Ovarian Cancer Registry

The OvCR Annual Report
July 2020 – December 2021

OvCR
OVARIAN CANCER REGISTRY

MONASH University

OVARIAN CANCER AUSTRALIA

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Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
ASA	American Society of Anesthesiologists
BMI	Body Mass Index
CASS Foundation	Contributing to Australian Scholarship and Science Foundation
COVID-19	Novel coronavirus, 2019 pandemic
CQI	Clinical Quality Indicator
CQR	Clinical Quality Registry
CT	Computerised tomography
ECOG	Eastern Cooperative Oncology Group
FIGO	International Federation of Gynecology and Obstetrics
ICCR	International Collaboration on Cancer Reporting
MDM	Multidisciplinary team meeting
MRFF	Medical Research Future Fund
MRI	Magnetic resonance imaging
NGOR	National Gynae-Oncology Registry
OTP	Ovarian/Tubal/Peritoneal cancer
OvCR	Ovarian Cancer Registry
PARP	Poly (ADP-ribose) polymerase
PBS	Pharmaceutical Benefits Scheme
PET	Positron emission tomography
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
RCPA	Royal College of Pathologists of Australasia

Foreword

By Associate Professor Robert Rome, NGOR Clinical Lead

I am delighted to present the July 2020 – December 2021 NGOR Annual Report. The NGOR was established in 2017 and aims to collect information on patterns of care, quality of care and clinical outcomes for patients with gynaecological cancer. The gynaecological cancers are a diverse group of cancers which are grouped according to their site of origin – ovary/tube/peritoneum (OTP), endometrium/myometrium, cervix, and vulva/vagina. Together they account for the 4th most common cancers in women, and the 4th most common cause of death from cancer in women.

To establish the registry, collaboration was established between clinicians, consumers, and researchers. Currently, 20 hospitals in five states are participating in the registry. Funding has been obtained through generous support from the CASS Foundation, Ovarian Cancer Australia, the Epworth Foundation, and the Australian Society of Gynaecological Oncologists. In 2020 we received a major grant from the Medical Research Future Fund. Working Groups were established to develop and refine Clinical Quality Indicators for all four disease groups. Accrual commenced for OTP and endometrial cancer and by the end of 2021, 1,321 eligible patients with OTP cancer and 985 with endometrial cancer have been registered. A rare ovarian tumour working group has also been established and 93 patients have been registered. Accrual is soon to commence for cervical and vulvar cancer. A subcommittee has also been examining how to integrate patient reported outcome measures (PROMs) into the registry.

I am grateful to the many patients who consented to participate in the NGOR. I would also like to thank the clinicians and members of the overarching Steering Committee, the various disease specific Working Groups for their interest and wise input. Data Managers and Collectors have also made significant contributions to the registry's establishment. All concerned have generously given their time to see the NGOR develop during a difficult time during the COVID-19 pandemic.

The NGOR is managed by the Monash University School of Public Health and Preventive Medicine, and I also extend my gratitude to the registry staff for their work in the establishment and operational support of the registry. We have established contacts with similar gynaecological oncology registries in the Netherlands and Scotland. There is international interest in collaborating and developing a common set of Quality Indicators, comparing clinical outcomes, and establishing international benchmarks.

This report outlines the progress that the NGOR has made in its formative years. It can be now regarded as a 5-year survivor!

Associate Professor Robert Rome

FRCS(Ed), FRCOG, FRANZCOG, CGO
Clinical Lead, National Gynae-Oncology Registry.

Foreword

By Professor John Zalcberg, NGOR Academic Lead

It gives me great pleasure to introduce the National Gynae-Oncology Registry's (NGOR) first Annual Report. I am incredibly proud of the hard work that has gone into this report, especially for such a young registry that has overcome the many challenges of COVID-19. During this period, we never lost sight of the fundamental importance of safe and effective patient care for patients with gynaecological cancers.

This Annual Report presents the data from the NGOR's first module, the ovarian/tubal/peritoneal (OTP) cancer module. It represents the first 18 months of funded operations. We chose OTP cancer as the foundational module because ovarian cancer is the most lethal of all gynaecological cancers. The ability to develop an ongoing understanding of patterns of care for patients with OTP cancer is paramount in understanding the extent to which patients are receiving high quality care, the ultimate, long-term goal of the NGOR.

In this Report, 15 clinical quality indicators (QIs) were selected by a group of experts as appropriate measures that reflect optimal, evidence-based care. The data presented for each indicator were collected from our collaborating hospitals across six Australian states, for patients diagnosed during the period of July 2020 to December 2021. The success of this work relies heavily upon the support of patients involved in this registry, our valued collaborations with Ovarian Cancer Australia, the NGOR Steering Committee, the Ovarian Cancer Working Group, the NGOR Operational Team, and the many clinicians and data collectors at each hospital. I would like to thank everyone involved for their commitment and dedication, and for their hard work and enthusiasm in seeing the NGOR achieve this important milestone.

Work on the remaining modules of the NGOR are ongoing; we have commenced data collection for modules addressing endometrial cancer, as well as rare ovarian tumours. We also hope to start data collection for patients diagnosed with cervical cancer in 2023. There are also imminent plans to conduct a pilot study assessing patient-reported outcomes and patient experiences within the OTP module, in order to provide further insight into patient health and wellbeing throughout their illness. Bringing the patient voice into healthcare reporting is rightfully becoming a valued part of the routine assessment of care. Our future reports will incorporate patient-reported outcomes alongside clinical outcomes to provide a more comprehensive overview of the quality of care received.

I am excited to watch the NGOR grow and progress from its formative years to become an important resource for clinicians, scientists and the community to measure the quality of care received by patients diagnosed with gynaecological cancers.

Professor John Zalcberg, OAM

MB, BS, PhD, FRACP, FRACMA, FAHMS, FAICD
Tony Charlton Chair of Oncology
Academic Lead, National Gynae-Oncology Registry

Foreword

By Sue Hegarty, Chief, National Ovarian Cancer Advocacy

At Ovarian Cancer Australia, we work tirelessly to advocate for people affected by ovarian cancer. Among our top priorities is improving access to high quality treatment options and we are honoured to support the NGOR and their team of expert clinicians and researchers who are working to achieve that.

Ovarian cancer is Australia's deadliest female cancer, with a survival rate of just 49%. There is no early detection test, and the symptoms are often vague and can mimic other conditions. What's more, by the time symptoms do present, most people will already be in the late stages of the disease. Therefore, ensuring all women have access to optimal care is critical.

We know that not enough is known about the pattern of care within Australia for women with ovarian cancer. The NGOR is allowing the development of insights and longitudinal data for clinicians and researchers to improve outcomes and quality of life for patients. It provides insight into the best-performing treatment and treating centres, and provides early warning signs on deteriorating outcomes to identify variations in treatment.

We are grateful to all the women who bravely volunteered to participate in the NGOR. Your involvement is crucial to improving the lives of people affected by ovarian cancer both now and into the future. Ovarian cancer can be an isolating disease and it's heartening to see so many people come together to work on a common cause.

As an initial funder of the program, we're proud to be part of such an essential program in its formative years. Today, we continue to contribute to the NGOR through assisting with the development of the steering committee and Patient Reported Outcome Measures (PROMs).

We look forward to continuing to work together into the future to save lives and ensure no woman with ovarian cancer walks alone.

Suzanne Hegarty

Chief, National Ovarian Cancer Advocacy

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Executive Summary

Established in 2017, the National Gynae–Oncology Registry (NGOR) is a clinical quality registry (CQR) capturing clinical data on all newly diagnosed cancers of the uterus, ovary, fallopian tube, peritoneum, cervix, vulva and vagina in Australia. This report presents key findings from the ovarian/tubal/peritoneal (OTP) cancer module over an 18–month period from **1st July 2020 to 31st December 2021**.

The NGOR data report on a number of clinical quality indicators (CQIs) that measure compliance with agreed best practice. The CQIs included in this report are benchmarked to allow hospitals to measure their performance relative to other participating Australian hospitals. In this report, CQIs are not risk–adjusted. Some CQIs reported low numbers and therefore must be interpreted with caution.

Key Findings within the Reporting Period:

Patients

Participants diagnosed between 1st July 2020 and 31st December 2021

668

Most common participant age range at diagnosis:

60-69 Years

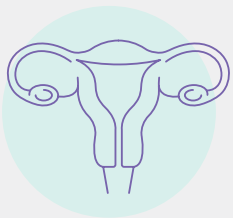
At Diagnosis

Most common tumour grade:

Grade III

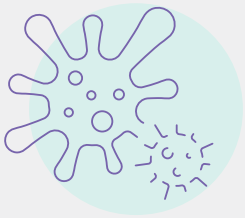
Most common FIGO stage:

IIIC



Most common morphology:

Serous

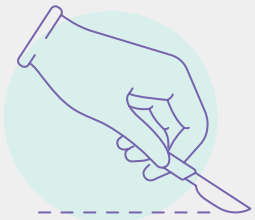


Most common method of diagnosis:

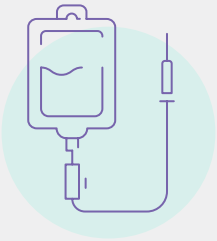
Histopathology

Treatment & Management

98.6%
of patients were presented at a multidisciplinary meeting (MDM)

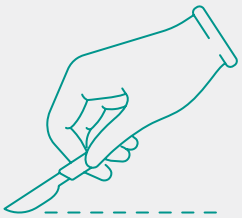


51.1%
of patients had primary surgery



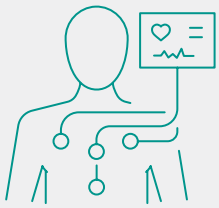
83.5%
of patients had first-line chemotherapy with a platinum-taxane doublet

32.5%
of patients had interval surgery



21.7% of patients who were sub-optimally debulked received first-line chemotherapy (platinum-taxane doublet) and bevacizumab

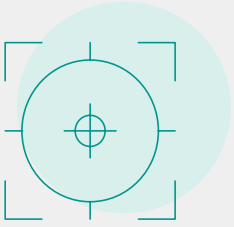
Surgical Adverse Events



9.2%
of patients experienced an intraoperative event

2.5%
of patients experienced a serious post-operative event

Targeted Therapy



82.8%
of eligible patients underwent genetic testing

62.0%
of patients with germline or somatic mutations commenced maintenance PARPI therapy within eight weeks of ceasing chemotherapy

About the National Gynae-Oncology Registry and the Ovarian Cancer Registry

The NGOR is a multi-modular CQR that monitors and identifies variation in gynaecological cancer treatment between hospitals in Australia. Gynaecological cancer includes cancers of the uterus, ovary, fallopian tube, peritoneum, cervix, vulva, and vagina. Our goal is to drive improvements in quality of care and patient outcomes for patients diagnosed with gynaecological cancer by capturing data pertaining to patient diagnosis, treatment, and disease outcomes. Data is reported against agreed measures of best practice, in benchmarked reports. Figure 1 shows the NGOR's feedback loop.

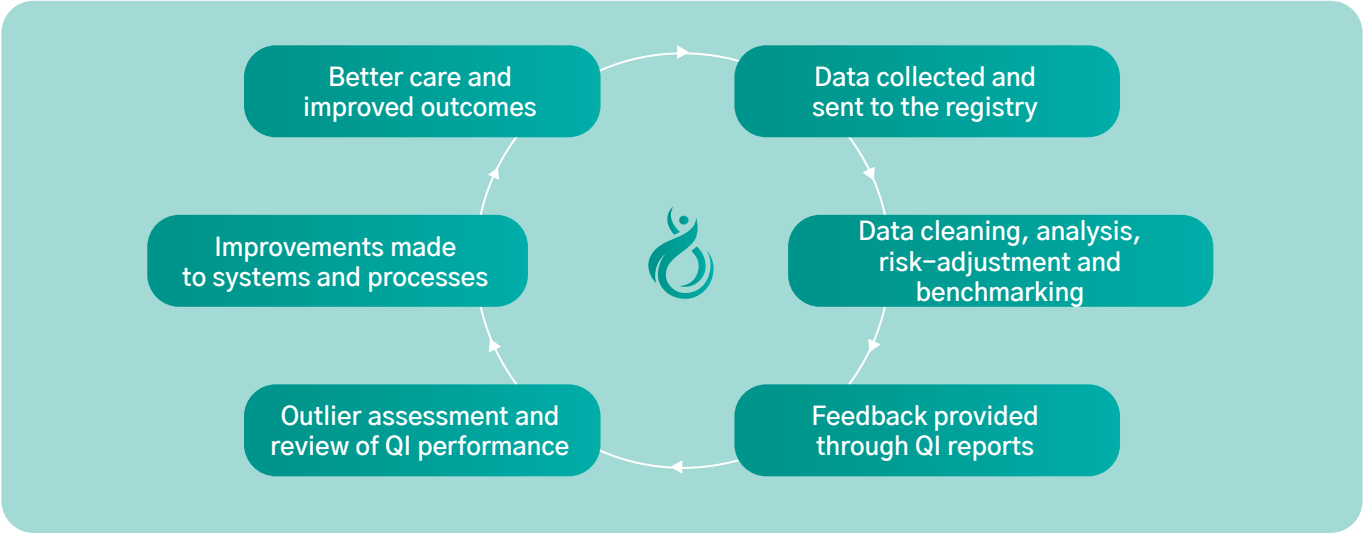


Figure 1: The NGOR's feedback loop. Adapted from the Australian Commission on Safety and Quality in Health Care[1].

The NGOR collaborates with major gynaecological oncology treatment centres across Australia to collect real-world, observational data on patient experiences and patterns of care for patients with a gynaecological cancer diagnosis. This includes patient demographics, diagnostic information, treatment received, treatment outcomes, timeliness of care and the impact of treatment on patient quality of life. These types of data can help to assist in identifying patterns in patient experiences and treatment practices. This allows for the identification of gaps in service provision and moves towards the standardisation of best practice gynaecological cancer treatment.

The NGOR has established four modules, each addressing a different anatomical location of gynaecological cancer: (1) ovarian/tubal/peritoneal (OTP), (2) endometrial, (3) cervical, and (4) vulvar/vaginal. The first module created was for OTP cancer, which was piloted in 2017, and funded in 2020. The 'Ovarian Cancer Registry' (OvCR) collects data across multiple hospitals, reporting against a set of 15 CQIs that measure the standard of patient care between these healthcare services. These CQIs were developed in 2020 through a collaboration between clinical and academic experts, and consumers. This Report presents the OvCR's key findings according to these CQIs from its first 18 months of operation: **1st July 2020 to 31st December 2021.**

A Registry to Ensure all Ovarian Cancer Patients Receive the Best Care

"I was diagnosed with Stage III Ovarian Cancer back in 2008 and underwent the usual debulking surgery, followed by chemotherapy. In 2010 the cancer returned as a tumour and I had further surgery, together with another round of chemo. In 2012 it returned again, this time as a tumour sitting on the surface of the liver and it was surgically removed plus a section of the liver, but no chemo to follow. Eighteen months later in November 2013, a new tumour emerged between the liver and the kidney and again it was removed surgically but again no chemo followed.

I am delighted to say I have been cancer free for the past nine years. I always wanted to be the little fish that swam through the net. I am very grateful for the extra years of life I have been granted and am enjoying them immensely.

I was well aware from the onset that I was particularly fortunate to have an eminent, highly skilled surgeon and a medical team who worked assiduously to get me to where I am now. I have met many patients and survivors since, and it has always concerned me that there can be a huge disparity between the treatment they received. It is a huge honour therefore to be part of the National Gynae-Oncology Registry, which aims to lessen this divide by comparing hospital outcomes across Australia, and then instilling best practice so that no matter where you live or what your circumstances are, you will have access to the best treatment.

It is truly amazing to me how fast this registry has been established and how many hospitals are already aligned. I therefore was delighted to be asked to join this amazing project and to contribute in a small way for all those women out there who are trying to live the best life they can with this ghastly cancer."

Janice Antony
Patient Advocate (Ovarian Cancer)
NGOR Consumer Representative

Acknowledgements & Funding Statement

The NGOR acknowledges and pays respect to the past, present, and future Elders and Traditional Custodians of the lands on which we conduct our work and collaborate with our registry partners.

We would like to thank all of the patients who have agreed to be a part of the Registry, as well as each participating hospital, their clinical staff, data collectors, and other hospital personnel, whose collaboration has significantly contributed towards the NGOR's progress. We also wish to thank Natalie Heriot, whose work was pivotal in building the NGOR.

Our organisational collaborators have also been instrumental in steering the NGOR towards key milestones. In this, we thank Ovarian Cancer Australia for their ongoing support of the registry, in particular their involvement with the Patient Reported Outcomes pilot study.

Finally, we would like to thank all of the members of the NGOR's Steering Committee, Working Groups, and Reference Groups for generously volunteering their time in support of the registry.

Funding Statement

The OvCR is funded by an Australian Government Medical Research Future Fund (MRFF) 2019 Ovarian Cancer Research Grant Opportunity, awarded in 2020. The grant has allowed the registry to expand from a small pilot to a national registry of high-quality, population-level, clinical data that will inform translational research.

The registry has previously received funding from the Australian Society of Gynaecologic Oncologists, Ovarian Cancer Australia, The CASS Foundation and The Epworth Medical Foundation to support the Ovarian Cancer Pilot (2017–2020). The development of the endometrial, cervical, and vulvar cancer modules received funding from The Audrey Voss Gynaecological Cancer Research Grant, awarded by The Epworth Medical Foundation.

Registry Overview & Reporting

The Incidence and Outcomes of Ovarian Cancer

Of the 20 most commonly diagnosed cancers in Australian women, those of the uterus, ovary, and cervix collectively accounted for 8.4% of female cancer diagnoses in 2019, with ovarian cancer accounting for 27% of these diagnoses[2]. Around 75% of patients who develop ovarian cancer are diagnosed at an advanced stage, likely due to experiencing non-specific symptoms beforehand, resulting in ovarian cancer having the highest mortality rate of all gynaecological cancers where less than half (45.7%) of patients survive past 5 years[2,3]. Rare ovarian tumours (e.g. granulosa cell tumours, germ cell tumours, and carcinoid tumours) present an added complexity as they account for less than 5% of all ovarian malignancies[4–6], and each tumour type differs in its epidemiology, clinical patterns, and treatment outcomes[7]. Risk factors for ovarian cancer include advanced age (85–89 years), genetic predisposition, obesity, and nicotine use[8].

Due to ovarian cancer's high mortality rate, it is important that care is guided by evidence-based clinical guidelines[9]. Clinical guidelines are tools which can improve care and outcomes for patients with ovarian cancer, for example, optimal cytoreductive surgery is a key aspect of effective ovarian cancer care[10]. However, there is often variation in adherence to these guidelines[9]. For example, despite evidence suggesting that patients receiving treatment in specialised centres have longer survival rates, a study exploring variation in ovarian cancer care in NSW found 55% of patients did not receive their first treatment in a specialist gynae-oncology hospital[9].

Overview of Data Collection in the Ovarian Cancer Registry (OvCR)

The primary purpose of the OvCR is to collect data pertaining to diagnosis and treatment outcomes for patients with newly diagnosed cancers of the ovary, fallopian tubes, and/or peritoneum. The OvCR also encompasses a pilot sub-registry focusing on diagnoses and outcomes for patients with rare ovarian tumours, e.g. primary non-epithelial histological subtypes of ovarian cancer (henceforth 'OvCR' will refer to the primary registry, and 'Rare Ovarian Tumours' will refer to the rare ovarian tumours sub-registry). Pilot data collection for the Rare Ovarian Tumours sub-registry commenced in 2021. These data will establish patterns of care and enable discussions about appropriate CQIs for these tumour types to be determined. Data for both the OvCR and the Rare Ovarian Tumours sub-registry are obtained from the patient medical records by trained data collectors from 20 participating hospitals around Australia.

Within the reporting period, a total of 668 eligible participants were recruited into the OvCR. In this same timeframe, the Rare Ovarian Tumours sub-registry collected pilot data from 66 eligible participants. Given that the pilot phase of the Rare Ovarian Tumours sub-registry is incomplete, this report will focus only on the aggregate data from the OvCR.

Limitations and Considerations when Interpreting OvCR Data

It is important to consider the limitations that are inherent to registries. While registries are a valuable mechanism through which population data can be captured, they are also limited by the 'administrative' nature of medical records, from which registry data are extracted[11,12]. This can lead to registries being designed around what data are *available*, rather than what data is *most useful*. It is possible however, that through registries, a revision of medical records to include more pertinent information could occur in the long-term.

None of the data presented in this Annual Report have been risk-adjusted, but will include explanations to aid interpretation, as well as a summary of potential limitations where applicable.

Patient–Reported Outcome/Experiences Measures (PROMs/PREMs) in the OvCR

The focus on patient–centred care has grown significantly over the last decade and has become a cornerstone of modern, high–quality healthcare[13]. Gaining an understanding of the patient experience, particularly how illness and treatment impact quality of life (QoL), are key indicators of wellness. Patients can highlight the subjective impact of different treatment approaches (PROMs), as well as the level of care they receive (PREMs). PROMs and PREMs offer reliable indicators of treatment safety and acceptability[14], because they are completed by the patients themselves.

PROMs/PREMs will be piloted in the registry in 2022. Following clinical and consumer consultation, the European Organisation for the Research and Treatment of Cancer Quality of Life Questionnaire, combined with the Ovarian Cancer module (EORTC QLQ–30–OV28)[15,16] was selected as the most appropriate and reliable PROMs tool for the registry. The Australian Hospital Patient Experience Question Set (AHPEQ)[1,17] was selected as the most appropriate and reliable PREMs tool.

Statement of Ethics and Governance Approval

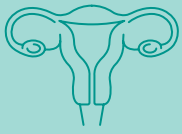
The NGOR operates within a National Mutual Acceptance (NMA) ethics approved protocol (HREC/17/MonH/198), and it is managed by a governance structure consistent with the framework developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC)[18]. Patient data collection only commenced once relevant approvals were obtained.

NGOR History

2017 – April 2020:
Ovarian Cancer Pilot.
First CQI report is released.

May 2020:
Awarded a Medical Research Future Fund grant to create the OvCR.

December 2020:
Endometrial cancer CQIs finalised.



October 2021:
Rare Ovarian Tumours pilot begins.

September 2017:
Funding received from The Australian Society of Gynaecologic Oncologists.

August 2019:
Awarded the Audrey Voss Gynaecological Cancer Research Grant to establish the endometrial, cervical, and vulvar cancer modules.

October 2020:
Patient Reported Outcome Measure qualitative project begins.

March 2021:
1,000 patients in NGOR across 5 Australian states; Endometrial Cancer pilot begins.

December 2021:
2,000 eligible patients in NGOR across 5 Australian states.

Registry Methodology & Governance

Participating hospitals identify patients with a new diagnosis of OTP cancer and screen them against the registry's inclusion criteria (see below). Eligible patients receive information on the purpose of the registry, what participation involves, and what information is collected (see Figure 1). They are given two weeks to 'opt-out' of the registry before data collection begins. If patients are deceased before the registry can send recruitment materials, they are considered eligible for data collection through a waiver of consent.

Inclusion Criteria

- All newly-diagnosed patients presenting to a participating hospital with a histologically or cytologically confirmed primary malignant tumour of the ovaries, fallopian tubes or peritoneum.
- Patients whose initial diagnosis date occurs no more than three months before governance approval was obtained at their treating hospital.
- Patient is aged 18 years or older.

Exclusion Criteria

- Patients who are not aware of their diagnosis.
- Patients who may be distressed by receiving an invitation to be included in the registry.

Participant Opt-Outs

If the patient does not contact the registry within the two-week opt-out period, they automatically become registry participants (though are able to withdraw from the registry at any time). Two opt-out options are available:

1. **Full opt-out of the NGOR** – where the patient elects to be excluded from the NGOR completely. In these cases, the patient's name, date of birth, Medicare number, date of diagnosis, and primary treatment site are retained in order to ensure that they are not re-recruited in the event of them being identified as a potential registry participant by another hospital in the future.
2. **Partial opt-out of the NGOR** – where the patient elects to be excluded from any follow-up contact (e.g. PROMs data collection), but permits the inclusion of their personal and health data in the registry.

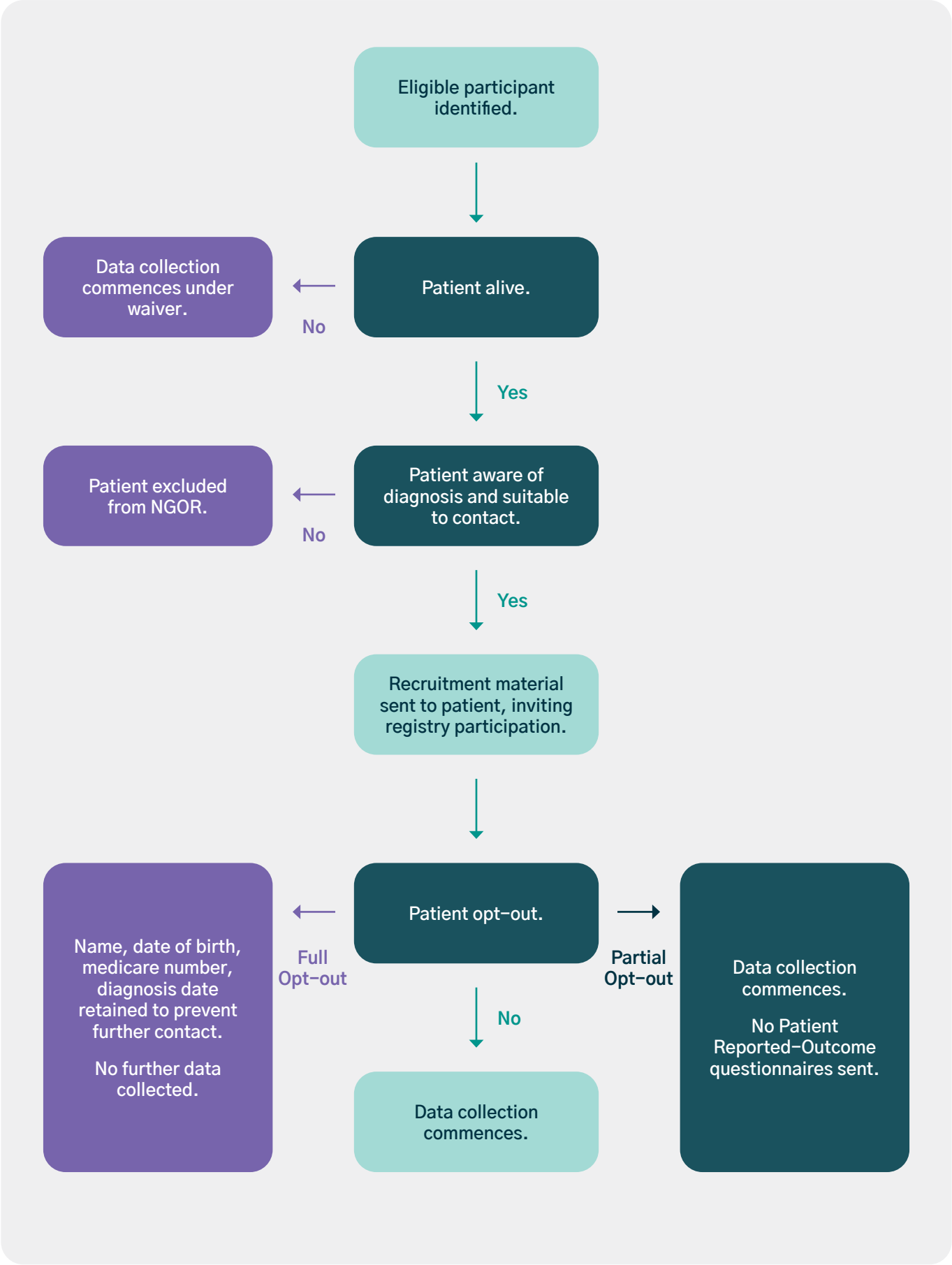


Figure 2: The NGOR/OvCR workflow

Registry Governance

The NGOR is led by a multidisciplinary Steering Committee which provides clinical oversight and strategic guidance. The Steering Committee includes members from all participating jurisdictions across Australia and has representation of the following specialities and/or expertise:

- Medical oncologist
- Gynaecological oncologist
- Radiation oncologist
- Palliative care physician
- Consumer representative
- Patient advocate
- Data manager
- Biostatistician
- Registry scientist
- Behavioural scientist
- Cancer pathologist
- Nurse

The NGOR is supported by four clinical Working Groups for 1) OTP cancer, 2) cervical cancer, 3) endometrial cancer, and 4) vulvar cancer. The OvCR Executive Committee and associated reference groups have oversight of the MRFF grant and registry milestones (see Figure 3).

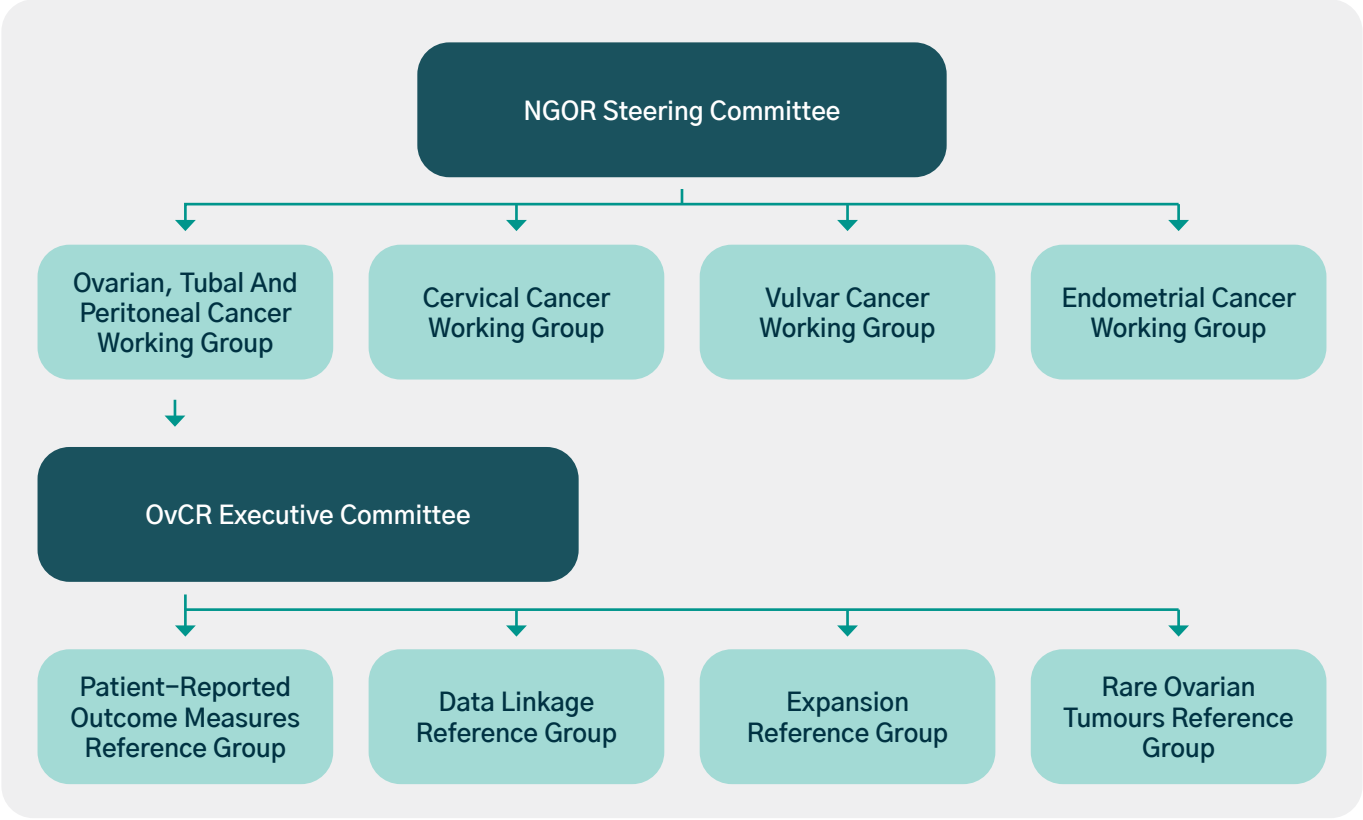


Figure 3: The NGOR governance structure.

Registry Engagement

Hospital Engagement and Participant Recruitment

By the end of 2021, the NGOR had established connections with 20 public and private hospitals across Australia (Table 1), with plans for expansion to other states and territories in the future. A total of 1,700 patients were recruited for the OvCR who were initially diagnosed with OTP cancer between the registry commencement in 2017 and the end of 2021 (Figure 4).

Table 1: Participating hospitals within the reporting period.

Location	Name of Hospital*
New South Wales	Chris O'Brien Lifehouse
	Prince of Wales Private Hospital
	St George Hospital
	St George Private Hospital
	Westmead Hospital
	Westmead Private Hospital
South Australia	Burnside Hospital
	Royal Adelaide Hospital
Tasmania	Hobart Private Hospital
	Royal Hobart Hospital
Victoria	Cabrini Health
	Epworth Healthcare
	Frances Perry House
	Mercy Health
	Monash Health
	Royal Women's Hospital
	Warringal Private Hospital
Western Australia	Hollywood Private Hospital
	St John of God, Murdoch Hospital
	St John of God, Subiaco Hospital

*Three hospitals have contributed patients to the NGOR in the past but have not been included in this Annual Report due to data quality concerns and/or a lack of data being provided on patients diagnosed in the reporting period.

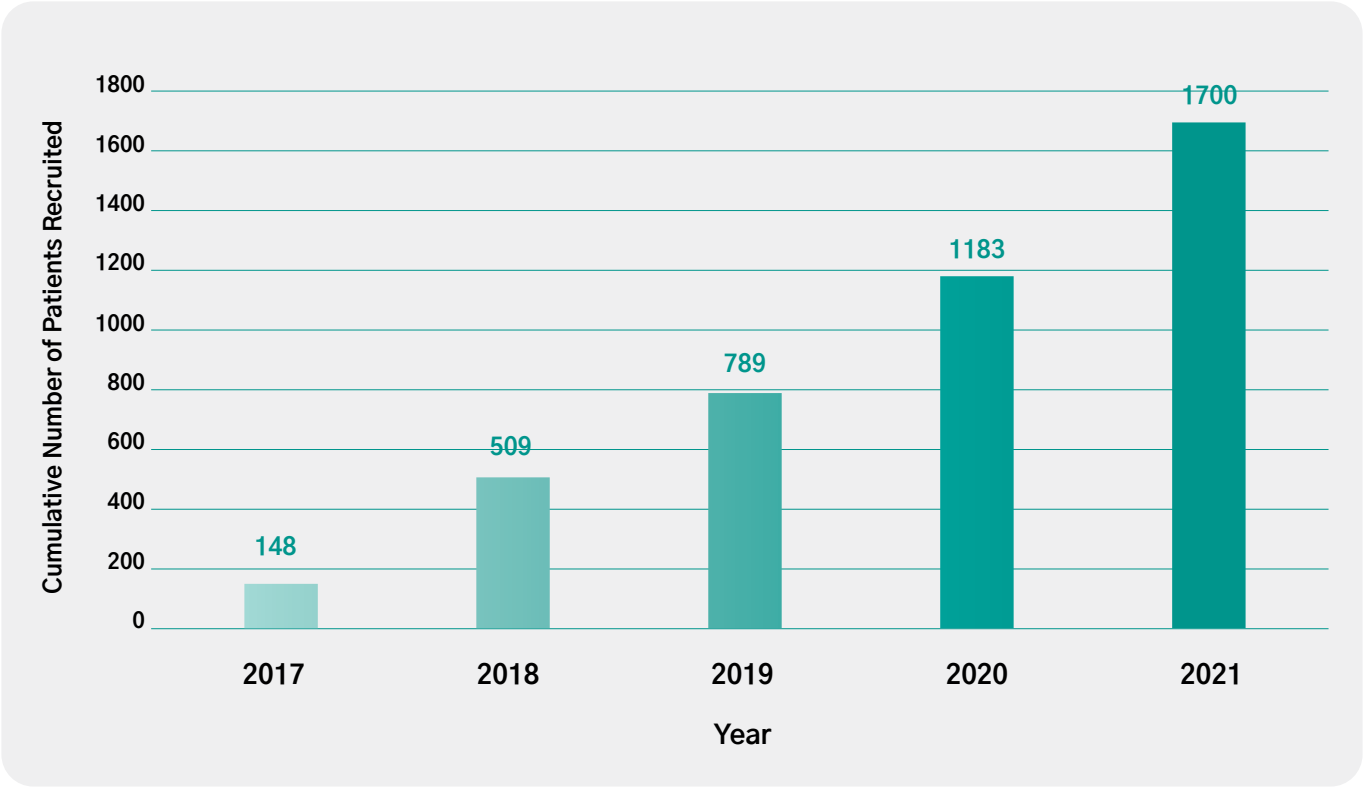


Figure 4A: Cumulative number of patients recruited (N=1700) into the OvCR who were diagnosed between December 2017 and December 2021.

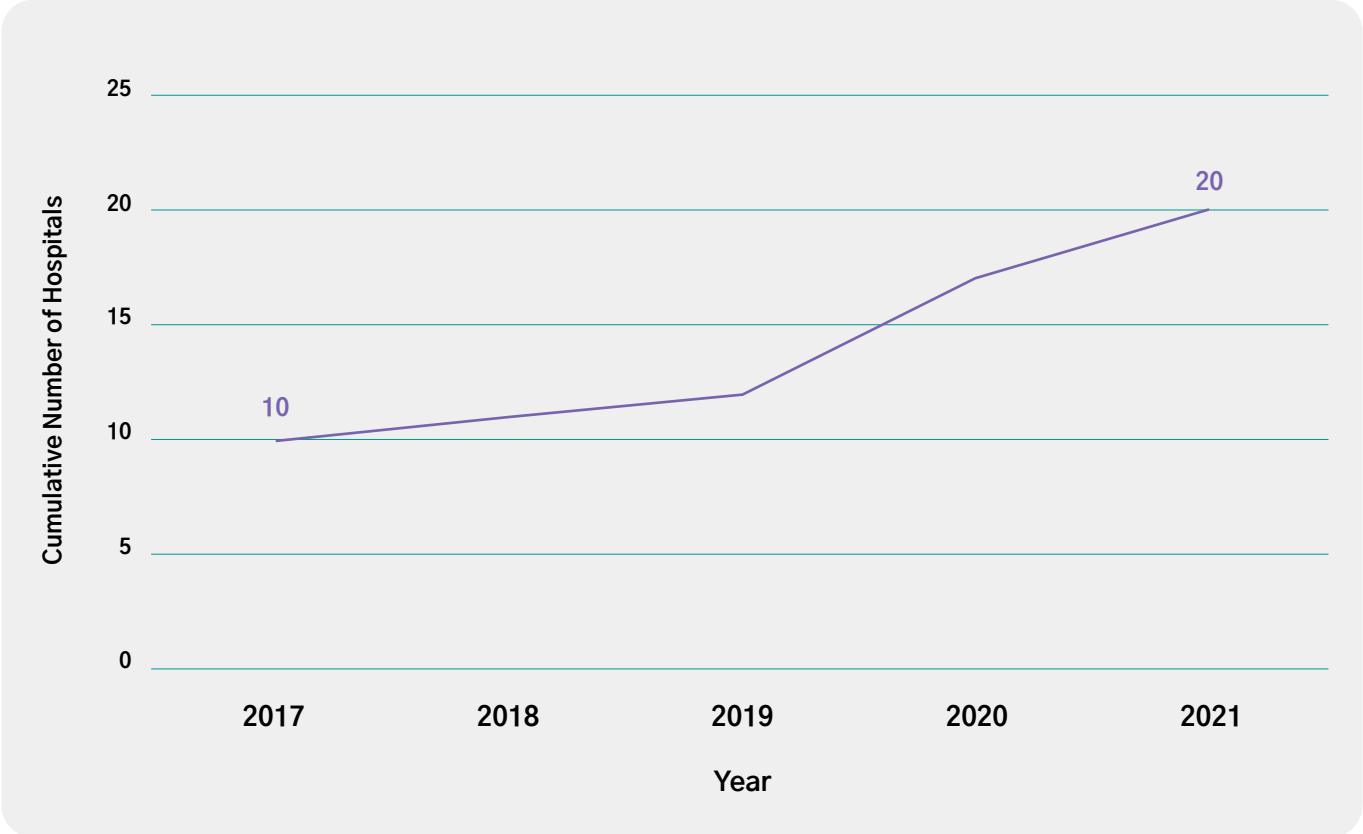


Figure 4B: Cumulative number of hospitals engaged with the OvCR (N=20) between December 2017 and December 2021.

Of those diagnosed within the reporting period, a total of 722 participants were identified as potentially eligible for inclusion in the OvCR. Of these, 29 fully opted-out of the registry, 12 were reallocated to a different registry module (e.g. endometrial cancer), nine were later determined to be ineligible, 13 were treated at a non-collaborating hospital, and four were uncontactable. This resulted in an overall total of 655 eligible and included participants in the OvCR diagnosed within the reporting period (Figure 5).

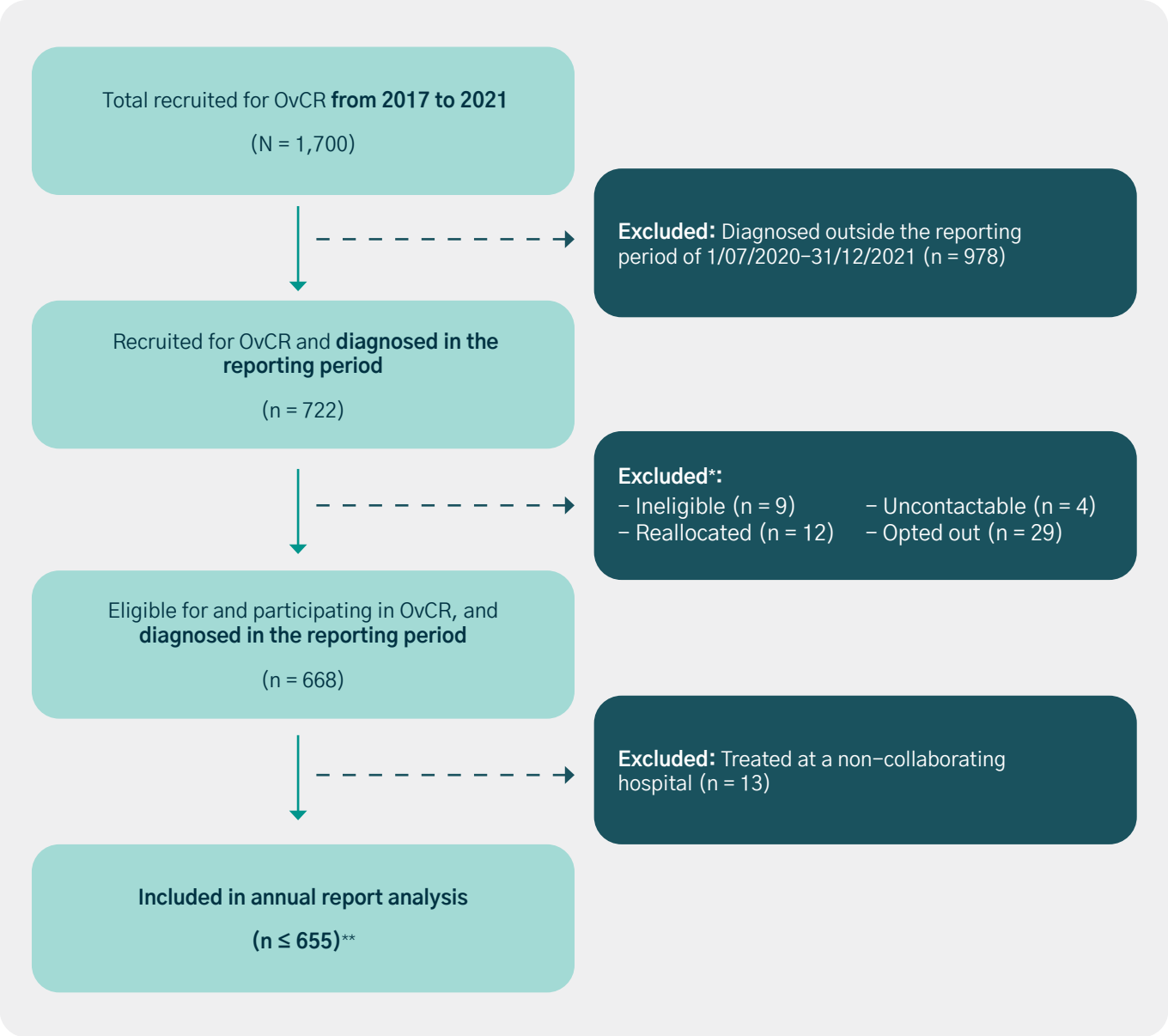


Figure 5: NGOR patient recruitment CONSORT diagram.

*Excluded at a later date due to updated information regarding patient's eligibility;
**numbers for each analysis will be ≤655, as missing data varies for each domain.

All patients are given a period of two weeks to either fully opt-out or partially opt-out of the registry, prior to data collection commencing. On average, 3.82% of patients per year elected to fully opt-out of the registry during 2017–2021, while 2.47% of participants per year elected to partially opt-out during this same period. Figure 6 shows the participant opt-out statistics for 2017–2021.

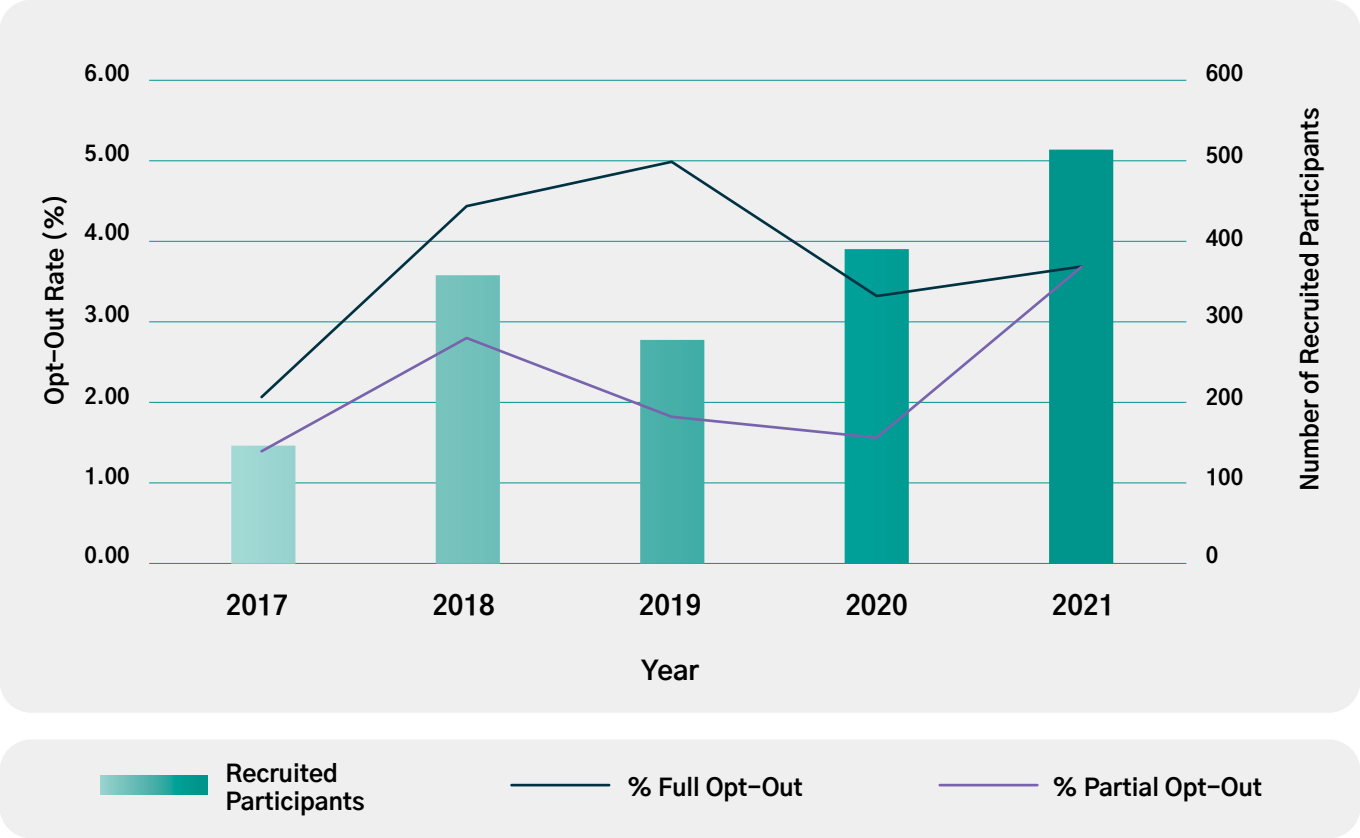


Figure 6: Participant yearly opt-out rates displayed as a percentage of the number of recruited participants each year, from 2017–2021.

A Registry to Ensure all Ovarian Cancer Patients Receive the Best Care

"I was diagnosed with Stage IIIC Ovarian Cancer in September 2009. That may seem like a long time ago but, in the time since then, I have had one recurrence and participated in two Clinical Trials and am now in my ninth year on maintenance therapy on a PARP Inhibitor. I am what they call a Super Responder and this new treatment has changed my terminal diagnosis into an open-ended future where we are making the science as we go.

My Ovarian Cancer is not behind me, far from it, as I continue to live with the side effects of my maintenance therapy and have regular scans, tests and reviews. I am deeply involved in the patient support and advocacy communities where I have made many close friends and experienced new challenges. Sadly, although my side effects are relatively mild, they were not consistent with my professional role as a psychologist working in a public sector, multi-disciplinary health setting, and I medically retired in 2018. But my mind is still relatively active, despite the brain fog, and my urge to get involved, to problem-solve and to promote good health practices has not died away.

Being a consumer representative on the National Gynae-Oncology Registry has been intellectually challenging and has made me feel that I still have some value for what I can contribute. My hope is not just to represent my own experience as a patient, but to collate and bring forward all the disparate and complicated voices from all the women I have met over my years in 'Ovarian Cancer World'.

What the NGOR folk are doing is brilliant and their commitment to patient care and wellbeing is obvious. I can see they are doing what they do because they want us to live well, and hopefully longer, in spite of our disease. The NGOR will get everyone providing cancer care talking together and will build a solid foundation on which to do so. Cancer is complicated and only by collecting and sharing data can we make progress. Of course, it has to be the right data and including the patient perspective is part of making sure the right questions are being asked. I am proud to do my bit for women living with this disease and will keep going while I can, hopefully for a very long time."

Kristin Young
Patient Advocate (Ovarian Cancer)
NGOR Consumer Representative

Descriptive Statistics

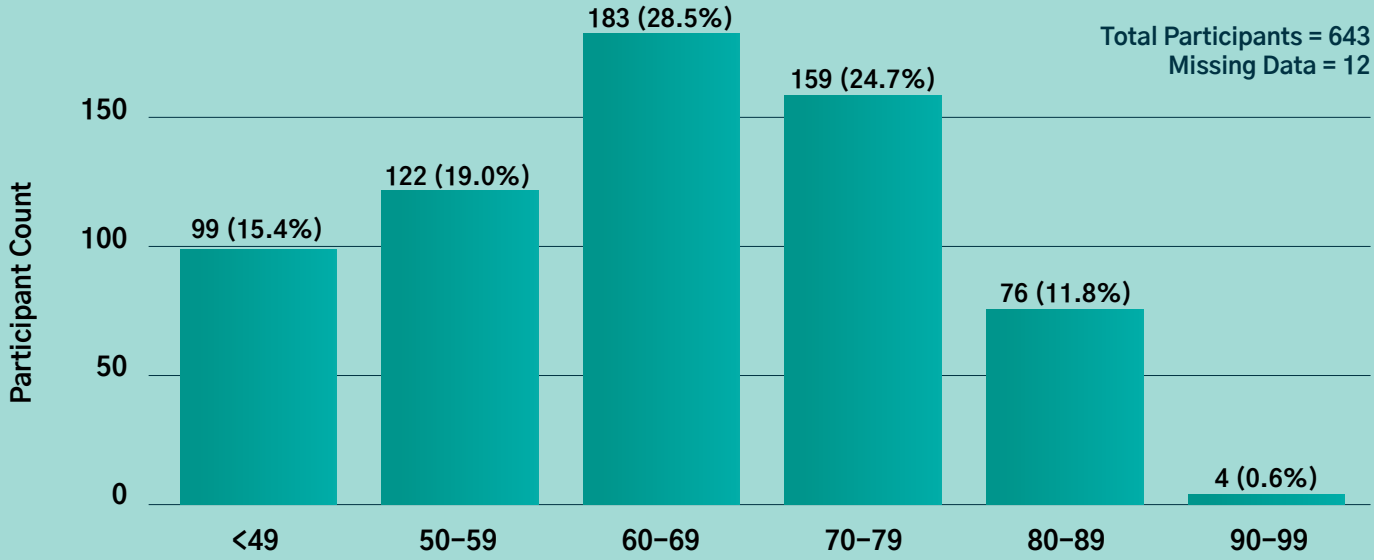


Figure 7: Participant age at diagnosis.

The above graph shows the distribution of the participants' age at diagnosis.

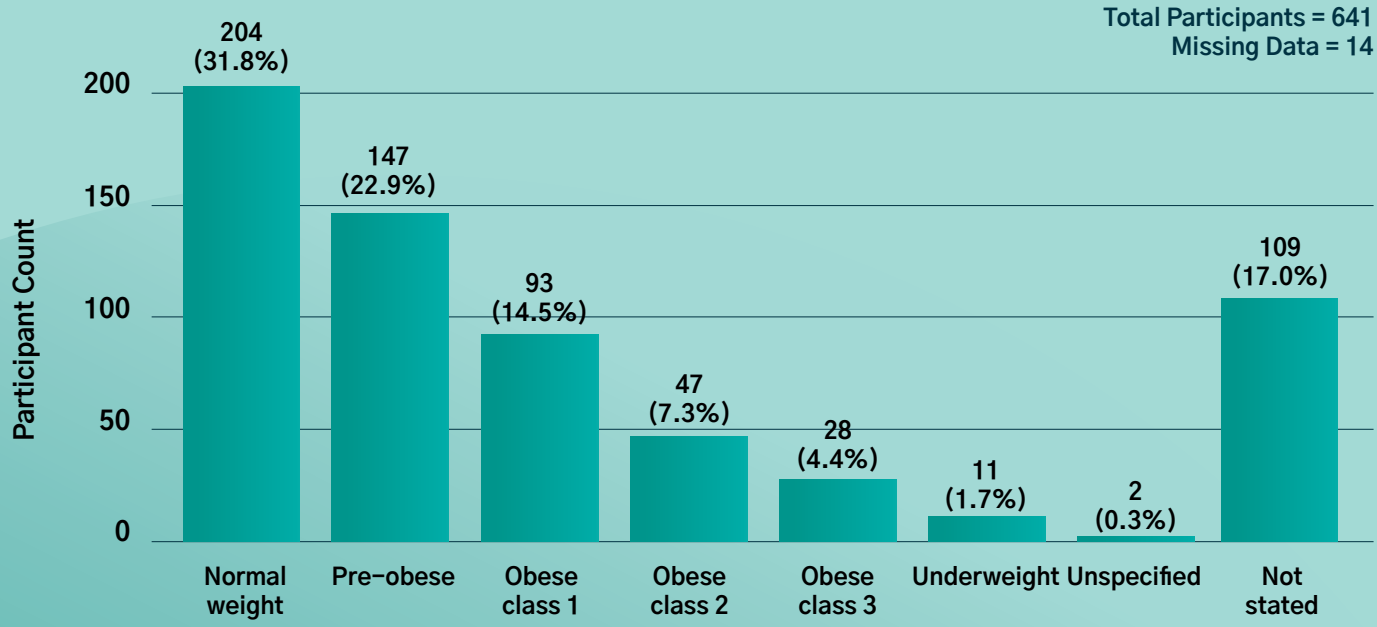
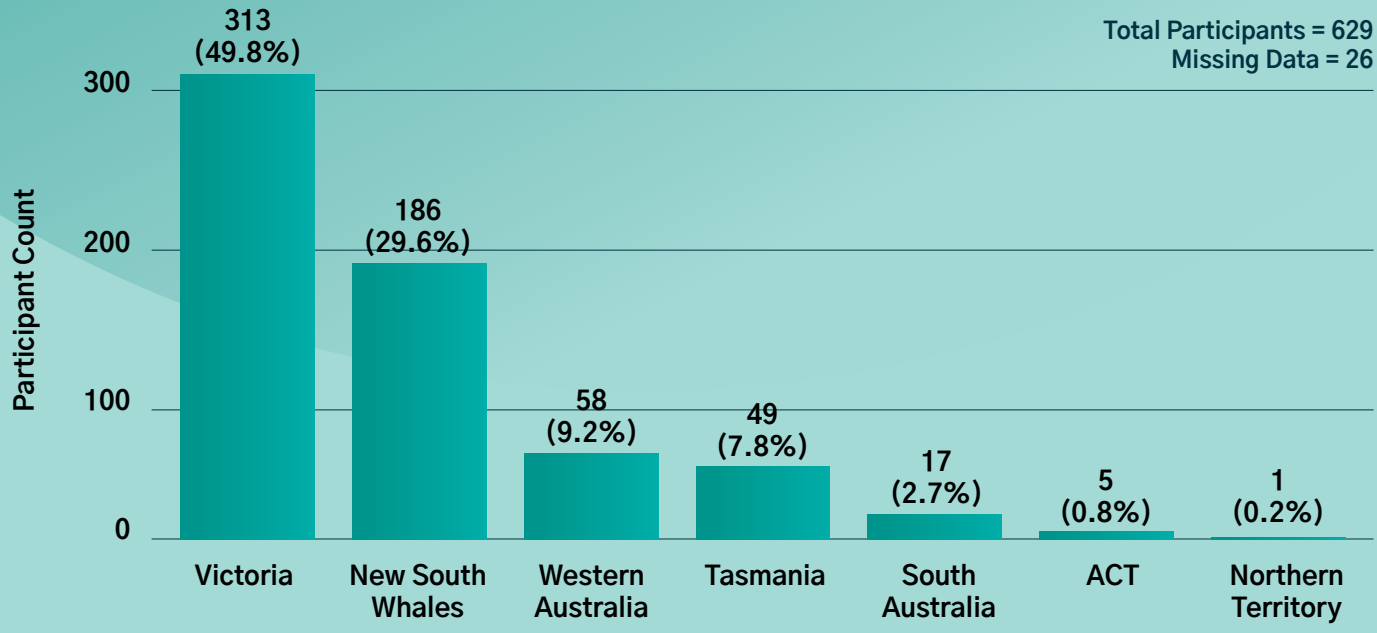


Figure 8: Participant Body Mass Index (BMI).

The above graph shows the distribution of the participants' BMI at the time of diagnosis. The classification of 'not stated' indicates that there was no information on the patient's weight or BMI score in their medical record; 'unspecified' indicates that there was some information referring to the patient's weight, but not enough to allow BMI classification. BMI of 18.5–24.99 = normal weight; BMI of 25–29.99 = pre-obese; BMI of 30–34.99 = obese class 1; BMI of 35–39.99 = obese class 2; BMI of ≥40 = obese class 3.



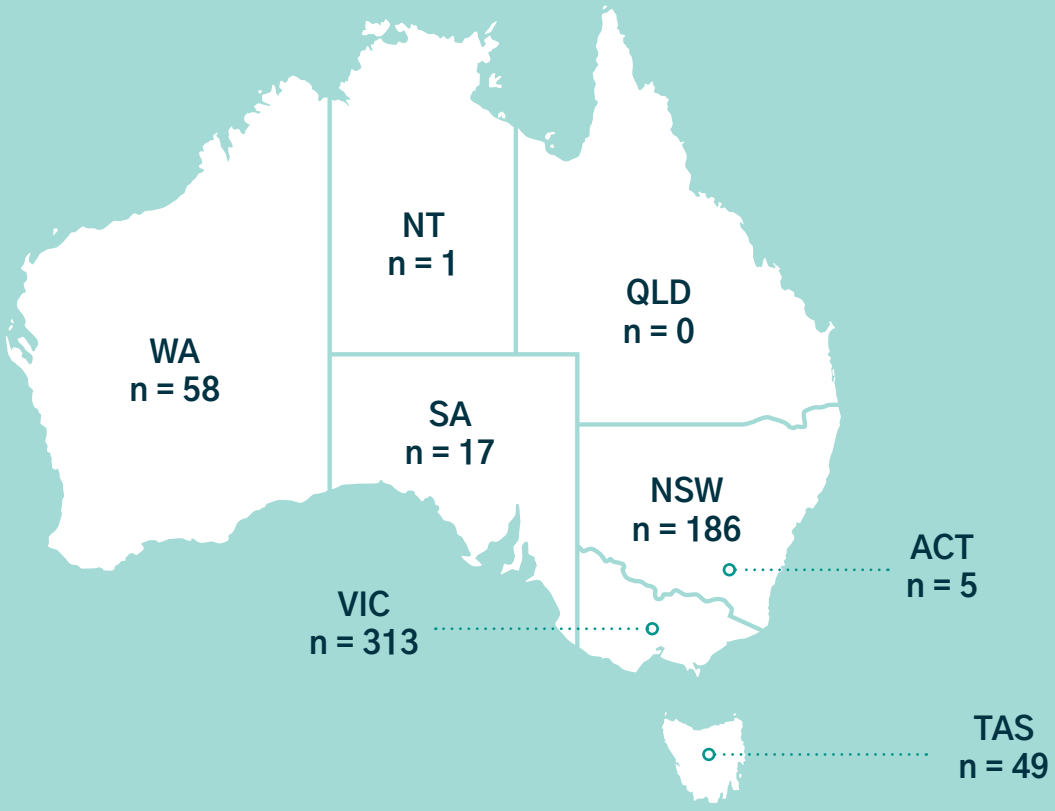


Figure 9: Residential distribution.

The above diagram shows the distribution of participant residential location at the time of diagnosis, across Australia. A small number of participants are shown as residing in the Northern Territory (NT) or the Australian Capital Territory (ACT) however the NGOR did not have any participating hospitals within these territories during the current reporting period. This means that although some participants were living in NT or ACT, they received their treatment at a participating hospital in either Victoria, New South Wales, South Australia, Western Australia or Tasmania.

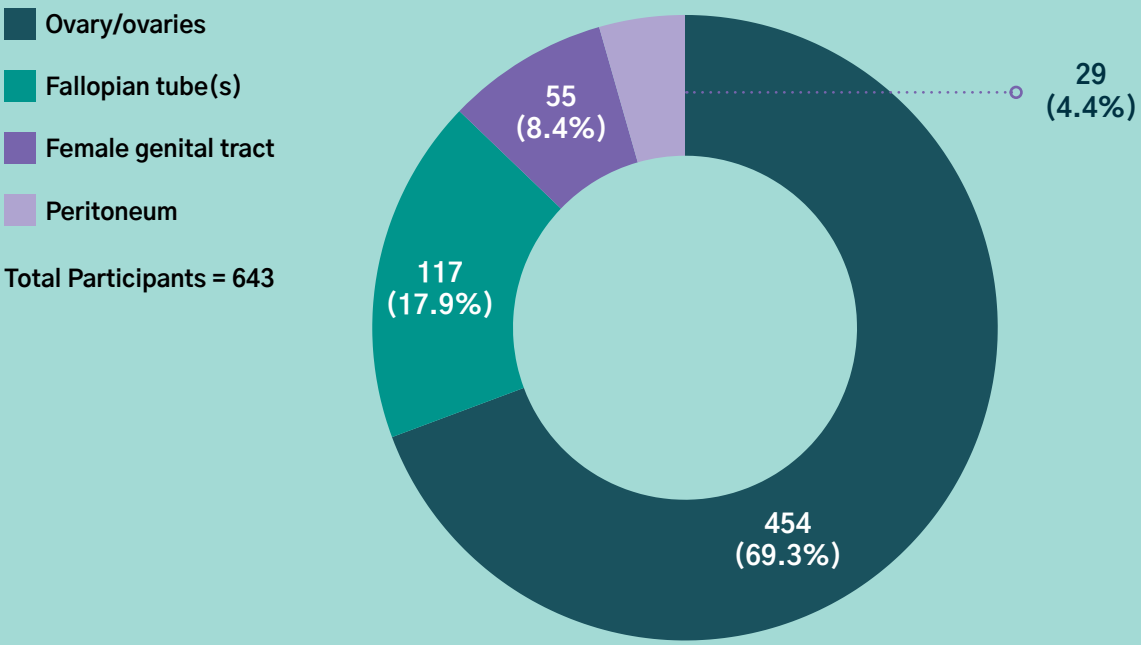


Figure 10: Primary tumour site.

The above graph shows the distribution for the primary site of the tumour at the time of diagnosis. Given that these data are for the OTP cancer module, the primary site will be either the ovary, fallopian tube(s) or the peritoneum, unless the specific primary site is not determined. If the primary tumour site is listed as 'female genital tract', this may indicate an inability to determine primary site due to tumour complexities.

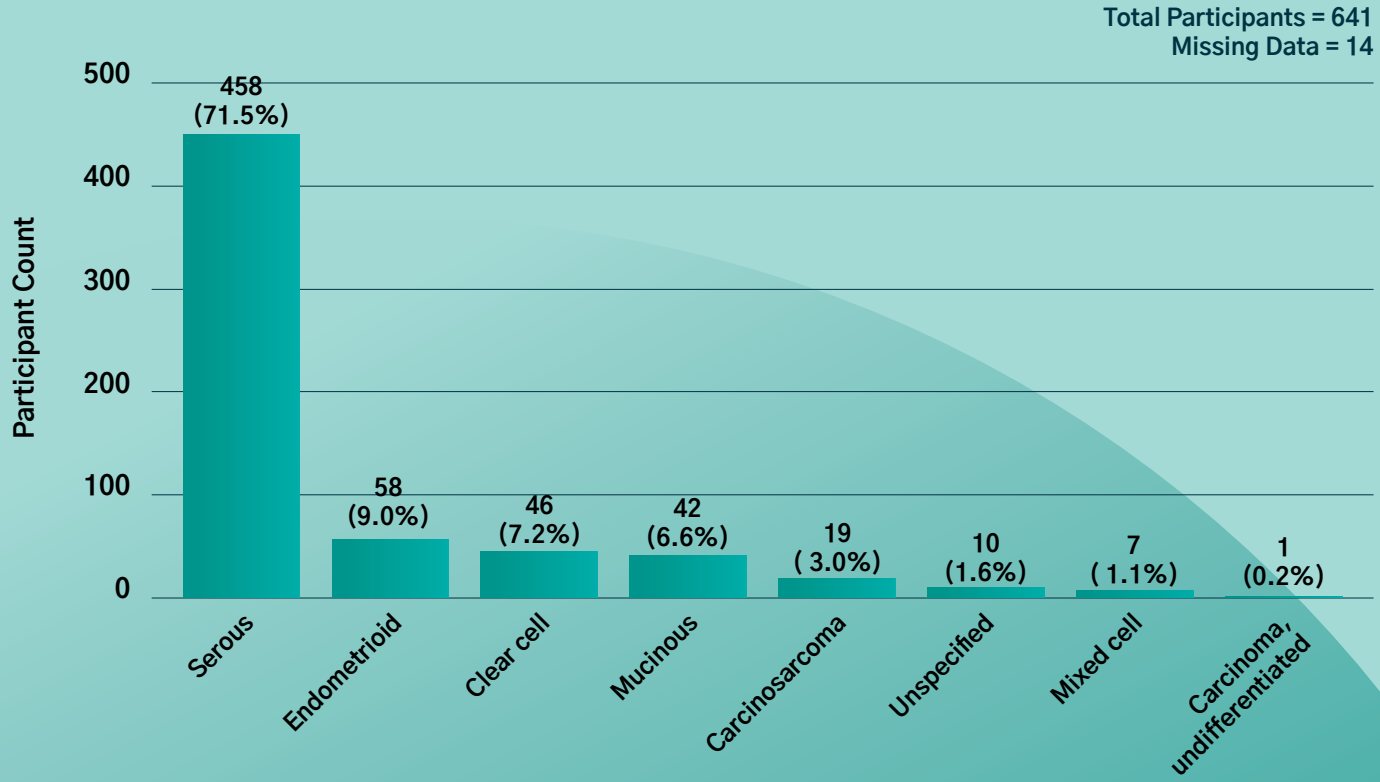


Figure 11: Cancer morphology.

The above graph shows the cancer tissue's histopathological type or classification, at the time of diagnosis. All cancer types shown are malignant.

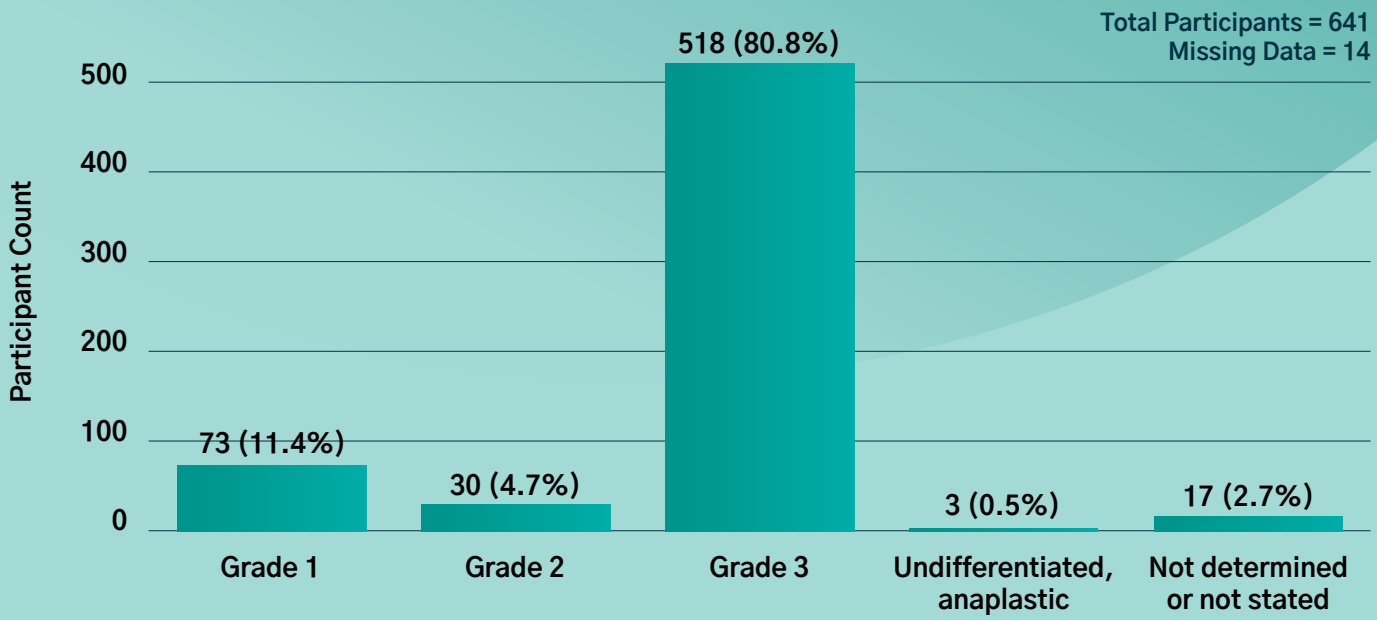


Figure 12: Tumour grade.

The above graph shows the distribution of tumour grades at the time of diagnosis. Tumour grade refers to the level of abnormality of the cells, where higher grades indicates greater abnormality. Tumour grades marked as 'not determined or not stated' indicate that the available information relating to the tumour grade was either missing or difficult to determine from the patient's medical record.

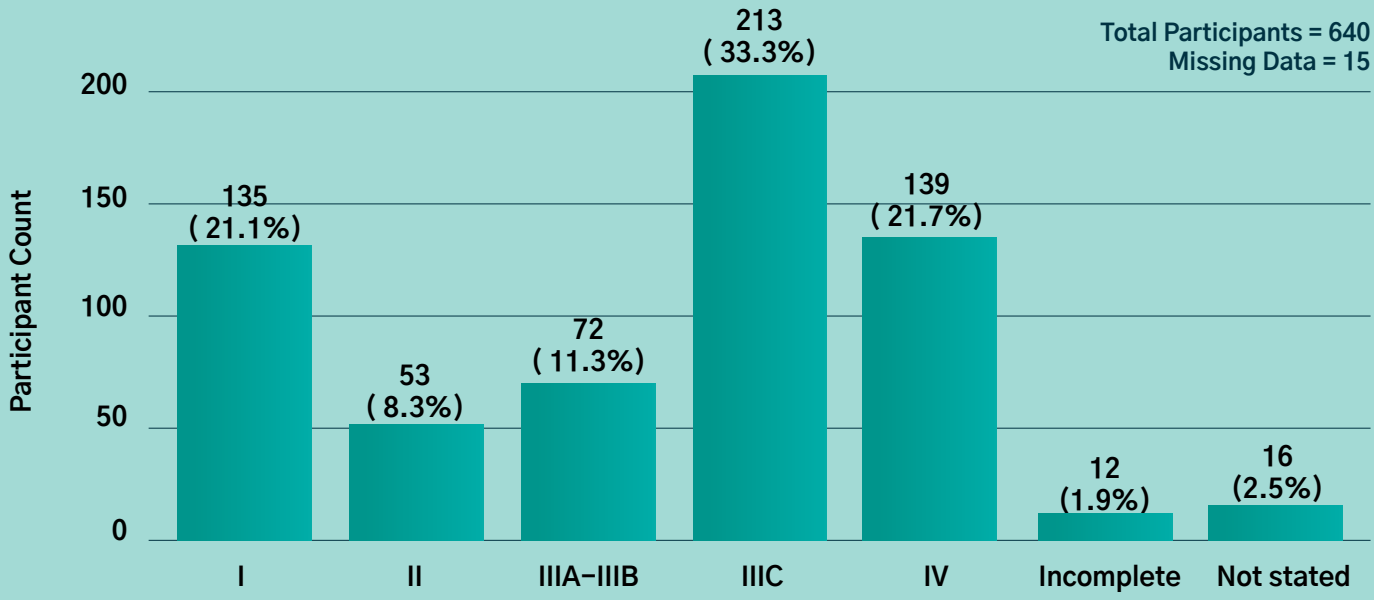


Figure 13: FIGO stage.

The above graph shows the distribution of staging according to the International Federation of Gynecology and Obstetrics (FIGO), which is the most widely adopted approach to staging gynaecological cancers. All staging information was obtained at the time of diagnosis. FIGO stage refers to the spread of the tumour, where higher FIGO stages indicates greater tumour spread. The classification of 'incomplete' indicates that FIGO staging may not have been completed due to patients not undergoing any staging surgery, or that staging was planned but incomplete at the time of data collection.

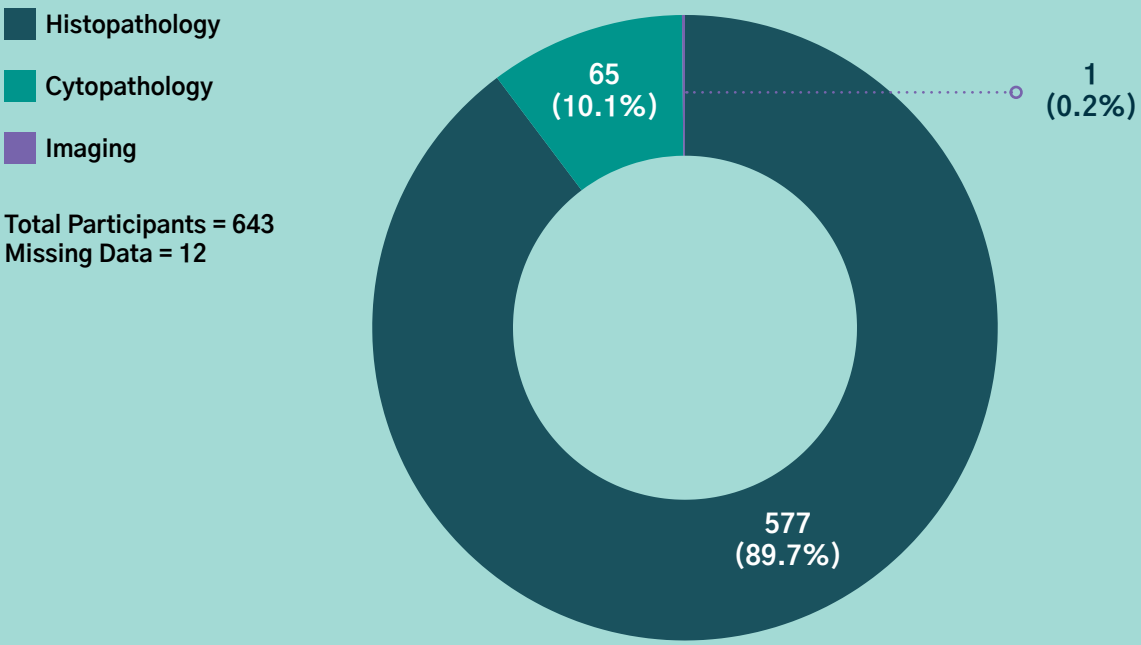


Figure 14: Level of diagnostic evidence.

Though a variety of methods are typically used to determine and confirm a cancer diagnosis, this graph depicts the highest/most reliable diagnostic methods used within the OvCR cohort.

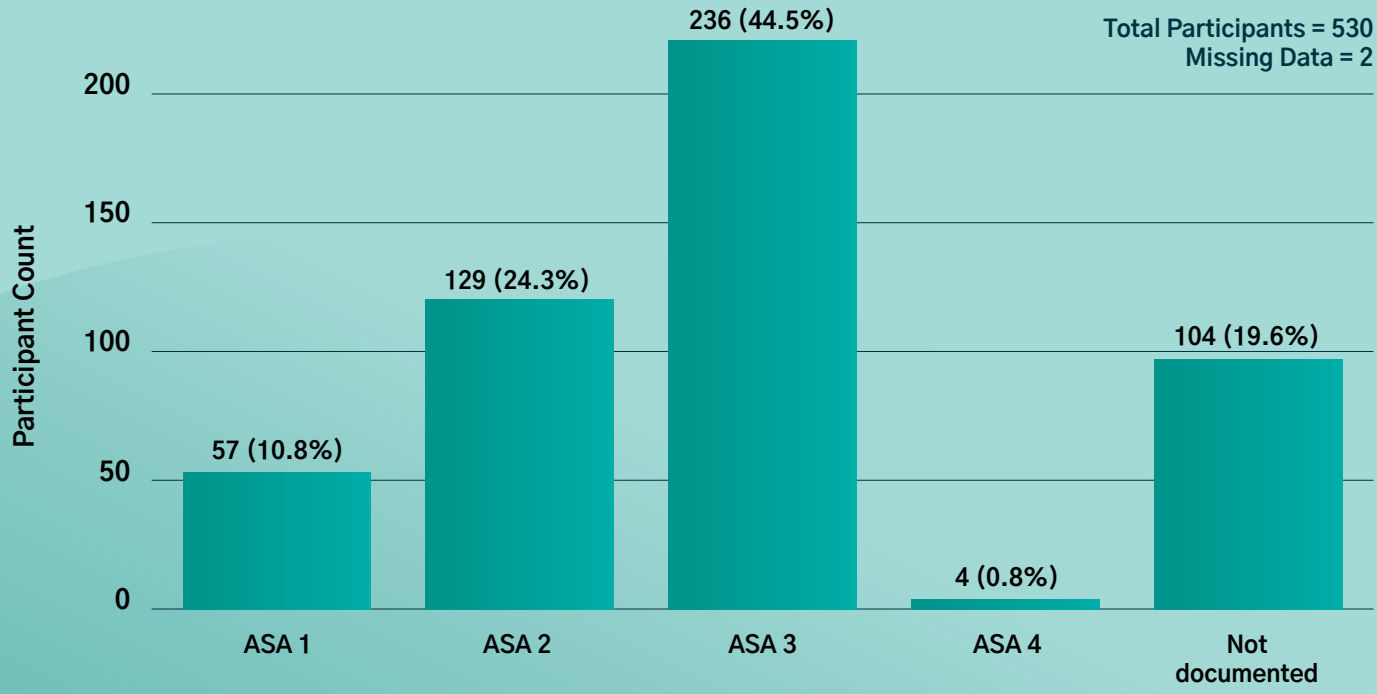


Figure 15: ASA score.

This graph shows the American Society of Anesthesiologists (ASA) method of determining physical status, with scores ranging from 1–6. Lower scores indicate greater health. ASA scores in the OvCR are only captured for patients who are undergoing surgery. Scores not shown indicate that no patient within the OvCR cohort was classified as that score. 'Not documented' indicates that data relating to ASA score was either missing or difficult to determine from the patient's medical record.

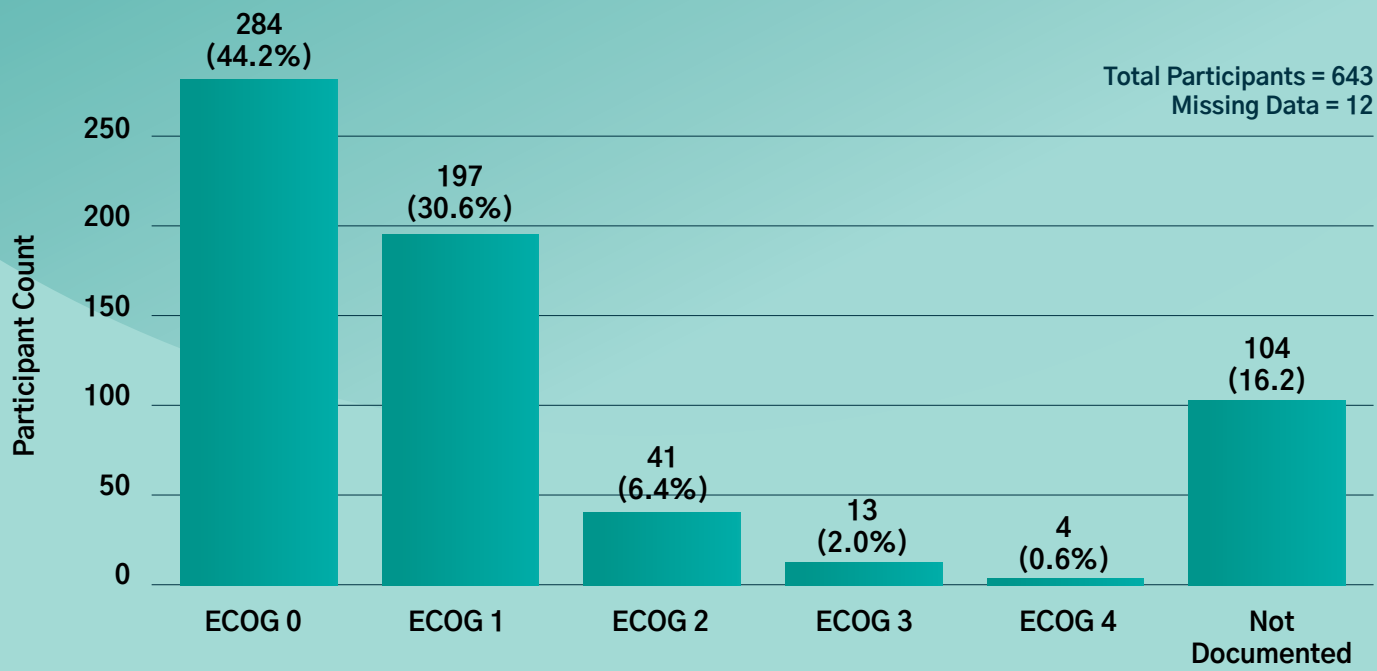


Figure 16: ECOG score.

The above graph shows the distribution of physical functioning at diagnosis according to the Eastern Cooperative Oncology Group (ECOG). ECOG scores range from 0–5, with lower scores indicating greater physical health and activity levels. A classification of 'not documented' indicates that ECOG score was either missing or difficult to determine from the patient's medical record.

Clinical Quality Indicators

A set of 15 CQIs were developed in 2021 in collaboration with clinical and research experts, and consumers to capture 'best practice' in the care of patients with newly diagnosed OTP cancer. Data from each of these 15 CQIs are presented as funnel plots (see Figure 17 for an example funnel plot), which are the recommended form of graphical representation when comparing institutional data[19]. In this way, each hospital can be compared to each other for benchmarking purposes.

All participating hospitals will receive regular CQI reports containing funnel plots for each of the 15 CQIs. This allows for visual comparison and benchmarking of their site's performance against that of all other sites. Hospitals confirmed as an outlier on any of the CQIs are encouraged to review and confirm their data accuracy. The data presented in this report for each of the 15 CQIs have not been risk-adjusted, therefore any inter-institution comparisons must be interpreted with caution at this stage.

OvCR CQIs

1. Proportion of patients with newly diagnosed OTP cancer who are discussed at a multidisciplinary team meeting.
2. Proportion of patients with newly diagnosed OTP cancer who had CT and/or PET imaging to stage their cancer prior to commencing treatment.
3. Proportion of patients with newly diagnosed OTP cancer who have the histological or cytological diagnosis confirmed prior to receiving first-line neoadjuvant chemotherapy.
4. Proportion of patients with clinically apparent stage I or II ovarian or tubal cancer who are adequately surgically staged.
5. Proportion of patients with advanced OTP cancer who undergo primary cytoreductive surgery who have
   a) no macroscopic residual cancer (0cm)
   b) greater than 0cm, but less than 1cm macroscopic residual cancer
6. Proportion of patients with advanced OTP cancer who undergo interval cytoreductive surgery who have:
   a) no macroscopic residual cancer (0cm)
   b) greater than 0cm, but less than 1cm macroscopic residual cancer
7. Proportion of patients undergoing surgery for OTP cancer who suffer one or more unplanned intraoperative events.
8. Proportion of patients who suffer one or more serious adverse events which are Clavien-Dindo
9. ≥ Grade III severity during the first 30 days after surgery for OTP cancer.
10. Proportion of patients with newly diagnosed OTP cancer whose pathology report contains the minimum required elements.
11. Proportion of patients with OTP cancer receiving first-line chemotherapy with a platinum and taxane doublet.
12. Proportion of patients with sub-optimally debulked OTP cancer (residual disease ≥1cm) or Stage IV OTP cancer who receive first-line chemotherapy with a platinum taxane doublet and bevacizumab.
13. Proportion of patients with OTP cancer who commenced first-line chemotherapy within 28 days of surgery or diagnosis.
14. Proportion of eligible patients who have germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completion of first-line chemotherapy.
15. Proportion of patients with germline or somatic mutations of BRCA1 or BRCA2 who commence maintenance PARPI therapy within eight weeks of ceasing first-line chemotherapy.
16. Proportion of patients with OTP cancer who are enrolled in an interventional clinical trial or translational research.

These CQIs are described in more detail in Appendix A.

How to Interpret Funnel Plots

A funnel plot illustrates the outcomes of a specific cohort for an indicator of interest (e.g. a CQI). The 'funnel' shape allows for data variance that typically occurs with low patient numbers (number of cases), and as such, presents a more appropriate graphical representation of clinical data, than other formats. *However, data for hospitals with a low number of cases should always be interpreted with caution*.

The horizontal x–axis shows the number of patients at each hospital, while the vertical y–axis shows the precision or performance of each site according to the CQI. The funnel plot itself comprises an inner funnel (darker shaded area), an outer funnel (lighter shaded area), and a mean line presented as a percentage. Each site is represented as a dot in the funnel plot. Sites within the inner (darker shade) funnel are sites whose performance on the CQI is within 95% (two standard deviations) of the overall mean. Sites within the outer (lighter shade) funnel, are sites whose performance is within 99.8% (three standard deviations) of the mean. Any site that is outside of the outer funnel would be considered an outlier, as their performance is greater than three standard deviations from the mean. In Figure 17, an example funnel plot is shown. Here, the mean is 55%. Out of the 16 sites represented as teal–coloured dots, 12 sites are within 95% of the mean, two sites with less than 30 participants are within 99.8% of the mean, and a further two sites are outliers (one with around 65 participants, and another with 120 participants).

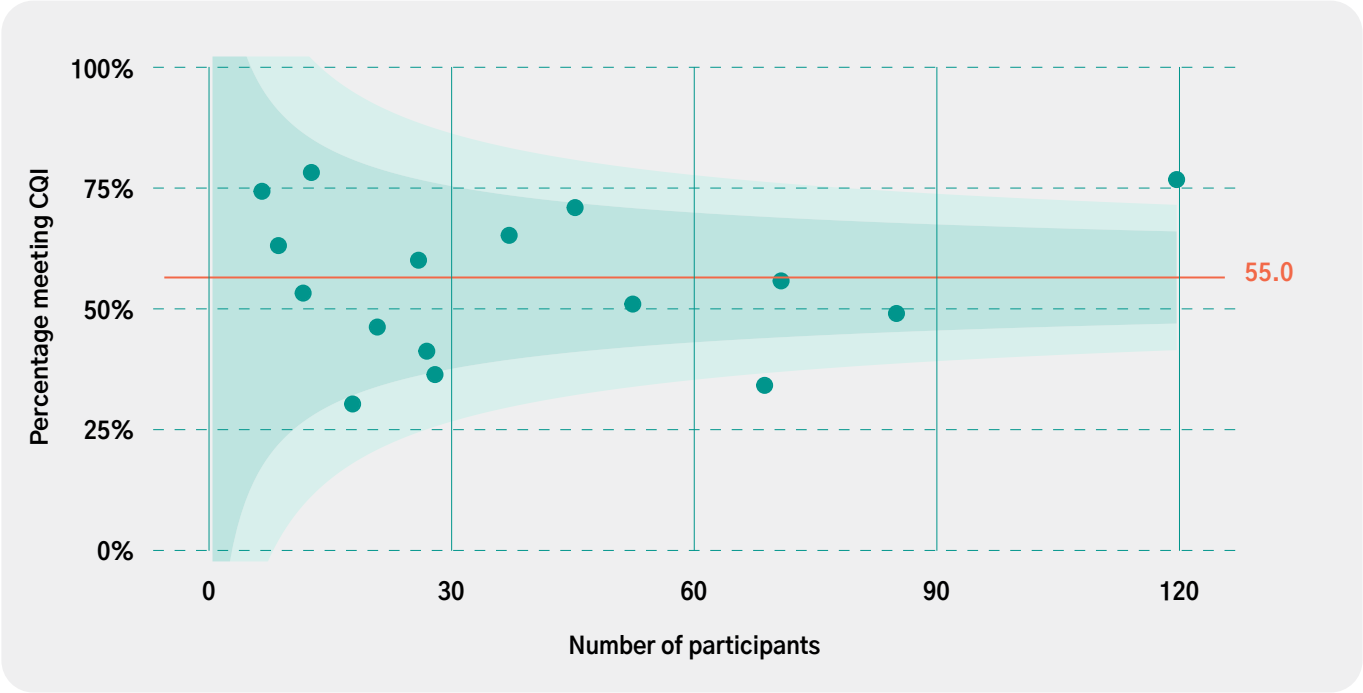


Figure 17: Example funnel plot.

Darker shaded area represents the 95% limits (2 standard deviations from the mean); lighter shaded area represents the 99.8% limits (3 standard deviations from the mean). Sites are represented as dots on the graph. Any site that is outside the darker or lighter shaded area is an outlier. The overall mean value across all patients is shown as a percentage.

Comparing Quality of Care for Ovarian Cancer

Diagnosis and Staging

Optimal diagnosis and staging practices for ovarian cancer involves several interconnected processes. In the NGOR, these processes have been defined as CQIs 1–4, and 9. The funnel plots illustrating the outcomes for each of the CQIs relating to diagnosis and staging are shown below in Figures 18–22.

CQI 1: Proportion of patients with newly diagnosed OTP cancer who are discussed at a multi-disciplinary team meeting

Multi-disciplinary meetings (MDMs) provide an essential avenue through which clinicians and other health practitioners (e.g. social work) can develop treatment and management plans in a collaborative format. The collaborative aspect of the MDM is an important step in ensuring a holistic, patient-centred approach to treatment and care. Throughout this reporting period, 98.6% of patients with newly diagnosed OTP cancer were discussed at an MDM (Figure 18). Outliers on this CQI may indicate sites where data collection occurred prior to a patient being discussed at an MDM, or where documentation was incomplete.

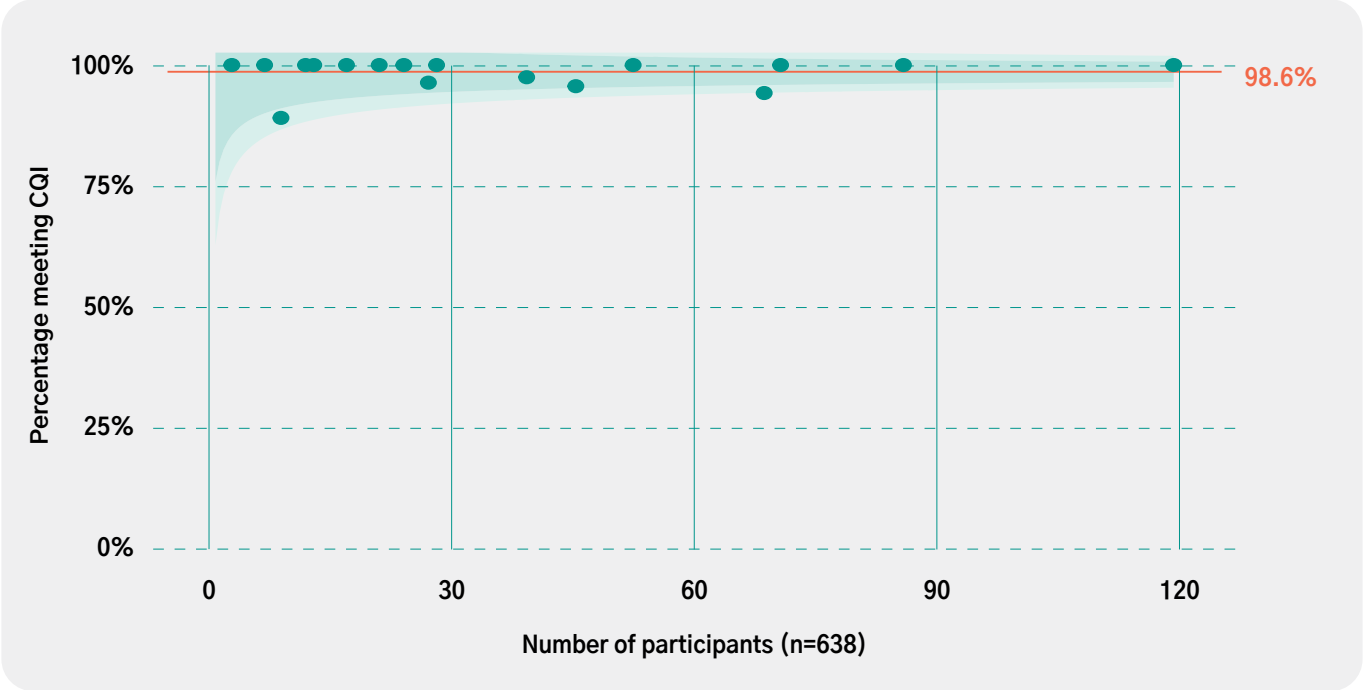


Figure 18: CQI #1.

Proportion of patients with newly diagnosed OTP cancer who are discussed at a multidisciplinary team meeting.

CQI 2: Proportion of patients who underwent CT or PET imaging to stage their cancer prior to commencing treatment

Computed tomography (CT) scans are a common means of identifying ovarian tumours, particularly if they are large, or have spread to other organs in the body. CT scans of the chest are typically done if there is suspected tumour spread to the lungs. Positron emission tomography (PET) scans also provide images of suspected tumours, and can be used when tumour spread is suspected but the location of the spread is unknown. Both CT and PET scans are commonly used in the diagnosis of cancer, as well as in the staging of illness and assessment of tumour spread prior to commencing treatment. During the reporting period, 45.5% of patients had a full-body CT *or* PET scan to stage their cancer prior to commencing treatment (Figure 19; CQI 2a), while 72.3% of patients had a CT scan of their abdomen and pelvis *or* a PET scan to stage their cancer prior to commencing treatment (Figure 20; CQI 2b). Lower averages may indicate sites that performed other imaging modalities, such as magnetic resonance imaging (MRI) or ultrasound. These modalities may be included in future reports. Patients whose imaging was completed after surgery or the commencement of chemotherapy were excluded from the analysis.

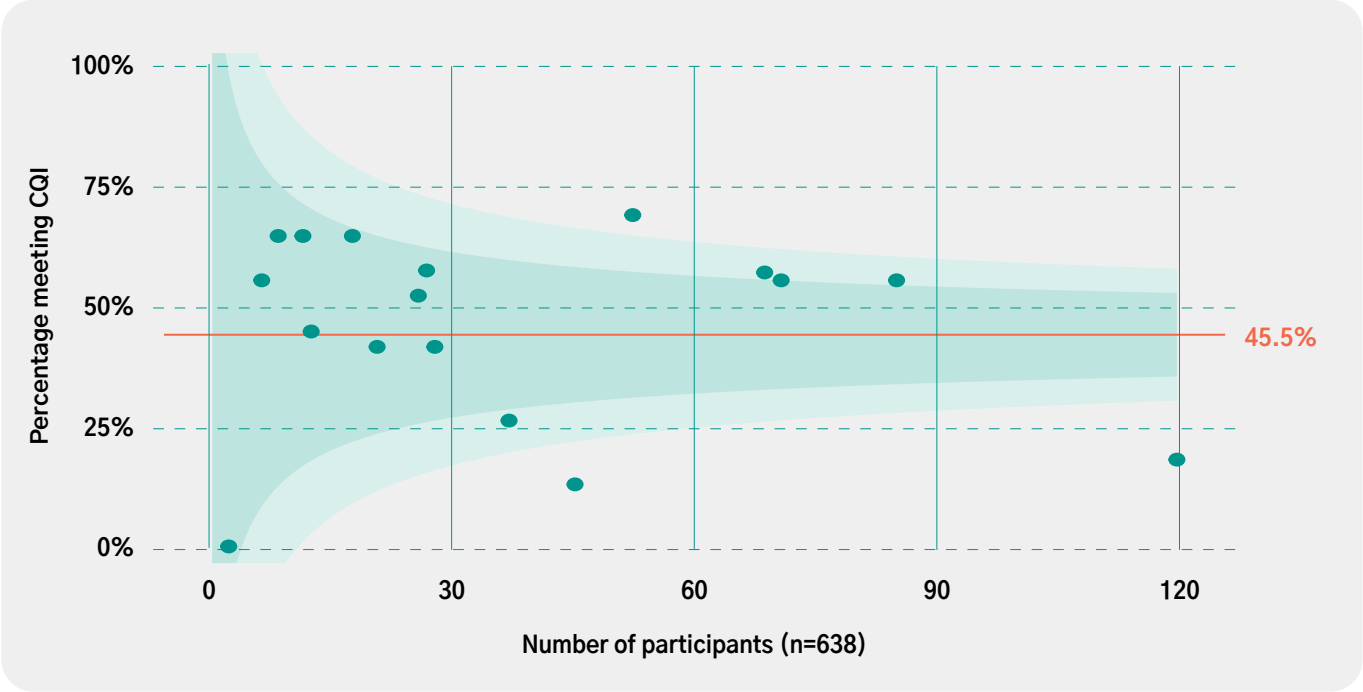


Figure 19: CQI #2a.

Proportion of patients who had a full-body CT scan or PET imaging to stage their cancer prior to commencing treatment.

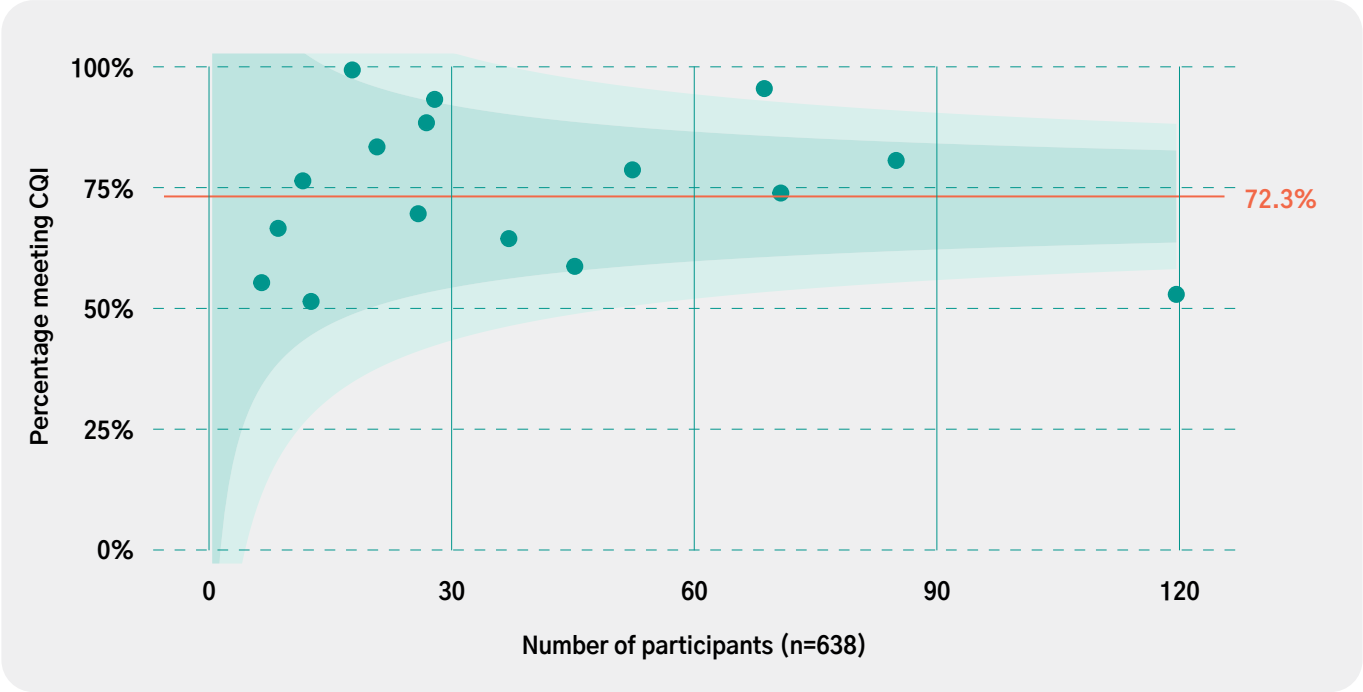


Figure 20: CQI #2b.

Proportion of patients who had a CT scan of the abdomen and pelvis or PET imaging to stage their cancer prior to commencing treatment.

CQI 3: Proportion of patients with newly diagnosed OTP cancer who have the histological or cytological diagnosis confirmed prior to receiving first-line neoadjuvant chemotherapy

One of the most accurate methods of cancer diagnosis is via a biopsy, where a small piece of the abnormal growth is examined in a laboratory. For OTP cancer, this often occurs after surgery where the growth is removed, but can also occur during procedures such as a laparoscopy. The tissue collected during the biopsy is sent to a laboratory where it is assessed by a pathologist, and the pathologist's histological and cytological findings are used to determine the diagnosis. In the reporting period, 97.3% of patients had their OTP cancer diagnosis confirmed via histology or cytology, prior to commencing first-line neo-adjuvant chemotherapy (Figure 21). A lower average may indicate sites that were able to confirm diagnosis via imaging techniques rather than via histology/cytology, or the data may have been recorded in the registry prior to histological/cytological confirmation.

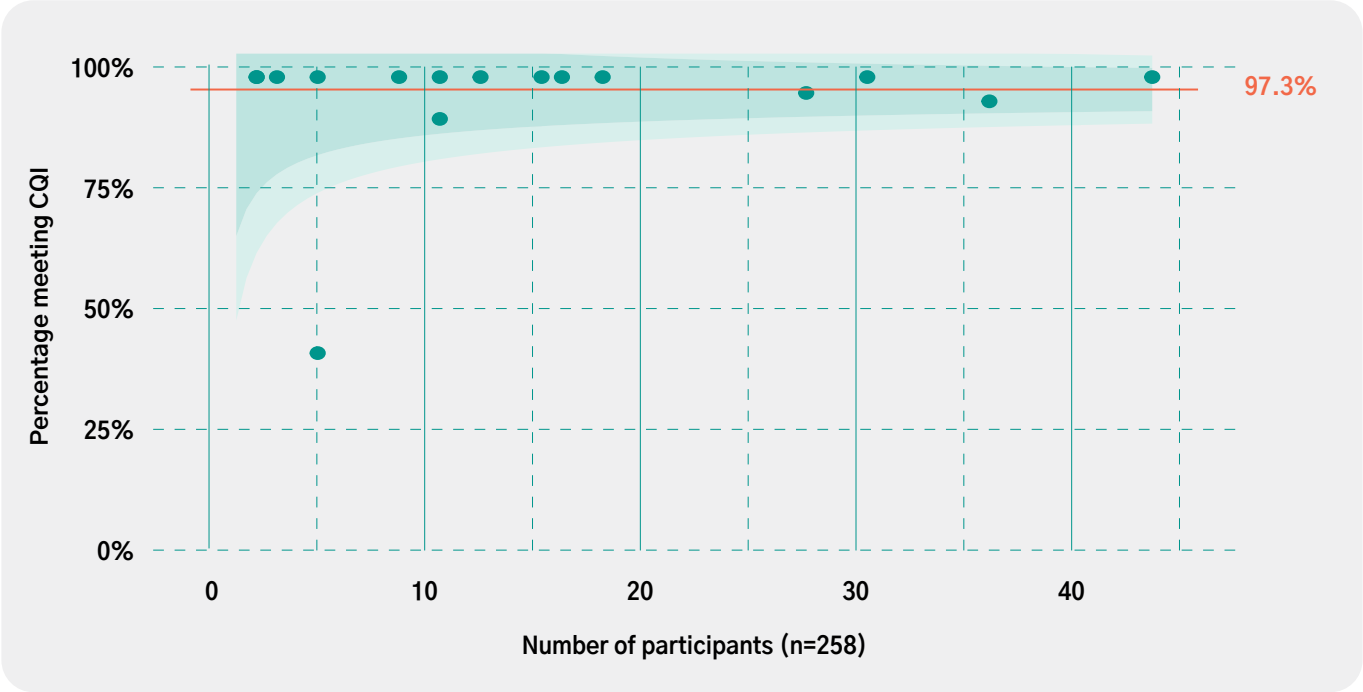


Figure 21: CQI #3.

Proportion of patients with newly diagnosed OTP cancer who have their histological or cytological diagnosis confirmed prior to receiving first-line neoadjuvant chemotherapy.

CQI 4: Proportion of patients with clinically apparent early stage ovarian or tubal cancer who are adequately surgically staged

Cancer staging provides information regarding the amount of cancer as well as the extent of cancer spread, and this is useful in guiding treatment options. Surgical staging aims to detect small macroscopic or microscopic metastatic disease at laparotomy or laparoscopy. The OvCR uses the staging convention outlined by the International Federation of Gynecology and Obstetrics (FIGO)[21]. 'Adequate' surgical staging has been defined as including peritoneal washings, omentectomy/omental biopsy, biopsy of any suspicious lesions/masses, and an appendicectomy (the latter only for mucinous tumours)[22]. Sampling of the pelvic and para-aortic lymph nodes is recommended as ovarian cancer can metastasise to the regional lymph nodes, however nodal sampling remains a contentious issue[20,23]. Total abdominal hysterectomy and bilateral salpingo-oophorectomy (TAHBSO) is usually performed but is not a requirement for "adequate" surgical staging.

The data collection process for this CQI is currently being refined to ensure data accuracy. It is anticipated that data for this CQI will be available for the 2022 report.

CQI 9: Proportion of patients with newly diagnosed OTP cancer whose pathology report contains the minimum required elements

The pathology report outlines key information regarding tissue that has been extracted via a biopsy or surgical intervention. Effective pathology reporting should include the minimum required elements, such as those defined by the Royal College of Pathologists of Australasia (RCPA)[24] and/or the International Collaboration on Cancer Reporting (ICCR)[25]. Minimum reporting requirements often include elements such as clinical information, surgical handling, macroscopic and microscopic findings, and a synthesis or overview. During the reporting period, 96.9% of patients with a new OTP diagnosis had a pathology report containing the minimum required elements (Figure 22). Patients for whom the histopathology report was not available at the time of data collection have been excluded from this analysis.

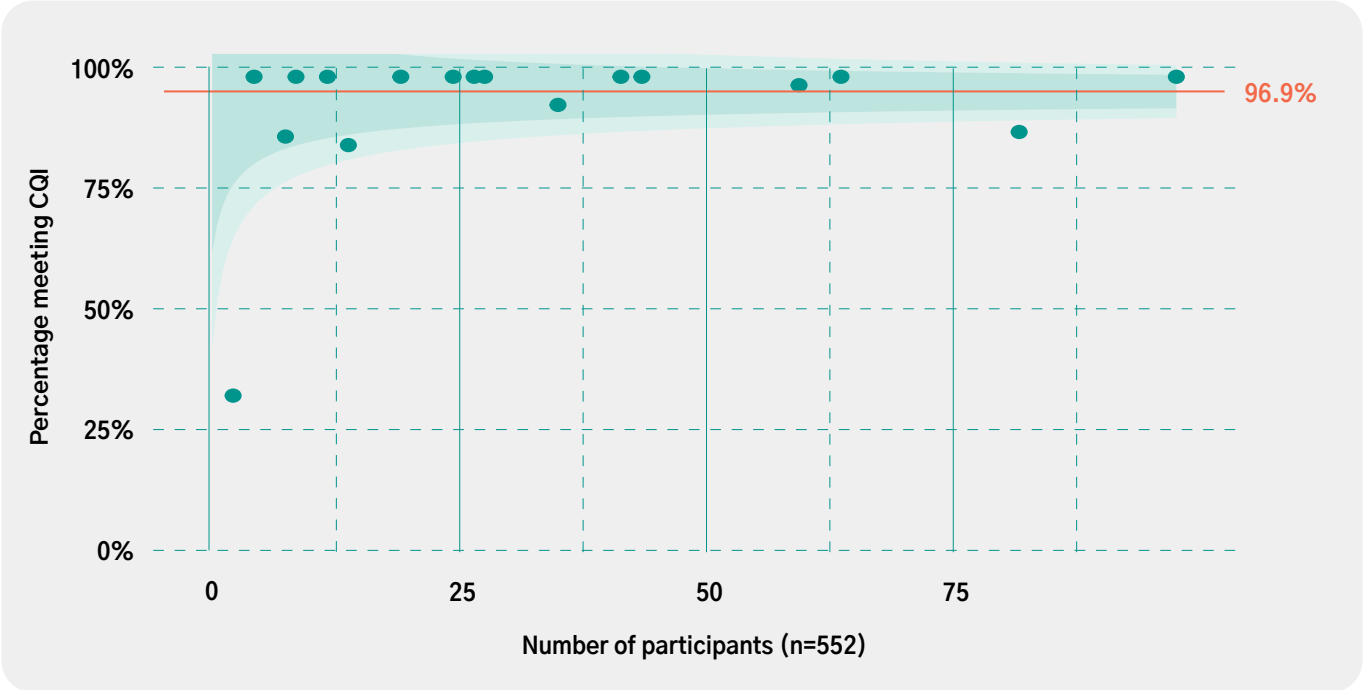


Figure 22: CQI #9.

Proportion of patients with newly diagnosed OTP cancer whose pathology report contains the minimum required elements.

Surgery and Adverse Events

Surgical intervention is the most common treatment for ovarian cancer, though the appropriateness of surgery will depend on the patient's general health as well as the extent of disease. For example, surgery may not be appropriate if the cancer has spread beyond the pelvis, requiring multiple surgeries that the patient may be too unwell to tolerate. For these reasons, it is important to assess the types of surgery performed, and the rate at which adverse events occur. In the OvCR, this has been defined by CQIs 5–8. The funnel plots illustrating the outcomes from each of these CQIs are shown below in Figures 23–28.

CQI 5: Proportion of patients with advanced OTP cancer who underwent primary cytoreductive surgery who have no macroscopic residual cancer

Primary surgery is defined by the OvCR as surgical treatment that is conducted prior to the commencement of other treatments such as chemotherapy. It is during this surgical intervention that the tumour is both staged and debulked (the latter is also known as cytoreductive surgery). If optimal debulking is achieved, this indicates that either all of the cancer was removed (i.e. no macroscopic residual cancer), or only up to 1cm of the tumour remains. Optimal debulking is associated with a better patient prognosis than sub-optimal debulking where tumours greater than 1cm remain after surgery[26,27]. In the current reporting period, 62.8% of patients with advanced (FIGO Stage III or IV) OTP cancer were optimally surgically debulked, with no macroscopic residual cancer (Figure 23; CQI 5a), while 25.5% were optimally surgically debulked with some (less than 1cm) macroscopic residual cancer (Figure 24; CQI 5b). A small number of patients who received induction chemotherapy (i.e. one cycle) prior to surgery were also included in this CQI. Patients who did not have surgery at a collaborating NGOR hospital were excluded from this analysis, as were patients who did not have information regarding residual cancer in their medical record.

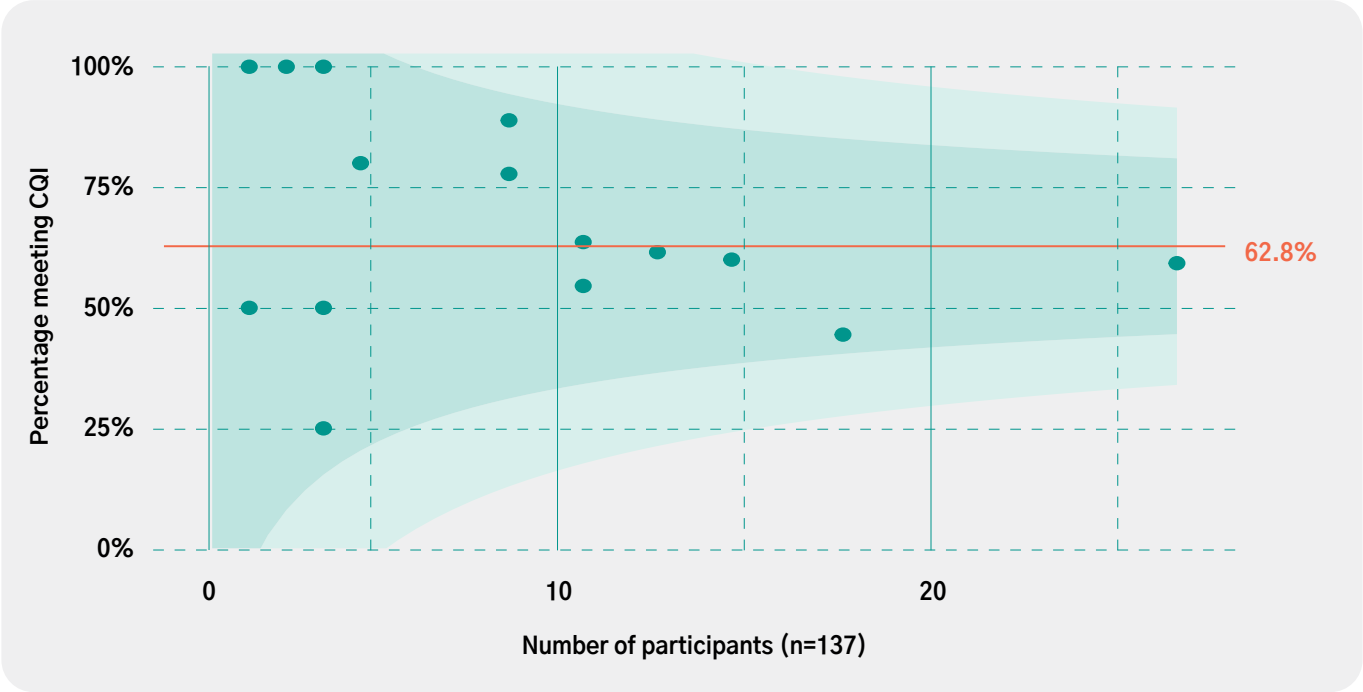


Figure 23: CQI #5a.

Proportion of patients with advanced OTP cancer who undergo primary cytoreductive surgery who have no macroscopic residual cancer.

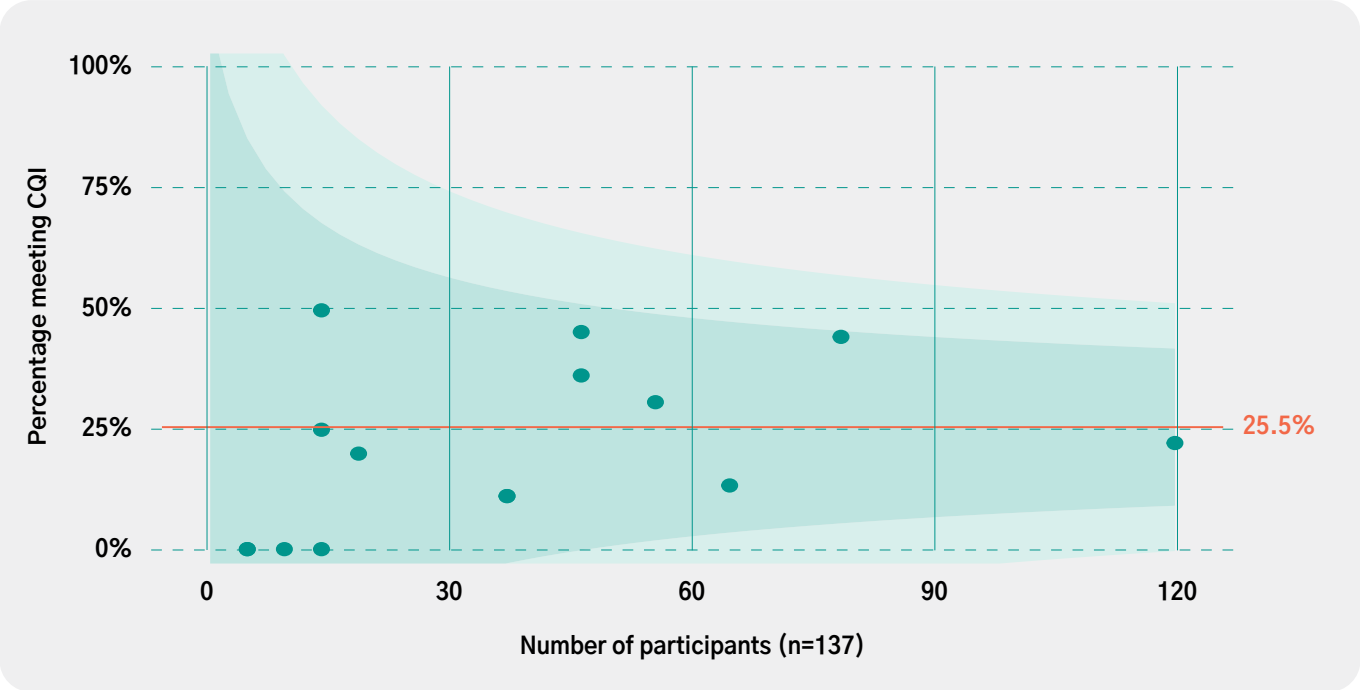


Figure 24: CQI #5b.

Proportion of patients with advanced OTP cancer who undergo primary cytoreductive surgery who have <1cm macroscopic residual cancer.

CQI 6: Proportion of patients with advanced OTP cancer who undergo interval cytoreductive surgery (with and without macroscopic residual cancer)

Interval debulking/cytoreductive surgery is defined by OvCR as surgical treatment that occurs after two or more cycles of chemotherapy. In this reporting period, 43.6% of patients with advanced (FIGO Stage III or IV) OTP cancer were optimally surgically debulked with no macroscopic residual cancer (Figure 25; CQI 6a), and 41.9% of patients with advanced OTP cancer were surgically debulked with some (less than 1cm) macroscopic residual cancer (Figure 26; CQI 6b). Patients undergoing surgery for recurrent or progressive disease were excluded from this analysis, as well as any patient who did not have surgery at a collaborating NGOR hospital. Patients who did not have information regarding residual cancer in their medical record were also excluded from this analysis. Patients who received more than four cycles of chemotherapy prior to surgery may be included in this analysis due to inherent difficulties in collecting chemotherapy cycle data.

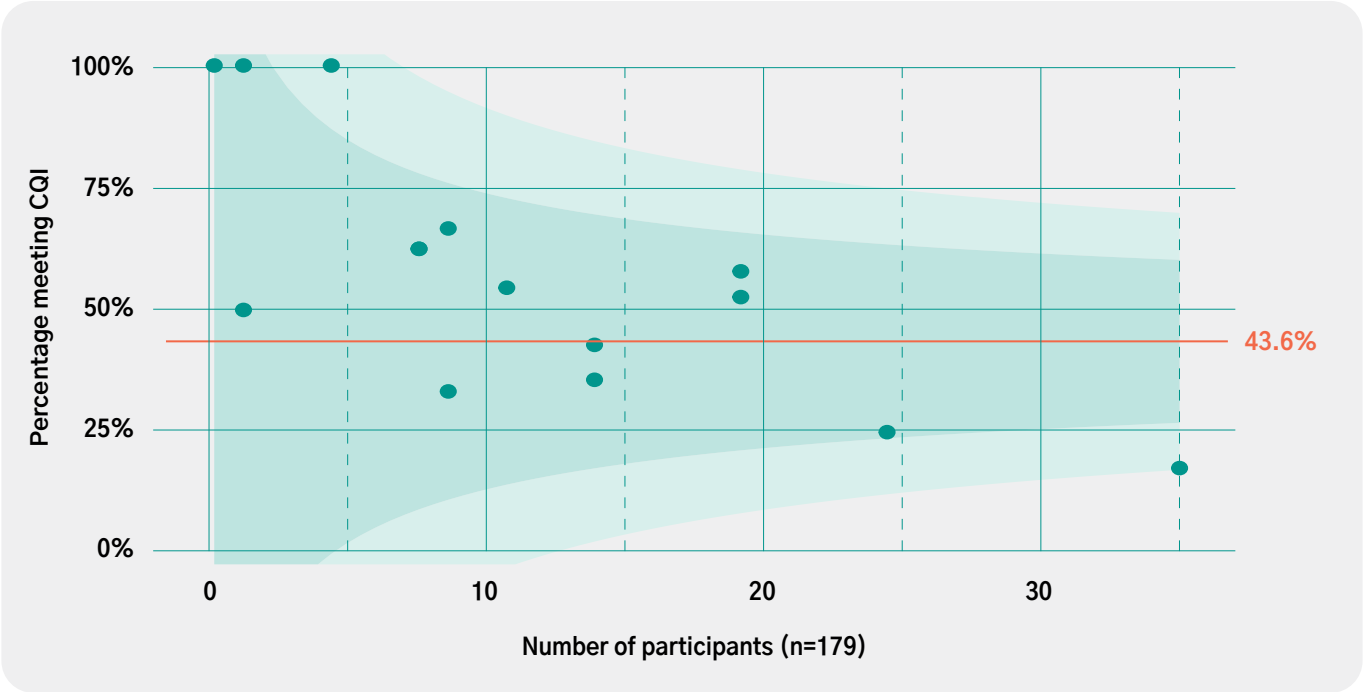


Figure 25: CQI #6a.

Proportion of patients with advanced OTP cancer who undergo interval cytoreductive surgery who have no macroscopic residual cancer.

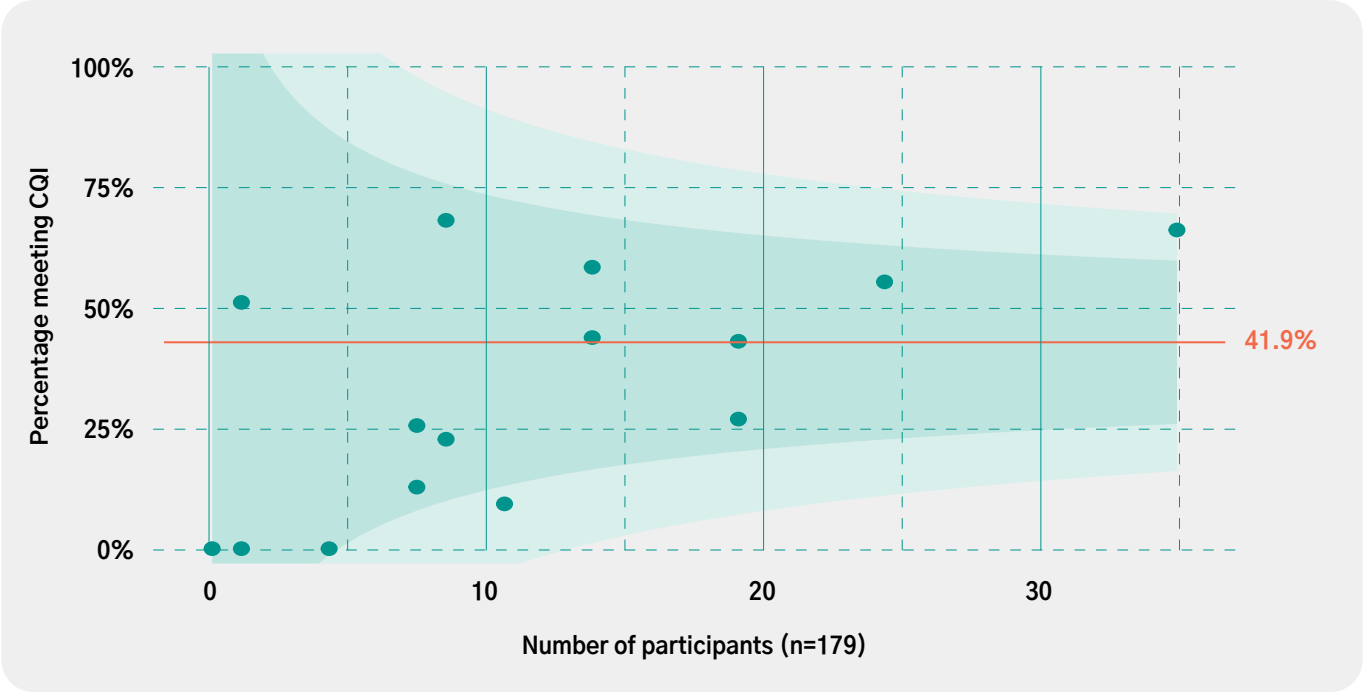


Figure 26: CQI #6b.

Proportion of patients with advanced OTP cancer who undergo interval cytoreductive surgery who have <1cm macroscopic residual cancer.

CQI 7: Proportion of patients undergoing primary or interval surgery for OTP cancer who experience one or more unplanned intraoperative events

An unplanned intraoperative event refers to a negative event that occurs during surgery that could not be anticipated prior to surgery, such as excessive bleeding or damage to an adjacent internal organ. During the reporting period, 9.2% of patients undergoing surgery for OTP cancer experienced at least one unplanned intraoperative event (Figure 27). Patients who did not have surgery at a collaborating NGOR hospital are excluded from this analysis. Patients who did not have information regarding unplanned intraoperative events in their medical record were also excluded from this analysis.

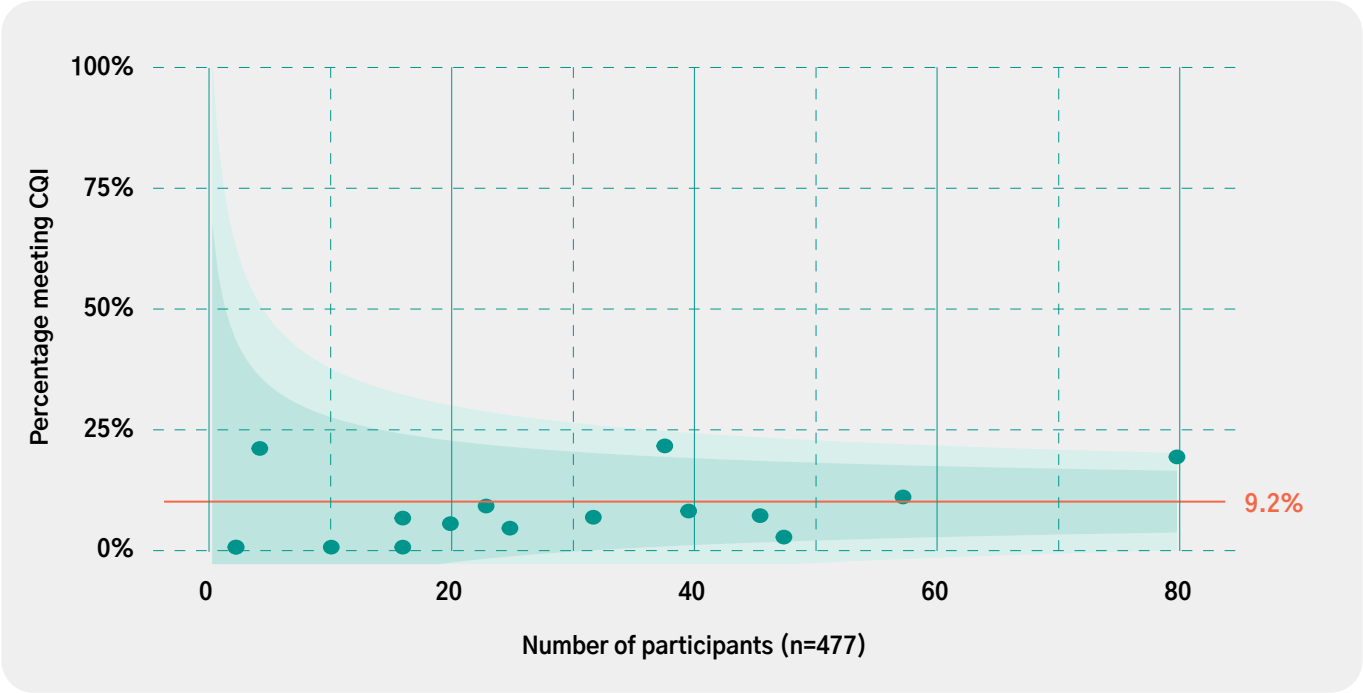


Figure 27: CQI #7.

Proportion of patients undergoing primary or interval surgery for OTP cancer who experience one or more unplanned intraoperative events.

CQI 8: Proportion of patients who experience one or more serious adverse events which are Clavien–Dindo Grade III or higher in severity, during the first 30 days after primary or interval surgery for OTP cancer

The Clavien–Dindo Classification system[28] was developed in order to define and grade adverse surgical outcomes. It consists of five grades that range from any deviation from normal postoperative course, not requiring further treatment other than antiemetics, antipyretics, analgesics, diuretics/electrolytes, and physiotherapy (Grade I), to patient death (Grade V). Clavien–Dindo Grade III reflects any serious post–operative adverse event that requires surgical, endoscopic or radiological intervention. During the reporting period, 2.5% of sites reporting patients having experienced one or more Clavien–Dindo Grade III–V serious adverse events during the first 30 days after primary or interval surgery for OTP cancer (Figure 28). Patients who did not have surgery at a collaborating NGOR hospital were not included in this analysis, nor were those for whom postoperative adverse event information was not available or not documented.

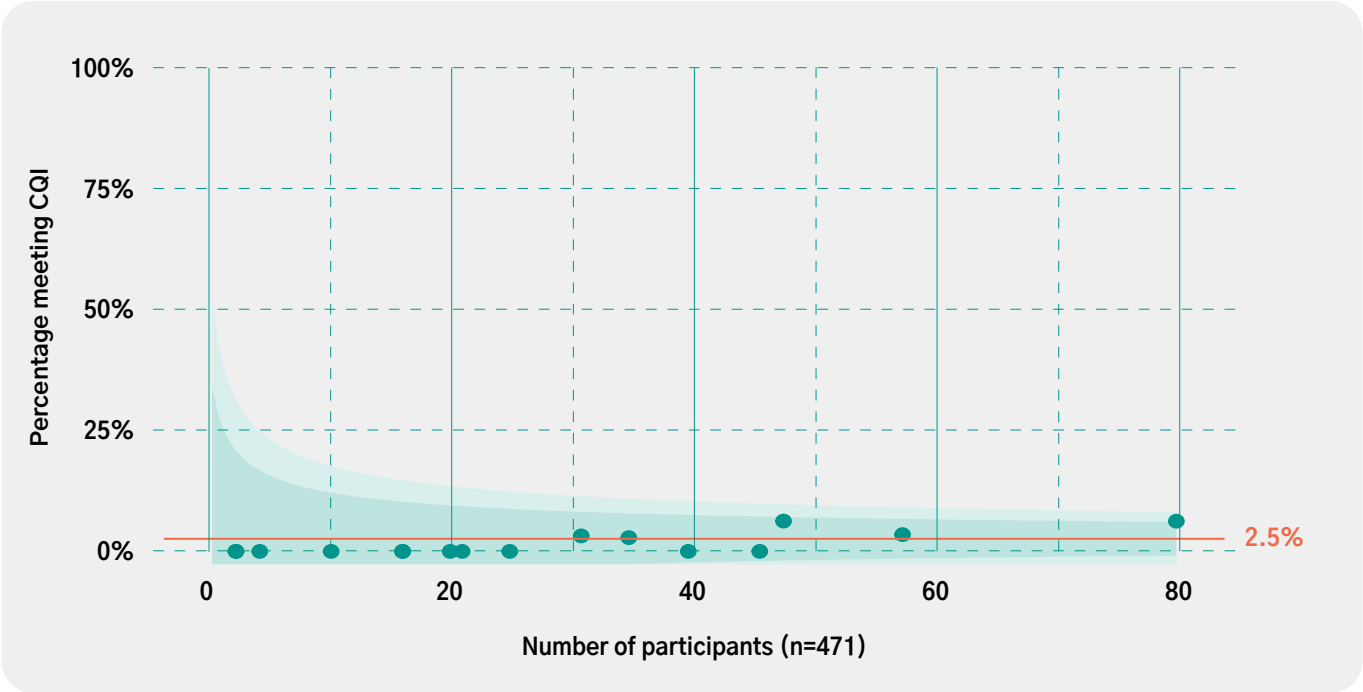


Figure 28: CQI #8.

Proportion of patients who experience one or more serious adverse events which are Clavien–Dindo ≥ Grade III severity during the first 30 days after surgery for OTP cancer.

Chemotherapy

Chemotherapy is a common intervention used to treat most cancer types, and typically involves administering specific drugs intravenously (into the vein), though some types of chemotherapy medications can be administered via other means. For a given cancer sub-type, the decision regarding which chemotherapy regimen to use often depends on patient factors, such as general health and disease progression. For ovarian cancer, chemotherapy often involves the administration of two different types of drugs as a 'doublet'; the platinum and taxane doublet being a key part of initial treatment[29]. Given the importance of chemotherapy in effective ovarian cancer treatment, patterns in administration should be monitored. In the NGOR, this is covered by CQIs 10–12. The funnel plots illustrating outcomes from each of these CQIs are shown below in Figures 29–32.

CQI 10: Proportion of patients with OTP cancer receiving first-line chemotherapy with a platinum and taxane doublet

First-line chemotherapy refers to the first round of chemotherapy for initial disease, which can occur either before or after primary surgery (the term 'second-line' chemotherapy typically relates to treatment for recurrence). As per the Cancer Australia guidelines on first-line treatment for epithelial ovarian cancer[30], this should include a platinum compound, which can be in the form of a doublet with a taxane. During the reporting period, 83.5% of patients with OTP cancer received first-line chemotherapy with a platinum and taxane doublet (Figure 29). Patient factors presenting any contraindication to this form of chemotherapy may impact this average. Patients with such factors may be included in this analysis as such background information may not be clearly documented in medical records.

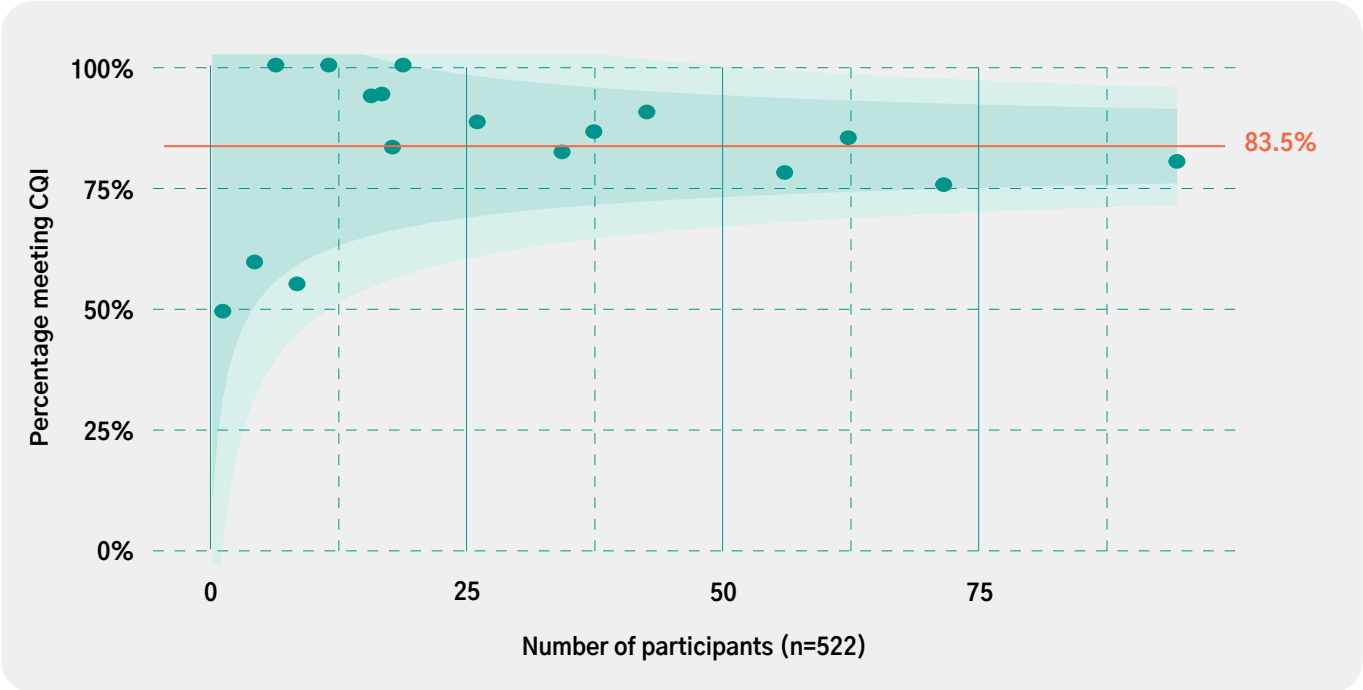


Figure 29: CQI #10.

Proportion of patients with OTP cancer receiving first-line chemotherapy with a platinum and taxane doublet.

CQI 11: Proportion of patients with sub–optimally debulked OTP cancer (at least 1cm of residual cancer) or Stage IV OTP cancer who receive first–line chemotherapy with a platinum and taxane doublet, and bevacizumab

Where the cancer is sub–optimally debulked (i.e. at least 1cm of residual cancer remains after surgery), or where the cancer is categorised as late stage (Stage IV), targeted therapies can be administered alongside first–line chemotherapy to improve outcomes. Bevacizumab is an effective targeted therapy given alongside chemotherapy with a platinum and taxane doublet. It is associated with improved patient outcomes[31]. In the reporting period, 21.7% of patients with sub–optimally debulked OTP cancer or Stage IV cancer received first–line (platinum–taxane doublet) chemotherapy as well as bevacizumab (Figure 30). A lower average may indicate commencement of bevacizumab after data was entered into the registry, as treatment with bevacizumab often occurs later in the treatment trajectory.

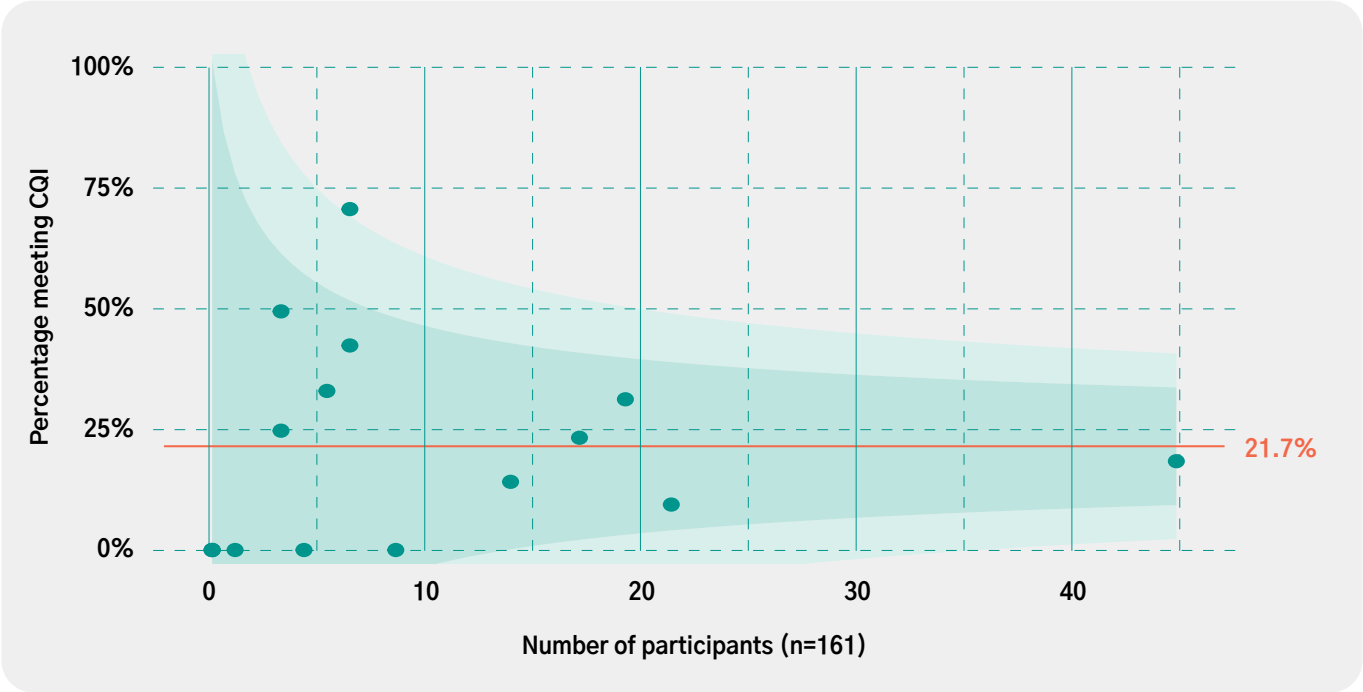


Figure 30: CQI #11.

Proportion of patients with sub–optimally debulked OTP cancer (residual cancer ≥1cm) or Stage IV OTP cancer who receive first–line chemotherapy with a platinum taxane doublet and bevacizumab.

CQI 12: Proportion of patients with OTP cancer who commenced first-line chemotherapy within 28 days of surgery or diagnosis

There is strong evidence to suggest that lower survival rates for patients with ovarian cancer are associated with longer wait times between surgery and the initiation of adjuvant chemotherapy[32–35]. Even in patients with no residual cancer following surgery, delayed initiation of chemotherapy can lead to earlier cancer recurrence[33]. Guidelines on optimal care for patients with ovarian cancer were released in 2021 by Cancer Council Victoria and Cancer Australia, stating that adjuvant chemotherapy should commence within 4 weeks (28 days) of surgery[36]. This concurs with previous research where overall survival was significantly compromised for sub-optimally debulked patients commencing adjuvant chemotherapy more than 28 days after surgery[32]. For some Stage III or IV cancers, chemotherapy can be commenced *prior to surgery* (neoadjuvant chemotherapy), or chemotherapy can be commenced as the *sole treatment* (e.g. if the patient is too unwell or where the disease is too advanced to undergo surgery). Neoadjuvant chemotherapy should be commenced within 4 weeks of the patient being diagnosed[36], as the aim of this approach is to try to shrink the tumour in order to improve surgical outcomes. In the current reporting period, 32.5% of patients with OTP cancer commenced adjuvant chemotherapy within 28 days of surgery (Figure 31; CQI 12a), and 76.3% of patients with OTP cancer commenced neoadjuvant or sole chemotherapy within 28 days of diagnosis (Figure 32; CQI 12b). Lower averages may indicate the presence of post-surgery complications that result in the delay of adjuvant chemotherapy, the presence of comorbidities or contraindications to chemotherapy, or that the patient may have refused chemotherapy.

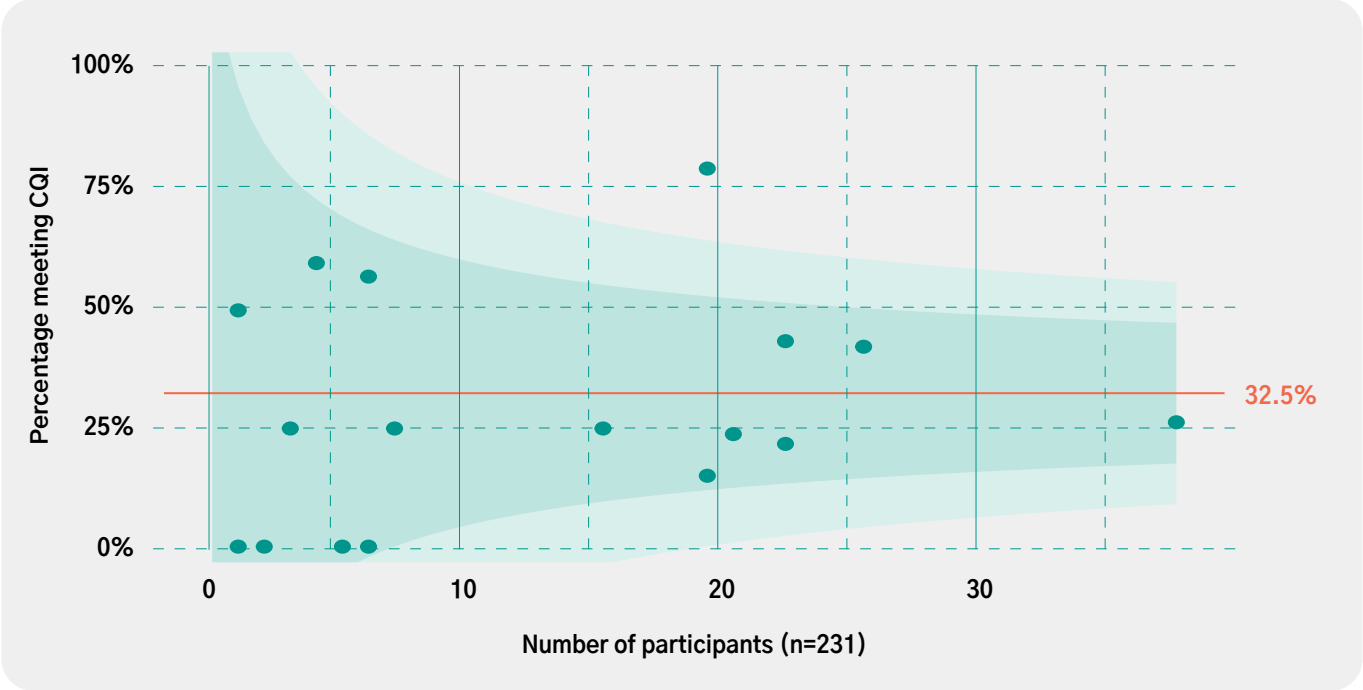


Figure 31: CQI #12a.

Proportion of patients with OTP cancer who commenced first-line adjuvant chemotherapy within 28 days of surgery.

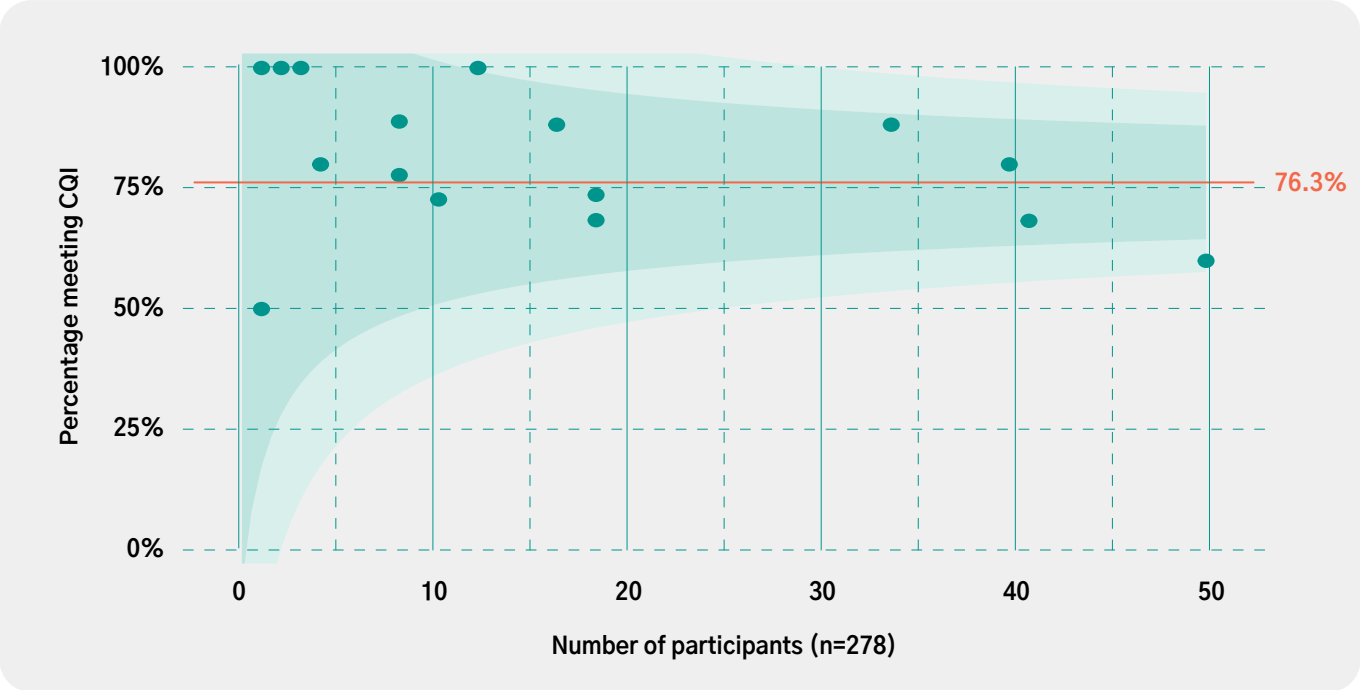


Figure 32: CQI #12b.

Proportion of patients with OTP cancer who commenced first–line neoadjuvant or sole chemotherapy within 28 days of diagnosis.

Targeted Therapies

The main goal of targeted therapies is to impact the ways in which tumour cells function, for example how they grow and spread. For ovarian cancer, targeted therapies are typically used to treat recurrence, or cancers that are advanced/late stage[37]. There are several types of targeted therapies for gynaecological cancers, though most can be classified as either antiangiogenic agents (e.g. bevacizumab, which targets the vasculature), or poly (ADP–ribose) polymerase (PARP) inhibitors (which target DNA repair). In the NGOR, targeted therapies are addressed by CQIs 13 and 14. The funnel plots illustrating outcomes from these CQIs are shown below in Figures 33 and 34.

CQI 13: Proportion of eligible patients who have germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completion of first–line chemotherapy

Genetic testing is conducted to search for specific gene mutations, and if found, identify what type of mutation is present. Testing can identify either germline or somatic mutations, where germline refers to genetic mutations that occurred during conception (i.e. mutations originating from the egg or sperm), whereas somatic refers to genetic mutations that occurred after conception and are largely confined to tumour cells (i.e. involving cells other than the egg or sperm). For ovarian cancer, genetic testing involves an assessment of whether there is a germline or somatic mutation in the BRCA1 or BRCA2 gene. Research has shown an approximate 39% risk of developing ovarian cancer with a BRCA1 mutation, and an 11% risk with a BRCA2 mutation[38]. There is consensus that all patients with OTP cancer are offered genetic counselling and testing for BRCA1 and BRCA2 mutations[36,39]. In the current reporting period, 82.8% of eligible patients had germline or somatic testing for genetic mutations (including BRCA1 and BRCA2) prior to completing first–line chemotherapy (Figure 33). A lower average may reflect the inherent difficulty in capturing these data due to patient confidentiality. Patients with Grade I or mucinous OTP carcinomas are excluded from this analysis as the PBS does not reimburse BRCA testing for this group, and mucinous OTP carcinoma is not associated with BRCA mutations and therefore such testing is not indicated.

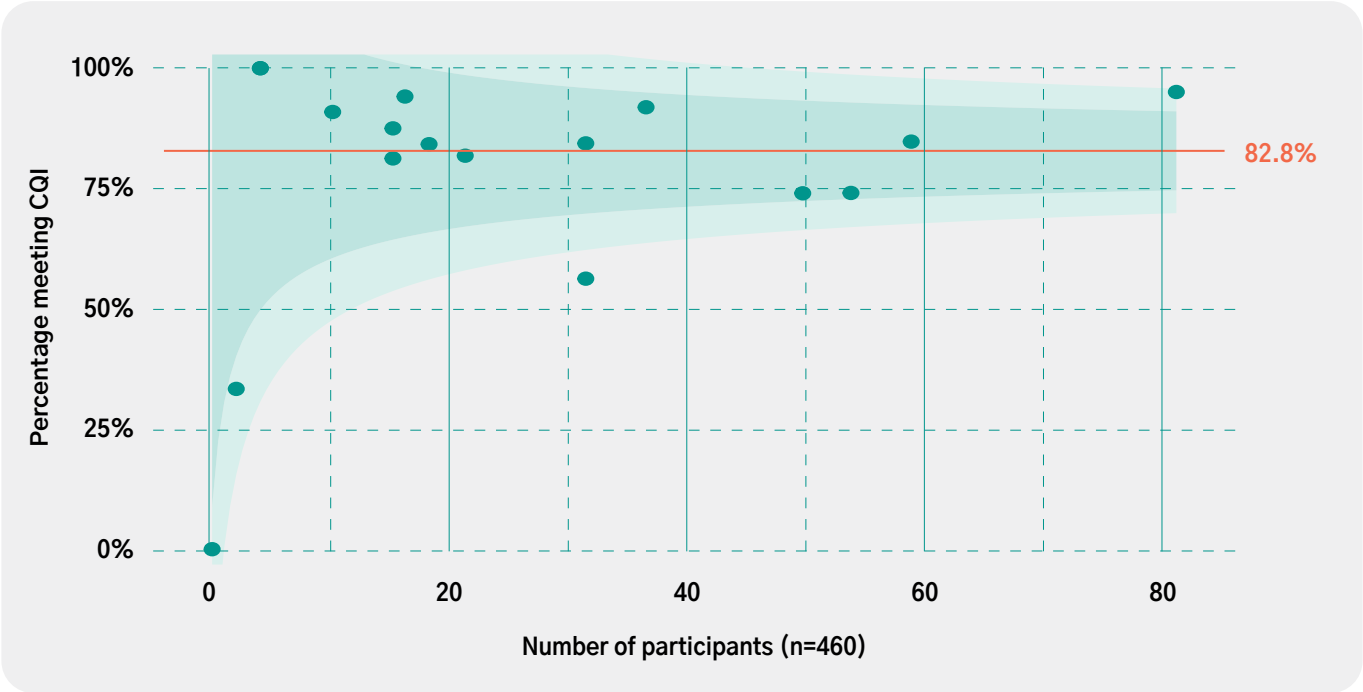


Figure 33: CQI #13.

Proportion of eligible patients who have germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completion of first–line chemotherapy.

CQI 14: Proportion of patients with germline or somatic mutations of BRCA1 or BRCA2 who commence maintenance PARPI therapy within eight weeks of ceasing first-line chemotherapy

PARP inhibitors relate specifically to gene mutations in BRCA1 and BRCA2. If tumour cells possess a mutated BRCA gene, PARP inhibitors can further prevent or slow DNA repair within cells, which can ultimately lead to tumour cell death[40]. Therefore, PARP inhibitors are typically only prescribed to patients with a known BRCA mutation. 'Maintenance treatment' refers to the administration of PARP inhibitors once chemotherapy has finished; it has been recommended that the interval between cessation of chemotherapy and commencement of PARP inhibitors is no longer than eight weeks[41]. In the current reporting period, 62% of patients with BRCA1 or BRCA2 germline or somatic mutations commenced maintenance PARP treatment within eight weeks of ceasing first-line chemotherapy (Figure 34). A lower average may relate to inherent difficulties in accessing and interpreting information on genetic testing, as well as information around remission status following cessation of first-line chemotherapy.

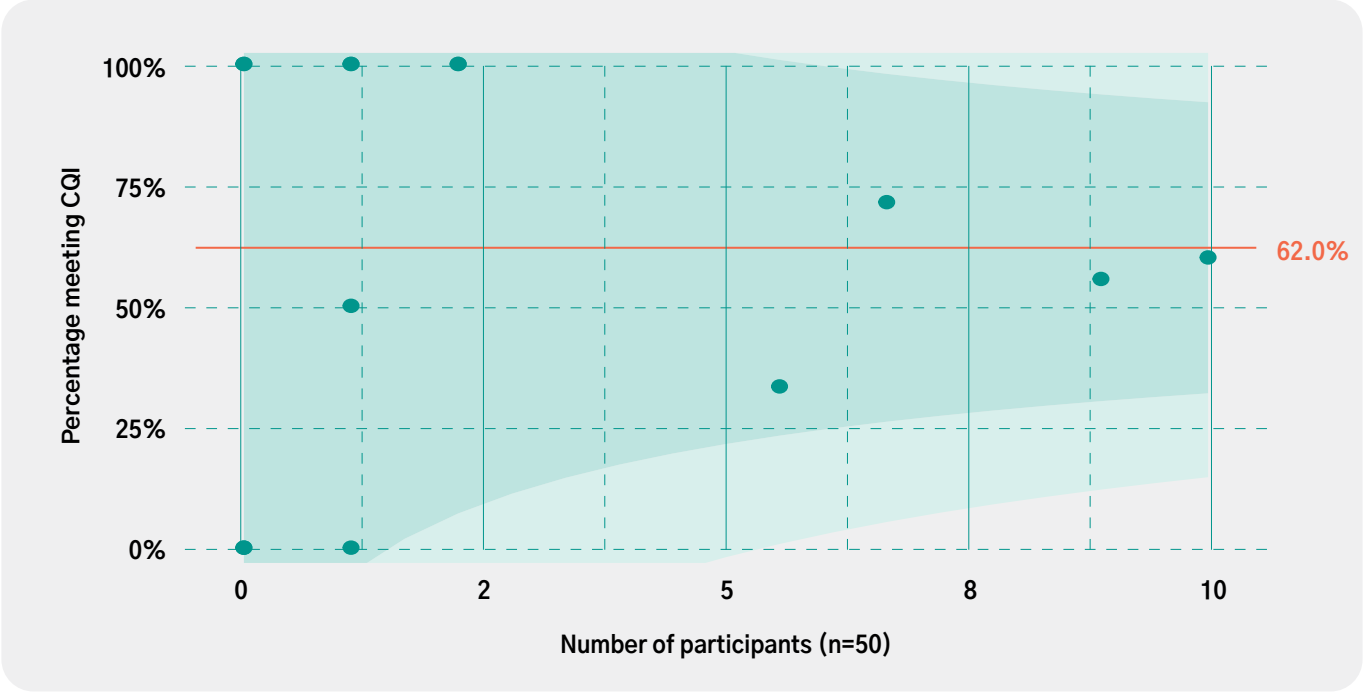


Figure 34: CQI #14.

Proportion of patients with germline or somatic mutations of BRCA1 or BRCA2 who commence maintenance PARPI therapy within eight weeks of ceasing first-line chemotherapy.

Patient Participation in Clinical Trials and Translational Research

The primary purpose of clinical trials is to further investigate new treatments (e.g. new pharmaceutical approaches) and procedures (e.g. advances in surgery, imaging, etc.) that show positive preliminary outcomes in treating disease. These trials assess the safety and efficacy of new treatments and procedures, to determine whether they produce better outcomes for patients than current approaches. It has been argued that one of the factors influencing better outcomes in ovarian cancer treatment, is patient participation in clinical trials[42]. In the NGOR, patient participation in clinical trials and translational research is addressed by CQI 15. The funnel plot illustrating the outcome for this CQIs is shown below in Figure 35.

CQI 15: Proportion of patients with OTP cancer who are enrolled in an interventional clinical trial or translational research

Whereas clinical trials relate to an in-depth assessment of new treatments and approaches, translational research refers to implementing the outcomes from clinical trials, into standard clinical practice. Both types of research are vital in testing promising new treatments and ensuring these treatments reach patients in a safe and effective manner. In the current reporting period, 15.7% of patients with OTP cancer were enrolled in an interventional clinical trial or in translational research (Figure 35). The lower average may reflect the fact that research incorporates strict participant inclusion/exclusion criteria. Therefore, not all patients will be eligible for participation in a clinical trial or translational research; for instance, they may be too unwell to take part, or may have comorbidities that could cloud the understanding of treatment procedures and outcomes. Research also depends heavily on available funding, without which they would be very limited in their scope, or unable to be conducted at all. It is also important to note that this CQI relates to patient involvement in research at any time throughout their cancer journey, i.e. it is not limited to diagnostic or treatment timeframes.

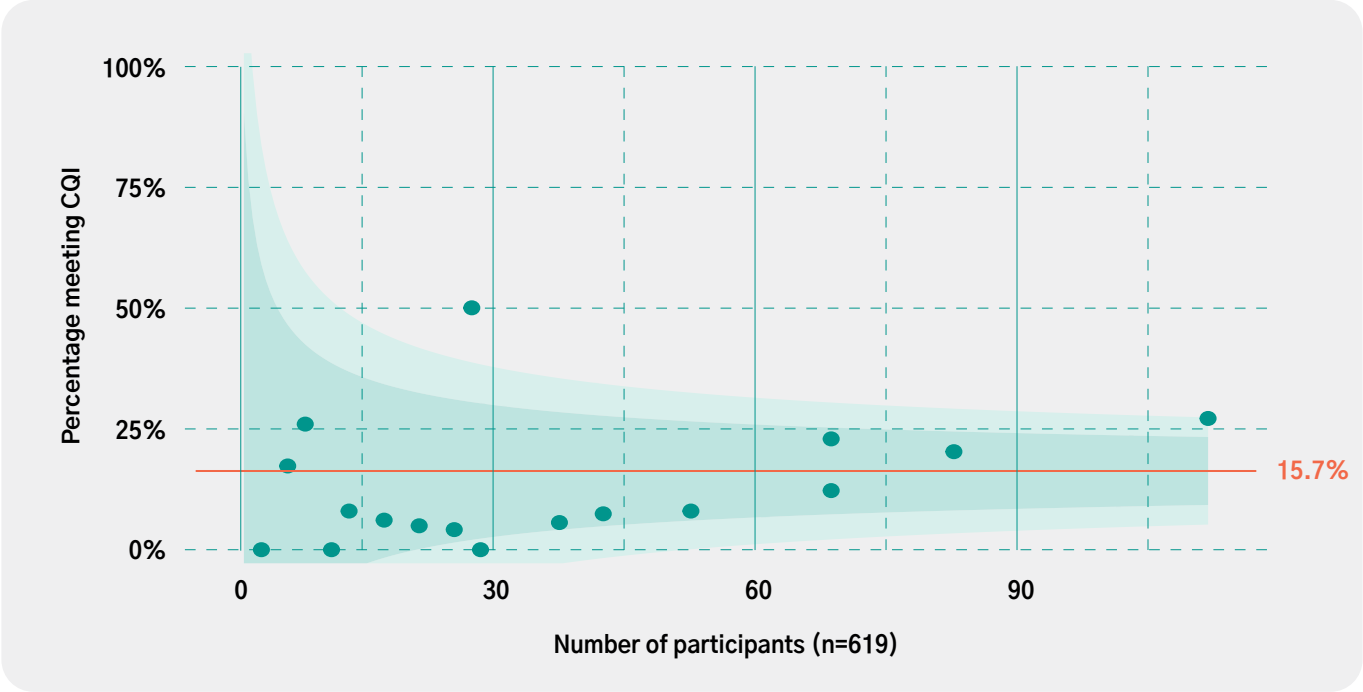


Figure 35: CQI #15.

Proportion of patients with OTP cancer who are enrolled in an interventional clinical trial or translational research.

Future Directions

The OvCR will focus on building connections with specialist gynae-oncologist hospitals in Queensland, as well as additional hospitals in New South Wales, Victoria, Western Australia and South Australia to ensure complete data capture across the country. Expansion to gynaecological cancer treatments centres in the Northern Territory and Australian Capital Territory is also expected to occur in the future. The OvCR will be focusing on including data on surgical staging for future reports by refining the data collection process.

The NGOR will also be focusing on strong data collection within the Endometrial Cancer Module, and will finalise the CQIs for the Rare Ovarian Tumours sub-registry in 2022. The PROMs pilot study is expected to commence this year as well, with data collection expected to conclude in 2023. From 2022 onwards, the NGOR intends to integrate ethically approved data linkage with a view to enhancing the quality and breadth of clinical data captured, and consequently the findings generated by the registry.

The NGOR's partnership with OCA has been pivotal in developing an understanding of the experiences of patients with ovarian cancer. As each NGOR module develops, meaningful partnerships with patient advocacy groups will be sought, to ensure the patients' voice is considered.

Secure and ongoing funding is also currently being sought for each module to ensure the registry's longevity.

Glossary of Terms

Adjuvant (therapy): Therapy given after the primary treatment to reduce the risk of recurrence. This may include chemotherapy, radiation therapy or hormone therapy.

ASA (The American Society of Anaesthesiologists): A 1 to 5 scale which measures a patient's overall health and fitness for surgery. The score ranges from 1 (completely healthy and fit) to 5 (moribund and not expected to live)

BRCA1: A gene on chromosome 17 that normally helps to suppress cell growth. A person who inherits certain mutations (changes) in a BRCA1 gene has a higher risk of getting breast, ovarian, prostate, and other types of cancer.

BRCA2: A gene on chromosome 13 that normally helps to suppress cell growth. A person who inherits certain mutations (changes) in a BRCA2 gene has a higher risk of getting breast, ovarian, prostate, and other types of cancer.

Charlson Comorbidity Index (CCI): An index used to categorise comorbidities of patients based on the international classification of diseases diagnosis codes found in administrative data (i.e. hospital abstract data or administrative data).

Clavien-Dindo Postoperative Adverse Events: Occur in the first 30 days after surgery. These are graded I to V according to severity. Of interest in OTP cancer are events that are grade III-V which are complications that require surgical or radiological intervention.

Clavien-Dindo Score: A therapy-oriented grading system that rates any deviation from the normal postoperative course in five grades.

Cytology: The exam of a single cell type, as often found in fluid specimens.

Cytoreductive surgery: Describes surgery which aims to reduce the size of tumour deposits (and the overall tumour burden) to the smallest possible size. In OTP cancer surgery the terms optimal (=<1cm residual tumour) and complete (no visible or palpable residual tumour) are in common usage.

Debulking Surgery: Removal of as much of the tumour as possible to increase the effectiveness of other cancer treatments. **Primary debulking** occurs before other treatment. **Interval debulking** is performed after other treatments. This is synonymous with cytoreductive surgery.

Eastern Cooperative Oncology Group (ECOG): A measure of patient's level of functioning in terms of their ability to care for themselves, daily activity and physical ability. The score ranges from 0 (no impairment of function) to 4 (totally bed-bound and dependent on others). A score of 5 applies to a deceased patient.

Germline Testing: Genetic testing of non-cancerous cells, usually through a blood test.

Histology: The study of tissues and cells under a microscope.

Interval cytoreductive (debulking) surgery: Surgery that occurs after 2 to 4 cycles of neo-adjuvant treatment.

Multidisciplinary Team Meeting: A meeting of the group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients.

Neo-adjuvant (therapy): Treatment given before the main treatment, which is usually treatment, with the aim of reducing the size of the tumour. This may include chemotherapy, radiation therapy or hormone therapy.

Neo-adjuvant therapy: Treatment given prior to surgery. In OTP cancer this is usually chemotherapy.

Primary cytoreductive (debulking) surgery: Surgery that occurs prior to any other adjuvant treatment.

Residual Disease: Cancer cells that remain after cancer treatments. This term applies to the largest deposit of tumour after cytoreductive surgery, and the size is its largest dimension.

Somatic Testing: Genetic testing of tumour or cancer cells, usually through a biopsy.

Surgical Staging: A clinical examination to determine how far the tumour has spread within the body. Stage 1 refers to when the cancer is confined to the organ of origin, stage 2 occurs when then disease extents locally beyond the site of origin to involve adjacent organs or structures. Stage 3 represents more extensive involvement, such as wide infiltration reaching neighbouring organs. Stage 4 is when the cancer has spread to other body parts. For OTP cancer it involves obtaining specimens including free intraperitoneal fluid or ascites for cytology and biopsies from common areas of spread including the omentum, peritoneal surfaces, dense adhesions, areas of induration and the retroperitoneal nodes in the pelvis or para-aortic region.

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Appendix A: NGOR Clinical Quality Indicators

No	CQI Name	Numerator	Denominator	Exclusions (if applicable)
1	Proportion of patients with newly diagnosed OTP cancer who are discussed at a multidisciplinary team meeting.	Number of patients with newly diagnosed OTP cancer who are discussed at an MDT meeting.	All newly diagnosed patients with OTP cancer.	N/A
2	Proportion of patients with newly diagnosed OTP cancer who had CT and/or PET imaging to stage their cancer prior to commencing treatment. **A)** CT chest + CT abdomen + CT pelvis before treatment **OR** PET before treatment. **B)** CT abdomen + CT pelvis before treatment **OR** PET before treatment.	Number of patients with newly diagnosed OTP cancer who had imaging of the pelvis and abdomen (and chest for QI 2a) to assess the extent of disease.	All patients with newly diagnosed OTP cancer.	Imaging that is performed following the date of surgery or chemotherapy commencement.
3	Proportion of patients with newly diagnosed OTP cancer who have the histological or cytological diagnosis confirmed prior to receiving first–line neoadjuvant chemotherapy.	Number of patients who have a histological or cytological diagnosis of OTP cancer confirmed prior to receiving first–line neoadjuvant chemotherapy.	Total number of patients with OTP cancer who received first–line neoadjuvant chemotherapy for proven or presumed OTP cancer.	N/A
4	Proportion of patients with clinically apparent stage I or II ovarian or tubal cancer who are adequately surgically staged. 'Adequate' surgical staging has been defined as requiring the following procedures to be performed: peritoneal washings + omentectomy / omental biopsy + biopsy of any suspicious lesions, masses etc. + appendectomy (mucinous tumours only) +/– pelvic / paraaortic lymph node sampling. Although TAHBSO is performed in most cases it is not a requirement for 'adequate' surgical staging.	Number of patients with stage I or II ovarian (or tubal) cancer who have adequate staging procedures to determine the stage of their disease.	All patients with apparent stage I or II ovarian (or tubal) cancer who undergo surgery.	Patients who did not undergo surgery at an NGOR participating site.

No	CQI Name	Numerator	Denominator	Exclusions (if applicable)
5	Proportion of patients with advanced OTP cancer who undergo primary cytoreductive surgery who have: **A) no** macroscopic residual cancer. **B) some** macroscopic residual cancer that is less than 1cm.	Number of patients with advanced (stage IIB, III and Stage IV) OTP cancer undergoing primary cytoreductive surgery who have (a) no macroscopic residual cancer or (b) macroscopic residual cancer that is greater than 0 but less than 1cm.	All patients with advanced OTP cancer undergoing primary cytoreductive surgery who have had either no chemotherapy (or one cycle) prior to surgery.	Patients who did not undergo surgery at an NGOR participating site.
6	Proportion of patients with advanced OTP cancer who undergo interval cytoreductive surgery who have: **A) no** macroscopic residual cancer. **B) some** macroscopic residual cancer that is less than 1cm.	Number of patients with advanced (stage IIB, III and Stage IV) OTP cancer undergoing interval cytoreductive surgery who have (a) no macroscopic residual cancer or (b) macroscopic residual cancer that is greater than 0 but less than 1cm.	All patients with advanced OTP cancer undergoing interval cytoreductive surgery who have had between two and four cycles of neoadjuvant chemotherapy prior to surgery.	Patients who are having surgery for recurrent or progressive disease. Patients who did not undergo surgery at an NGOR participating site.
7	Proportion of patients undergoing surgery for OTP cancer who suffer one or more unplanned intraoperative events.	Number of patients who suffer one or more unplanned intraoperative events.	All patients undergoing surgery for OTP cancer.	N/A
8	Proportion of patients who suffer one or more serious adverse events which are Clavien–Dindo ≥ Grade III severity during the first 30 days after surgery for OTP cancer.	Number of patients who suffer one or more serious adverse events (Clavien–Dindo ≥ grade III) during the first 30 days after surgery for OTP cancer.	All patients undergoing surgery for OTP cancer.	N/A
9	Proportion of patients with newly diagnosed OTP cancer whose pathology report contains the minimum required elements.	Proportion of patients with newly diagnosed OTP cancer whose pathology report contains the minimum required elements such as those defined by the RCPA or the ICCR (i.e. clinical information / surgical handling, macroscopic findings, microscopic findings and synthesis / overview).	All patients with newly diagnosed OTP cancer who had histopathology.	Patients for whom the histopathology report could not be viewed by the data collector.

No	CQI Name	Numerator	Denominator	Exclusions (if applicable)
10	Proportion of patients with OTP cancer receiving first-line chemotherapy with a platinum and taxane doublet.	Number of patients with OTP cancer who receive first-line chemotherapy with a platinum and taxane doublet.	All patients with OTP cancer who receive first-line chemotherapy either after primary surgery or as neoadjuvant chemotherapy prior to interval surgery.	N/A
11	Proportion of patients with sub-optimally debulked OTP cancer (residual disease ≥1cm) or Stage IV OTP cancer who receive first-line chemotherapy with a platinum taxane doublet and bevacizumab.	Number of patients with sub-optimally debulked OTP cancer (residual disease ≥1cm.) or Stage IV OTP cancer who receive first-line chemotherapy with a platinum taxane doublet and bevacizumab.	All patients with sub-optimally debulked OTP cancer (residual disease ≥1cm.) or Stage 4 OTP cancer who receive first-line chemotherapy.	N/A
12	Proportion of patients with OTP cancer who commenced first-line chemotherapy within 28 days of surgery or diagnosis. **A)** primary surgery + adjuvant chemotherapy. **B)** interval surgery + neoadjuvant chemotherapy **OR** sole chemotherapy.	Patients who commenced first-line chemotherapy within 28 days of surgery (for QI 12a) or diagnosis (for QI 12b).	All newly diagnosed patients with OTP cancer who received chemotherapy.	N/A
13	Proportion of eligible patients who have germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completion of first-line chemotherapy.	Number of eligible patients who have germline or somatic testing for BRCA1, BRCA2 and other relevant mutations before completion of first-line chemotherapy.	All patients with grade 2-3 non-mucinous OTP carcinoma who receive first-line chemotherapy.	Patients with grade 1 and/or mucinous OTP carcinoma.
14	Proportion of patients with germline or somatic mutations of BRCA1 or BRCA2 who commence maintenance PARPI therapy within eight weeks of ceasing first-line chemotherapy.	The number of patients with germline or somatic mutations of BRCA1 or BRCA2 who commence maintenance PARPI treatment within eight weeks of ceasing first-line chemotherapy.	All patients with germline or somatic mutations of BRCA1 and BRCA2 who are in complete or partial remission at the time of completion of first-line chemotherapy.	Patients whose OTP cancer was initially stage I or II.
15	Proportion of patients with OTP cancer who are enrolled in an interventional clinical trial or translational research.	The number of patients with OTP cancer who are enrolled in an interventional clinical trial or translational research.	All patients with OTP cancer	N/A

Appendix B: NGOR Academic Activities Jul 2020 – Dec 2021

Publications:

- Heriot, N., Brand, A., Cohen, P., Hegarty, S., Hyde, S., Leung, Yee., Zalcberg, J. & Rome, R. (2020). Developing an Australian multi-module clinical quality registry for gynaecological cancers: A protocol paper. BMJ Open, 10(2), e034579 https://bmjopen.bmj.com/content/10/2/e034579

Presentations:

- Rome, RM.,Heriot, N.R. & Sporik, A.V ., Bunting, M., Brand, A., McNally, O., Do, V., Ananda, S., Steane, H., Stenlake, A., Vicario, E.,. Zalcberg, J (October 2021). Progress towards a national gynaecological oncology registry module 2: Endometrial cancer [Poster presentation]. Epworth Research Month, Victoria, Australia.
- Sporik, A.V., Rome, R., Heriot, N.R., Zalcberg, J (October 2020) Developing a multi-modular clinical quality registry for gynaecological cancers [Poster presentation]. Epworth Research Month, Victoria, Australia.

Students:

- Joel Zimmerman (2021): A review of the Charlson Comorbidity Index and a preliminary evaluation of the Ovarian Cancer Comorbidity Index within the context of the National Gynae-Oncology Registry (NGOR).
- Lauren Frisken (2021): Comorbidity data – levelling the playing field for ovarian cancer clinical quality analysis

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