**	**166**	**62.9%**

Responses from people aged under 40 years of age are not presented due to low response numbers in 2022.

compared to older respondents (BOX 3). However, there was a substantive increase in awareness across all age ranges 40 years and above in 2022 compared to 2015.

A comparison of awareness of the link between family history and genetic risk for OC prior to diagnosis by jurisdiction (New South Wales, Victoria and Queensland only; comparisons for remaining states / territory could not be made due to low response numbers) between 2022 and 2018 showed an increase in awareness in all states with an average increase of 15.4 percentage points [data not shown]. The greatest increase was observed in Victoria (18.6 percentage points), which was also the state with the highest rate of awareness in both years (51.1% in 2018 and 70.1% in 2022).

In the 2022 survey cohort, awareness of family history was slightly higher among respondents living in metropolitan areas (120 of 183, 65.6%) compared to non-metropolitan areas (42 of 72, 58.3%) [data not shown]. This was higher than observed for the 2018 survey responses which showed 50.8% of respondents living in metropolitan areas (99 of 196) and 50.0% of respondents living in non-metropolitan areas (86 of 172) having an awareness of the link between a family history of breast and/or OC and the risk of developing breast or OC before diagnosis. These data were not collected in the 2015 survey.

3.2. Self-reported genetic testing

In the 2002 survey cohort, 198 respondents underwent genetic testing (69.5% of all survey respondents). This was comparable to the number of respondents who underwent genetic testing in the 2018 survey cohort (67.7%, n=285), and an increase from the 2015 survey cohort at 44.7% (n=71).

3.3. Self-reported awareness of non-BRCA gene variants and links to hereditary OC

When asked '*Are you aware of any genes other than BRCA1 and BRCA2 that have been linked to hereditary ovarian cancer?*' in 2022, only 27.0% of respondents indicated an awareness of genes other than *BRCA*1 and *BRCA2* linked to hereditary OC (68 of 252) [data not shown]. This was a slight decrease from the 2018 survey where 30.7% of respondents indicated an awareness of non-*BRCA* genes that increase the risk of OC (113 of 368) when asked '*There are other potential genetic syndromes aside from the BRCA 1 & 2 that are associated with ovarian cancer. Do you know about these other syndromes?*' [data not shown].

Of the 79 survey respondents in 2022 who indicated they had undergone germline genetic testing for gene variants other than *BRCA1* or *BRCA2* (in response to *'Have you been tested for any genes other than BRCA1 and BRCA2 linked to hereditary ovarian cancer?*'), just over half indicated an awareness of the link between non-BRCA variants and hereditary OC (43 of 79, 54.4%) [data not shown]. This could not be compared to the 2018 survey because of changes to question wording and order.

3.4. Self-reported awareness of the difference between germline and somatic testing

The 2022 survey included a question about the awareness of the difference between germline and somatic genetic testing: 'There are different types of genetic tests. Are you aware of the difference between the somatic genetic testing done on a tumour tissue compared to the germline genetic testing done on a person's blood or saliva sample?' This question was not asked in previous survey years.

Less than half of respondents were aware of the difference between somatic and germline testing (120 of 266, 45.1%). The remaining respondents were unaware (104 of 266, 39.1%) or unsure (42 of 266, 15.8%). Of the respondents that indicated they had undergone genetic testing, a slightly higher proportion (108 of 198, 54.5%) indicated they were aware of the difference between somatic and germline testing compared to the total 2022 survey cohort.

3.5. Self-reported awareness of treatments that target OC caused by specific gene variants

In 2022, 43.8% (109 of 249) of respondents were aware of OC treatments that target specific gene variants when asked '*Did you know that there are treatments that target ovarian cancers caused by specific gene variants?*'. This was unchanged from 43.7% of respondents in 2018 (139 of 318), but an increase from 2015 when only 30.6% of respondents were aware (44 of 144) [data not shown). Note: in 2018 and 2015 the survey question asked specifically about *BRCA*-related variants ('*Did you know that new targeted treatments are currently available that target ovarian cancers that result from BRCA mutations?*'), while in 2022 the questions referred to gene variants generally.

3.6. Self-reported awareness of and participation in clinical trials

When asked '*Have you been told about or been offered to take part in a clinical trial*?; 69.8% (169 of 242) of respondents were aware of clinical trials in 2022. This was relatively unchanged from 65.6% 2018 (206 of 314) and 68.8% in 2015 (44 of 64) (BOX 4).

There was a small increase in the proportion of people who (were aware and) had participated in a clinical trial in 2022 (45 of 242, 18.6%), compared to 2018 (56 of 314, 17.8%) and 2015 (23 of 135, 17.0%). There was an increase in the proportion of people aware of clinical trials but ineligible in 2022 (35 of 242, 14.5%) compared to 2018 (34 of 314, 10.8%) and 2015 (16 of 135, 11.9%). Reasons for ineligibility were not explored further in the surveys. A decrease in the proportion of people aware of clinical trials who did not recall having a discussion about clinical trials with their treating team was observed in 2022 (51 of 242, 21.1%) compared to 2018 (83 of 314, 26.4%) and 2015 (38 of 135, 28.1%). There was little change in the proportion of people who were unaware of clinical trials in 2022 (71 of 242, 29.3%) compared to 2018 (99 of 314, 31.5%) and 2015 (44 of 135, 32.6%). BOX 5.

Self-reported awareness of clinical trials was similar across all age ranges with a notable increase in awareness among people aged 60 years and above in 2022 (95 of 136, 69.9%) compared to 2015 (30 of 54, 55.6%) [data not shown].

There was an increase in self-reported participation in clinical trials for respondents residing in non-metropolitan areas in 2022 (12 of 64, 18.8%) compared to 2018 (22 of 145, 15.2%) [data not shown]. However, self-reported clinical trial participation for respondents residing in metropolitan areas decreased slightly in 2022 (32 of 169, 18.9%) compared to 2018 (133 of 169, 19.5%).

In 2022, 16.0% (27 of 169) of respondents living in metropolitan areas reported they were interested but ineligible for a trial, compared to 12.5% (8 of 64) living in non-metropolitan areas (note lower response numbers in non-metropolitan areas in 2022). Whereas in 2018, respondents living in non-metropolitan areas were more likely to report clinical trial ineligibility compared to those in metropolitan areas (non-metro: 19 of 145, 13.1% compared to metro: 15 of 169, 8.9%) [data not shown].

4. Discussion

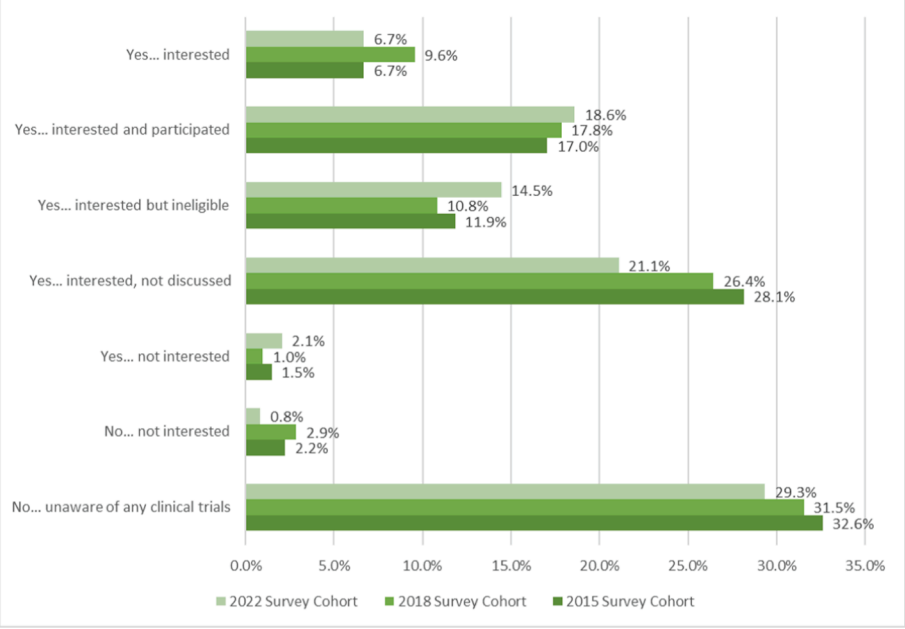
The analysis of the survey data showed improvements in the awareness of family history and risk of OC among people diagnosed with OC in the 2022 survey compared to 2015. Despite these improvements, approximately 37% (98 of 264) of respondents in 2022 were still unaware. However, this is notably lower than results from a multinational survey of women diagnosed with ovarian cancer in 2018, that showed on average 69.1% of women had never heard of ovarian cancer or knew nothing about it (Reid et al., 2021).

BOX 4
Survey respondent awareness of clinical trials in 2022, 2018 and 2015.

Response	2015 Survey Cohort		2018 Survey Cohort		2022 Survey Cohort	
	n	%	n	%	n	%
Aware	88	65.2%	206	65.6%	169	69.8%
Unaware	47	34.8%	108	34.4%	73	30.2%
Total	**135**	**100.0%**	**314**	**100.0%**	**242**	**100.0%**

Awareness was defined as respondents who answered: '*Yes, I was interested*', '*Yes, I was interested and have taken part or am taking part in a trial*', '*I am interested but this hasn't been discussed with me*', '*Yes, but I was not interested*', and '*Yes, I was interested but not eligible for a trial*'. Respondents who answered '*No*' and '*I am not interested*' were defined as 'unaware'.

BOX 5
Awareness and attitudes towards clinical trials, 2015, 2018 and 2022 responses.



The proportion of survey respondents that underwent genetic testing in 2022 (69.5%, n=198) was higher than international averages (51.1% based on 2018 multinational survey results; higher than UK genetic testing rates (59.8%), comparable to Canada (64.5%) and Italy (63.5%), but lower than the US (79.1%) (Reid et al., 2021).

Only 27.0% (68 of 252) of 2022 survey respondents indicated an awareness of non-*BRCA* related gene variants and links to hereditary OC, with similar proportions reported in 2018 (30.7%, 113 of 368). This suggests information about the risk of OC associated with variants in genes other than *BRCA1* and *BRCA2* is not well understood. Only half of the 2022 respondents who underwent germline genetic testing for non-*BRCA* gene variants were aware of the link between these variants and hereditary OC (54.4%, 43 of 79).

Promotion of germline genetic testing for all those diagnosed with high grade epithelial OC is important regardless of family history (AGDH, 2023b). This is now reflected in national Australian guidelines for *BRCA1* and *BRCA2* genetic testing (CIN, 2023) which no longer require evidence of a family history in people diagnosed with isolated high grade invasive non-mucinous ovarian, fallopian tube or primary peritoneal cancer, together with broadening of access to funding for testing via Medicare or family cancer clinics.

PARPi treatments have been shown to be more effective on tumours with *BRCA1* or *BRCA2* gene variants (causing homologous recombination repair deficiency (HRD)) (DiSilvestro et al., 2022) (Alsop et al., 2012) (Vergote et al., 2022). Therefore, understanding the genetic aetiology of OC is important for tailoring optimal care for patients. However, less than half of the survey respondents indicated an awareness of gene variant targeted therapies across all survey years. Although some improvement in awareness was observed in 2018 (43.7%, after introduction of MBS item 73296 for germline genetic testing of *BRCA1* and *BRCA2* pathogenic gene variants that warrant treatment with PARPi (AGDH, 2023a) and 2022 (43.8%, after introduction of MBS item 73301 for somatic genetic testing (OCA, 2023) compared to 2015 (30.6%), further work is needed to raise awareness of gene variant targeted

therapies. Studies in the US have also shown that awareness of pathogenic BRCA variants is lower among people of ethnic minority groups, which may indicate that targeted work with Australian First Nations people and people from culturally and linguistically diverse backgrounds should be investigated (Rubinsak et al., 2019) (Williams et al., 2019).

It is important for people to have an understanding the difference between germline (inherited) and somatic (tumour) testing. However, less than half of the 2022 survey respondents (45.1%, 120 of 266) understood the difference between somatic and germline testing. Although awareness was slightly higher among respondents that had undergone genetic testing (108 of 198, 54.5%), the results indicate awareness raising activities are warranted on this topic.

The Australian Optimal Care Pathways for Cancer Treatment highlight the value of clinical trials (Cancer Council Victoria. Optimal care pathway for women with ovarian cancer: Second edition, 2021), but access to clinical trials has not always been equitable for people in non-metropolitan areas across Australia. There was little change in the proportion of people diagnosed with OC reporting an awareness of clinical trials in 2022 compared to 2015. However, there was an increase in the proportion of people residing in non-metropolitan areas reporting participation in clinical trials in 2022 (18.8%, 12 of 64) compared to 2018 (15.2%, 22 of 145), bringing non-metropolitan participation on par with metropolitan participation in 2022 (18.9%, 32 of 169). At an average of 18.9%, participation in clinical trials for ovarian cancer patients in Australia is still below the international average estimated at 23.7% based on a multinational survey (although we note these results came from only two countries: Germany at 41.3% and Japan at 12.5%) (Reid et al., 2021). The proportion of people unaware of clinal trials was relatively unchanged (29.3% in 2022 compared to 32.6% in 2015). This may be due to information overload at the time of diagnosis (patients may not remember discussions about clinical trials), or it could reflect clinician lack of awareness or communication about clinical trials which may be a contributing factor to low clinical trial recruitment rates in Australia (at 0.4% of the population in 2019, compared to 1.5% in the UK and approximately 2.0% in the US (Todd and Nutbeam, 2023)). Although, people who are unaware of clinical trials may be doing well on standard treatment, and may therefore not have had clinical trials discussed.

The self-reported proportion of people diagnosed with OC ineligible for a clinical trial increased in metropolitan areas in 2022 (16.0%, 27 of 169) compared to 2018 (8.9%, 15 of 169), but not in non-metropolitan areas (12.5% (8 of 64) in 2022 compared to 13.1% (19 of 145) in 2018). Reasons for ineligibility were not explored in the survey but the increase may reflect respondents focusing their response on treatment based trials due to the nature of the survey and proceeding questions. It could also be due to trials that have specific criteria such as stage of tumour development, genetic variant pre-requisites, or lack of response to other treatment options. Understanding the reasons for clinical trial ineligibility, other barriers to access, and if the barriers can be overcome may warrant further investigation.

4.1. Strengths and limitations

A strength of the survey method was targeting members of the OCA database (2,467 members in 2022) representing a large proportion of Australians with OC (49.0% based on the estimated number of people living with OC at the end of 2017, diagnosed in the five-year period of 2013–2017 (5035) (AGCA, 2023).

Limitations of the study included self-reported measures that were not verifiable; limited engagement or under-representation from First Nations people, people from non-English speaking backgrounds, people in regional, rural and remote areas, and people living in the Australian Capital Territory, Tasmania and the Northern Territory (2022, 2015). It was noted that survey respondents were on average younger than the average age at diagnosis for OC diagnosis (with an underrepresentation of people aged 70+ in survey responses). It is also noted that OCA memberships encompasses all types of OC, while the germline testing referred to in the surveys is relevant for epithelial OC and not for other types of OC that might impact younger patients.

5. Conclusions

There have been improvements to the understanding and awareness of people diagnosed with OC regarding familial risk and clinical trials, and self-reported improvements to clinical trial access in non-metropolitan areas (albeit self-reported from a sub-set of diagnosed people). The work of OCA and other advocacy organisations is likely to have contributed in part to these results. Nonetheless, knowledge gaps remain in understanding of the difference between germline and somatic testing and further work is needed to improve clinical trial awareness for the estimated 30% of people who are unaware. Lack of understanding of genetic testing types and relevance for people without a family history, along with a lack of understanding of gene variant targeted therapies, may influence an individual's decision to undergo genetic testing when diagnosed with OC. This may in turn impact on best practice care and limit clinical trial options. The study highlighted areas for future focus for OCA which will be used to update OCA's resource and information packs.

CRediT authorship contribution statement

Deborah Roczo: Writing – original draft, Formal analysis, Data curation. **Vanessa Alford:** . **Alison Trainer:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Anna DeFazio:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Amy Pearn:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Caitlin Delaney:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Megan Cotter:** Writing – review & editing, Methodology, Data curation, Conceptualization. **Sue Hegarty:** Writing – review & editing, Supervision, Resources, Methodology, Data curation, Conceptualization.

Acknowledgements:

This study was funded by a grant from AstraZeneca.

The authors acknowledge contributions to manuscript review by Associate Professor Yoland Antill (medical oncologist at Peter MacCallum Cancer Centre and Royal Melbourne Hospital).

Competing interests: ADeF received funding from AstraZeneca for unrelated research; AP was a paid consultant with OCA in 2022 and received direct and indirect consultancy fees from AstraZeneca unrelated to this research.

Appendix A. Supplementary data

Supplementary data (Ovarian Cancer Australia genetics survey questions from 2015, 2018 and 2022) to this article can be found online at https://doi.org/10.1016/j.gore.2022.100921.

References

Australian Government, Cancer Australia [webpage], subpage: Ovarian cancer statistics in Australia. URL: https://www.canceraustralia.gov.au/cancer-types/ovarian-cancer/statistics. [Accessed 26 June 2023].

Australian Government Department of Health and Aged Care, MBS Online website, Medical Benefit Schedule item 73296, https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=73296&qt=item [Accessed 27 July 2023].

Australian Government Department of Health and Aged Care, MBS Online website, Medical Benefit Schedule item 73301, https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=73301&qt=item)/ [Accessed 27 July 2023].

Alsop, K., Fereday, S., Meldrum, C., et al., 2012. BRCA Mutation Frequency and Patterns of Treatment Response in BRCA Mutation-Positive Women With Ovarian Cancer. A Report from the Ovarian Study Group. Journal of Clinical Oncology 30 (21), 2654–2663. https://doi.org/10.1200/JCO.2011.39.8545.

Australian Institute of Health and Welfare, Cancer Data in Australia [Web report]. Cancer by state and territory data visualisation, age-standardised incidence rates for ovarian cancer and serious carcinomas of the fallopian tube (females) (2018, 2015) and age-standardised incidence rates for peritoneal cancers (females) (2018, 2015). [Updated 27 September 2022]. URL: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-by-state-and-territory-data-visualisation. [Accessed 7 June 2023].

Australian Institute of Health and Welfare, Cancer Data in Australia [Web report]. Cancer summary data visualisation, new cancer cases diagnosed (2022) for ovarian cancer and serous carcinomas of the fallopian tube. [Updated 13 September 2022]. URL: https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/cancer-summary-data-visualisation. [Accessed 7 June 2023].

Cancer Council Victoria. Optimal care pathway for women with ovarian cancer: Second edition, 2021.

Cancer Institute NSW EviQ website, genetic testing for heritable pathogenic variants, BRCA1 and BRCA2 – genetic testing [Web report]. ID: 620 v.12 – Target population. URL: https://www.eviq.org.au/cancer-genetics/adult/genetic-testing-for-heritable-pathogenic-variants/620-brca1-and-brca2-genetic-testing#history. [Accessed 26 June 2023].

DiSilvestro, P., Banerjee, S., Colombo, N., et al., 2022. Overall survival with maintenance Olaparib at a 7-Year follow-up in patients with newly diagnosed advanced ovarian cancer and a BRCA mutation: The SOLO1/GOG 3004 trial. J Clin Oncol. 41, 609–617. https://doi.org/10.1200/JCO.22.01549.

Esplin, E., Nielsen, S., Bristow, S., et al., 2022. Universal Germline Genetic Testing for Hereditary Cancer Syndromes in Patients With Solid Tumor Cancer. JCO Precis Oncol. 6, e2100516.

Jones, M., Kamara, D., Karlan, B., et al., 2017. Genetic epidemiology of ovarian cancer and prospects for polygenic risk prediction. Gynecologic Oncology 147, 705–713. https://doi.org/10.1016/j.ygyno.2017.10.001.

Kuchenbaecker, K., Hopper, J., Barnes, D., et al., 2017. Risks of Breast, Ovarian, and Contralateral Breast Cancer for BRCA1 and BRCA2 Mutation Carriers. JAMA. 317 (23), 2402–2416. https://doi.org/10.1001/jama.2017.7112.

Liu, Y., Breen, K., Catchings, A., et al., 2021. Risk-Reducing Bilateral Salpingo-Oophorectomy for Ovarian Cancer: A Review and Clinical Guide for Hereditary Predisposition Genes. JCO Oncol Pract. 18, 201–209. https://doi.org/10.1200/OP.21.00382.

Medicare Benefits Schedule - Item 73296, URL: https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=73296&qt=ItemID#assocNotes [Accessed 21 May 2024].

Norquist, B., Harrell, M., Brady, M., et al., 2016. Inherited Mutations in Women With Ovarian Carcinoma. JAMA Oncol. 2 (4), 482–490. https://doi.org/10.1001/jamaoncol.2015.5495.

Ovarian Cancer Australia website, News: OCA welcomes Federal budget announcement of olaparib's expanded listing on PBS, https://www.ovariancancer.net.au/news/48/oca-welcomes-federal-budget-announcement-of-olaparibs-expanded-listing-on-pbs#:~:text=Olaparib%20is%20now%20listed%20on,different%20to%20the%20last%20announcement%3F [accessed 28 July 2023].

Reid, F., Bhatla, N., Oza, A.M., et al., 2021. The World Ovarian Cancer Coalition Every Woman Study: identifying challenges and opportunities to improve survival and quality of life. International Journal of Gynecological Cancer. https://doi.org/10.1136/ijgc-2019-000983.

Rubinsak, L., Kleinman, A., Quillin, J., et al., 2019. Awareness and acceptability of population-based screening for pathogenic BRCA variants: Do race and ethnicity matter? Gynecol Oncol. 154 (2), 383–387. https://doi.org/10.1016/j.ygyno.2019.06.009.

Todd, A., Nutbeam, D., 2023. More and better clinical trials in health care: focusing on people, not just systems and processes. The Medical Journal of Australia. https://doi.org/10.5694/mja2.51856.

Vergote, I., Denys, H., Altintas, S., et al., 2022. Homologous recombination repair deficiency (HRD) testing in newly diagnosed advanced-stage epithelial ovarian cancer: A Belgian expert opinion. Facts Views Vis Obgyn. 14 (2), 111–120. https://doi.org/10.52054/FVVO.14.2.024.

Weissman, S., Weiss, S., Newlin, A., 2012 Jul-Aug;. Genetic testing by cancer site: ovary. Cancer J. 18(4):320–7 https://doi.org/10.1097/PPO.0b013e31826246c2.

Williams, C., Bullard, A., O'Leary, M., et al., 2019. Racial/Ethnic Disparities in BRCA Counseling and Testing: a Narrative Review. J Racial Ethn Health Disparities. 6 (3), 570–583. https://doi.org/10.1007/s40615-018-00556-7.